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**Vicarious Futurity: Parents' Perspectives on  
Locating Strength in Adolescents with Autism**

This thesis is presented in partial fulfilment  
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## Abstract

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Research into Autism Spectrum Disorder (ASD) has largely taken place within the biomedical model of illness and disease. It has focussed on young children, based on the understanding that early intervention provides the most positive outcomes for social, cognitive, and communication development. However, this has tended to overlook the need for research throughout the life span, including adolescence and adulthood, where very poor outcomes develop.

This study provides a space for parents to identify the strengths of adolescents with ASD and challenges the assumptions that the lived experience of ASD is associated mostly with dysfunctional family life. By identifying strengths in adolescents with ASD, parents engaged with conceptions of how these strengths might generate a positive perspective on the future for their adolescent child. Ten parents were asked to take or collect five photographs each of what they perceived as strengths that their adolescent displayed. A semi-structured interview was then carried out to explore the images. Analysis of the interviews was guided by a hermeneutic phenomenological epistemology where the researcher attempts to make sense of the participant's experience. The data was analysed by latent thematic analysis that is theorised as an examination of the underlying ideas, assumptions and conceptualisations of the semantic content of the data.

The research found that the identified strengths of adolescents with ASD were those valued in functional and cultural terms by the family and supported daily family functioning in the home, at school, and other mainstream systems. Furthermore, parents identified it was ASD itself that constituted the inherent strength for the adolescent and promoting suitable attributes of the disorder was beneficial for family life. The strengths of adolescents with ASD reinforced the parent's belief in a more positive future as their adolescent grows into adulthood.

The principal implication of this research is that the professional systems supporting adolescents with ASD would benefit from shifting their conventional understanding of ASD and negative family experiences. By doing so, these systems could facilitate more positive attitudes towards ASD and harness these attitudes towards better support for parental well-being.

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## Chapter 1: Introduction

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### History and context of ASD

Parenting alters one's life dramatically not least due to substantial responsibilities assigned to the new parent. It begins with the complete dependence of another human being on the parent including a need for constant protection. Beyond this, following typical human development patterns, milestone achievements of walking, talking, playing and learning commence. The next phase of adolescence is a time of tremendous biological change with puberty, significant physical growth and change, and cortical re-development, all of which prepare the young person for adulthood and procreation. From a psychosocial viewpoint, adolescents begin to develop their identity, experience their sexuality, and locate where they stand in the world. Having a child diagnosed with Autism Spectrum Disorder (ASD) and an Intellectual Disability (ID) will obviously impact on life span development and permanently modify the normative and typical pathways that parents experience.

The experience of parenting an adolescent with ASD and an ID is often positioned in deficit terms. Research tends to highlight challenging behaviours and disruptive family dynamics while overlooking the strengths of these young people and how these strengths can facilitate a sense of hope for the future within their families. The Centers for Disease Control and Prevention (2014) suggest ASD diagnoses are increasing and in addition, research is increasingly suggesting the frequency of co-morbidity of ASD with ID. If we accept these arguments, there is an urgent need for research into a key transition period of an especially marginalised population: adolescents with ASD and an ID as they mature into adulthood.

Research into adolescents with ASD and an ID tends to be presented in limited ways consistent with ableism. They are linked to discourses and assumptions that serve to further "disable" any strengths in this population, often by disregarding them or highlighting only those "miracle" savant skills. This thesis seeks to challenge those discourses by focussing on the strengths of these adolescents with ASD and an ID through the perspective of the parents.

By way of framing the thesis, this introduction offers a brief history and description of ASD, an exploration of the pervasive effects of the disorder for those who have ASD together with an

ID, and a description of the lived experience of the people who support them. Next, current research will be outlined, particularly in the context of ableism and the biomedical model. Finally, the research process, carried out in an atmosphere of positive psychology and strengths-based practice will be explained.

This thesis focusses on the strengths of those with ASD and an ID. I will firstly, therefore, identify the deficits of both disorders as a place from which to begin to discuss, negotiate, and challenge ableism through a social model of disability which prioritises psychology, education, and social justice.\*

### **A brief history of Autism**

The work of Leo Kanner and Hans Asperger are linked with the discovery of autism in 1943 and 1944 respectively. There have been arguments about the label “discoverer” and conspiracy theories around plagiarism but what is undisputed is that both described in their research children with similar patterns of observable behaviour including social aloofness, need for isolation, monotonous verbal repetitions, fixations on interests, an anxious need for sameness, and variable cognitive abilities. These symptoms were later described as Autism and Asperger Syndrome along a spectrum which offered values for the level of functionality of those with ASD and their families that impacted daily living.

The work of Hans Asperger investigated 400 children in 1943, centering around what he termed “autistic psychopathy”. His work first approached prominence through the exploration of Lorna Wing whose interest was inspired by having an autistic daughter (Chown & Hughes, 2016). His work was further promoted after his death in 1980 and thus the term Asperger Syndrome (AS) came into being. AS is characterised by an absence of empathy, socialisation deficits particularly around building and maintaining friendships, high focus interests, and one-sided conversations. Hans Asperger described ‘threads of genius and disability inextricably intertwined (cited in Chown & Hughes, 2016, p. 188). Perhaps this discourse filtered down into the stereotypical and unrepresentative accounts of savant-like genius skills exhibited by some

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\* Throughout this thesis, the word “parent” is taken to mean biological parent, non-biological parent, primary caregiver, caregiver, whānau, or family. The term ASD will be used to indicate those adolescents with a diagnosis of Autism Spectrum Disorder or ASD with a co-morbid diagnosis of an intellectual disability (ID).

autistic people who play classical music without lessons, recite passages of the Bible verbatim or, like Stephen Wiltshire who can draw central London including, roads, lanes, the river Thames, and buildings almost perfectly from memory (Wiltshire, 2016). These specialist skills or splinter skills are discussed below

Leo Kanner worked at John Hopkins University with 11 “disturbed” children who shared symptoms such as severely limited use of language, an aloofness that was indicative of an anxiously obsessive requirement to preserve sameness, and the need to shut out the world and be alone (Rimland, 1964). Kanner reflected on these children as manifesting specific features and family constellations: children who had been labelled “feeble minded” or schizophrenic, but whose characteristics linked to an inability to connect to people and objects in ordinary ways, being happiest when alone or left alone, withdrawn into a world of silent wisdom. Responses to any intrusions resulted in the autistic children treating the disturber as non-existent, as if they threatened this need to be alone. Kanner’s term, “infantile autism”, was damaging to autistic people, indicating that ASD only appears in childhood; it ignored the lifelong effects of ASD for the diagnosed child and their family alike. It is argued that this has led to most research focusing on ASD in childhood whilst ignoring lifespan development for adolescents and adults (Beadle-Brown, Murphy, & Wing, 2005).

Both Kanner and Asperger contributed many insights, producing knowledge and treatments for ASD. Today, ASD refers to a syndrome, a disorder, and a syndrome linked with the idea of a negative social affect, known as “autistic isolation”, observed with psychiatric disorders. Considered pervasive, autism is a developmental disorder characterised by “qualitative impairments” in language, communication, and social interactions coupled with ritualism and repetitive stereotypical patterns of behaviour, with onset prior to the age of three years old (Silverman, 2012).

## **Diagnosis of ASD**

Initial worries about development of young children often start with children not reaching milestone achievements. Studies have indicated that language delay and abnormalities in social responses are the first clues that raise parental awareness of the situation (Chawarska et al.,

2007). Some parents discuss how they felt right from birth that their child was different. This could have been through comparisons with older children, suggestions from other family members, or previous familial experiences of ASD, prompting the parents to seek professional advice (Farrugia, 2009).

Developmental regression indicated by a loss of former language, social, or motor skills is known to affect 15-30% of cases of ASD and form a significant stimulus to seek a medical assessment (Ben-Itzhak, Ben-Shachar, & Zachor, 2013). Movement deficits have been found to be a pervasive feature of ASD and there are suggestions that motor deficits may be a marker of the disorder (Dowd, McGinley, Taffe, & Rinehart, 2012). Motor deficits can include anomalies in walking patterns, hand movements, and eye-hand coordination.

In the absence of neurological and biochemical markers, clinical diagnosis is based on observations of behaviour and the historical information of both the child and parents. This is normally done through an Individual Developmental Assessment with professionals in linguistics, occupational therapy, and psychology observing the child in a clinical setting. Developmental level hearing tests may be ordered along with blood tests for other conditions associated with ASD including Fragile X and Retts Disorder (Paynter, 2015).

According to the DSM-IV-TR (*Diagnostic and Statistical Manual of Mental Disorders, IV-Text Revision*) (American Psychiatric Association, 2000), a diagnosis of ASD is indicative of three major deficits in communication, cognition, and socialisation that are pervasive and spread across the lifespan (Ingersoll, Walton, Carlsen, & Hamlin, 2013). Moreover, ASD is representative of a group of neurodevelopmental disorders that includes Autism Disorder; Asperger's Disorder; Retts Disorder; Childhood Disintegrative Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (American Psychiatric Association, 2000), which adds complexity to the assessment of behaviours displayed and, therefore, the diagnosis.

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) (American Psychiatric Association, 2013) removed Asperger's Disorder and Autism, replacing them with one diagnostic condition, Autism Spectrum Disorder (Bennett & Goodall, 2016). The change relates to the lack of support through research of the distinctive categories of ASD on the DSM-IV-TR denoted as autistic disorder; Asperger disorder; pervasive developmental disorder not otherwise specified; and childhood disintegrative disorder. DSM-V's diagnostic criteria

include seven distinct eligibility benchmarks, an increase of one criterion from DSM-IV-TR. Most of the adolescents in this research were diagnosed with the DSM-IV-TR. The DSM-IV-TR diagnostic criteria used until 2013 is given in Table 1 below:

**Table 1: DSM-IV-TR diagnostic criteria used until 2013**

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- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
    - (a) marked impairment in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
    - (b) failure to develop peer relationships appropriate to developmental level;
    - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people; (eg. by a lack of showing, bringing, or pointing out objects of interest); or
    - (d) lack of social or emotional reciprocity.
  - (2) qualitative impairments in communication as manifested by at least one of the following:
    - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime);
    - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
    - (c) stereotyped and repetitive use of language or idiosyncratic language; or
    - (d) lack of varied, spontaneous, make-believe play or social imitative play appropriate to developmental level.

- (3) restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
    - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
    - (b) apparently inflexible adherence to specific, non-functional routines or rituals;
    - (c) stereotyped and repetitive motor mannerisms (eg. hand or finger flapping or twisting, or complex whole-body movements); or
    - (d) persistent preoccupation with parts of objects.
  - B. Delays or abnormal functioning in at least one of the following areas, with onset before 3 years old:
    - (1) social interaction;
    - (2) language as used in social communication; or
    - (3) symbolic or imaginative play.
  - C. The disturbance is not better accounted for by Rett’s Disorder or childhood disintegrative disorder.
- 

Cited in Johnson, Myers, & The Council on Children with Disabilities (2007).

## **ASD symptoms**

### *Social and emotional disturbances*

The social context of the world we live in is profoundly difficult for children with ASD to understand. As noted in Kanner’s original work, children with ASD often will not spontaneously respond to a greeting or farewell (smiling, gestures, eye contact) or even acknowledge people in close proximity to them, preferring to look “through” or past people. Often eye contact is avoided: research in adults with ASD found they focus on the mouth region, avoiding the eyes, which was linked to the likelihood of having difficulty in reading others’ emotions (Spezio, Adolphs, Hurley, & Piven, 2007). Children typically use intentional eye contact and gesture to

share attention and to direct another person to an object of interest. Known as joint attention, this skill plays an important role in social and language development. Impaired development of joint attention is a key feature of ASD (Dawson et al., 2004).

Social communication and social interaction across environments are characterised by unusual social approaches, failure of conversations back and forth, and limited shared interests. The severity of this can be seen in some people with ASD displaying a total lack of social interaction. These behaviours may be coupled with poor integrated verbal and non-verbal communication, a lack of understanding and use of non-verbal communication and, frequently, with a total lack of facial expressions or gestures. This leads to a difficulty in cultivating and maintaining relationships appropriate to the developmental level of the child, adapting to different environments, engaging in imaginative play, and sharing or making friends, and can culminate in an enduring lack of interest in people (McPartland, Reichow, & Volker, 2012). Simply not making socially appropriate forms of communication that link to meeting and greeting others will severely impact on the ability to socialise, make friends. and have lasting relationships with others.

## **ASD and an ID**

ASD is commonly linked to intellectual functioning as being the best predictor of the severity of the symptoms of the disorder (Ozonoff, Goodlin-Jones, & Solomon, 2005). According to the DSM-IV-TR, 75% of individuals with ASD will also have an ID. It has been noted by the Centres for Disease Control and Prevention that between 33.1% and 58.5% of 8-year olds with ASD also had IQs less than 70 (Centre for Disease Control, 2014). Therefore, research data suggests that there are a significant number of children who reach the criteria for an ID with ASD. This is further impacted by the misconceptions of both ASD and an ID held by parents, teachers, and other professionals from developmental, emotional and cognitive perspectives, leading to large discrepancies in satisfaction with services and predictions about lifetime trajectories (Geiger, Smith, & Creaghead, 2002).

The bi-directionality of ASD and an ID may make diagnosis difficult for professionals. Misdiagnosis has impacts in relation to intervention strategies and how people are perceived by

others, including families and wider systems such as school and the community. Support funding—including funding for a teacher aide in school or respite for families—is directly linked to diagnosis and expressed behaviours. Having ASD and an ID, with only one formal diagnosis will influence how much help and support is going to be available for a family or a school (Konstantareas, 1990). It can be argued that this bi-directionality will also impact on the behaviour of the adolescent with ASD and the resulting impacts of those behaviours across environments.

### **Diagnosis of an ID**

An ID is categorised by concurrent deficits in intellectual and adaptive functioning with onset prior to adulthood. The intellectual functioning component of the diagnosis refers to ‘significant sub average intellectual performance: an IQ of approximately 70 or below’ (American Psychiatric Association, 2000, p. 49). Adaptive functioning deficits are concurrent impairments in at least two theoretically derived adaptive skill areas relating to self-care, communication, social/interpersonal skills, use of resources within the community, self-direction, functional academic skills, health, and safety (American Psychiatric Association, 2000).

According to the American Association on Intellectual and Developmental Disabilities (2002), an ID is characterised by significant limitations in intellectual functions and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills (*see Table 2*). Age of onset is prior to 18 years old.

### **Table 2: American Association on Intellectual and Developmental Disabilities assumptions on applying the definition of intellectual disability**

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Five assumptions essential to the application of the definition:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age, peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioural factors.

3. Within an individual, limitations often coexist with strength.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalised supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.”

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Kring, Johnson, Davidson, & Neale (2012, p. 47).

### **Prevalence of ASD**

There has been considerable debate regarding the prevalence of ASD. According to Carpenter, Boan, Wahlquist, Cohen, Charles, Jenner & Bradley, (2016) in the 1960s and 1970s, it was believed prevalence was 1 : 2500. By the 2000s, it was considered that ASD affected 1-2% of the population. Carpenter et al. (2016), argue that estimates are associated with three key factors: time, definition, and methodology. Time relates to more recent studies that show a higher incidence of ASD than those implemented in the past. The cause of this is unknown; however, there is a belief that it is associated with growing awareness in the professional community, lowering the age for diagnosis, and a broadening of the ASD criteria.

Secondly, the definition of ASD also affects prevalence. According to Maenner et al. (2014), the application of the DSM-IV-TR and the DSM-V respectively result in a prevalence of 11.3 per 1000 versus 10 per 1000 in the same population. Finally, the methodology used that does not directly assess children has led to both false positives and false negatives in the results. This might indicate ASD diagnoses are underestimated because not all children with ASD are identified as having the disorder, suggesting population-based screening and assessment may identify those who have gone undetected.

Prevalence of ASD in 2014 was estimated to be 1 : 68 according to the Centres for Disease Control and Prevention (CDC) and the Autism and Developmental Disabilities Monitoring Network (ADDM) (Centre for Disease Control and Prevention, 2014). The ADDM approach to prevalence prioritises methodological commonality across participatory sites and study years. This approach has decreased comparison errors associated with methodology variation. The strength of this approach is in its recognition of the complex nature of ASD and the high

incidence of misdiagnosis as well as alterations from the DSM-IV-TR to the DSM-V.

Prevalence of ASD is important in terms of governmental planning for funding. In Aotearoa New Zealand a broad number of government departments are involved, including the Ministries of Health, Education, Social Development, and Justice. Therefore, inaccurate estimates could affect the criteria and equity of funding for families.

## **Brain development**

There is wide agreement that the brain of an autistic child is characterised by dysfunctions in its form, structure, and functionality, reflected in the abnormal growth of several brain structures including the frontal cortex, amygdala, and cerebellum (Polsek, Jagatic, Capanec, Hof, & Simic, 2011). Moreover, at a cellular level, impacts on brain development include abnormal cell division and increased neuronal inflammation. Recent work has focused on the irregular patterns of hypo and hyper connectivity (Kana, Uddin, Kenet, Chugani, & Muller, 2014; Muller et al., 2011) that relate to the development of ASD. According to Courchesne, Carnes & Davis (2001), the brains of children and adults with ASD are larger than those without ASD and, interestingly, this growth starts at around 2-4 years for the child with ASD. There have been some suggestions that the reason for this growth might be associated with a lack of neural pruning that becomes evident as the brain matures. This trend does not continue: other studies have shown that brain growth slows abnormally in later childhood for children with ASD.

## **Genetics**

It is believed that ASD has a genetic basis, observed in monozygotic twin studies that suggest heritability, and this belief is supported by ASD being linked to chromosomal disorders like Fragile-X, tuberous sclerosis and neurofibromatosis type-1 (Jeste & Geschwind, 2014). However only about 5-10% of individuals with ASD will have a clear monogenic origin, whereas in 20-30% of individuals, known genetic risk variants are found and this is associated with copy number variants and sequence variants. A deletion on chromosome 16 that is indicative of a genetic flaw has been identified as increasing the risk of developing ASD (Weiss et al., 2008). Genetic contribution is further supported in studies of families where more than

one child has ASD or a language delay. In these families, unaffected siblings will exhibit social communication and interaction deficits (Constantino, Zhang, Frazier, Abbachi, & Law, 2010).

## **Treatments for ASD**

### *Medication*

Haloperidol (an antipsychotic medication used in the treatment of schizophrenia) is the most common medication used to treat problem behaviours in ASD. Its use, in some studies, has been linked to the reduction of aggression, social withdrawal, stereotyped motor behaviour, maladaptive behaviour and self-injury (McBride, Anderson, & Shapiro, 1996). However, it has shown no positive results in relation to social functioning and language impairments.

Furthermore, Haloperidol has serious side effects such as drug-related dyskinesia, or jerky muscle disturbances. Other drug interventions have centred on lowering abnormally high levels of serotonin in children with ASD. The drug in question was Fenfluramine which initially seemed to have positive effects on thought processes and behaviour; however, subsequent testing has not reproduced such positive outcomes (Kring, Johnson, Davidson, & Neale, 2012).

### *Behaviour modification*

Ivar Lovaas was a name synonymous with operant conditioning treatment for children with ASD in the late 1980s. His program of therapy involved 40 hours a week with a clinician and almost every waking hour at home with the parents of intensive behavioural modification where four-year-old children were rewarded for being less aggressive and more compliant. His work investigating antecedents and consequences and how these maintained a problem behaviour was the precursor to experimental functional analysis.

The results of initial studies were positive and encouraging, showing increases in IQ and retention of the gains from this program. There were, however, weaknesses highlighted in the study, because it was not a randomised, controlled clinical trial and controversy over the administration of aversive “punishments” including shock treatment for high end life-threatening behaviours and thigh slapping for less urgent behaviours. Nonetheless his work has been

declared to be pioneering and many believe that he worked tirelessly until his death in the service of families with experience of ASD (Smith & Eikeseth, 2011).

Parental education is important, according to Koegel, Schreibman, Britten, Burkey, & O'Neill (1982) who observed that 25-30 hours of parental training is equivalent to 200 hours of clinical treatment to improve behaviour of children with ASD. This observation is associated with pivotal response treatment where children are offered choices and then reinforced for desired behaviours with natural motivators such as play and social rewards including proximal praise.

Communication difficulties experienced in ASD have been approached by traditional speech and language therapies and can include augmentative communication systems such as the low technology Picture Exchange Communication System, story boards, electronic talking word processors, interactive errorless writing software, and high-technology iPad apps currently used in schools (Hill & Flores, 2014).

## **The social location of ASD**

### *The biomedical model of ASD*

For the past two hundred years, the biomedical model of health and disease has been the dominant perspective within medicine. The assumptions of the biomedical model are that the body and the mind are separate entities and all disease and physical disorders are biological in origin, born from viruses, bacteria, physical injury, or biochemical imbalances. Explorations within medicine has been mechanistic, searching for the primary biological cause of disease and largely ignoring the social and psychological aspects of health (Lyons & Chamberlain, 2008).

This reductionist view has seeped into ASD research which has concentrated on brain and genetic structures for clues as to why ASD develops. This approach has highlighted the abnormal, maladaptive, and pathological behaviour, and this focus, in turn, informs stereotypes and partial views of disability. There is certainly a need for the biomedical model which has given rise to two centuries of discovery and development in medicine. However, because it tends to avoid the social contexts of health, it also overlooks the positive lived experience of ASD that may prove useful for science and families alike.

Common treatments for ASD have focused on medication and behavioural therapy. The most successful have included both; however, notably very few have had positive results and this is indicative of the difficulty in altering the pervasive course of this disorder. Treatments have targeted changing the most unusual behaviours of ASD, expanding the individual's social and communication skills, and modifying behaviours that are deemed outside social norms. It is this adjustment of unwanted behaviours that is encouraged by the social normative golden standard, which is perpetuated by the deficit biomedical attitude which highlights individual failure and gives rise to an "othering" of the experience of diversity. These perspectives have generated negative stereotypes and biases that highlight personal failure and deviance. This model is consistent with ableism (Nelson & Prilleltensky, 2010).

### *Ableism*

Ableism is identified as a 'non-factual negative judgement about the attributes and capabilities of an individual with a disabling condition' (Nelson & Prilleltensky, 2010, p. 432). The historical record of disability was documented as far back as ancient Greece and Rome where hard daily manual labour, poor living conditions, and feudal wars were common, resulting in many people being born disabled or becoming disabled in later life.

During the Middle Ages, disability and mental health conditions were associated with the demonic, the supernatural, and spiritual possession. "Treatments" were often brutal, ranging from ingesting foul liquids to torture and execution by fire or drowning, with mostly women and children being put to death (Zilboorg & Henry, 1941).

New developments in the 1800s saw education as a tool to support those people who were deaf or blind, followed by a rapid expansion of institutional structures that indicated a custodial approach where people with an ID spent the course of their lives institutionalised. This model of professional health support reflected the objectification of people and the need for them to be fixed to a socially normative standard, ascribing the problem to the individual, emphasising their failures (Nelson & Prilleltensky, 2010).

In modern times, the use of language, particularly in the media, can perpetuate ableism by portraying the disabled person as a poor, unfortunate "victim", "wheelchair-bound" or

“crippled”, highlighting the deficit rather than the person. Perhaps just as disabling is the foregrounding of those disabled people who overcome adversity by climbing mountains or winning races by overcoming the odds.

Autism has been associated with savant skills as previously noted, and the “hidden genius skill” discourse has not encouraged a realistic view of either the savant skill or the person who displays this extraordinary attribute. The discipline of Critical Health Psychology challenges the many assumptions that are applied to those with a diagnosis, arguing that any strengths are virtually invisible unless they are valued in some way as being outside the average human capability.

Ableism not only focuses on the individual adolescent with ASD. Parents are often blamed for poor parenting skills and a lack of engagement with schools and health services (Neely-Barnes, Hall, Roberts, & Graff, 2011). According to Hoogesteen & Woodgate (2013), the invisibility of autism encourages professional and public perceptions of odd or aggressive behaviour in public from the adolescents with ASD as stemming from a lack of parental discipline. This is further reinforced by other family members who attribute the behaviour of adolescents with ASD to inferior parenting styles (Neely-Barnes, Hall, Roberts, & Graff, 2011).

The marginalisation of individuals with ASD and their families exists in every aspect of living throughout the lifespan. Often families will be stereotyped, ignored, punished, and made to battle for recognition, equality, and adequate funding to live a life appropriate to each unique person and family that live with ASD (Neely-Barnes, Hall, Roberts, & Graff, 2011). It is my contention that these negative experiences should be challenged with what positive psychology can offer families with the lived experience of ASD. There is a need to identify and describe the strengths in adolescents with ASD to create hope for the future in terms of a parental perspective of *vicarious futurity*, by which I mean that a parent should be facilitated to engage with positive thoughts of a future for their adolescent with ASD which does not include them (Faso, Neal-Beever & Carlson, 2012).

## **Effects of ASD on adolescents**

Some of the characteristics that are indicative of an adolescent having ASD can include restricted and repetitive behaviour, adaptive skills delay, irritability, and severe behavioural disturbances that may include tantrums, aggression, non-compliance, destructiveness, self-injury, and psychiatric co-morbidities. These associated symptoms perpetuate and maintain impaired social functioning and can increase family stress and burden (Attwood, 2003). According to Klin, Danovitch, Merz, and Volkmar (2007), most children diagnosed with ASD exhibit restricted interests (RI). However, these RIs can be extremely variable in terms of intensity or manner of expression and can manifest, for example, through high-focused interests, (for example, dinosaurs), repetitive engagement in favoured activities such as lining up objects, spinning a coin, or self-stimulating by rocking. These interests can also include more obscure fascinations such as continuously turning light switches off and on, touching running washing machines, and unpicking household curtain hems. However, it is still unclear why RI is pervasive in children with ASD or the elements that give rise to this characteristic.

Attwood (2003) notes that RI in children will inhibit their ability to process environmental information, self-guided activities, and social interactions with significant others within and across environments. There is agreement that these types of RIs interfere with daily functioning and can induce and perpetuate anxiety (Attwood, 2003). Additionally, there are many adolescents with ASD who display clinically significant anxiety symptoms including separation anxiety, generalised anxiety, social anxiety, and Obsessive-Compulsive Disorder (Scahill et al., 1997). It has been theorised that RI functions to cope with negative emotional experiences (the RI offers distraction), therefore, avoiding a situation and reducing distress (Attwood, 2003).

Attwood (2003) also notes that children with ASD often display a lack of imaginative play and this links to the view that abstract thought is very difficult for individuals with ASD as they grow older. According to Erad (1985) concrete thinking is considered in the context that a person has a fixedness in the immediacy of an experience and finds it difficult to move from that experience. For an adolescent with ASD, often there is an inability to form or sustain a frame of reference that reaches past a single-minded perspective. Furthermore, not being able to shift this single-minded focus is coupled with a relatively impoverished pool of perspectives from which to make comparisons. This inflexibility has been linked to a lack of empathy for other people's

thoughts, feelings, or points of view and refers to a lack of individual, spontaneous movement-in-thought between diverse interpretation of objects or events.

Language acquisition may be delayed or even non-existent for adolescents with ASD. Adolescents can exhibit behaviours that can include stereotyped language patterns and verbalisations including echolalia or echoing what is said to them, or delayed echolalia where the surface form of a sentence or phrase may be repeated in contexts far removed from an actual event in space or time where the autistic individual encountered it. Pronominal reversal, where an individual with ASD refers to him- or herself as “you” and to others as “I” is another language peculiarity characteristic of ASD (Kanner, 1946). Additionally, another diagnostic feature of ASD is where speech is not used as a method of communication even after it has developed.

Obsessive adherence to routines, ritualistic patterns of non-verbal behaviour, and extreme insistence on sameness (where intense distress is generated by even minimal change) are hallmarks of ASD. Other behaviours include hyper- or hypo-reactivity to sensory input, frequently with a lack of response to pain, heat, or cold, or adverse responses to specific or unexpected sounds (McPartland, Reichow, & Volker, 2012). These behaviours can impact on social and environmental participation for an adolescent and can include difficulty in accessing mainstream schooling, community events, activities, places (eg. shopping, church, movies), and healthcare (eg. hospitals, doctors, dental surgeries). This further perpetuates the marginalisation of families living with ASD, commonly isolating them from opportunities to socialise in the community (Bodde & Seo, 2009). Furthermore, relationships are mediated by adequate social interactions: behaviours inherent in ASD can create barriers through challenging social skills, leading to a lack of participation in the social environments (Wilkinson-Meyers et al., 2014).

Another factor affecting an adolescent with ASD that is not usually discussed either in the private sphere or within research is faecal and urinary incontinence. According to von Gontard, (2015), there are three types of incontinence: nocturnal enuresis, daytime urinary incontinence, and faecal incontinence. All three types are more common in children with physical and intellectual disabilities and are highly persistent in adolescence and adulthood where incontinence can become a chronic condition. Accepting that ASD is commonly associated with an ID, this behaviour will significantly impact on the adolescent and their family. Cognitive

behaviour therapy is the most common form of behavioural modification around incontinence; therefore, adolescents with a low IQ may find it difficult to engage with this type of therapy.

### **Effects of ASD on parents**

Parenthood is a step in human development that is socially valorised with expectations and cultural influences and is seen to be the natural next step after couples commit to each other. Normal patterns of parenthood include loving, protecting, nurturing, and teaching children to become productive members of society. A diagnosis of ASD at some point in childhood alters these normative pathways and future planning for parents and families.

There are many impacts for parents of raising a child with ASD and these can include psychological impacts on mental health and well-being, extra financial costs of having a member of the family who is disabled, and a sense of loss stemming from uncertainty over the future. Furthermore, parental anxiety may increase when considering what the future will bring when they are no longer able to care for their loved one (Benjak, 2009).

According to Benjak (2009), there is clear evidence in research that parents of children with ASD report increased negative impacts on mental health over parents of children in other clinical and non-clinical groups. Furthermore, negative impacts for parents of adolescents with ASD include stigmatisation from others, uncertainty of the future, deterioration of marital or child-parent relationships, feelings of loss and grief, and a lack of perceived social support and attachment (Falk, Norris, & Quinn, 2014). Additionally, boys are more often affected with ASD than girls, with ratios ranging from 2 : 1 to 6.5 : 1. This may impact on parenting in the case of mothers who are primary caregivers raising boys who, as adolescents, are often physically stronger than women (Johnson & Myers, 2007).

Moreover, an argument has been offered that parental stress and mental health and well-being are directly correlative with the severity of the autistic behaviours exhibited by their adolescent son or daughter (Durate, Bordin, Yazigi, & Mooney, 2005). This is supported through research where the majority of studies focus on three core predictive variables, autism symptom severity, adolescent externalising behaviours, and social support. Symptoms of ASD have already been discussed above in terms of severity and this further links with maladaptive behaviours.

However, according to Estes et al., (2009) mothers of children with ASD experience significantly higher stress than mothers of children with developmental delay who do not have ASD.

In contrast, there appears to be a difference in this experience where fathers are comparatively unaffected by the severity of symptoms associated with the adolescents with ASD, but affected more by the stress on their partner. This supports a view that mothers experience higher levels of mental health impacts than fathers. There are, however, mediators of this outcome that include the parental perception of a respite caregiver's expertise in being able to provide quality care for their adolescents with ASD (Gray & Holden, 1992). Harper, Dyches, Harper, Roper, and South (2013) found a positive correlation for marital quality for both women and men that was associated with the number of hours of respite care available to the adolescent with ASD. In terms of social support, formal and informal respite care for the primary caregivers indicates lower scores of depression, anxiety and antagonism (Gray & Holden, 1992). Formal supports for parents are also linked to governmental funding streams. Funding that is criteria-driven or difficult to access are also sources of frustration and anger for parents. This thesis does not address this area of parental experience in depth but it is worth noting that there are many barriers to equitable funding in a neoliberal, criteria-driven environment that seeks to ringfence entitlements for support for parents of disabled adolescents (Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014).

There is a need to understand the mechanisms of resilience that can be built by parents who deal daily with adolescents with ASD. Furthermore, there is a need for research into adolescents with ASD approached from a positive perspective and challenges the deficit stereotypes associated with ASD by grounding the parenting experience as rewarding and hopeful. According to Bultas & Pohlman (2014), parents will engage in thoughts of the future for their offspring that include stereotypical ideas of marriage and grandchildren and other normative, socially-validated human lifespan milestones. Seen in the context of having an adolescent with ASD, this can create anxiety around what the future might hold for your loved one as they grow into adulthood. According to Harper, Dyches, Harper, Roper, and South, (2013) there is a growing body of evidence relating to how parental perceptions can impact on levels of relationship satisfaction for the adolescent and the family. It can be argued that being able to

focus on the strengths of the adolescent with ASD will support health and well-being for the parent and other members of the family. According to Carver and Connor-Smith (2010), dispositional optimism is linked with positive parental physical and psychological well-being.

## **Psychological perspectives on ASD**

### *Positive Psychology and ASD*

Recent studies within positive psychology have focused on the contribution of positive adjustment in terms of well-being and life satisfaction in families with adolescents with disabilities. Through an understanding of positive psychology, optimism has been shown to decrease some of the ongoing stressors experienced by parents in the day to day care of an adolescent with ASD. Optimism is associated with the expectation of good or positive outcomes occurring and is correlative to improved social support and well-being of mothers of adolescents with ASD. Hopefulness is another construct linked to beneficial outcomes, including improved psychological well-being. Known as trait hope (tHope), it is clarified as being associated with hope *pathways* which connect to the belief that routes to the desired goals can be obtained and hope *agency* that connects to the belief that a desired goal may be achieved. Furthermore, these beliefs mediate and influence each other (Snyder, Rand, King, Feldman, & Woodward, 2002).

According to O'Brien (2015), a large proportion (84%) of adolescents with ASD still reside at home with their parents into adulthood. This may be a result of multiple factors including an adolescent's resistance to transitions, parental anxiety, or a lack of appropriate resourcing (Vernon, 2014). Other things remaining equal, parents are less likely to outlive their offspring. Therefore, being able to engage in thinking about how to best support the independence of adolescents with ASD after the parents are no longer able to, is important to future optimism and lowering anxiety for the parents. This thesis, therefore, explores parents' perspective of the strengths that are inherent in adolescents with ASD and how these strengths contribute to life satisfaction for the whole family. Emotions that are linked to strengths include self-esteem, a sense of achievement, mastery, and control. Furthermore, being able to identify and articulate what strengths parents see in their loved ones could allow them to engage in thoughts for the

future where these strengths can be utilised to provide life satisfaction for their loved one when they are no longer residing at home.

### *Strengths in adolescents with ASD*

When considering strengths in adolescents in the context of the present research, one must identify what these strengths are and how they are associated with this cohort in the context of ASD. This then generates the question of whether ASD can be utilised to enhance these strengths. As previously discussed, both Kanner and Asperger described incongruent specialist skills displayed among large deficits within cognitive abilities, personality structures, and other individual personality systems. Skills such as visuospatial abilities, pitch discrimination and melodic memory, calendar calculation, and extraordinary memory for facts are far more common in individuals with ASD than other groups (Treffert, 2009). These skills have been given various labels including savant syndrome, idiot savant, islets of abilities, special isolated skills, and uneven cognitive profiles.

In research by Colavita, Luthra, & Perry (2014), parents identified strengths of adolescents with ASD that aligned with five meta-themes based on conceptual commonalities. These include personality characteristics, social personality characteristics, cognitive functioning, behavioural coping mechanisms, skills of displaying loving behaviours, having a sense of humour, enjoying playful fun, and displaying problem-solving skills where adolescents can problem solve by trial and error. There were mediators to these behaviours such as the family contexts including the level of income and education of the parents alongside where the adolescent was placed in age relative to other siblings and the number of siblings in the family.

Of interest to me within this research is how parents perceive strengths and if they feel that these strengths can support transition over the changing lifespan to facilitate productive and valued lives in the future. Having skills in completing puzzles, doing art, or dancing to music may be considered as something for an adolescent to engage that, in the future, could facilitate self-esteem, exercise, cognitive engagement, fun, and enjoyment. Utilising strengths in a creative manner can support health and well-being for the adolescent in the present and into the future.

## **Attitudes of families**

Every aspect of family life is impacted in some way by the lived experience of ASD. Clearly, there are impacts for the overall well-being of a family. These include the need to source outside avenues of both informal and formal care. Parents often become experts in many areas of their adolescent's life. In New Zealand, the Ministries of Health, Education, and Social Development are the main agencies that support adolescents with ASD. This support can include referrals for a formal diagnosis, assessments for respite care, behavioural specialist services, child disability allowances, adult disability allowances, and individual financial benefits.

Adult resources for ASD can be accessed from approximately 17 years old when they can enter some residential services in certain areas of the country (Ministry of Health, 2016). The specialist education system allocates funding for a disabled child to remain at school until they are 21 years old and fund access to specialist services including occupational therapy, speech and language therapy, orientation and mobility services, and educational psychologists (Ministry of Education, 2012).

At 18 years, an application may be made to the New Zealand Ministry of Justice under the Protection of Personal and Property Act (1988) for a relative, other adult person, or institution to administer welfare guardianship and property management on behalf of a person with ASD who lacks capacity to make informed decisions about their care or assets (Aotearoa New Zealand Association of Social Workers, 2015). Parents are frequently advocates for their adolescent's rights and, particularly, mothers seek full participation within the community for their loved one with ASD (Seligman & Darling, 2007). This has been described as a "crusadership" model where mothers develop specialised capability in navigating systems and dealing with professionals, redefining the identity of the parent to someone with expertise across the environments that adolescents with ASD will engage with over their lifetime (Voysey, 1972).

## **Optimism**

Ekas, Timmons, Pruit, Ghilain, and Alessandri (2015) highlighted positive ways that resilience to aversive events and ongoing challenges can be constructed. There are individual factors that are important in the context of personality and coping styles. They include optimism, benefit

finding, coping techniques, and perceived social support. Benefit finding is characterised by being able to find positives within a situation. For parents of adolescents with ASD some of these benefits have included considering new possibilities, growth in character, fostering appreciation, spiritual growth, and developing a deeper understanding of their adolescent and of ASD.

Dispositional optimism has been linked to an increase in psychological and physical well-being in a significant body of literature. Optimism has been a predictor of increased happiness, as family satisfaction, and higher levels of optimism are related to lower levels of negative outcomes. There has been a small number of relationship satisfaction studies for parents of adolescents with ASD and the insight has emerged that a more positive perception of an adolescent's behaviour correlates to an equally more positive perspective of relationship adjustment. According to Gordon and Baucom, (2009) personal characteristics including optimism, coping strategies, and positive affectivity are restoratives for relationship satisfaction. These strategies include positive reinterpretation of behaviours that are associated with ASD, active coping or acceptance, and planning in terms of strategies and interventions. Moreover, they found having social support, whether from a partner or family, is extremely important in the context of day to day care and a protective factor in terms of family well-being.

## **Hope**

Hope may be seen as involving such factors as temporality, desirability, and expectancy. Temporality is where hope is implicitly oriented towards the future (McCarthy & Warrington, 1990). Desirability links hope to a wished-for future, towards the attainment or possession of something. Hope is not only cognitive but conative and implicit to motivation, and is linked to the intensity of individual value and importance of what is hoped for. Hope is associated with expectancy, where there is a belief that the desired future is both possible and probable. Therefore, hope is the tendency to visualise and engage with perceptions of the future positively. A hopeful person makes a subjective assessment of a desired future, deems it significant and achievable and, therefore, maintains the belief that it is possible (Stotland, 1969).

A balance between benefitting the self and benefitting others is a requirement of social living, framed in Brewer's (2004) argument that humans are neither absolutely selfish nor altruistic but, instead, their behaviour and motivation are highly adaptable and responsive to social and contextual elements within their environment. Hope and gratitude are important concepts within studies about happiness and are both positively correlated with well-being. Lazarus (1999, p.653) purports that hope is 'to believe that something positive, which does not presently apply to one's own life, could still materialise'. It could be argued that this can include a person's hope for another's well-being and, where the other is a significant person in one's life, that the hope for that person's well-being forms one's own hope. This has been supported by other theorists. McGeer (2004) contrasted egocentric hope with hope concerning others' well-being. Godfrey (1987) identified the difference between the hope of one's own benefit (hope-for-me) and hope of another's benefit (hope-for-another). Wong & Heriot (2007) suggested that vicarious hope was a support mechanism for parents to maintain hope for their child sick with Cystic Fibrosis.

### **Vicarious futurity**

These elements, then, bring me to the key proposition of my thesis, that of "vicarious futurity". Vicarious futurity is identified as the hope and despair that one person has for another's future. In the health realm, aligning goals or examining expectations for the future are associated with five domains of importance, according to Nunn (1996). The first relates to a positive appraisal of the future where a parent holds a belief that their adolescent will get what they want in life. The second speaks of perceived worth where a parent believes that the adolescent will live a valued and productive life. The third domain addresses mastery and control where a parent believes the adolescent will be able to cope with most issues that she or he may face. The fourth domain describes having a sense of drive and enthusiasm where a parent has a positive perspective of the adolescent as they move to new stages and phases in life. The final domain relates to future interpersonal support where a parent can predict that other people will see their loved one as the sort of person who will have a valuable and productive life.

Nunn (1996) goes on to suggest that positive health outcomes are increased by professionals working with the hopes and aspirations that parents hold for their child's future. He also concludes that those aspects of an adolescents' life as they age that are future sensitive, will

require careful consideration when planning personal goals. This understanding can relate to future relationships, moving out of the family home and residential care as the adolescent ages into adulthood. Therefore, probing into a parent's understanding of a hoped-for future, will help facilitate the planning process of long term care. He suggests that hope is a construct that contributes to therapeutic efficacy in terms of a study factor, outcome factor, intervention variable, and recovery factor than can promote a desired result (Brown, Lemyre & Bifulo, 1992). Conversely, loss of hope has been shown to predict suicide more powerfully than depressive disorder, supporting the case for research that provides an understanding of the mechanisms that furnish hope for parents of adolescents with ASD since they have been highlighted as a group impacted by mental health and caregiver burden (Beck, Steer, Kovacs & Garrison, 1985). Finally, Nunn (1996) purports that if professionals focus on the capacity of personal hopefulness with their clients, this will lead to new skills that will support clinical practice. Therefore, these five domains are important and relevant to this research.

According to Weiss & Riosa (2015), thriving, a term used in the context of ASD, relates to the pursuit of "idealised personhood" underpinned by the functionally-valued behaviours that contribute to the identity of self, family and community. Moreover, it relates to positive outcomes such as happiness, satisfaction, and resilience and is found in positive Youth Development Theory (Lerner, 2005). This positive psychology perspective is further advanced in a study by Bultas & Pohlman (2014), whose research highlighted the "silver lining" associated with the optimism and self-efficacy of parenting adolescents with ASD. This silver lining analogy can reasonably be associated with the hope that a parent has for the future, particularly in the context of functionally valued behaviours (for example, utilising an adolescent's restricted interests, discussed earlier in this chapter). The need for order and routine is closely identified in ASD and can support daily living skills such as cooking, cleaning, and purchasing groceries, with the support of a paid or voluntary worker.

Additionally, according to Nota, Soresi, Ferrarai, Wilgosh, and Scorgie (2003) quality of life is generated by parents who develop adaptive coping strategies, reframe negative thoughts, and maintain a positive outlook, all of which are indicative of the silver lining perspective. There is a legitimate case to be made that supporting a parent's vicarious futurity is a predictor for life

satisfaction. In the context of the foregoing discussion, it supports a positive effect for the parent's and, ultimately, the adolescent's, mental health and well-being.

According to Gray (2002) who conducted one of the few longitudinal studies of families living with ASD, just under half of the parents researched had notably less emotional stress ten years after the initial research. This was attributed to several reasons including the increased independence of the adolescent with ASD, and an increased awareness and acceptance of ASD by the parents. Parents indicated that other children in the family had developed more independence and were socialising outside of the family home with a stable network of friends whom they interacted with regularly. In turn, these friends were accepting of the sister or brother with ASD. This was extremely encouraging for the parents and it was expressed in terms of the other members of the family having a "normal life". There also appeared to be an increase of acceptance and support from the wider family including grandparents.

In Gray's research, a common theme was the lack of understanding and support from grandparents of adolescents with ASD. An important insight in this research was that the adolescents with ASD continued to increase their skills and abilities, fostering independence and autonomy across a variety of environments. Moreover, this increase in the level of skills was linked to a higher level of family satisfaction. This would likely promote a parent's view of the inherent strengths of their adolescent with ASD and the possibilities for a positive future.

## **Summary**

ASD is a neurological developmental disorder that is characterised by three major deficits of cognition, communication, and socialisation. The journey of diagnosis usually begins with a baby missing or having delayed developmental milestones, regressing from previous attained skills, or developmental differences noted by comparison with other children in the family. Whatever triggers the parent to begin the pathway to an evaluation, it is through a comprehensive assessment from professionals within medicine and education and an exploration of parental history that a diagnosis of ASD emerges. Receiving an ASD diagnosis will have different meanings for different families and there will be a variety of responses. Furthermore, as noted above, ASD is often co-morbid with an ID and this will further complicate the reaction to the

news. Many of the traits of ASD and an ID will overlap and be difficult to untangle, even for professionals. Moreover, as the young person encounters brain re-development and physical growth during the adolescent phase, being big, strong, and self-determined may add extra dynamics to the family environment.

Most research in ASD has been focused on children as early intervention is often the most effective for positive educational and therapeutic outcomes. This is a common-sense approach where intensive therapy and teaching can support social, language, and cognitive skills during early brain development. However, children with ASD grow, mature, and continue to develop and ASD continues to impact on their behaviour and personalities as they move into adulthood. This, therefore, create gaps in knowledge, not only in research but also in the evaluative systems that seek to support those with this lifelong disorder beyond childhood.

Having an adolescent with ASD creates family stressors and stress levels have been linked to the severity of the behaviours associated with ASD. My interest in this research is to confront the biomedical model that underscores ASD in negative and burdensome terms. For parents of an adolescent with ASD, it is important to remember that one day their loved one will be without their support. Ordinarily, parents do not outlive their children and if a child is to grow into an adult who still requires support, the parent will need to plan for the future they envisage for their child. Higher hope predicts overall life satisfaction and individuals with higher hope have been found to have more positive emotions than those with lower hope (Oettingen & Gollwitzer, 2002). Furthermore, hope has been observed to play an important role in parental adjustment and adapting to their loved one's condition and disability where it is used as a tool of resilience (Watson & Hayes, 2011).

Vicarious futurity supports a positive outlook for the future. According to Watson, Hayes, Coons, and Radfors-Paz (2013), parents in their research discussed thoughts of the future pertaining to their anticipation that their adolescent could live away from home with some support. It is, therefore, the contention of this thesis that if a parent holds on to hope as a tool for resilience in the present moment, they can utilise this tool as a mechanism to set up future living arrangements that best suit the individual adolescent, considering their specialist skills and high focus interests, positively utilising ASD as part of their adolescent's future.

## **Rationale for the present study**

### *Research objectives*

In the past decade, there has been a call to consider the experience of ASD through the lens of positive psychology, challenging reductionist, pathologising perspectives that ignore positive aspects of the parental experience. This can support individuals to flourish by promoting the development of factors that increase capacity for love, forgiveness, courage, perseverance, and future-mindedness (Seligman & Csikszentmihalyi, 2000).

According to Boyd, Conroy, Mancil, Nakao, and Alter (2007), strengths and talents can influence other positive attributes or offset weaknesses, thus, are useful in daily interactions of those with ASD. This is further supported by Trivette & Dunst (2011) who argue that interests can be utilised as strengths in terms of capitalising on them to support social responses and responsibilities. Recognising strengths is a method that can identify personal, familial, and larger contextual measures that are valuable to adolescents with ASD and have been found to mediate more positive attitudes and beliefs of parents. This creates greater hope about the abilities of the adolescents, contributes to stronger bonds with the parents (Cosden, Koegel, Koegel, Greenwell, & Klein, 2006), and generates increase of relationship satisfaction for the adolescent and other family members (Harper, Dyches, Harper, Roper & South 2013).

In some research parents report that their loved ones have strengths despite having ASD, those associated with being loving, playful, having a sense of humour, and being able to independently problem solve (Colavita, Luthra, & Perry, 2014). According to Howlin, Goode, Hutton, and Rutter (2004) individuals with ASD rarely gain independent living, full employment status, or complete accessibility in the community. Therefore, if we accept the longitudinal research by Gray (2002), who suggests that adolescents with ASD will improve over time from childhood in terms of less challenging behaviour and the development of skills towards independence, this supports a compelling case for identification of strengths in adolescents with ASD, as focusing on strengths can increase this skill development. Carter et al., (2015) argued that strengths and opportunities for the development of these strengths was mediated by parent education level, family income, and number of siblings within a family, and could be associated with personal agency and competence. Parents are, therefore, in a key position to identify

strengths in their loved one across different environmental contexts including home, school, and community.

### **Research questions**

In seeking to explore vicarious futurity and the role of the parent in framing a positive future for their adolescent, this research seeks to explore how parents themselves frame their approach. The research questions of this thesis have been designed to engage the parental discourse: What strengths do parents identify in their adolescent children with ASD? Secondly, how do parents identify hope for the future through the strengths of their adolescents with ASD?

Larson (1988) argued that mothers of adolescents with a disability maintained hopefulness in the face of negative information about their loved one's future and this conflict promoted an expectation for a positive future that he described as embracing the paradox. Voysey (1972) suggested that mothers will seek full participation for their adolescents with ASD in all levels of the community by becoming experts in a complicated system dominated by professionals and government departments. The concept of mastery over the future is important in terms of personal hopefulness where there is a belief that the environment can be manipulated through parental contribution. This is supported through a sense of responsibility and efficacy that aligns powerfully with this aspirational perspective for the future.

Accordingly, the second question relates to what the parent hopes for in the future for their loved one and will be based around Nunn's five domains (Nunn, 1996). These domains include a positive evaluation for a life that links with a desired future for their adolescent (positive appraisal of future possibilities); that their adolescent will live a life that is perceived as valuable and productive (perceived worth); be able to cope with issues that arise throughout their lifetime (mastery and control); and including new and different phases in their life (sense of drive and enthusiasm). The final domain is associated with interpersonal support where others will be able to identify the adolescent as a person who will have a valued and productive life (perceived future interpersonal support). The domains are linked with parental expectations that can determine positive future outcomes for their loved one in terms of health, happiness and well-being.

## Chapter 2: Methodology and Method

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### Methodology

A qualitative design has been used in this research that is informed by hermeneutic phenomenology (Heidegger, 1962) where human experience is highlighted in temporal and cultural understandings and where a developing story is captured naturally within a social context through shared meanings of the world.

Hermeneutic phenomenology has several major epistemological assumptions. Knowledge is compared with shared backgrounds of family practices, abilities, and communication that is collectively recognised or understood by others (Taylor 1991). Furthermore, Taylor (1991) argues that we are constantly immersed in this hermeneutic sphere that creates knowledge and that the identification or clarification of meaning of this shared knowledge is linked to the involvement of an interpreter (researcher) and the interpreted (the participant) in a semantic, dialogical relationship. From this standpoint, the researcher and the parent can be considered as part of the hermeneutic sphere where experiences of the researcher and the parent will collide, be negotiated, and accepted into a space where meanings are shared and understood by each other.

The first research question asked parents or primary caregivers to identify the strengths of the adolescents with ASD. Family members are some of the most important and consistent people in the lives of children and adolescents, and parents have extensive experience in managing an adolescent with ASD on the daily basis. Many of these interactions will be some of the most important for the adolescent in terms of conveying love and affection, teaching skills and creating boundaries of behaviour. Therefore, from this position of long term care, parents are experts in the lives of the adolescents, being able to identify many intricate factors of their personalities, their restoratives, and their triggers. Moreover, having this kind of personal relationship allowed them to identify strengths that are not obvious in other areas of daily life such as school or a day service.

Parents constructed their knowledge regarding the strengths of adolescents with ASD through the lived experience of parenting that is filtered through the characteristics of ASD and how this impacts on the everyday functioning of the family home. These strengths become integral parts

of daily routines allowing ordinary aspects of life to be played out in ordinary ways. Household management is characterised by routines of cleaning, cooking, and keeping the home warm and secure. How ASD is expressed by the adolescent will influence this management process. Conventional operations of daily life for an adolescent will include attending school, being at home, weekend activities and community activities like sports and church. Strengths of ASD that support these ordinary activities were foregrounded by the parent so that they participate in other social norms like employment or socialising with others.

The second research question relates to how the identified strengths of an adolescent supports the parent to have hope for the future for their son or daughter. Parents were recognised as active participants in the construction of knowledge about the strengths of the adolescents with ASD and this understanding allowed a deeply personal narrative that was interpreted through a lens of strengths and supporting the parent's ability to hold hope for the future. This positioned the adolescent with ASD as the researched participant being interpreted and whose unique strengths were foregrounded to support positive family relationships, household functioning and a sense of predictability for the adolescent and the family. The practical engagement with everyday life, things and significant others, cumulatively create meaning that is defined within by a dyadic relationship. My role in the research was to elicit data from a semi-structured interview that was supported by a discussion of photographs provided by the parent, displaying the strengths of the adolescent with ASD and were influenced, firstly, by the discussion about strengths and, secondly, about how these strengths supported the parent to have hope for the future of their son or daughter.

## **Method**

### *Criteria for participation*

Parents or primary caregivers of adolescents aged between 13-16 years were invited to participate in this research. Originally the age range for the adolescents was 16-19 years. The first recruitment attempt through a non-governmental organisation (NGO) did not generate any participants. Feedback from the NGO highlighted that they had very few clients in the age range currently using their services. It was indicated that there was a significantly greater number of

adolescents aged between 13-16 years in the service and would I consider lowering the criteria for the age of the adolescent with ASD (J. Herbert, personal communication, March 8, 2017). An application was made to the Ethics Committee to lower the age group of the research from 16-19 years to 13-19 years. This change was approved.

### *Recruitment*

Recruitment for participants was conducted through the databases of the specialist education sector and non-governmental organisations (NGOs) which support people with disabilities in Aotearoa New Zealand. Two specialist needs schools and two NGOs were approached through emails, face to face contact, or phone contact, asking if they would support the research by posting out participant invitations and information sheets to parents and primary caregivers of adolescents with a diagnosis of Autism aged from 13-19 years. For those who showed interest in the proposal, a letter to the organisation was sent, outlining what the research was about and contact details of the research supervisor at Massey University (Appendix 1). A letter of agreement to the terms of the research was requested from all organisations who agreed to assist in the research and once this was received, information packs were posted to the organisation to mail out to potential participants. Participating organisations were given research participant packs that included an information sheet for parents and primary caregivers (Appendix 2) and a parent participant invitation (Appendix 3). A pre-paid envelope was supplied for a signed parent participant invitation to be returned. One organisation utilized an electronic form of the information and invitation documents and these were emailed to participants who met the criteria for the research.

Both specialist schools were Ministry of Education schools and hold a special character designation. The NGOs were organisations that hold government contracts to support people with disabilities and their families. The organisations approached held databases that specifically identified the client's diagnosis and, therefore, the invitations were sent to only those parents and adolescents who met the criteria for the research.

## Participants

Eight participants replied to the parent participant invitation, returning their forms by the self-addressed envelope. The eight participants were contacted and an appointment was made for an initial interview. The following table (Table 3) identifies the gender and age of the adolescent with ASD and if there was a co-morbid diagnosis with ASD. The pseudonym provided by the parent or the adolescent is also given.

**Table 3: Participants' Details**

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Co-morbidity (if any)</b>	<b>Pseudonym</b>	<b>Relationship (if any)</b>
Participant 1	Female	14 years	-	Alexandra	-
Participant 2	Male	19 years	Intellectual Disability	Brandon	-
Participant 3	Male	15 years	-	Finn	-
Participant 4	Male	14 years	Intellectual Disability	Todd	Twins
	Female	14 years	General Anxiety Disorder	Tia	
Participant 5	Male	14 years	-	Star Child	-
Participant 6	Female	14 years	Visual impairment	Miranda	-
Participant 7	Male	19 years	-	Thomas	-
Participant 8	Male	14 years	-	Michael	-

### *Procedure*

At the initial interview I introduced myself, and discussed the research in full, giving the parent time to ask any questions about the research. Food was taken to share as a cultural protocol and general courtesy. The parents signed the parent participant consent form – individual (Appendix 4), at the end of this initial interview acknowledging their willingness to participate.

A decision was made during the writing of the research proposal that the adolescent was going to be treated like a research participant although it was their parent or primary caregiver who was the actual research participant. Therefore, two adolescent consent forms were designed. One for was for those adolescents who could understand what consent denotes and other was an adapted form, using pictures and simple language, for those adolescents who required this type of communication to support their understanding. During the initial interview, I discussed the rationale behind this idea and advised the parent on how to seek permission from the adolescent to be part of the research. The parents were given the choice of either the adolescent consent form (Appendix 5) or the adapted adolescent consent form (Appendix 6). Either form was left with the parent to be signed by the adolescent, and I would collect them at the substantive interview.

The research required the parents to take five photographs over a period of two weeks that, for them, displayed the strengths of the adolescents with ASD. They were used to elicit data through discussing them with the researcher. Contact was made with the parents after two weeks to see if they had managed to take the five photographs. A suitable time for the parent was made to conduct the second substantive interview.

### *Semi structured interviews*

The substantive interviews included ten parents, with two fathers, seven mothers and one legal primary caregiver being interviewed and was conducted in each participant's home. Two adolescents participated in the interviews.

Participants discussed their photographs and this conversation was used to frame and structure the strengths of the adolescent. This was supported by a set of general questions (Appendix 7)

that prompted the parent. What the parents were saying was paraphrased and often the conversation identified further strengths not always obvious in the photographs. The substantive interviews were recorded on a digital recorder that were later transcribed by the researcher. Four parents wanted to discuss a photograph that were taken at a significant event prior to the two-week timeframe of the research. These photographs were used as part of the research data as they were indicative of strengths that were displayed in other environments that had not been attainable during the timeframe of the research. Therefore, this was a way for the parents to actively direct the research and have control over what they wanted to provide to the researcher. These older photographs linked to very proud parent moments of great achievement like attending the final college school ball, or receiving a special award.

Four of the participants had the adolescent present at the time of the substantive interview due to the interview being completed late in the afternoon or in the evening. Two of the adolescents actively engaged during the interview and their contribution was included in the data analysis. Two substantive interviews were conducted with both parents present; therefore, two fathers have given their perspective of adolescent strengths and hope for the future alongside their partners.

A printed copy of the transcript was couriered to the parent along with an authority for the release of participant interview transcripts form (Appendix 8). The transcripts were couriered to the parents along with a \$20 petrol voucher for participating in the research. The researcher also included a \$20 voucher from stationary warehouse for each adolescent with ASD as a mark of respect and cultural expectation that acknowledges their participation in terms of signing the consent form. A short letter was included thanking the parents for supporting the research and some instructions regarding the right for them to alter the transcript if they wanted to. In addition, a photograph release form – parents/caregivers (Appendix 9) was added to the envelope if the researcher wanted to use a photograph in the thesis or any future publications. In one case, permission was gained to reproduce a poem written by an adolescent. A pre-paid and self-addressed envelope was included to return the documents. All transcripts were returned with the release of participant interview transcripts form signed.

## **Ethical Issues**

A number of ethical considerations were identified by researcher, the research supervisor, and Massey University Human Ethics Committee (MUHEC) regarding this research. These included privacy, confidentiality, and rights of the participants, vulnerability of the participants due to the lived experience of ASD and, whether having worked as a social worker in the regions that this research was conducted in, that the researcher might know some of participants.

Being a fully Registered Social Worker with a current Annual Practicing Certificate, I am regulated by the Social Workers Registration Act and have a comprehensive understanding of research participants' rights and the responsibilities. Therefore, the privacy and confidentiality of the participants were upheld at all times in both the face-to-face contact stage and the writing of this thesis. In terms of the research, participants were allocated pseudonyms at the writing stage of the thesis. All original recordings and research documents were kept and are being stored as per the requirements of the Massey University Human Ethics Committee: Southern B, Application 16/47 approved in January 2017.

Interviews were conducted in the homes of the participants and, therefore, there was a requirement to consider the researcher's safety. All interviews were done solely by the researcher. An assessment was made at the initial personal contact with potential participants over the phone, including information about dogs on the property and who would be present at the interview before making an appointment to meet them for the first time. Upon arrival at the home of the participant, the researcher made an assessment regarding the immediate vicinity of the home checking for congruence of what was discussed during the initial phone contact. Furthermore, the researcher had arranged with her partner a safety plan including him knowing the location of the interview, and an agreement that the researcher would text stating that everything was fine and the approximate time the interview would conclude. Any deviation from this plan would have facilitated a pre-arranged strategy to ensure the researcher's safety. At any time if the researcher had felt uncomfortable during the initial or substantive interview, she would have removed herself from the situation. At no time, during any of the research did this occur.

Other ethical issues within this research was associated with the vulnerability of adolescents and parents who participated in the research. By participating in the research, the parents were

asked to identify the strengths of the adolescents with ASD and then consider how these strengths would support the adolescents in the future. Engaging with thoughts of the future regarding a son or daughter who will require support, possibly for rest of their life, may cause anxiety for some parents. At some point in the future, the parents may not be able to support their son or daughter due to age or illness. Furthermore, all things being fair, the parent is unlikely to outlive the adolescent with ASD. Therefore, the researcher designed a services booklet with the lists of every agency that supports ASD, and counselling services, in the area where the families lived. This booklet was offered to parent's as a resource that they could read and keep for use if necessary after the research.

The adolescents with ASD were considered as participants in the research and this is underpinned by the understanding that they had a significant role within the research and this needed to be acknowledged. Furthermore, it is important to allow adolescents who are starting to develop their own ideas and identity to feel that they have some control over how they are perceived and represented particularly in research. Therefore, adolescent consent forms were designed as a method of enabling the adolescents to experience being part of the process. One adolescent read, corrected and approved his contribution in the transcript.

Although the collection of ethnicity data was not significant to this research, because the researcher is Māori with knowledge of the protocols that are required for engagement with Māori, this was exercised when required for those participants that the researcher identified as being Māori. Furthermore, the researcher consulted personal whānau members to discuss and realign the protocols of the different Iwi in the different regions where the research was being conducted. The researcher considered that these contacts had the expertise relating to Tikanga and they were readily available to support her during this research.

### **Personal reflexivity**

My 19-year-old daughter has a diagnosis of Autism and a co-morbid diagnosis of an Intellectual Disability. What I have brought to the research is personal experience of life with a baby, a toddler, a child, and now an adolescent with a diagnosis of ASD. This was highlighted against a

background of family functioning that included being employed, having other children, getting them educated and accessing the community in ordinary ways.

The inspiration to study Autism initially was driven by my daughter's diagnosis in 2001 when she was 3 years old, while parenting alone after a marital separation that coincided with this diagnosis. It seemed that my family experience aligned perfectly with the research that is indicative of negative outcomes like marriage ending in separation, and associates ASD with caregiver burden and family dysfunction. This was closely followed by engaging in the early intervention strategies from the Ministry of Education and other various supports from the specialist system of funding, including the Ministry of Health and the Ministry of Social Development. Each parent's perspective of their life with a child diagnosed with ASD was subjectively positioned against a background of values and beliefs, some positive and some negative. This is also attributable to the chaos that ensues after a diagnosis where parents will naturally try to make sense of their own and their families' lives for the present moment and for the future that lay ahead.

I have completed the Bachelor of Applied Social Science (Social Work) with Waiariki Institute of Technology. As a registered social worker and I worked in the disability and the family therapy domains of social work for 11 years. I have completed the Graduate Diploma in Arts in Psychology with Massey University. This thesis is a partial requirement of the Master of Science in Health Psychology with Massey University. I hold the Advanced Certificate of Autism and Severe Communication Disorders from Canterbury University. I am also fully accredited as a Parent Group Leader with the Incredible Years Parenting Program, completed with the Werry Centre, which is part of Auckland University.

Taken together, these qualifications, life experiences and work experiences provide a wide range of knowledge to access regarding parenting, ASD and the lived experience of ASD. Furthermore, having worked as a social worker, I still hold a strong belief in social justice and the aspiration of liberation and well-being for those members of our community who experience difference. This personal reflection on raising a family where ASD is part of everyday life, allows for the deep sense of appreciation of another parent's experience. I am exactly in the same position as the parents in the research where I am currently predicting what the future may

hold for my daughter and wondering how that future might look if her strengths are taken into consideration.

The research questions are positively oriented so the parents engaged with the positive attributes and strengths of the adolescents that they admire, in contrast to the diagnosis and stereotypical understandings of the lived experiences of ASD. Moreover, these thoughts were then discussed in terms of supporting the adolescent where strengths can be utilised to provide a sense of mastery over the future for both the adolescent and the parent. I acknowledge that my life experiences with ASD could influence the way I asked the research question, heard the answers, interpreted and analysed the parents' perspectives of strengths in adolescents with ASD, and how these strengths can support parental hope for the future. However, I believe that my experiences will also increase the thoughtfulness to the analysis of the families lived experiences of ASD.

### **Data analysis**

Analysis of the text data was guided by the process of latent thematic analysis. Therefore, interpretation of the data was employed. Latent thematic analysis takes a standpoint of the identification or examination of the underlying assumptions and patterns that shape the semantic content of the data. Using the metaphor of jelly, this relates to the surface of the jelly with its imperfect undulating surface. The surface was created by experiences or forces underneath it that created this surface (Braun & Clarke 2006). In this manner, patterns formed by the research data are examined to identify the features that have created the idiosyncratic features of the lived experiences of those parents raising adolescents with ASD. Furthermore, this data was compared across the participants to identify patterns of similar experiences that is common for those living with an adolescent with ASD. ASD was the underlying force that created the themes highlighted in the data from the interviews.

Common and repetitive words used by the parents in the discussion of the photographs formed the list of strengths or special attributes that the adolescent displayed. This list included social skills, researching information on the internet, the use of advanced technology, the use of simple technology, memory, cooking ability, artistic skills, bravery, perseverance, humor and

autonomy. Thematic analysis of the data was also supported through the five domains of Nunn's work on vicarious futurity (Nunn, 1996). Identification of strengths and a positive perspective of the future was linked to the diagnostic features of ASD through the lens of the five domains of vicarious futurity.

Domain one relates to positive appraisal of the future where parents believe that the adolescent will get what they want in life. Domain two relates to a parent's belief that the adolescent will live a valued and productive life, and is known as perceived worth. Domain three, mastery and control, is associated with a parent's belief that the adolescent will cope with most issues they face in life. Domain four, drive and enthusiasm, relates to the parents holding a positive perspective of the adolescent as they move through new stages and phases in their life. Domain five links to future interpersonal support where the parent believes that people around the adolescent identify that they will have a valued and productive life. Data was continuously reread for meanings and through interpretation that linked to the five domains of vicarious futurity. Common themes across the data included expressions the parents used to describe how ASD affects their understanding of the future.

## Chapter 3: Results

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### Strengths of adolescents with ASD

This chapter outlines the data in terms of the first research question that asks the parents to identify the strengths of the adolescents with ASD and why these attributes are considered strengths. These special skills included social skills, researching information on the internet, the use of advanced technology, the use of simple technology, memory, cooking ability, artistic skills, bravery, perseverance, humor and autonomy. For the purposes of describing these results, I will address each special skill separately, and how it was classified in the data. Participants will be identified numerically from 1-8. The letter (m), indicates the adolescent's mother and (f), indicates the adolescent's father. Pseudonym names as listed in Table 3 are used for the adolescents with ASD.

### Social skills

One of the deficits for ASD is linked to a marked reduction in socialisation. This may include a marked impairment in non-verbal behaviours and the ability to make and maintain friendships. Parents identified social skills as a strength of the adolescent because it supports interactions outside of the normal family environments.

Participant 7(f) talked about the use of technology and social media for Thomas to keep connected to friends since he has left school, creating a lively social network of people who have been a consistent part of his life since he was young. This was set against a background of 8-9 years of implementing Applied Behavior Analysis as the therapy of choice to support him to communicate.

*“He has built quite a social network. That is not a trait that people with Autism usually have. We get the feeling that we were really lucky to kind of haul him out of the Autistic place he was in, a bit more into the real world. All the ABA we did with him for years and years. We taught*

*him to talk, taught him to read, we taught him everything through that. Positive side, we couldn't be happier really, what he has achieved and where he is going”*

*“He seems to have a lot of female friends. They like him and they kind of look after him. And he organizes them to take him out on a date, go for coffee or go to movies. Facebook has been a boon for Thomas. He can communicate from home here to his friends. All of his friends are on it. And all of his friends are female pretty much, all of them. And at school they always mothered him a bit. They always looked after him. They had certain ones in each class that would look after him. That is a real neat thing, it is only because he is pleasant.*

Being polite is an important social skill. It is valued as part of a positive beginning and ending of communication that supports conversations back and forth between people. Participant 7(m) felt that if Thomas communicated in a polite manner this would facilitate positive responses from others. This strength was exemplified by a recent experience where Thomas wanted to buy a magazine and did not have enough money to pay for it. This was noticed by an older woman standing next to the adolescent and over hearing his conversation as described in the following extract.

*“Last week he went to Pak and Save and gets off the bus and he has got to catch another bus, but he got outside Pak and Save, and he went into Pak and Save, he wanted to buy a little Princess magazine. But he didn't have enough money. And so, the lady next to him gave him \$1.10 so he could buy it. I said to Thomas that is so nice. Yes, and I thanked her very, very much too. So that is cool aye? He wrote it in his diary. “If he can communicate his wants and needs, politely, we always ask him to have good manners, you always say, don't forget your please and thank you. You will go a long way if you are polite”.*

Participant 7(f), who was unaware this interaction had taken place, makes a comment about this linking to a positive perspective of the future.

*“Wow that is really cool, that is an example of getting by on his own. She could see he needed help”.*

Participant 4(f) (family with twins) discussed being polite as a sign of respect to be shown by the adolescent towards their grandparents by greeting them. This understanding linked to being part of a family and the importance of significant members of that group by acknowledging them. It

also corresponds with a social norm, however the discussion of this taking 14 years to develop into a routine is indicative of the time that it taken for Todd to learn this behaviour due in the greater part to ASD where the need to socialize is greatly reduced.

*“If grandparents arrive you have to greet the grandparents and you say goodbye when they leave. They’re not invisible, they are part of the family so there are certain things that we’ve always made as a structure of the household. The kids have to respect their elders, and they have to do as they are told, and bits and pieces, and Todd even now will know when he has crossed the line and where the line is. That has been 14 years of slog”*

Participant 4(f) discussed the use of technology to connect socially with others even though the capacity for Todd to do this, is influenced by an intellectual disability.

*“He games, he is a gamer, and in the majority of the games he plays he actually has the interaction with the other players as well going. He likes to sit out there and he will play his games, and he will sit there and he will type responses and he will also yell at it, because for these particular games you supposed to have headphones and mics on to talk to the other people playing, but we have never been that keen in him having a microphone and talk to other people because, largely what he says is inappropriate. But in saying that he does it with dialogue (typed) anyway”.*

Participant 2(m) identified a strength of Brandon’s that linked to a cultural protocol. When meeting a whānau member for the first time, Brandon who has a comorbid diagnosis of an ID performed a haka for his young niece. For Māori, the importance of Whakawhanaungatanga (reciprocal relationships) cannot be understated. It is the formal announcement of who you are and where you are from that underpins the values and beliefs of whānau (family). For the adolescent, his ability to adhere to Tikanga (custom) is highlighted as a strength through his demonstration verbally with utterances, and non-verbally with physical actions that mihi (greet) and acknowledge his connection to his niece.

*“Yes, and so I noticed that whenever he needed to meet anyone, and I was telling him look someone’s coming, you’re going to have to meet so and so, and when they come, he’ll greet them normally, but with her, it was the first time that I ever seen him have a little korero with her, then the haka with her, everyone else he will just have a little mihi to them, and then just sit down, but*

*with her, he done the haka”. “And when she sees him on Facebook, and they talk, it’s like they understand with each other, she is jabbering away in her baby talk and he goes “mm”, and she goes Ok bye uncle Brandon and he goes bye bye, and he turns the camera off”*

### **Researching information on the internet**

The internet has arguably become a consistent part of ordinary life. It has made connection to the outside world faster and easier and facilitated a world-wide stage for expression and investigation for many. Every adolescent in this research used the internet in some way. In terms of researching information, the internet was an easily accessible way find information and increase learning opportunities for the adolescent in different areas.

The use of the internet was linked to the development of learning by most families. For participant 4(f), Todd being able to research on the internet supported his daily functioning. He spent most of his time on the internet outside of attending school. For these parents, it allowed home life to be predictable and consistent. Furthermore, it has allowed Todd to learn and observe different areas of life that are not normally accessible to him and replaced using an academic book. His love for technology has supported his learning.

*“He does a lot of you-tubing, a lot of research, that he will find the information he needs on the computer, it’s got to a stage a while ago that, perhaps a year ago, researching operations. You would wander out to his screen and there would be an operation going and people would be getting their gall bladders out or whatever he was particularly interested in at the time, all of his research, even a lot of the way he talks is all generated from what he has watched on the computer”.*

Participant 7(f) identified the adolescent’s strength in research as a way for him to learn and share his findings with the other members of the family therefore allowing an opportunity to celebrate his new learning and the development of his printed project.

*“Yeah, I should go back a step and say that research is something he is really good at. Research is a really high skill for him. He will go online, he will know everything about it. He researches*

*things then he writes summaries about them. He prints them up in like a project, pages and pages of stuff, pictures, and then he reads it all to you”*

### **Use of advanced technology**

Participant 3(m) attributed strengths of Finn to his phenomenal skills in computers. The fifteen-year old's skill is related to fixing and programing computers as well as testing new programs designed by Microsoft prior to being released for public sale. This is known as the “Windows Insider Program”. Finn's input and feedback to Microsoft (America) has earned him a new Surface-Pro Tablet, a Microsoft phone and an offer of employment from the company when he leaves school. Furthermore, Finn works after school as a computer technician with a local computer repair business, owned by a family friend. Participant 3(m) discusses Finn's computer skills in terms of her lack of knowledge in this area.

*“Computers, he is part of the windows insider program, he has been involved with that since it started. “Yeah so, the woman who sent him the Surface Pro, has told him via email that she wants to employ him, so these people are genuinely impressed by his ability in terms of programming and what have you, it all goes completely over my head and I find that slightly difficult because I have no clue what he is talking about”.*

Finn participated in the semi-structured interviews with participant 3(m) and discussed how his skills in computers is sought after by others.

*“Are you kidding me, even my teachers tend to come to me before they go to the IT guys just to see if I can fix it before they go to the techies that are so busy, and it always takes forever to get something fixed. That's no problem there as the techies are great but they are so busy that if the job is not high priority it never happens (laughter) which is not their fault, I have experienced a fair bit of why that is since I took my part time job, cause there are just too many jobs”.*

It could be argued that this adolescent's skill, although being a restricted interest has supported his learning, his self-esteem and his ability to secure a career in the future.

## Simple technology

The use of simple technology was acknowledged by the participants as a strength of the adolescent's in terms of reading that linked to new learning, and a way to understand the world that is often confusing for an adolescent with ASD. Reading can be a solitary activity and therefore is a way for someone with ASD to be alone with their thoughts giving them time and space to feel safe.

According to participant 4(m), Tia could build resilience to the over-whelming anxiety that she faced daily by an expression of her feelings through art, design and reading books on her tablet. Moreover, this is also a valuable way for Tia to start forming a sense of identity which links to her age and brain cortical re-development that starts in adolescence.

*“Literacy is her thing. Her writing and her expression. She made this the other day (a laminated poster), that is what she made in English (class) the other day, she is very self-aware. Because she is so self-aware of how she feels, and she is aware of how much her anxiety affects her every day, joys of a high functioning autistic kid. Some of the stuff she is reading is beyond her years. It is because she questions everything and she is not quite sure who she is, she is having a bit of an identity crisis at the moment with sexuality and all kinds of things. The things she is reading like someone said to me the other day, are you going to let her read that, I said yeah, it is not up to me to judge what she reads. Because her comprehension and her reading ability is so high, if she was not understanding what she had read, I would be restricting things more, but because she can understand what she is reading, and because she is so non-judgmental, she accepts people for who they are, it doesn't matter what they are, gay, black, white, purple. It doesn't matter”.*

Participant 3(m) identified that reading for Finn was a strength that linked to attending school. Finn would carry a stack of books to school daily that according to participant 3(m) was used as a form of comfort. This is indicative of the anxiety that is normally associated with ASD and since reading can be a solitary activity it is a way to lower anxiety and to be “alone” at the same time.

*“he goes to school a stack of books, that is his safety blanket, most of them are about a couple of inches thick”. So, he will always have a book with him, and he can read a big, big book in less than a day, and when you ask what was in it, he can tell you, so I don’t know how he does that, it’s incredible, so he is excellent at reading”.*

During the interview with participant 3(m), Finn states, *“in my opinion any book with less than 300 pages is not a book worth reading”.*

## **Memory**

Memory has been identified in literature as a splinter skill observed in ASD. Parents identified memory as a strength that was helpful to daily family functioning, and for the adolescent it was supportive in the areas of education and community participation. Furthermore, a good memory is advantageous for school and learning by being able to retrieve facts and figures that are useful in everyday situations.

Participant 3(m) identified Finn’s memory as a strength regarding being able to remember passwords, vehicle registration plate numbers and other useful information. Finn’s skill in this area is positively reinforced by family members and supports his after-school job where he fixes computers.

*He has the most incredible memory, I think he possibly has like a photographic memory, it’s unbelievable, so when you ask him about some computing thing that is in his window 7 bible, he will reel it off verbatim. It is just like the book”*

Participant 6(m) identified that the strength of having a good memory as a tool that supported her daughter to memorize important club anthems. Miranda has a visual impairment and therefore reading the anthem from a display board was difficult for her. Furthermore, this aligns with an adolescent desire to belong to a group and wanting to fit into that group.

*“She has memorized all the chants or whatever they call them, pledges, she can’t see them from the board where she is standing, so all of the youth promise and the anthem, she has memorized it”.*

Participant 7(f) discussed Thomas having an excellent memory that is linked to his interest in local shops and stores where he can remember a large amount of historic information about them. Thomas likes to share this information with others within the community of interest.

*He has an incredible memory, and he studies shopping centers and shops and so you could ask him about almost any shop in the whole Tauranga area, about what date it opened, who owned it, when it moved from there to here, he knows, so he goes into shops that are closing down and moving and talks to the owners, “why are you closing, why are you moving, you used to be here, and you used to be here and you used to have a shop there, that used to owned by so and so. They would go “wow” how do you know all of this, that is incredible. He has huge knowledge in his chosen interests.*

## **Cooking**

Being able to cook and present food for others is linked to group activities that brings people together not only to eat, but to celebrate connectedness, reinforcing the understanding of family. Food is also culturally located for many families where celebrations and rituals include ceremonial food that indicates a sealing of an agreement. Cooking and baking highlights the skills of those cooking the food and builds self-esteem thorough positive comments from others as the food is consumed.

Participant 1(m) identified that a strength her daughter showed was in baking. Her skill was demonstrated in a very artistic skill in decorating cakes. This skill was also evident in her artwork although fewer people were invited to view her artwork. Alexandra enjoyed spending time in the kitchen and this linked to family events and celebrations where her baking skills could be acknowledged and supported.

*“Cooking, she has an incredible ability to judge whether something is sweet enough, tart enough, doesn’t always need to follow the recipe to a tee, she is very talented”.*

*Cooking, obviously everyone enjoys it, and food always brings family together, so when there is a birthday or a special occasion the adolescent will always bake and what better way to bring family together as said other than food.*

Alexandra discussed the baking in terms of people's positive reactions which contrasted with her experiences at her old school where her talents were not acknowledged.

*"Baking, the cheesecake, it took ages to bake. Probably a full day, but once I finished it everyone loved it, so that was good".*

*"oh yeah baking, I bake it and my stepdad eats it all, if we don't get it in time, technically I make it for him, so yeah, they enjoy it and I take it to school and they just love it, and they say make more, I think they love it. I have never made something bad or burnt it, or not put enough baking soda, or salt instead of sugar, or you know, yeah".*

*"I don't think my talents were recognised at school, when I was there, which is pretty sad, so stuff you school. The people at school I feel sorry for because they don't get recognised".*

## **Art**

It has been discussed by academics that artistic ability is a splinter skill associated with ASD however, it could be argued that this might have been foregrounded through the discourse of savant skills like those of Stephen Wiltshire whose phenomenal ability to draw a cityscape from memory has been well documented. The participants identified art as a strength and this was associated with the beautification of household walls with paintings and drawings, photography, designing and making masks and miniature clay models.

Art was viewed by participant 6(m) as a strength because it allowed opportunities to share this talent with family, friends and the community and was also linked to a sense of identity for [Nadine]. This was further highlighted by the adolescent focusing on eyes in her artwork which participant 6(m) suggests is linked to her wanting to overcome her visual impairment.

*“I am pretty sure she is in her bedroom right now collating a big pile of pictures to show you, there is some part of me that knows or believes that she knows that she is very good at art, she is definitely well known for her art. I have had friends that have come around and gone, that is amazing Miranda could you draw a picture for me? I have had her draw pictures for people before, and they are just been blown away, and there is that massive appreciation for what she does as well”.*

*“I think that sometimes Miranda has a real focus or concentration on eyes because she identifies that as a deficit, so she wants to draw them as perfect as possible, but she is unbelievably talented”.*

Participant 1(m) was very certain that photography was going to have an ongoing long term positive benefit for Alexandra.

*“she wants to become a photographer and I have absolutely no doubt whatsoever that that is going to be the making of this young woman”.*

Participant 3(m) identified writing poetry as a strength of Finn’s and this was reinforced by other members of the family. Finn states as follows:

*“Are you kidding me, aunty still has all my poems, I see them on the wall when I have visited her the last few times when she has taken me into the house, I have seen that she has those things on the walls, especially the one, the poem I wrote for great uncle’s funeral, that one is a big one, she loves that poem”.*

Furthermore, a local ceremony celebrant uses Finn’s poem as a teaching tool for others learning to become a celebrant. This resulted in positive reinforcement coming from outside the family circle.

Participant 3(m) exemplifies this by the following discussion; *“The celebrant actually uses (the poem) when she’s teaching people, she asked if she could take it and use it. My stepmother has been to a thing that the celebrant took and she said that she used Finn’s poem”.*

Participant 7(m) identified Thomas as a prolific artist in terms of making promotional flyers and placing art designs on carry bags of high focus interests. At the time of this research, the New Zealand television program, Shortland Street, was having its 25<sup>th</sup> anniversary of this long

running series. Participant 7(m), discussed how the adolescent would create flyers and draw art designs on carry bags that represent this anniversary of his favourite New Zealand television show. Participants 7 (m and f) celebrated this creative skill and high focus interest of the adolescent because it allows him to interact with others outside of the family environment.

*Participant 7(m) “Shortland Street, is a big thing at the moment. 25 years is coming up on the 25<sup>th</sup> of May, so he has gone back 25 years. We don’t watch it, I hope it is not too much of a drama on the 25<sup>th</sup> of May”.*

*Participant 7(f) “He likes to collect figurines and things, from McDonalds for instance, so he has made his own set of figurines for Shortland Street. He has drawn them all, by hand, and he has them all on a sheet and as he collects them”.*

*Participant 7(m) “So on the 25<sup>th</sup> May him and I, have to go to countdown and we have to pretend that you go in and you can do a swap of all of the Shortland Street characters”.*

*Participant 7(f) “And he shows it to us”.*

*Participant 7(m) “And he has a countdown shopping bag and he has got 25 years celebrate, you know how they do”?*

*Participant 7(f) “He makes his own McDonald bags and he does his own art work on them. This week is the Shortland Street collectables. And he loves showing them to the staff at the drive through, he holds them out the window, and he says you are doing this, this week”.*

*Participant 7(m) “If he gets the same worker it’s not so bad”.*

*Participant 7(f) “They get to know him after a while”.*

For participant 4(f) reinforcing family connections is linked to Todd by his high focus interests. The paternal grandmother has been a large part of Todd’s interest in building artefacts.

*“Creativity, he does a lot of masks and bits and pieces and they’re also attached to a lot of his games and bits and pieces. He decides he wants a mask and if you go and look in his bedroom, the whole wall is covered in stuff that he has built. A lot of it with his nanna, his nanna really likes building stuff with him, the last one they built was the Golden Gate Bridge. (shows the photo to me) - there is a dam. It’s not the Golden Gate Bridge, it’s the Hoover Dam. Suddenly*

*he got interested in that, so they had to build that. Everything he builds, once he has built it, he moves on from that. But you cannot part him from it either. So, we have walls full of stuff that he has built with his nanna, but no you are not allowed to throw any of it away”.*

Participant 4(m) described how Tia spent time designing and creating miniature objects from polymer clay. According to the participant this was a way to make her daughter happy. When I asked participant 4(m) to define what being “happy” meant she replied as follows.

*“Yeah well that’s a bit tough at the moment. It gives her a sense of peace and it lets her block everything else out. I am not sure if that is a good thing or not, it depends on how you look at it. She is all internal. It’s all internal stuff, and the only external stuff is you see the self-injuring stuff coming out if I’ve missed cues and things”*

## **Bravery**

The parents identified bravery as a term that is associated to the adolescent when stepping outside of their comfort zone, and being able to cope with stressful everyday events. Bravery was evaluated against the adolescents having ASD and the associated characteristics that make ordinary daily life more difficult for the family and less accessible for the adolescent. Some of the adolescents in this research, had co-morbidities ranging from a visual impairment, cardiovascular conditions and intellectual disabilities that are cumulative in the effects for the adolescent. Participant 6(m) talked about the bravery of Miranda.

*“Those are the things that represent her really well, is that she is very brave, she is not too afraid of anything. So, this is her coat of arms, she has done this at school, the things that are important to her, her family, her country, St Johns and I think that is an art easel, and some drawing stuff, I would actually have to get her out here to explain that one. But she is very proud of these things, and she is patriotic, like she would fight for her family, literally, if someone hurt her little brother, look out”*

Participant 5(m) has a son, Star Child with ASD and a life threatening medical condition seeing him having had some 300 hospital appointments over his lifetime, identified bravery with a photograph of him in the waves at the beach.

*“bravery, a wanting to be present, a normality really because we go to the beach all of the time as a family. And I guess this was way of finally saying I can predict the elements, I’m no longer fearful of the elements. I guess that (the photo) was his permission to explore his manhood and the toughness”. The bravery, he will give everything a go. And he will decide very easily if he is good at it or not. Usually if he is not good, he will practice until the cows come home, if he is good, he will move onto something else. If it doesn’t float my boat, I want something more challenging”.*

Participant 1(m) identified bravery as a lack of understanding by others linked to ordinary daily things like bike riding that was underpinned by Alexandra’s use of exercise to combat depression she experienced that in part, was attributable to the negative messages she received at her old school.

*“I don’t think they truly get to see or experience or hear about the limits she has pushed herself to, or the perseverance that she’s displayed or the bravery that she has displayed, they don’t get to see or hear about that, so I don’t think that truly gets recognised”.*

## **Perseverance**

Perseverance was a common description that the parents used to discuss how the identified strengths will empower the adolescents. This was highlighted in various ways that described the adolescent’s motivation to continue against perceived barriers that are linked to ASD and to a greater extent to a lack of awareness from others about the experiences of having ASD and trying to cope in a neuro-typical world. Participant 1(m) talked about Miranda’s ability to move towards her goals.

*“Her strength of perseverance will get her to where she wants to be, and she wants to be a photographer and she wants a family, and she will get those things, she has such a beautiful kind heart mixed with, I think perseverance is probably the biggest strength that she has.*

ASD is closely linked to anxiety and for Tia getting to school and managing during the day was a strength that participant 4(m) identified linked to interpersonal support. This is understood from the perspective that the adolescent has a diagnosis of ASD level 1 and General Anxiety Disorder.

According to participant 4(m), when Tia has been provided with the right environment she can excel.

*“It is all based around the teacher. And for the adolescent it was the same last year, it was all about the teacher. The teacher got her, understood her, knew what she could do to push her, without breaking her. Academically she is not struggling. Although they do have her name down not this year but next for specialized exam conditions. Like Tia goes into school 10 minutes late, leaves 10 minutes early, doesn’t do lunchtime or interval, she just stays in her class. Doesn’t do PE (physical education), and she is not doing an option (elective class). We are lucky that the DP (Deputy Principal) is letting me do what I want to do”.*

*“That’s her resilience stuff, she is still doing it and we are still getting her there, and as long as she is there with her teacher, she is OK. She is still going to one other option but it is not going to last. While it still is, she goes”.*

### **A sense of humor**

Parent’s identified how a sense of humor was a strength in the adolescent that added positively to family life. This humor was filtered through ASD in terms of the parent finding the way the adolescent shares their thoughts as being very funny. Laughter and good humor are emotional restoratives, can relieve stressful situations and allows shared communication of common meanings.

Participant 3(m) described the pedantic way that Finn talked was often very amusing.

*“he has a very good sense of humor and sometimes, just the way he says things”.*

Finn adds as an example.

*“Like yesterday, I had to make a deposit (using the toilet) shall we say, and then mum said what took you so bloody long, I said “you kill the magic mum” and she just killed herself laughing. Not literally of course because she is still breathing”.*

## **Being in a routine**

Routines are identified as a strength by the parents because of the predictability they provide in supporting the daily functioning of the household. This predictability may also allow spaces of respite for the parents and other members of the family. For example, many of the adolescents with ASD enjoyed routines, so families who employed routines found that the day went smoothly, transition between school and home worked better and allowed for a peaceful environment to be maintained in the home before and after school. In contrast going outside of the routine could create tension and anxiety leading to negative behaviours from the adolescents. Home environments were set up for routine activities with easy access to high interest items like laptops, and art supplies that the adolescent could engage at various times. Parents discussed providing access to these activities particularly useful for the period after school. Some of the comments from the parents about these afternoon activities included descriptors like “defragging, and downloading from the day”. Some special areas like bedrooms with heavy dark curtains to block out light were utilised as part of the routine as a time to relax straight after school. Other routines revolved around having paid carers to engage in after school activities with the adolescents upon returning from school or college. Familiar routines supported the adolescent to know what was happening next and allowed the parents to get on with other activities such as cooking dinner or doing other chores required to keep the household in a succinct rhythm. This routine supported societal rules of getting the adolescents to school on time and allowing those parents who were employed to get to work on time.

For participant 5(m) Star Child’s predictability of routines supported well-being for his family.

*He is our alarm clock (laughter). 5.30am every morning. He puts the jug on, turns the TV on first, you hear the preaching go on, then he will pop on the jug. He will have three plates of 6 weetbix, 18 weetbix for breakfast. He is left handed so you hear the click, you know exactly what action he is doing, he doesn’t chew it or dissolve it, it is swallowed straight away. He will whistle up to the next lot, to do his next plate of 6. He comes back down, you hear the bang crash, everything is so structured and robotic. It is beautiful. Everything right down to the amount of times he brushes his top teeth down to the bottom teeth, how many spits he does. Everything is just on cue. I love it. It is so predictable”*

*“He shows us routine, he is out of the door at 7.30am every morning, a good hour before school even starts, but he counted, it takes him 12 minutes to get to school. Today he didn’t want to go to school because it was raining. But those are the little challenges that we face”*

For participant 4(m), the routine was about aligning themselves as a family who follow routines to support the predictability for Todd.

*“Because he is in a routine, we all have to be. And it is not even a fixed routine, he does the same things everyday but it is not at 8 o’clock he does this, he does the same things, but it is more about the order rather than the same time and things like that. It kind of keeps you all in line. We know exactly what Todd is doing, he gets up in the morning, if I am not up he get his tablet and goes back to bed”*

Daily entries in diaries for 5-6 years, according to participant 7(m) have been a way for Thomas to make sense of his day and has allowed a unique insight to day activities, who he interacts with and how this information then becomes something to share with his family.

*“He has diaries, he kept diaries for the last how many years. 5-6 years. He writes everything down, so it is quite neat for us because we can read what we did 6 years ago on this day”.*

## **Autonomy**

The parent’s identified autonomy as a strength in the adolescents as it linked with independence and to the adolescent being able to negotiate their wants and needs. It is also a transferable skill across other parts of daily life including being empowered to make decisions and maintain calmness in the face of changes by becoming more flexible. The belief that an adolescent can, through their strengths get what they want in life is linked to their hope for the future.

According to participant 7(f), Thomas’s sheer will and single focus on an object or activity that he wants to do, combined with his ability to ask for help supports the parent to have hope that he will have his needs met.

*“Because of the force of his will, he single-mindedly is focused on what he wants, and when you are like that people sort of just, not bow to your will, but they will say come over here and I will show you where that is, people will help you. Because you are determined to go where you are going, people will assist you normally”.*

*“We used to be more afraid of giving him the bad news that something was changing. But now he will grump around for a while, and then go “oh alright, I suppose I will just have to do this then. We look at each other and go great. He is becoming a bit more flexible”*

Since the passing of his primary caregiver Brandon has been in the care of his aunty, participant 2(m). In the past 12 months, he has become more autonomous in making decisions linked to free will. This strength was identified as an explosion of new learning for Brandon to make independent choices identified by participant 2(m).

*“What he used to do is have his stereo and CD player and listen to his music up in his room. I didn’t want him to stay in the room, I wanted him to be seen, for him to be acknowledged. I had to figure out how to get him to stay down here with us. I think it was last year about May I thought OK why don’t I just get headphones, he still went up in the room and I said, no you can stay up here. He got a shock, that he could stay down here. So, I keep them down here so when people came if he wanted to interact with people he could take off his headphones, come over here and have a bit of a yarn then go back over there and do his own thing. You can be here for hours and forget that the adolescent is even here. I think I get a bit jealous when he goes away every second weekend, cause I miss him and I’m frightened I might miss something new about him or something he has done”.*

## Chapter 4: Results

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### **Linking adolescent strengths to a positive future**

This chapter will highlight what the parents expressed in terms of adolescent strengths and their thoughts of what the future might hold for the adolescents. Parents identified more positive expectations where the strengths that the adolescents displayed now, could be transitioned into the future. According to Hershberger (1989) the action of hope is associated with motivation and is also connected to the possibility of a less desirable outcome to eventuate. Furthermore, Blue-Banning, Turnbull, and Pereira, (2002) found that parents of children with ASD have similar life goals as those of typically developing children. This links to completing the highest level of education possible, future financial security, living independently, being employed, socially responsible and being accepted in the community. During this research parents were asked to engage with the understandings of strengths that they identified in the adolescents and how these strengths could support the parent to have hope for the future

### **Participant 1**

For participant 1(m) perseverance, art, cooking and photography were identified as strengths for Alexandra against a background of being bullied and isolated at mainstream school. Alexandra discussed in chapter 3, how she felt ignored at school and how her new school is far more inclusive. Participant 1(m) predicts a positive future for adolescent by focusing on the skills that the adolescent currently has as a foundational framework to build on.

*“I think she can only grow from these talents and abilities, she can only become a stronger woman, and with nurturing, and.... I think she will just flourish into becoming an awesome capable citizen, of New Zealand, I think that’s really important”.*

*“The photography, is recognised by others absolutely and much the same though as with the modelling they appreciate the end product, but they don’t appreciate or understand how she got there, and again that is her perseverance, and her eye for talent that has got her there, that’s not truly appreciated I don’t think”.*

Participant 1(m), holds a strong belief that a positive future for adolescent includes her becoming a photographer.

*“she wants to become a photographer and I have absolutely no doubt whatsoever that that is going to be the making of this young woman”. I think perseverance is probably the biggest strength that she has, and that shows through all of those five things right there, five things that she is wonderful at, and in the face of adversity, she has fought, all be it we have been behind her and with her, standing by her, but she has fought for what she loved, what she loves, and that is also going to be the making of an incredible young woman”.*

## **Participant 2**

Participant 2(m) had in the past twelve months become the primary caregiver for Brandon who is Māori and has ASD, an ID and other medical conditions. The adolescent communicates by using his hands and facial expressions and a series of verbal sounds. Hope for the future for participant 2(m) was articulated through a cultural perspective that focused on whānau support. Brandon was known for his challenging behaviours with family members, particularly young children. Since being with this relatively new caregiver, his behaviours have changed, and there has been an explosion of communication and new learning. The primary caregiver is trying to understand what the adolescent would like to do in the future through this new and ongoing development of his ability to communicate as indicated by participant 2(m) below.

*“I’m trying to figure out what he wants in life first. I hear what everyone else wants for him, but I want to know, I want eventually for Brandon to tell me what he wants. Whether it’s through pictures, talking to me, or I don’t know however the way he wants to. I understand people want the best for him, but if he can’t tell you, so how do you know”.*

*“I think he understands that I can communicate for him. And so as long as I am around him, to help him, and that is my greatest fear is that I need more people like me to understand and help and communicate with Brandon. Like I said, in reality, I know I’m not going to live forever, so*

*already I have put in place who can be there to communicate for him, and look after him, when I am gone. She (the caregiver's granddaughter) is definitely one of them”.*

This understanding was underpinned by recent behaviours that have supported a new perspective from other whānau members of participant 2(m).

*“I saw a cousin of mine and her children; her granddaughter is 8 and is still scared of Brandon because he always pushed her and rag-dolled them. So, when I was telling her about Brandon, doing this (indicating the photograph), holding my granddaughter, playing with her and everything, she was quite shocked”.*

Ongoing development in communication, according to participant 2(m), will be one way to keep assessing what the future will look like for Brandon.

### **Participant 3**

When questioned about their hope for the future for the adolescent, participant 3(m) talked about how some behaviours of ASD are a barrier to some aspects of hope for the future. However, participant 3(m) had some ideas of how the adolescent could be supported to overcome these barriers.

*“I think he has got a good future ahead, and I hope that he won't become one of the 80% of people with ASD who are unemployed. Which I find that statistic just appalling. Yeah and I see so many strengths and incredible abilities that are not valued because of the other side of ASD. I just think we are missing out on a huge incredibly valuable resource that is right there, I think it will be maintained by other people acknowledging his strengths and ignoring his quirks. Whomever is there in his social and support network I guess. And probably especially me”.*

Finn was very certain about the positive prospects of his future and how he could manage in the future.

*“I won't because the thing is that 80% of people with ASD don't have programming and computer skills, and they also don't have my irrational desire to buy new technology. Based on that, skills I have are highly sought after so if I can't get a job in programming I will still get a job in IT somewhere, therefore I will find it easy to get a job. My particular skill set is the kind*

*of skill set that, we need so many of them, no matter how many new people we get and we still don't have enough. I won't be one of those 80%. I've got the support I need to handle any situation right here, phone, Nintendo and computer, I'm good".*

The relationship between participant 3(m) and Finn was clearly very positive and very supportive.

*Participant 3(m), "Will they help you at the supermarket"? (the phone, Nintendo and computer).*

*Finn "You know there is this cool thing called "Amazon Go" which allows you to walk by yourself online and thus avoids any contact, it's a pity it is not available in New Zealand".*

*Participant 3(m) "Will they help you cooking dinner"?*

*Finn "I can cook dinner".*

*Participant 3(m) "What are you going to cook"?*

*Finn "I can cook".*

*Participant 3(m) "What"?*

*Finn "Toasties, omelets, burgers, mac and cheese, I have seen you do it like a million times. I can make really good scrambled egg. I can also cook, most varieties of pasta, lasagna".*

*Participant 3(m) "Laughter"*

*Finn "Spaghetti, baked beans, probably not that pasta you do, that's not too hard, scalloped potatoes, oh it winter, its scallop potato season".*

*Participant 3(m) "Laughter"*

*Finn "That's the sort of random process I use. By the way I want scallop potatoes this week, its scallop potato season, its cold and I don't want to get out of bed in the morning cause my toes and other things will freeze, if I get out, if I remove myself from my blankets. It must mean it is time to make scallop potatoes. I'm a creature of habit, Sundays has to be burger night".*

When questioned again, participant 3(m) believes that the future does hold promise for the adolescent and Finn supports her thoughts with some of his own that indicates how far they have both come.

*“You’ve done a good job mum, four years ago do you really think I could have achieved NCEA 1 with Merit and furthermore do you think I could be where I am starting to work towards NECA 2, do you really think I could have done that, did you really see me passing NECA 1 with flying colours at year 9 or could you see me barely scrape by and leaving school as soon as possible, because I couldn’t take it”.*

This conversation alludes to participant 3(m) and the discussion on some of the barriers that ASD presents in the daily lives of families who have an adolescent with the disorder. However, this is a very positive perspective of this understanding.

#### **Participant 4**

This family included twins, one male Todd and one female Tia, both on the spectrum however at different levels, and this impacted on how family life functioned daily. Todd has a co-morbid intellectual disability. Tia had ASD diagnosed in the last 4 years as level 1 ASD, (Diagnostic and Statistical Manual of Mental Health, version 5) with a co-morbid diagnosis of General Anxiety Disorder.

Participant 4(f) linked hope for the future for Todd through his unique way of creating his individual identity. This was described by participant 4(f) as Todd having a presence, and to make himself visible to others.

*“It gives him a real sense of individuality. Because he is so passionate about his interests, it creates interest in him because he’s different, and how he perceives things and how he goes about them, and with him, with the way he is, it is quite easy for him to blend into the background when he is doing his own thing and not actually impacting on anyone”.*

Another link to hope for the future for participant 4(f) included Todd participating in indoor bowling that he plays competitively, winning trophies and other accolades. Moreover, it was also associated with fitness and well-being and the longevity of the activity indicates that it can continue in the future.

*“Achievement in holding up his trophies. Special Olympics bowling, I am not sure if it is 10 pin bowling or indoor bowling. He does both as a method to keep him active more than anything,*

*because he is a sloth by nature, getting out there and getting him to compete is good in multiple ways, gets him active as well, we are still trying to teach him sportsmanship. It is something that he doesn't get, but he has been doing it for quite a long time now, he enjoys it, they are looking at going to the nationals".*

This is reflected by participant 4(m) who describes hope for the future linked to Todd being reinforced by the encouragement from others.

*"As long as he is surrounded by people who keep encouraging him further. I mean his indoor bowls, that started at school. We now do it as part of Special Olympics, but it is keeping those people around him, the minute that he finds something he is after, it is about how to keep going".*

In terms of how strengths might be supportive for Todd in the future, participant 4(m) predicts that his high focus interest will be one way to engage with these thoughts.

*"I would hope at some stage we can channel some of those computer skills. We will see. We would hope".*

For Tia, there is a belief that by living with her twin brother has supported learning and development in a therapeutic knowledge that the parent feels will be advantageous in the future. This is articulated by participant 4(m) as the following discussion highlights.

*"She has almost got the therapeutic background already. I mean she does all of that stuff, and its yeah and I can see all of those things taking her into somewhere. she can logically figure it out by putting herself in someone else's shoes and how they might feel, because she doesn't have the intellectual disability. She can figure it out. That is why she has come as far as she has because she can figure stuff out".*

*"I would like to see her living independently. Being happy, to be able to do what she wants to do. Achieving the things, she wants to achieve. And being safe".*

Participant 4(m) describes how hope for the future for both twins is interpersonal support from others.

*"All I want is people around the kids that have their best interests at heart and it's not all about the money, having the community around them, but it is just finding it though".*

## Participant 5

For participant 5(m), hope for the future was linked to Star Child's love of people and wanting to be part of the community. This also links to being part a very large and supportive whānau. The cultural influence for this whānau, is a way of "being" for Māori, that is highlighted by every member of the whānau having a role in the care of, the understanding of, and the acceptance of Star Child. Regarding the future aspirations for Star Child it is assumed that, the whānau will have input into this decision.

*"We are lucky that in our family, we have a lot of family here. There are 10 children in my family, my sister also has 10 children, and she is coming down this weekend, we are very tight and we give each other permission to explore all areas of with each other, to support and empower, encourage".*

*"I tell people that our house is our Marae, and so when we are at the table the adolescent is allowed to eat with his hat on, we wouldn't do it at a Marae, but this is our whare, when we go out to society we can comply to their ways. People know that when they come over that he is walking around with his chest out, because he won't wear clothes but that is ok because it is our place. When we go out he is dressed. The adolescent has worn a hearing aid since the age of three, so he wore them for 9 years, and I was told he was deaf, no my son is hard of hearing, my son is not deaf and dumb, he is not stupid. I refused to speak "deaf" into his life, if that makes sense, so I would never say you can't, I'd say let's park that, lets revisit that, what does that look like to you. What are you trying to achieve? And just get something going. I am blessed that I can do that with him because of his comprehension and our relationship. But I refuse to think that at the age of 7, I was told to institutionalize him and just send him to the local special needs school. You know, he is not an idiot, no one is an idiot, its untapped. Find the language, find the vibration, find the love, the passion, the frequency".*

*"For us, family contact is very important. The adolescent is smack bang in the middle of his siblings, the older ones are 26, 24, and are very protective of him, and again I do not want to set him up for failure, and a lot of it will come down to attitude in the future too".*

Participant 5(m) goes on to describe why she has hope for the future of Star Child in terms of giving back to the community.

*“He won’t limit himself, he won’t take no for an answer. He will be, the most amazing person, I believe he is going to serve the community. I hope that he will inform and educate people about Autism. That’s what I would like to see. That he stands in that space, and advocates, and informs. That they are not all freaks, or stupid, I believe that he will be very successful, he is driven by money, he does like to travel, and he will see the world”.*

## **Participant 6**

The experiences for participant 6(m) are impacted through Miranda having a visual impairment and other physical concerns that requires ongoing support. However, according to participant 6(m), Miranda is highly motivated to overcome anything she perceives as a barrier to her life.

*“I think that once she finds what she is looking for, or what she is destined for, that she is so determined, she just won’t give up. She will give it 150%. Whatever she does in life she will give it her all. No failure. Once she finds that, her calling I guess. What is designed for her, then I think that her strength and determination, is a good quality to have”.*

Participant 6(m) has similar understandings to other participants in the research where hope is linked to employment that corresponds with the high focus interests and strengths that Miranda has.

*“Realistically I see the Miranda living in a supported living environment. Of which she is encouraged to participate in some sort of paid employment that around her art definitely. I don’t know whether that would be, her grandmother made mention of it at one point, around creating a business for her. Creating a job, I would hope for more than that, that somebody would employ Miranda. But it would have to be someone who is very patient, because art is something that is created in time, it is not something that is rushed. I would love to see her do more with the art, I would like to see her being paid in that way”.*

*“I think I see Miranda in some sort of volunteer capacity for most of her time. I see her getting to a place of calmness and stillness within herself that she can actually offer some support and education for other people. I am not too sure, but definitely a volunteer position, will take up most of her time”.*

## Participant 7

The interview included both parents. They felt that Thomas's strengths would be supportive in the future for him and therefore they had a positive view of his future. Participant 7(f) wanted Thomas to gain productive paid work which corresponds to having goals that are like typically developing adolescents. Participant 7(f), discussed Thomas's positive personality traits, that linked to having hope for the future that also included Thomas being employed.

*“He is very intelligent, very smart person and he is a fun guy, he is happy, he has a lot of happiness in him, he has no malice, no problems at all. No kind of negative, no negative personality traits, or any of those sort of bad things, he has none of them. The all help him to get by in life and they will help him to be liked by people. And to fit into society better I guess. Which is always a wish for a parent. He is fun to have around. That is the good thing about his qualities. He has lots of good strengths that will help him get through life”.*

*“I hope that we can find him work. productive work, a job, doing what he loves doing somehow, because if he gets that then he will be successful and have a good life”.*

*“For him to have the confidence, and learning the social skills, feeling accepted, that it is OK, that he is slightly different, because you are still part of the community”.*

Participant 7(m) however had a different perspective regarding future employment for Thomas.

*“I see him in a supported living situation. Working, but I don't know if he would be getting paid, it would be nice, but I am only looking five years down the track, and in five years' time, I don't know if he is employable, he might be. I don't want to set myself up too high, in case it doesn't get there. But it is great that one of us thinks that will happen, and I come down, its good”*

Participant 7(m) believed that perceived worth would be maintained by Thomas continuing to learn new things and being encouraged to use his strengths.

*“Maintained, by getting him out of the house, and I don't mind what it is, I don't want him sitting in his bedroom on the computer. I don't mind it a couple of days a week, but not every day. It is important that he gets out. And it keeps him learning”.*

*“I think that communication is a big thing, if he can just talk about things, as much as he can, ask the questions, ask for help, be polite. Most people are there to help one another aren't they,*

*the general public would be more than happy to help if he were to ask nicely. A prime example was when he did not have enough money to buy that magazine. I would have loved to have known who that was and thank them in some way. All the bus drivers know him now, if something was to happen on the bus they would help”*

## **Participant 8**

Participant 8(m) discussed how Michael’s anxiety impacts on his daily life. However, the parent felt that with the right kind of environmental and interpersonal support her son in the future would be the defining point of difference for his success. Hope for the future for participant 8(m) is linked to the ability of Michael to advocate for himself about what kind of future he wants.

*“I think he will, in his own quiet way. He will have choice, we talk about what he may like to do in the future. We want him to have choice and be involved in an occupation that he enjoys and people he chooses to be with”.*

*“Quiet seems to be the main prerequisite. Once he said he wanted to work in a church, he explained because it is quiet. I really don’t know at this stage. With the support of a structured, organised, living environment and being given time to communicate his wishes”.*

*“We are future planning for Michael. It is an ongoing plan that evolves with time and what Michael chooses”.*

## Chapter 5: Results

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### **Vicarious futurity (Hope for the future)**

*‘To believe that something positive, which does not presently apply to one’s life, could still materialise.’*

(Lazarus, 1999, p. 653).

This chapter will link the work of Kenneth Nunn (1996) and the theory of vicarious futurity. Nunn’s work concerning the relevance of the perceived future to psychiatry acknowledged the contribution of hope to part of a recovery model for the prevention of depression and suicidal ideation. As previously discussed Nunn believed that having hope increased positive health outcomes for those parents who currently held hope for their children and who could project hope into the future as the child ages. Having hope for the future was identified by the parents and was associated with their understanding and knowledge about the adolescent and how their strengths, skills, and attributes could be utilised into the future and have positive benefits for the adolescent. The research findings linked to those diagnostic features of ASD that are utilised as the strength for the adolescent or as a measure of how far the adolescent has developed despite ASD, will be analysed through the five domains of vicarious futurity, designated as positive appraisal of the future, perceived worth, mastery and control, drive and enthusiasm, and future interpersonal support.

#### **Domain one: Positive appraisal of the future**

A positive appraisal of the future is linked to the parent’s belief that the adolescent will get what they want in life. This perspective is moderated by the abilities of the adolescent and mediated through the hopes of the parents engaging with an understanding that the adolescent will likely require support throughout their lifetime.

Participant 1(m) identified perseverance as a way for her daughter to get what she wants in life and this was coupled with Alexandra's aptitude in advocating for herself. Since attending a specialist character school that supports diversity and difference, Alexandra has thrived according to her mother, with an increase in self-esteem regarding her talents in art and a willingness to keep trying even when things become difficult. These new skills have allowed Alexandra to flourish into a more confident young woman. According to participant 1(m), Alexandra was impacted by depression and since gaining more confidence the frequency of depression has decreased. Alexandra has some clear ideas about what she wants to do in life and these ideas adhere to social norms that include finding a husband and having children. This has allowed participant 1(m) to consider that the future for Alexandra will be positive.

*"I see Alexandra having a simple life, but simple in the fact that she is going to make her life about the simple things in life. Love, family and happiness".*

Participant 2(m) was highly engaged with Brandon and was continuously trying to understand his communicative efforts, so that she could identify what he was trying to express. While residing with his grandmother, if he had difficulty in communicating with her or got upset, he would turn the stove elements on high, or dial 111 on the telephone. Those people working on the emergency line came to know Brandon and his behaviours due to the frequency of these calls. According to participant 2(m), this behaviour has decreased over the past year and she attributes this to Brandon having more autonomy and being able to make his needs understood by participant 2(m). The development of new ways to communicate has had positive flow on effect in other areas of Brandon's life. Frequent medical appointments that Brandon is required to attend due a serious medical condition, has been marked by increased co-operation with the nurses at the hospital who have known Brandon over a long period of time. According to participant 2(m), her confidence in his newly developed communication skills is maintaining her perspective that in the future he will get what he wants by communicating this in a manner that is understood by others.

Participant 3(m), holds a strong belief that Finn will get what he wants in life because he is a very high achiever in terms of success at school and his skills and knowledge of computer systems that includes coding and repairing computers. These skills are related to the diagnostic features of ASD and Finn's intelligence and verbatim memory. What participant 3(m) is

concerned about relates to what she terms as the “quirks” that Finn displays that is indicative of ASD. Finn finds it difficult to take turns in communication and this was evident during the interview for this research, where he answered a question, not always directed to him, forcing participant 3(m) to utilise the gaps between Finn’s constant verbalisations to answer the research questions. This links to a lack of understanding the rules of social interaction, or difficulty in applying these rules that results in Finn not pausing between the question and the answer or taking turns in conversations. Finn did have some insights into his behaviour and how this affects him daily. Participant 3(m) described Finn’s insight as a protective factor that would support a more positive future for him through the continued development of this awareness. The improvement of his understanding of social rules will support Finn’s natural and phenomenal strengths, to overcome the other less socially acceptable characteristics of ASD and will support him to attain the goals he has for himself.

Participant 4(m) held the belief that Todd would get what he wants in life through his interest in technology. Todd uses his computer and tablet to research what interests him and this research, according to participant 4(f), underpins the development of his identity. Todd designs, constructs and wears masks that mimic scenes from his computer game interests. Wearing a mask supports him to go outside the family home, although participant 4(f) does talk about restrictions of wearing a mask out in the community where it may be less acceptable.



Todd carries a “Wilson” Rebel Sports volleyball (associated with the movie Castaway) in a bag when leaving the family home. The volleyball is placed on a movie seat when attending the local cinema. However, there are boundaries around taking “Wilson” out that relates to the

volleyball being left in the car when Todd attends school or going into the Rebel Sports store where there are many “Wilson’s” on display. An Intellectual Disability is indicative of difficulties associated with social anxiety, therefore, Todd’s use of objects to support accessing community environments may relate to this. However, in terms of strengths these objects that include masks and a volleyball are like other restoratives that lower anxiety for young children. What Todd wants in life has been influenced by his Intellectual Disability in terms of wanting things that according to participant 4(m) are unrealistic. Todd wants to have a high powered V8 car he has identified from an internet game, when he turns 16-years-old. However, his parents understand that this is not possible, opting for the more modest goal of him being able to cross the road safely first. By filtering what is possible and what is not realistic for Todd his parents remain positive about his future. Furthermore, their understanding of Todd’s unique way of interacting with the community aligns with Todd’s rights to do things differently.

Tia is Todd’s twin sister. She does not have an intellectual disability however, she does have a co-morbid diagnosis of General Anxiety Disorder (GAD). She is impacted by anxiety that is over whelming for her at times according to participant 4(m). Getting what she wants in life is associated with her high intellect that is reinforced through her own research and the development of knowledge of how anxiety affects her daily. Tia has no issues with school from an academic perspective, however her experiences of anxiety impact on her ability to go into the school environment. Participant 4(m) has negotiated with the school to allow Tia to enter the school grounds 10 minutes after the official start time and exit school 10 minutes before the official finish time. Furthermore, Tia’s teachers continue to acknowledge Tia’s difficulties by allowing her to participate in classes that best suit her abilities. This acknowledgement supports Tia to increase her resilience and coping ability directly related to her anxiety. By understanding how her body is feeling, and how these feelings influence her thoughts has been a way, with the support of her mother and the school, for Tia to manage her anxiety more effectively. The combination of Tia’s capacity to learn and support from her family links to the understanding that she will get what she wants in life through her ability to work things out independently. Furthermore, her creativity in art, making miniature clay figurines, miniature bottles of coloured sands and other forms of art including designing written affirmations, has been a way for her to disconnect from the anxiety and relax. This is described by her mother as Tia finding a calm and peaceful place.



Participant 5(m) is the parent of Star Child who has ASD and a life-threatening health condition. A belief that Star Child will get what he wants in life is associated with his own love of life and wanting to be present despite his serious medical condition. This desire to take control over his life is exemplified in the photograph discussed in the interviews according to participant 5(m), where Star Child, who had recently come out of hospital, wanted participant 5(m) to take the photograph of him in the surf of the ocean. Participant 5(m) discussed these series of photographs as Star Child “*reclaiming freedom, belonging and restoration of self*”. This quote linked to the photographs being taken just after Star Child had spent 6 weeks in hospital including time in the intensive care unit. The photograph was according to participant 5(m), Star Child turning his back on the unpredictable ocean, showing his bravery and mastery of the elements, asserting his manhood, and making a pact of “he” is here for a reason. Although difficult to identify in the photograph, participant 5(m) described how Star Child has “pointy ribs” due to a side effect of the medication and his laboured breathing. Participant 5(m) holds an indelible belief that Star Child’s smile in this photograph is “*an invisible vibrational contract*” formed between a loving mother and her son.



Star Child is also surrounded by a very strong and large family who are totally committed to his best interests. Participant 5(m) is a passionate advocate for Star Child wanting to focus on his abilities rather than his disabilities refusing to speak “disability” into his world in any context.

For participant 6(m), the idea that Miranda’s tenacity is illustrated in her protectiveness of her family that also links to a patriotic sense of being a proud New Zealander. This is further exemplified by her desire to serve others by learning cardio-pulmonary resuscitation and acquiring other first aid skills that are associated with an organisation she belongs to. Miranda has a visual impairment and other medical conditions however, according to participant 6(m), she will not let her disabilities get in the way of what she wants and this determination fuels Miranda’s motivation to achieve her goals. Miranda strives to be recognised and wants to be known by others and this participation in the community is an example of this understanding. Having a “*can do attitude*”, according to participant 6(m) is a way for Miranda to build resilience and a dogged persistence that will link to a positive future.



Miranda getting a trophy for a “can do attitude”.

Participant 7(f) believes that Thomas will get what he wants in life, and attributes this to his skills in being able to socialise and having a pleasant disposition that has supported a large and consistent social network of friends. Furthermore, his skills of polite engagement connect to participant 7(m’s) belief that the community would respond positively if Thomas requires assistance. Examples of these behaviours included Thomas’s ability to negotiate to have his wants and needs met through negotiating with his family. Thomas has developed an excellent level of communication and comprehension skills through the parent’s hard work in applied behaviour analysis and they expressed their happiness in this attribute that allows Thomas to fully participate within the family and the community contexts. Thomas’s poignant focus on a plan or idea is foregrounded by the inflexibility of a single-minded perspective, and a pre-occupation with writing copious diary entries is a feature of ASD however, these attributes over time have become a strength in daily living. Furthermore, one of the persistent impairments of ASD is in reciprocal social communication; therefore, having developed good communication skills will reinforce the parent’s prediction that Thomas will get what he wants. Participant 7(f) discussed this understanding in the following way.

*“Will power and determination are great qualities to get you through life. He has got his own goals and things that make him happy, I am sure he will pursue those. He will have a happy life I think, he is having a happy life”.*

### **Domain two: Perceived worth**

Domain two relates to a parent’s belief that the adolescent will live a valued and productive life. Many of the values discussed by the parents included very normal, socially valued ideas of life that included completing an education, having relationships with others, getting married and having a family, gaining employment and taking one’s place in society. Living a valued and productive life was also linked to using the adolescent strengths and high focus interests constructively, leading to a more typical path of human development. These interests included being creative artistically and expressively.

Participant 1(m) believes that Alexandra will have a valued and productive life that links to her generous nature that was described as *“a beautiful, kind heart”*. Furthermore, the adolescent has highly valued skills that includes photography and baking. She has a keen eye for photography and artistic composition. Her baking is well received by the family and is the highlight of special occasions.



According to the participant 1(m) Alexandra’s artistic and culinary abilities will support her productivity in terms family connectedness and future study options or employment opportunities.

Being able to communicate his needs and desires is seen by participant 2(m) as a way for Brandon to live a valued and productive life. Brandon who is mostly non-verbal is developing his communication skills and the caregiver is hopeful that he will develop them sufficiently for him to “tell” her, where he wants to live in the future. Value is placed on him being able to advocate for himself. The development of language and communication is mediated by Brandon’s Intellectual Disability and therefore the caregiver’s patience in teaching and decoding his communications has become a focus for her and a way for her to be positive about the future.

Finn is already working in his area of expertise fixing computers. His “*irrational obsession for new technology*” as he describes it, is linked to his restricted interests that is a diagnostic feature of ASD. His skills are obviously held in high esteem considering a job offer from Microsoft upon leaving school and already working in a computer repair business at a young age according to participant 3(m). Finn is the go to person for anything in technology for his family members and teachers because his knowledge is valued. According to Finn he likes patterns and he will find creative ways to maintain structure and sameness in his life. One of his patterns is to wear some part of his school uniform even when it is the school holidays. During a school event called “P Day” where the students wore something that resonated with the letter “P”. Finn states that he went as himself, a “programmer”, articulating this as solving his problem of wanting to wear his school uniform on that day. He talked about this as being ingenious.

*“ingenuity in itself of just being able to always manage to turn basically any letter of the alphabet into something that allows me to wear the usual” (laughter).*

Living a valued and productive life for Finn is linked to him gaining employment in his high focus interest, however, this is moderated by participant 3(m’s) understanding of the incongruent splinter skills in socialisation articulated as his quirkiness that are characteristic of ASD.

Moreover, participant 3(m) would like Finn to consider attending university prior the offer of employment by Microsoft, to keep his options open particularly in terms of his love of English literature that is demonstrated by the poem he wrote aged 9 years old and was read at his great grandfather’s funeral.

*Life and death are everywhere on this earth*

*It streaks the land for miles around,*

*And in no place, there is no sound of life.*

*Of death, no living creature knows*

*Where those who die will always go.*

*Many have tried to seek the way,*

*Beyond the danger, grief and woes,*

*Without harming the body, it shows,*

*There is no way for anyone,*

*To escape the thing that always comes,*

*Yet nobody can hope to be the one,*

*Who escapes the worries of the day*

*Without harming body.*

*Life and death are Yin and Yang,*

*No way to avoid life,*

*Yet no way to escape death,*

*Those who die are always us,*

*Not visible, yet there still*

*From brother's old to babies new*

*The dead are for them too.*

For twins Todd and Tia, participant 4(m) believes that they will both have a valued and productive life through them being supported according to their level of functioning. Todd, who

has an Intellectual Disability, can melt into the background according to participant 4(f), so getting Todd out of the family home and visible is a priority. Attending competitive bowls and going to the shooting range is a way for Todd to be part of activities that supports his profile within the community. Furthermore, it supports fitness and other learning opportunities. Participant 4(f) is trying to teach Todd sportsmanship through these sport activities as an ongoing process for a valued and productive future.

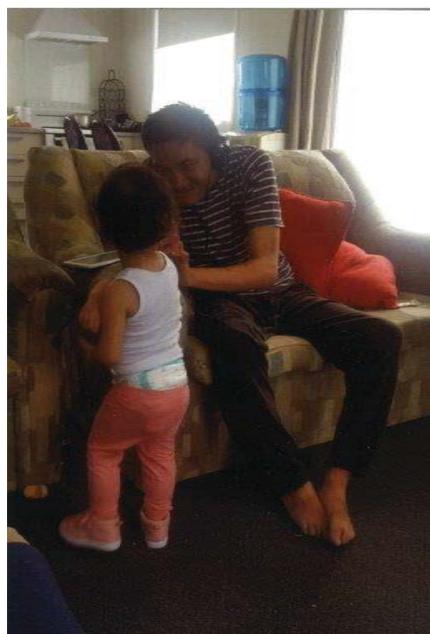
Participant 4(m) recognises Tia's strength in understanding how anxiety affects her life is a path that will lead Tia to develop strategies so she can access those environments outside of her home, therefore supporting a valued and productive life. Tia is a small-bore rifle shooter, having attended the shooting range with her father and twin brother. She is also a very competent but non-competitive swimmer. Both activities support her visibility across environments, her fitness, self-esteem, and her natural talent as a sportswoman. Furthermore, according to participant 4(m) the swimming is part of Tia's anxiety management. Both activities could be described as solitary pursuits and therefore, most suitable for someone with ASD and General Anxiety Disorder. According to participant 4(m) recognising and extending Tia without breaking her has been a successful strategy for personal growth for Tia.

### **Domain three: Mastery and control**

Domain three is associated with the parent's belief their adolescent will be able to cope with various issues and concerns that they will face across the lifespan. Adolescence is resonant with many areas of development including puberty, brain cortical re-development, sexual maturity and identity development. Many areas of development between adolescence and adulthood can potentially create issues and problems that will be exacerbated by ASD. Understanding the strengths of the adolescent and how they might cope with issues that they will face in the future, allows the parent to conceptualise how this might be done. All parents in the research articulated that the adolescent could cope with various levels of issues that they may face in the future. However, these levels ranged from able to cope with some issues, to coping with very few issues in the future and requiring significant support over the lifespan.

Participant 7(f) felt that Thomas will cope with most issues he will face in the future linking this to his strengths and skills in socialisation and communication. Thomas has developed a wide social network of other people outside of his family that are willing to help him. His friends have helped him to learn how to use Facebook and his mobile phone. Furthermore, the longevity of these relationships that Thomas has with this group of friends means that they are very aware of his unique personality and can easily identify when and how he requires support, purely by knowing him so well. Another great skill Thomas has accomplished relates to becoming more flexible over the years in terms of accepting change according to participant 7(f). Being able to ask for support from others and being able to accept that this help may take time, or may not be possible, is a poignant skill that will support Thomas to cope with most issues he will face.

Participant 2(m) is looking for a member of her family to take care of Brandon in the future when she was no longer able to. She had identified three members of the family who could possibly do this and she was actively connecting them with Brandon building relationships between them through sharing photographs and encouraging video conferencing. This pairing of potential future caregivers is mediated through developing an interest in Brandon's future and teaching the potential caregivers to understand how Brandon communicates and how to interpret those communications. Participant 2(m) believes that those people who are interested in Brandon will support him with any issues that he will face in the future through their connection to him.



Participant 4(m) believes that Tia will cope with most issues in her life if provided with the time and encouragement to do so. This is linked to her ability to problem solve for herself. However, this is mediated, according to participant 4(m), by being able to control her anxiety.

*“I think if she can keep, if we can get on top of her anxiety, because she can logic everything out, I think her strengths will take her far and give her the feel good she is looking for hopefully”.*

Participant 4(m) does not think that Todd will manage any issues he will face in the future without significant support. However, it was made very clear that his sister Tia was not going to be totally responsible for this type of support for him.

#### **Domain four: Drive and enthusiasm**

Domain four is associated with the parents maintaining a positive perspective of their adolescent as they move through new stages and phases in life. Development across the lifespan continues for everyone from birth until death. Parents will have to consider how the future looks and how development both for the adolescent and the parent is closely linked. The adolescent will grow older into adulthood. Thoughts of the future were linked to the parent’s belief that the challenges of these stages and phases will be adequately met by the adolescent’s skills and talents that they presently have and continue to develop.

For participant 1(m), a positive perspective for Alexandra as she moved through new stages and phases in life was associated with the Alexandra’s ability to appraise a situation and develop strategies that will support a positive outcome. She described how for Alexandra this would depend on each situation as it arises. Furthermore, participant 1(m) identified that the Alexandra has many talents and strengths reinforcing the ongoing perspective that these qualities will help carry Alexandra through most situations that she will face.

*“I think perseverance is probably the biggest strength that she has, and that shows through all of those five things right there, five things that she is wonderful at, and in the face of adversity, she has fought, all be it we have been behind her and with her, standing by her, but she has fought*

*for what she loved, what she loves, and that is also going to be the making of an incredible young woman”.*

Participant 3(m) discussed the domain of drive and enthusiasm for Finn aligned with the quality of the parenting time and effort that both parents had invested in working with Finn’s strengths and the belief that he is an incredible young man.

*“there will be some things that which will be quite difficult, but hopefully we would have done a good enough job that he will be able to manage most things”.*

Furthermore, confidence in this understanding relates to the personal skill participant 3(m) has that encourages Finn in not allowing him to give up easily. This was related to Finn being nagged to get things done. Finn remembers this as supportive.

*“You know I don’t like how much you understate the nagging you did to get me where we are today. Put it this way, mum has an Olympic gold medal in nagging”.*

Therefore, the tenacity and resilience that the participant 3(m) possesses, has been a tool that it used to build tenacity and resilience in Finn.

For participant 5(m) the idea of the future and how Star Child with ASD would move through new stages and phases is discussed as the adolescent knowing that his thoughts and ideas have a significant influence with his whānau. Therefore, as Star Child moves through these stages his whānau will be there to support him in a manner that he wants.

*“His strength teaches us that we need to be more transparent and vocal that we need to also cue each other of we are doing. We need to be mindful that we all can’t read minds, we all don’t appreciate just being thrown in the car and driven away, we need to communicate. He brings so much strength to us that, of course he is here because I loved him and I wanted him, but his sister who is only 10 months older than him, 12 actually, is like his twin, is a kindred spirit. And she will identify anything that, she is his eyes, his ears, and not because there is an expectation, but because she is protective of him. And we know him so well”.*

Participant 6(m) has gained greater clarity for a positive future where Miranda will cope, with good support, with most issues she will face as she grows older. This change of perspective has been facilitated through participant 6(m) focussing on Miranda’s abilities rather than her

challenges. Miranda displays a strong desire to overcome what she considers to be barriers to her and this is demonstrated in her actions including those activities that are seriously challenged by ASD and her visual impairment.

*“Yes, I think if she really wants something she will get it, come hell or high water. I don’t know if that is the Autism or just a born trait. The Autism makes it very cut and dried. She will set her mind to something and she will achieve it”.*

*“At one point she said to me, I’m going to find a cure for what is wrong with my eyes, and everything will be better. I was like, well you never know. I try to get her to see the beauty in her uniqueness”.*

Miranda focuses strongly on eyes in her artwork making them as perfect as she can. Furthermore, she delights in being known through her artwork that participant 6(m) posts on social media sites.



## **Domain Five: Future interpersonal support**

Future interpersonal support as a domain of vicarious futurity is associated with the belief that other people recognise and acknowledge attributes and strengths that adolescents demonstrate that will support them to lead a valuable and productive life.

In terms of future interpersonal support, participant 1(m) believed that the adolescent will seek support from those people around her that she trusts.

*“I think that Alexandra will find a way to cope with the issues, she is going to face in the future and that is going to look different for each and every problem that she encounters. Sometimes it might be that she hides away from the world for a while then tries to work through it on her own, other times it might be that she finds her mum, or finds family, and seeks guidance, I think there will always be support workers around her or support systems around her, that she may use if she needs to, so I think it’s going to depend on the situation and it is going to depend on what she feels she needs to get through with each problem, so it is going to look different with each one”.*

For participant 2(m), people often stop and talk to Brandon and she has come to realize that Brandon is valued by others who know and understand his likes and dislikes. This school friend demonstrates this as he understands that Brandon does not like loud noises.

*“Yesterday when Brandon and I went for a walk. It’s really interesting that there was this motorbike behind us that slowed down. I thought what is this fella up to. He pulled up beside us, quietly, and Brandon looked at him, and then he took off his helmet and said “Cher Brandon” and it was one of his school mates. He says oh I go to school with Brandon. He goes see you later Brandon, and Brandon goes bye, bye, and then instead of zooming off, he drove off like he was riding a bike, until he got further away and then he took off. Then Brandon claps”.*

Throughout the thesis there has been agreement from others outside of the family circle that has distinguished strengths that the adolescents have, highlighting them as valuable. These strengths relate to social situations where the adolescent can bake, take photographs, fix computers, greet and engage appropriately with others, perform a haka acknowledging family connections, and have been identified as behaviours that are functional in daily life and socially respected. Furthermore, considering the parents are unlikely to outlive their children, it is an important factor for parental resilience and happiness to know that this type of support exists for

the adolescent with ASD when the parents are no longer able to. This understanding was highlighted in the research although it was mediated by the amount of external supports available, the accessibility and permanency of that support. Most of the participants in the research stated that they could identify others that would recognise that the adolescent would have a valued and productive life. However, these people were usually family members or those people who interacted daily with the adolescent with ASD.

This is clearly identified by participant 4(m) in terms of support for Todd and Tia in the future.

*“I want people around both of them that are going to care. And right now they have their immediate family, but most of their immediate family is older than us. Do you know what I mean? Because Tia is higher functioning I do not want Todd to become her problem. I want Todd to be her brother. We often say maybe we should have had another one, if our family had been bigger there would be more support around him. But then on the other hand, I know big families with special needs kids and no one wants anything to do with the special needs child because they are just too hard”.*

## Chapter 6: Discussion and Conclusion

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### Discussion

This chapter will summarise the findings from the last three chapters that relate to strengths of adolescents with ASD, and a parent's perspective of a positive future, filtered through an understanding that there are natural and special skills associated with having ASD that are constructive and useful for the families now and in the future. There will be a discussion around the implications of this research and how it can support our understandings of adolescent strengths and how ASD impacts on the lived experiences of those people closest to them. The chapter will conclude with strategies going forward that will support those parents with the lived experience of ASD to feel more positive about the future of their son or daughter with ASD that is highlighted in this research and other literature within psychology.

The diagnostic features of ASD are indicative of deficits in three core areas that include socialisation, communication, and cognition. Any positive developments in these three areas were identified by the parents in the research as strengths in the adolescents because they were functionally valuable in terms of being beneficial at home or in a mainstream setting. Furthermore, many parents identified that some diagnostic features of ASD can be useful and they fostered this natural tendency to offset the less valued behaviours of ASD. These included the adolescent preferring routines, natural talents, knowledge of technology, an excellent memory, and recall of facts and figures. These strengths supported the adolescent to get to school on time, research on the computer allowed respite time for the parents after school, and having an excellent memory facilitated success in school and other areas of life.

Being social was identified by the parents as extremely important because it supported daily interactions, and the parents perceived this skill as transferable into the future. Social skills were clearly linked to friendships and interpersonal relationships that supported the parents to have hope for the adolescent as they grow older, that there would be someone who wanted to engage with the adolescent and later, the adult with ASD. Being social is associated with being able to communicate effectively and parents felt that if the adolescent could communicate appropriately, this increased the chances of them getting what they want in life by simply being able to ask for

it. This was supported by an understanding that societal expectations for reciprocity of communication is vital for acceptance from others. Furthermore, socialisation is associated with the creation and development of identity for the adolescent and finding where they stand in the world. Being able to express their thoughts, feelings and how they view themselves is an important part of lifespan development.

The use of the internet was recognised as a strength because the adolescent could increase their knowledge in areas of their interests, they could socialise with others through social media sites and, for some, they could research information about their own challenges to understand their personal experiences better. Using social network sites like Facebook built networks of friendship, assisted adolescents to create a sense of belonging, and provided a space where an adolescent could ask others for help. Being able to independently spend time with their high focus interests also made it easy for the parents to engage in other household duties. Furthermore, many of these special skills and interests, like reading and researching, were, for the most part, a solitary activity and, therefore, most suitable for the adolescent since wanting to be alone is a diagnostic feature of ASD.

Humour was identified as a strength by parents because it highlighted shared meanings and it was useful as a type of stress relief. Embracing the quirks of ASD and seeing the funny side of these quirks allowed a space for close, personal social relationships between family members that linked to joy, laughter, and love.

Parents in the research highlighted these autistic strengths as a mechanism for the adolescent to experience success as often as possible in as many different environments as possible, working with the best attributes of ASD to provide positive outcomes for the adolescent and the family. Furthermore, by paying attention to these valued strengths, they will naturally increase and provide more positive opportunities and outcomes for the adolescent to build on. Of interest, many of the strengths were identified against the perceived barriers that the adolescents faced due in some part to having ASD and the lack of empathy and awareness shown by others in the community, further increasing the desire to build resilience and skill level that will support the adolescent to develop courage and perseverance. Courage and perseverance are highly valued as tools that can be utilised over the adolescent's lifetime.

Some of the special skills identified were linked to the possibility of gaining some sort of employment or meaningful way for the adolescent to spend their day. These special skills included talents in photography, art, computer programming, and computer use. Other strengths included having a natural therapeutic focus or a natural talent of inspiring other people around the adolescent. For one parent having an infectious smile and a cheeky disposition was a way to identify that the adolescent will go on to inform the world of the experiences of having Autism as an advocate and positive promoter of diversity. Autonomy was the final strength that was identified by parents and this relates to the understanding that the adolescent would determine their own lives through their thoughts and actions. Becoming autonomous was for every parent in this research an ongoing process of watching, waiting, and interpreting what the adolescent was saying both verbally and non-verbally. Parents engaged with ideas about what kind of life they would like for their son or daughter, and how their strengths could be supported and increased so that the potential for a more successful future is maintained by the parent.

Identification of vicarious futurity (hope for the future) by the parents was closely associated with social norms including gaining an education, procuring employment, finding a life partner, getting married and having children. Being able to be hopeful regarding the future of the adolescent was underpinned by the understanding that included the ongoing development of the adolescent to effectively communicate, make and keep friends and increase connections with those people who will have a vested interest in the adolescent's future. Additionally, this further supports the understanding that parents identified hope for the future in contrast to the deficits of ASD already discussed in this thesis. Furthermore, the higher level of skills in this area of social, communicative, and cognitive abilities increased some of the parents' scope of possibilities for the future of the adolescent. Parents of adolescents with fewer abilities and skills in these three areas had fewer expectations of future success for the adolescent. However, this did not diminish their love, compassion and determination to support the adolescent to have the best future possible.

According to Smith (1991) hope is linked to the ability to manage and control outcomes in life and the world. For those parents in this research, being able to consider how the future might look for their son or daughter was closely linked to the strengths they displayed and whether these strengths helped the adolescent to fit into the systems of home, school and the wider

community. Moreover, the research prompted the parents to consider how the future might be influenced by these strengths, balanced against values held by the family, and the expectations of the community regarding the adolescent that is offset by any knowledge of ASD. Viewing values, strengths, and expectation together, and holding on to the positive part of life currently being experienced, allowed parents to predict that these positive aspects were transferable into the future. It was important that they were nurtured and fostered to facilitate optimism for the parents and to challenge any barriers that are created by stereotypical views of ASD. This relates to the high expectations that the parents held in other studies while still recognising the adolescent's limitations, though continuing to have elevated expectations for positive outcomes (Fleishmann, 2005). Hope stimulates action and this motivates the parents to pursue their goals and, therefore, increase the odds of a positive result or outcome.

Being able to hold this positive perspective has been highlighted in literature as being a protective factor for health and well-being parents with the lived experience of ASD (Scheier & Carver, 1985; Greenberg et al., 2004). Literature identifies that having lower personal control over situations is associated with higher parental stress and the lowering of psychological resilience for parents who raise children with Autism and an Intellectual Disability (Wiggs & Stores, 2001). Parents in this research held on to hope through the understanding that the adolescents had developed various strengths that supported them to fit into school and the community. However, the parents continued to work on other areas of valued behaviours such as sportsmanship, finding ways for the adolescent to manage anxiety, extending their communication skills, and for the adolescent to be able to accept change to become more flexible to maintain hope for the future. These strengths were emphasized through the discussion of how the adolescent with ASD had changed slowly over time becoming more independent and required less monitoring, therefore, holding the perspective this development continues across the lifespan was comforting for the parents.

An insight from this research is in the acknowledgement of expertise that the parents have about the intimate expressions of ASD that is outside the range of a diagnostic context of the disorder. An example of this was the family which allowed their son to wear masks to leave the home and to take a "Wilson" volleyball to the movies to lower anxiety, allowing him the freedom to be autistic in a community setting. According to Carter et al., (2013) the broader

range of activities outside of school that the adolescent with ASD can experience, provides more opportunities for development of positive traits. Todd's parents tapped into one of his quirks of ASD and used it to their advantage to support the adolescent to access ordinary activities in the community. Examples of this idiosyncratic understanding in literature includes the examination of Temple Grandin's squeeze machine and her proclivity to spin coins as a strategy of lowering anxiety (Almaza, 2014). This type of strategy sits outside conventional therapies and, I believe, practitioners need to be looking through the lens of ASD combined with the expertise of the parents to look for more unconventional strategies that support difference and diversity, particularly for adolescents who have significant barriers to accessing the community. This is essentially a celebration of the uniqueness of the adolescent and using ASD as the strength, it being equally important to celebrate those special interests and skills that build a picture of the whole person with aspirations of their own, outside the social norms.

### **Implications of the research**

Being able to get through the day in a positive manner was a goal for the parents in this research and, arguably, for all parents and caregivers in our community. However, living with the experience of raising an adolescent with ASD often created barriers to daily life for the family. Many of the parents reframed their perspective to focus on what could be done to support the adolescent from day to day and sometimes from moment to moment. ASD can be, fundamentally, a strength or *the* strength that can positively improve the life of a family with the lived experience of ASD and support parents to have a positive perspective of the future for their adolescent. Parents in this research highlighted many areas where the adolescent having ASD was an advantage rather than a deficit. According to Nota, Soresi, Ferrarai, Wilgosh, & Scorgie (2003), the perspective of the silver lining analogy linked to parents who are adaptive in terms of coping strategies, reframed negative perspectives of life, retained a positive outlook, and had more affirming experiences in mainstream life. Being able to adapt was an important skill to support resilience for parents and this is highlighted in the research by O'Brien (2015) where it was suggested that parents of adolescents with ASD most often use cognitive reappraisal and social support as a coping strategy for the stressors in their life.

The data in this research suggests that each participant could identify strengths despite the challenges that the adolescent with ASD may display. Furthermore, they discussed how this positive development had happened over time and with a large amount of input from the parents. According to Gray (2002) this parental perspective aligns with the understanding that things do improve for families with experiences of ASD as the adolescent matures and develops. The findings from this research agree with this position. The implications of this research for our understanding of ASD is that if we were to take for granted this knowledge and embrace the strengths of ASD from the point of diagnosis, then the adolescent would have more positive outcomes and more adaptable strengths as they grow into adulthood. As previously suggested by a parent in this research, this would be accepting the “quirks” of ASD instead of trying to change an intrinsic expression of ASD, to fit more socially normative behaviours. This understanding would require a shift in the perspective of the professional systems of medicine, psychology, social work, and education that is highly focused on changing the behaviour of the adolescent with ASD to conform to societal expectations.

### **Supporting families with the lived experience of ASD**

For those parents with small children with a diagnosis of ASD, knowledge of how strengths of ASD can be a strategy for lowering the less-valued behaviours associated with ASD as the child grows into adolescence is going to be useful and psychologically helpful in terms of well-being and resilience. Furthermore, being able to present a picture of a valued life for their loved one, in the light of a diagnosis that is loaded with stereotypical misunderstandings, can support mental health and motivate the parent to start making a plan for a positive future for their son or daughter that will ultimately support quality of life for the parent and other members of the family. Pushing the boundaries of acceptance for ASD is a place to locate helpful and aspirational understandings of social justice and non-discriminatory practice that will empower families with the lived experience of ASD. This is associated with the work of Sheldon & King (2001) where they theorised that positive psychology focusses on human potentiality rather than the traditional problem-focussed or fixing framework.

Any research conducted in ASD is advantageous to that part of the population that has been shown to experience marginalisation and stigmatisation across their lifetime, and this relates to

parents and those with ASD whether they are children, adolescents or adults. Research in ASD that is linked to adolescence is small in comparison to the amount of research around early childhood. Therefore, research with adults with ASD investigating their life experiences is an area that needs more interest from researchers. The parents in this research were in the ages around middle adulthood and, therefore, another area of research would be understanding the experiences of those parents as they age into late adulthood.

### **Limitations of the research**

This is a small research project with 10 participants. Increasing the length of time for the research and the size of the group being researched would have produced an increase in the amount of data available for analysis and possibly offered additional information about strengths inherent in adolescents with ASD. Furthermore, being a parent with an adolescent with ASD placed the researcher in the exact position as the research participants. The researcher may have influenced the participants in terms of the collection and analysis of the data. The semi-structured interview guide was heavily loaded with questions that focused on strengths and hope and so the data reflected this. However, by locating strengths and hope, the data invariably produced nuances of deficit and despair articulated by the parents when they talked about their adolescent with ASD. This is an important aspect to consider in future research that may produce strategies and interventions for these experiences. Two adolescents participated in the research and their discussion added to the data for the research. Both adolescents had experienced considerable marginalisation through the education system and this would be another thought-provoking and important topic to research.

This research focused on the parents or primary caregivers' perspective; therefore, researching from the adolescent's perspective concerning strengths would complement research in this area of ASD. A finding of this research highlighted how adolescents with ASD created their identity in unique ways. There has been little attention from researchers in this area of ASD. Two of the participants were of Māori descent and their data showed a striking difference of the coping mechanisms and understandings of ASD from those who identified as non-Māori. This highlights an area of research in ASD that is almost non-existent and urgently requires further investigation.

## **Conclusion**

Having a child diagnosed with Autism is a journey for any family, parent or primary caregiver. Mediating factors of this journey includes the gender of the child with ASD, their place among other siblings, and the age and culture of the parents. Understanding how these experiences impact on parental appraisals of the present, and how parents engage with thoughts of the future are equally important. Pondering the future as your child ages into adolescence and adulthood has not attracted any substantial research; therefore, we are missing an opportunity to recognise and utilise the valuable knowledge that parents produce over time that may inform insights about family resilience and satisfaction. This knowledge could underpin possible ways to gain mastery over potential barriers associated with new stages and phases in the adolescent's life and, ideally, inform disability policies for Aotearoa New Zealand. Much responsibility for changes in the way that adolescents with ASD are perceived must rest with the professional systems of medicine, psychology, social work, and education and whether they are prepared to embrace alternative philosophies about ASD. Trying to normalise an adolescent with ASD may be an effective strategy to support societally valued outcomes. However, embracing the paradox and quirks that ASD naturally offers as tools to help adolescents with ASD fit into mainstream settings, may provide more opportunities to increase these positive outcomes for those families with the lived experience of ASD.

## References

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- Almaza, M. (2014). Temple Grandin's squeeze machine as prosthesis. *Journal of Modern Literature*, 39(4), 162-175.
- American Association on Intellectual and Developmental Disabilities. (2002). Prevalence and characteristics of autism spectrum disorder among children aged 8 years – Autism and development monitoring network, 11 sites, United States, 2012. Retrieved from [http://www.aaid.org/intellectualdisabilitybook/content\\_2678.cfm?navID=282](http://www.aaid.org/intellectualdisabilitybook/content_2678.cfm?navID=282).
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (DSM-IV-TR)* (4th ed.). Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders - Fifth edition*. Arlington, VA: American Psychiatric Publishing.
- Aotearoa New Zealand Association of Social Workers. (2015). *An ANZASW practice note for social workers working with the Protection of Personal and Property Rights Act, 1988*. Wellington, New Zealand: Author. Retrieved from <http://anzasw.nz/wp-content/uploads/Practice-Note-for-SW-working-with-PPPR-Act-Sept-2015.pdf>.
- Attwood, T. (2003). Understanding and managing circumscribed interests. In M. Prior (Ed.), *Learning and behavior problems in Asperger Syndrome* (pp. 126-147). New York, NY: Guilford.
- Autism Developmental Disabilities Monitoring Network. (2007). Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network, 14 sites, United States, 2002. *MMWR Surveillance Summaries*, 56(SS01), 12–28.
- Beadle-Brown, J., Murphy, G., & Wing, L. (2005). Long-term outcome for people with severe intellectual disabilities: The impact of social impairment. *American Journal on Mental Retardation*, 110(1), 1-12.
- Beck, A. T., Steer, R. A., Kovacs, M., & Garrison, B. (1985). Hopelessness and eventual suicide: A 10-year prospective study of patients. *American Journal of Psychiatry*, 142, 559-563.

- Bennett, M., & Goodall, E. (2016). A meta-analysis of DSM-V Autism diagnoses in relation to DSM-IV and DSM-IV-TR. *Review Journal of Autism and Developmental Disorders, 3*(2), 119-124.
- Benjak, T. (2009). Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia. *Croatian Medical Journal, 50*, 403–409.
- Ben-Itzhak, E., Ben-Shachar, S., & Zachor, D. A. (2013). Specific neurological phenotypes in autism spectrum disorders are associated with sex representation. *Autism Research, 6*(6), 596–604.
- Blue-Banning, M., Turnbull, A. P., & Pereira, L. (2002). Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research and Practice for Persons with Severe Disabilities, 27*(3), 204-219.
- Bodde, A. E., & D. C. Seo. (2009). A review of social and environmental barriers to physical activity for adults with intellectual disabilities. *Disability and Health Journal, 2*, 57–66.
- Boyd, B. A., Conroy, M. A., Mancil, G. R., Nakao, T., & Alter, P. J. (2007). Effects of circumscribed interests on the social behaviors of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 37*, 1550–1561.
- Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Brewer, M. B. (2004). Taking the social origins of human nature seriously: Toward a more imperialist social psychology. *Personality and Social Psychology Review, 8*, 107–113.
- Brown, G. W., Lemyre, L., & Bifulco, A. (1992). Social factors and recovery from anxiety and depressive disorders: A test of specificity. *British Journal of Psychiatry, 161*, 44-54.
- Bultas, M., & W., Pohlman S. (2014). Silver linings. *Journal of Paediatric Nursing, 29*(6), 596-605.

- Carpenter, L. A., Boan, A. D., Wahlquist, A. E., Cohen, A., Charles, J., Jenner, W., & Bradley, C. C. (2016). Screening and direct assessment methodology to determine the prevalence of Autism Spectrum Disorders. *Annals of epidemiology*, 26(6), 395-400.
- Carter, E. W., Boehm, T. L., Biggs, E. E., Annandale, N. H., Taylor, C. E., Loock, A. K., & Liu, R. Y. (2015). Known for my strengths: Positive traits of transition-age youth with intellectual disability and/or Autism. *Research and Practice for Persons with Severe Disabilities*, 40(2), 101-119.
- Carter, E. W., Lane, K. L., Cooney, M., Weir, K., Moss, C. K., & Machalicek, W. (2013). Parent assessments of self-determination importance and performance for students with autism or intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 88, 16-31. DOI:10.1352/1944-7558-118.1.16.
- Carver, C. S., & Connor-Smith, J. (2010). Personality and coping. *Annual Review of psychology*, 61, 679–704.
- Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorders among children aged 8 years: Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *MMWR Surveillance Summaries*, 63(2), 1–19.
- Chawarska, K., Paul, R., Klin, A., Hannigen, S., Dichtel, L. E., & Volkmar, F. (2007). Parental recognition of developmental problems in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 37(1), 62–72.
- Chown, N., & Hughes, L. (2016). History and first descriptions of autism: Asperger Versus Kanner revisited. *Journal of autism and developmental disorders* 46(6), 2270-2272.
- Colavita, A. A., Luthra, N., & Perry, A. (2014). Strengths and challenges of children with a developmental disability: A qualitative analysis of parent perceptions. *Journal on Developmental Disabilities*, 20(3), 80-87.
- Constantino, J. N., Zhang, Z., Frazier, T., Abbachi, A. M., & Law, P. (2010). Sibling recurrence and the genetic epidemiological of autism. *American Journal of Psychiatry*, 167(11), 1349-1356.

- Courchesne, E., Carnes, B. S., & Davis, H. R. (2001). Unusual brain growth patterns in early life in patients with autistic disorder: A MRI study. *Neurology*, *57*(2), 245-254.
- Cosden, M., Koegel, L. K., Koegel, R. L., Greenwell, A., & Klein, E. (2016). Strengths-based assessment for children with autism spectrum disorders. *Research and Practice for Persons with severe disabilities*, *31*(2), 134-143.
- Dawson, G., Toth, K., Abbott, R., Osterling, J., Munson, J., Estes, A., & Liaw, J. (2004). Early social attention impairments in autism: social orienting, joint attention and attention to distress. *Developmental Psychology*, *40*(2), 271-284.
- Dowd, A. M., McGinley, J. L., Taffe, J. R., & Rinehart, N. J. (2012). Do planning and visual integration difficulties underpin motor dysfunction in autism? A kinematic study of young children with autism. *Journal of autism and developmental disorders*, *42*(8), 1539–1548.
- Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, *9*(4), 416–427.
- Ekas, N. V., Timmons, L., Pruitt, M., Ghilain, C., & Alessandri, M. (2015). The power of positivity: Predictors of relationship satisfaction for parents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(7), 1997-2007.
- Erard, R. E. (1985). Concrete thinking and the categorical attitude. In I. Fast (Ed.), *Event Theory: A Piaget–Freud Integration* (pp. 111–134). Hillsdale, NJ: Erlbaum.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*(4), 375–387.
- Falk, N., H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in parents of children with autism. *Journal of Autism and Developmental Disorders*, *44*(2), 3185-3203.
- Faso, D., J., Neal-Beevers, A., & Carlson, C., L. (2012). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders* *7*(2), 288-297.

- Fleischmann, A. (2005). The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism, 9*(3), 299–316.
- Geiger, D. M., Smith, D. T., & Creaghead, N. A. (2002). Parent and professional agreement on cognitive level of children with autism. *Journal of Autism and Developmental Disorders, 32*(4), 307–312.
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability, 27*(3), 215-222.
- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities, 18*(2), 83–93.
- Greenberg, J. S., Seltzer, M. M., Krauss, M. W., Chou, R. J., & Hong, J. (2004). The effect of quality of the relationship between mothers and adult children with schizophrenia, autism, or down syndrome on maternal well-being: The mediating role of optimism. *American Journal of Orthopsychiatry, 74*(1), 14–25.
- Godfrey, J. J. (1987). *A philosophy of human hope*. Dordrecht, The Netherlands: Martinus Nijhoff Publishers.
- Gordon, C. L., & Baucom, D. H. (2009). Examining the individual within marriage: Personal strengths and relationship satisfaction. *Personal Relationships, 16*(3), 421–435.
- 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.
- Heidegger, M. (1962). *Being and time* (J. Macquerrie & E. Robinson, Trans.). New York, NY. Harper & Row.
- Hershberger, W.A. (Ed.). (1989). *Violation action* (Vol 62). N Elsevier.
- Hill, D., A., & Flores, M. M. (2014). Comparing the picture exchange communication systems and the iPad for communication of students with autism spectrum disorder and developmental delay. *Techtrends, 58*(3), 45.

- Hoogsteen, L., & Woodgate, R. L. (2013). The lived experience of parenting a child with autism in a rural area: Making the invisible, visible. *Pediatric Nursing, 39*(5), 233-237.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcomes for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212–229.
- Ingersoll, B., Walton, K., Carlsen, D., & Hamlin, T. (2013). Social intervention for adolescents with autism and significant intellectual disability. Initial efficacy of reciprocal imitation training. *American journal on intellectual and developmental disabilities, 118*(4), 247-261.
- Jeste, S. S., & Geschwind, D. H. (2014). Disentangling the heterogeneity of autism spectrum disorder through genetic findings. *Nature Reviews Neurology, 10*(2), 74-81.
- Johnson, C. P., Myers, S. M., & The Council on Children with Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Paediatrics, 120*(5), 1183-1215.
- Kana, R., K., Uddin, L., Q., Kenet, T., Chugani, D., & Müller, R.A. (2014). Brain connectivity in autism. *Front Human Neuroscience, 8*.
- Kanner, L. (1946). Irrelevant and metaphorical language in early infantile autism. *American Journal of Psychiatry, 103*(2), 242-246.
- Klin, A., Danovitch, J., Merz, A., & Volkmar, F. (2007). Circumscribed interests in higher functioning individuals with autism spectrum disorders: an exploratory study. *Research & Practice for Persons with Severe Disabilities, 32*(2), 89–100.
- Koegel, R. L., Schreibman, L., Britten, K. R., Burkey, J. C., & O’Neill, R. E. (1982). A comparison of parent training to direct child treatment. In R. L. Koegel, A. Rincover, & A. L. Egel (Eds.), *Educating and understanding autistic children*. San Diego, CA: College-Hill.
- Konstantareas, M. M. (1990). A psychoeducational model for working with families of autistic children. *Journal of Marital and Family Therapy 16*(1), 59–70.
- Kring, A. M., Johnson, S. L., Davidson, G. & Neale, J. (2012). *Abnormal psychology (12th ed.)* John Wiley and Sons, Inc.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science and Medicine, 47*(7), 865–875.

- Lazarus, R. S. (1999). Hope: An emotion and a vital coping resource against despair. *Social Research*, 66(2), 653–678.
- Lerner, R. M. (2005). Promoting positive youth development: Theoretical and empirical bases [White paper]. Washington, DC: National Academies of Science.
- Lyons, A. C., & Chamberlain, K. (2008). *Health psychology: A critical introduction*. Cambridge, United Kingdom: Cambridge University Press.
- Maenner M., J., Rice C., E., Arneson C., L., Cuniff, C., Carpenter, L., A., Van Naarden B. K., ... Furkin, M. S. (2014). Potential impact of DSM-V criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry*, 71(3), 292-300.
- McBride, P. A., Anderson, G. M., & Shapiro, T. (1996). Autism research: Bringing together approaches to pull apart the disorder. *Archives of General Psychiatry*, 53(11), 980-983.
- McCarthy, R. A., & Warrington, E. K. (1990). *Cognitive neuropsychology*. London, United Kingdom: Academic Press.
- McGeer, V. (2004). The art of good hope. *Annals of the American Academy of Political and Social Science*, 592(1), 100–127.
- McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and specificity of proposed DSM-V diagnostic criteria for autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(4), 368-383.
- Ministry of Health. (2016). *Autism spectrum disorder*. Retrieved from <http://www.health.govt.nz/your-health/conditions-and-treatments/disabilities/autism-service>.
- Ministry of Education. (2012). *Ministry of Education funded supports and services for learners with special education needs/disabilities*. Retrieved from [www.education.govt.nz/school/special-education/](http://www.education.govt.nz/school/special-education/).
- 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.

- Muller, R. A., Shih, P., Keehn, B., Deyoe, J. R., Leyden, K. M., & Shukla, D. K. (2011). Underconnected, but how? A survey of functional connectivity MRI studies in autism spectrum disorders. *Cerebral Cortex*, *21*(10), 2233–2243.
- Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, C. J. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work*, *14*(3), 208-225.
- Nelson G., & Prilleltensky, I. (2010). *Community psychology: In pursuit of liberation and well-being*. New York, NY: Palgrave Macmillian.
- Nota, S., Soresi, S., Ferrarai, L., Wilgosh, L., & Scorgie, K. (2003). Life management and quality of life of parents of children with diverse disabilities. *Developmental Disabilities Bulletin*, *31*, 155–181.
- Nunn, K. P. (1996). Personal hopefulness: A conceptual review of the relevance of the perceived future to psychiatry. *British Journal of Medical Psychology*, *69*(3), 227–245.
- O'Brien, S. (2015). Families of adolescents with autism: Facing the future. *Pediatric Nursing*, *31*(2), 204-213.
- Oettingen, G., & Gollwitzer, P. M. (2002). Turning hope thoughts into goal-directed behaviour. *Psychology Inquiry*, *13*(4), 304-307.
- Ozonoff, S., Goodlin-Jones, B. L., & Solomon, M. (2005). Evidence-based assessment of autism spectrum disorders in children and adolescents. *Journal of Clinical Child and Adolescent Psychology*, *34*(3), 523–540.
- Paynter, J. M. (2015). Assessment of school-aged children with autism spectrum disorder. *Journal of Psychologists and Counsellors in Schools*, *25*(1), 104-115.
- Polsek, D., Jagatic, T., Capanec, M., Hof, P. R., & Simic, G. (2011). Recent developments in neuropathology of autism spectrum disorders. *Transl. Neurosci*, *2*(3), 256–264.
- Rimland, B. (1964). *Infantile Autism*. New York, NY: Appleton-Century-Crofts.

- Scahill, L., Riddle, M., McSwiggin-Hardin, M., Ort, S., King R, et al. (1997) Children's Yale Brown obsessive-compulsive scale: Reliability and validity. *Journal of the American Academy of Child & Adolescent Psychiatry*, 36(6), 844–852.
- Scheier, M. F., & Carver, C. S. (1992). Effects of optimism on psychological and physical well-being: Theoretical overview and empirical update. *Cognitive Therapy and Research*, 16(2), 201–228.
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55, 5-14.
- Seligman M., & Darling R. B. (2007). *Ordinary families: Special children: A systems approach to childhood disability*. New York, NY: The Guildford Press.
- Sheldon, K. M., & King, L. (2001). Why positive psychology is necessary. *American Psychologist*, 56(3), 216-217.
- Silverman, C. (2012). *Understanding Autism*. Princeton, NJ: Princeton University Press.
- Smith, M. B. (1991). *Hope and Despair: Keys to the Socio-Psychodynamics of Youth. Values, Self and Society: Toward a Humanist Social Psychology*. New Brunswick, NJ: Transaction.
- Smith, T., & Eikeseth, S. (2011). O. Ivar Lovaas: Pioneer of applied behaviour analysis and intervention for children with autism. *Journal of Autism and Developmental Disorders*, 41(3), 375-378.
- Spezo, M. L., Adolphs R., Hurley, R. S., & Piven, J. (2007). Abnormal use of facial information in high-functioning autism. *Journal of Autism and Developmental Disorders*, 37(5), 929-939.
- Stotland, E. (1969). *The psychology of hope*. San Francisco, CA: Jossey-Bass.
- Snyder, C. R., Rand, K. L., & Sigmon, D. R. (2002). Hope theory: *Handbook of positive psychology*, 257–276.
- Taylor, C. (1991). *The interpretive turn: Philosophy, science, culture*. 304-314. New York, NY: Cornell University Press.
- Treffert, D. A. (2009). The savant syndrome: An extraordinary condition. A synopsis: Past, present and future. *Philosophical Transactions of the Royal Society*, 364(1522), 1351-1357.

- Trivette, C. M., & Dunst, C. J. (2011). Consequences of interest-based learning on the social-affective behavior of young children with autism. *Life Span and Disability, 14*(2), 101-110.
- Vernon, T. W. (2014). Fostering a social child with autism: A moment by moment sequential analysis of an early social engagement intervention. *Journal of Autism and Developmental Disorders, 44*(12), 3072-3082.
- von Gontard, A. (2015). Paediatrics: Nocturnal enuresis, daytime urinary and faecal incontinence in children with special needs. *Australian and New Zealand Continence Journal, 21*(2), 54-58.
- Voysey, M. (1972). Impression management by parents with disabled children. *Journal of Health and Social Behaviour, 13*, 80-89.
- Watson, S. L., & Hayes, S. A. (2011). Does having hope help? Resiliencies and challenges of families raising a child with autism. *The NADD Bulletin, 14*(1), 3-6.
- Watson, S. L., Hayes, S. A., Coons, K. D., & Radford-Paz, E. (2013). Autism and fetal alcohol spectrum disorder part II: A qualitative comparison of parenting stress. *Journal of Intellectual and Developmental Disability, 38*(2), 105-113.
- Weiss, J. A., & Riosa, P. B. (2015). Thriving in youth with Autism Spectrum Disorder and Intellectual Disorder. *Journal Autism and Developmental Disorder, 45*(8), 2474-2486.
- Weiss, L. A., Shen, Y., Korn, J. M., Arking, D. E., Miller, D. T., Fossdal, R., ... & Platt, O. S. (2008). Association between microdeletion and microduplication at 16p11.2 and autism. *New England Journal of Medicine, 358*(7), 667-675.
- Wiggs, L., & Stores G. (2001). Behaviour treatment for sleep problems in children with severe intellectual disabilities and daytime challenging behaviour: effect on mothers and fathers. *British Journal of Health Psychology 6*(3), 257-269.
- Wilkinson-Meyers, L., Brown, P., Reeve, J., McNeil, R., Patston, P., Dylan, S., McEldowney, J. (2014). Reducing disablement with adequate and appropriate resources: A New Zealand perspective. *Disability & Society, 29*(10), 1540-1553.

Wiltshire, S. (2016). *Stephen Wiltshire, MBE – Biography*. Retrieved from <http://www.stephenwiltshire.co.uk/biography.aspx>.

Wong, M. G., & Heriot, S. A. (2007). Vicarious futurity in autism and childhood dementia. *Journal of Autism and Developmental Disorders*, 37(10), 1833-1841.

Zilboorg, G., & Henry, G. W. (1941). *A history of medical psychology*. New York, NY: W. W. Norton & Co.

## Appendix 1: Letter to your organisation



**MASSEY UNIVERSITY**  
COLLEGE OF HUMANITIES  
AND SOCIAL SCIENCES  
TE KURA PŪKENGĀ TĀNGATA

8/2/17

Disability Organisation  
Hamilton 3216.

Dear Sir/Madam

***Identifying strengths in adolescents with Autism from a parent's perspective.***

**Letter to your organisation**

My name is Jan Hastie and I am currently completing my Master's degree in Science, in health psychology at Massey University. My supervisor for this research is Professor Christine Stephens, and our contact details are included below.

I am conducting research in Autism and I would like to ask for your organisation's permission, and your assistance, to advertise for potential participants through your organisation.

My research is interested in a parent's perspective of the strengths of adolescents with Autism. This is a positive approach to psychological research and will offer a positive perspective of Autism that is often missing in research.

Criteria for the parent's and adolescent's participation:

- Parents/Primary caregivers of adolescents (16-19 years old) with a diagnosis of Autism.

What I would like you to do:

If you agree to assist, I will request a letter from your organization to acknowledge your agreement. I will also ask that you post the enclosed information sheet and invitation to the parents or primary caregiver who you believe fit the criteria of my research.

If you agree to this request, self-stamped envelopes and information packs for each of the potential participants will be provided. I hope that you would be happy to address and post them or pass them on to interested parents.

In recognition of the significant part that your organisation will be playing in this research, a summary of the findings will be made available to the organisation. It is envisaged by the researcher that this research will provide additional information of the strengths of adolescents with Autism that may inform organisations in regard to how their service provisions are provided to this particular group within our community.

I will contact you soon to ask about your interest and answer any additional questions that you might have. I can be contacted on (07) 346 8633 during work hours if you require any further information. My full contact details, and those of Professor Christine Stephens are listed below.

I look forward to hearing from you.

Yours faithfully

Jan Hastie

**Contact details:**

Jan Hastie

Phone: 0273468002 (Please text).  
Work 07 346 8633  
Email [jan.hastie@toiohomai.ac.nz](mailto:jan.hastie@toiohomai.ac.nz)

Address: Toi-Ohomai Institute of Technology (Formerly Waiariki Institute of Technology)  
Mokoia Drive  
Rotorua 3015

Professor Christine Stephens

Phone: (06) 356 9099 ext. 8059  
Email [C.V.Stephens@massey.ac.nz](mailto:C.V.Stephens@massey.ac.nz)

Address: Massey University  
Tennent Drive  
Palmerston North 4474



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TE KURA PŪKENGĀ TĀNGATA

***Identifying strengths in adolescents with Autism from a parent's perspective.***

**Information sheet for Parents and Primary Caregivers.**

Kia Ora, My name is Jan Hastie and I am a student researcher currently completing a Master's degree in Science, in health psychology at Massey University. My supervisor for this research is Professor Christine Stephens.

I would like to invite you to participate in my research project on Autism. I am interested in increasing the knowledge about the strengths of adolescent with Autism from the perspective of their parents and primary caregivers. This is a positive approach to psychological research and will offer a positive perspective of Autism that is often missing in research.

**Who can take part in the research?**

- I am asking any parent or care-giver of an adolescent (aged between 16 and 19 years) who has been diagnosed with Autism, to take part in this research. CCS Disability Action or your local specialist school has been asked to send you this invitation as they have identified you as a potential participant. However, you are under no obligation at all to take part. This is simply an initial information sheet and invitation.

**What will participants be asked to do?**

- If you are interested in asking any questions about the study please contact me. If you are thinking about possibly taking part in the study, please complete and return the form enclosed in this letter to me, in the prepaid envelope (**no stamp is needed**).
- I will contact you to answer any questions that you have and to arrange an initial meeting (at your home or another place that suits you), to discuss the research.
- If you decide to take part in the research, I will ask you to gain your son or daughter's permission to be part of the study and take five photographs to show their positive achievements and qualities over about two weeks.
- The consent process for gaining your son or daughters permission to be part of this study will be discussed at this initial meeting. If you believe your son or daughter has the capacity to understand informed consent, then they may sign an adolescent participant consent form. There is also an adapted adolescent participant consent form done as a social story if you believe that this is appropriate,
- I can provide a camera or you can use your own phone to take the photographs.
- Then I will contact you again and we will arrange another time to discuss the photographs and their meanings for you, including your hopes for the positive future of your son or daughter.
- This interview will be audio recorded and I will send you a written transcript of the interview for your approval before any further analysis is conducted. If you wish, you can make any changes to the transcript before your final approval.
- The total time to participate in this research is 3.5 hours, including 1 hour for the initial meeting, 2 hours for the substantive interview, and 30 minutes to take the photographs over a two-week period.
- There is no time frame regarding the withdrawal from this research.
- Each participant will be given a \$20 petrol or grocery voucher to thank them for participating in the research.
- I do not envisage any discomfort will be experienced through participation in this research. However, if any fears or worries come up for you in thinking about this subject, please see the list I have

compiled of counselling and disability services in your local area in case you wish to seek support for your concerns.

#### **What will happen to the interview data and photographs?**

- The photographs will only be used to discuss the strengths of your son or daughter. If I would like to use any individual photographs for my Thesis or research presentations, I will ask for written permission to do this.
- The recorded interviews will be transcribed into a written document that will be used to answer the study questions and to write a thesis about the findings.
- Your name and your son or daughters name, will not be linked to the written document. All discussion of what you tell me will only be identified by a numerical identifier.
- All transcripts will be stored in a secure locked location as the responsibility of the researcher.
- Data will be stored for a period of 5 years at which time it will be disposed of.
- I will send you a summary of the research findings when I have finished my analysis. Once I have done this, all names and contact details will be destroyed.

#### **Participants' Rights**

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any question.
- withdraw from the study at any time.
- ask any questions about the study at any time during participation.
- provide information on the understanding that your identifiable information will be made anonymous.
- be given access to a summary of the project findings when it is concluded.

Thank you for reading this information. Please contact me or my supervisor using the contact details below if you have any immediate questions. Or send the response sheet back to me in the prepaid envelope and I will contact you soon. I look forward to hearing from you.

Kind regards

Jan Hastie

#### **Contact details:**

Jan Hastie

Phone: 0273468002 (Please text).  
Work 07 346 8633  
Email jan.hastie@toiohomai.ac.nz  
Address: Toi-Ohomai Institute of Technology (Formerly Waiariki Institute of Technology)  
Mokoia Drive  
Rotorua 3015

Professor Christine Stephens

Phone: (06) 356 9099 ext. 8059  
Email C.V.Stephens@massey.ac.nz  
Address: Massey University  
Tennent Drive  
Palmerston North 4474

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 16/47. If you have any concerns about the conduct of this research, please contact

Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz.

## Appendix 3: Parent participant invitation



**MASSEY UNIVERSITY**  
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AND SOCIAL SCIENCES  
TE KURA PŪKENGĀ TĀNGATA

### ***Identifying strengths in adolescents with Autism from a parent's perspective.***

#### **Parent Participant Invitation**

My name is Jan Hastie and I am a student researcher currently completing my Masters in Science in health psychology with Massey University. My supervisor for this research is Professor Christine Stephens. I am conducting research in Autism where I would like to increase the understanding around strengths of adolescents aged 16-19 years with Autism from the perspective of parents and primary caregivers.

The research will be done over two weeks and should take approximately 3.5 hours in total. This will include 1 hour for the initial meeting, 2 hours for the substantive interview and 30 minutes for taking photographs over a two-week period. Part of this research will require that you take five photographs that identify the strengths and positive qualities of adolescents with Autism. Semi-structured interviews will be conducted by me, at a place and time that suits you, to discuss the photographs to identify strengths in adolescents with Autism.

There is a small koha for participating in this study. Your participation will support a positive psychology perspective of Autism that is often missing in academic research, raising awareness of Autism in a positive light through a strength based understanding.

If you are willing to participate in this research, please complete this form with your contact details and post in the reply paid envelop that has been supplied.

Thanks, Jan

Name.....

Address.....

Contact number.....

Signature.....



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***Identifying strengths in adolescents with Autism from a parent's perspective.***

**PARENT/PRIMARY CAREGIVER PARTICIPANT CONSENT FORM - INDIVIDUAL**

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to the interview being sound recorded.

I agree to taking photographs for purposes of the research.

I agree to gain consent from the adolescent who is a participant in this project.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signature:**

**Date:**

.....

**Full Name - printed**

.....



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***Identifying strengths in adolescents with Autism from a parent's perspective.***

**ADOLESCENT CONSENT FORM - INDIVIDUAL**

I have had the details of the research explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to my parent/primary caregiver taking photographs for purposes of the research.

I agree to my parent/primary caregiver talking to the researcher about the photographs for the purposes of the research.

**Signature:**

.....

**Date:**

.....

**Full Name - printed**

.....



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My name is Jan Hastie I am a student researcher.



A researcher is like an investigator.

I am interested in finding out what family members think are the strengths of adolescents (16-19 years old), with Autism. Strengths are things you do that helps others, or things you love to spend time doing. Your strengths might be using the computer, listening to music, doing art or helping mum cook dinner.



I have asked your family member or caregiver to take photographs of things that they think are your strengths.



I will come and see your family member to talk to them about the photographs and discuss what strengths they see in the photographs. This discussion will help me to write a story about your strengths.

This will provide information for my research thesis. A research thesis is like a book. In the book I will talk about your strengths by using the stories I have discussed with your family. You are welcome to talk to me about what you like doing as well. I do not use your name in the book so no one will know that any of the stories are about you.



The stories in the book will help agencies like the government think about how to support other people your age, who have Autism, by thinking about their strengths when they are designing services for them.

If you are happy to part of this research please write your name and the date below. Your family member or caregiver can help you with this.

Name..... Date.....



## Appendix 7: Research question guide

### Research questions

Photographs:

Where and when were they taken? What is happening in them?

What strengths of your adolescent do these photographs display?

What are the good things about these strengths for your adolescent?

Do other people recognize these strengths?

How do these strengths add positively to family life?

How do these strengths help with the families daily functioning?

Do you think that your son or daughter will get what they want in life?

How does the environment (or where the photo was taken) compliment/support these strengths?

How will these strengths support your son or daughter into the future?

What sort of future do you envisage for your son or daughter?

How do you see these strengths as empowering for your son or daughter in the future?

How do you see this empowerment being maintained?

Do you think that your son or daughter will be able to cope with most issues he/she will face?

Is there anything else that you would like to share regarding the adolescent, strengths and the future?

## Appendix 8: Authority for the release of participant interview transcripts



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### ***Identifying strengths in adolescents with Autism from a parent's perspective.***

#### **AUTHORITY FOR THE RELEASE OF PARTICIPANT INTERVIEW TRANSCRIPTS**

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

**Signature:**

**Date:**

.....

**Full Name - printed**

.....



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***Identifying strengths in adolescents with Autism from a parent's perspective.***

**PHOTOGRAPH RELEASE FORM – PARENTS/CAREGIVERS**

**Purpose:**

Recently you participated in research conducted by Jan Hastie, student researcher at Massey University in the above titled study, where you took photographs of the strengths of adolescents with Autism. The photographs identified below are an ideal illustration of the research topic and I would like to ask for your permission to use the photograph/s in my master's thesis and other publications related to this project. Because people could recognize your son or daughter in this photograph I require your written permission to use them in my thesis and any other publications.

If you decide to allow the photograph to be used but not to have your son or daughters face displayed in any of the photographs, it will be covered through pixilation or other means of concealment.

Number of the photograph and number of the subject:

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- I consent to the use of photographs taken during this research project for use in the research thesis of Jan Hastie or other publications related to this project.
- I wish/do not wish to have the face of my son or daughter concealed in any photograph that is used for this research.

**Parent/Caregiver  
Signature:**

**Date:**

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**Child's full name  
(printed)**

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**Relationship to the  
child**

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