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Un-strangering 'the stranger' in a *strange land*: A multi-perspective, participant-led, exploration of in/ex-clusion in NZ mainstream high schools - privileging the voices of senior 'high-functioning' autistic students.

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Sharon Lee O'Donnell Crooks

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Abstract

New Zealand's (NZ) 'inclusive' school policies enable autistic students to attend a mainstream school of their choice, with the expectation they will belong, feel accepted, contribute, and participate in 'school life'. Research has typically focused on biogenetic origins and diagnostic specificity, providing medicalised and stereotypical ways of understanding autistic people. Few qualitative studies have explored autistic students' understandings and everyday lived experiences of 'being autistic' and 'being in an inclusive mainstream high school'. Excluding their voice from research, necessarily constrains development of policy, pedagogy, and praxis, which might facilitate more inclusive experiences for this population of students. This study was the first in NZ to focus on the lived experiences of autistic adolescents in their senior years (Levels 1-3 NCEA). A multi-perspective, qualitative phenomenological design enabled three tertiary students, three parents, and seven advocates, to augment contributions from five high-functioning autistic adolescents. This research was underpinned by a feminist standpoint epistemology and Bronfenbrenner's bioecological model, privileging first person experiences and contextual influences. Interpretative Phenomenological Analysis enabled participants' understandings and experiences to be explored. Tertiary students illumined how medical model understandings of disability constrained and enabled identity formation in high school and implicated being understood. Most of the autistic participants drew on neoliberal 'governmentality' to problematise barriers to inclusion, namely 'governance' (dominant culture, school rules, and regulation of 'space'), teacher performativity, and curriculum management. Salient interpersonal barriers included authoritative teachers, social cliques, 'invisible' bullying, and 'one-off' grievances. 'Being excluded' was painful and resulted in feeling 'de-valued', impacting motivation and opportunities for success. Facilitators to inclusion were embedded within meaningful interactions, demonstrative care, and common interests, aiding a sense of acceptance, and belonging, but not always resulting in 'contributing' and 'participating'. High school was experienced by autistic participants as a political site where in/ex-clusion 'gets done' through ordinary technologies that 'sift and shift' students, according to sameness and difference, or ontological 'otherness'. This study addresses prominent diagnostic and identity issues, academic and social achievement, and support, all of which are primary concerns for educationalists (including educational psychologists) striving to understand inclusion and improve outcomes for autistic students.

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Some things in life could never come to fruition without a miracle, or two! Completing a PhD without a high school qualification, seems like one! 'Being educated' was a slow process; an impossibility if were not for the Holy Goodness and Divine Mercy of Our Lord and Saviour, Jesus Christ. Before acknowledging anyone else, it is He who I owe the most, and love the greatest, that I dedicate this PhD. *Tuus totus ego sum, et omnia mea tua sunt.* To Him be the glory forever and ever, Amen.

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Abbreviations

APA	American Psychological Association
AS	Asperger Syndrome
ASD	Autistic Spectrum Disorder
BOT	Board of Trustees
CAMHS	Child and Adolescent Mental Health Services
CYFS	Child, Youth and Family (New Zealand)[1]
DHB	District Health Board
DSM	Diagnostic and Statistical Manual
ERO	Education Review Office
GP	General Practitioner (Family Doctor)
HFA	High Functioning Autism
ICD	International Classification of Diseases
IEP	Individual Education Plan
IPA	Interpretative Phenomenological Analysis
IQ	Intelligent Quotient
MoE	Ministry of Education
NCEA	National Certificate of Educational Achievement
NZ	New Zealand
NZPsS	New Zealand Psychological Society
NZQA	New Zealand Qualifications Authority
OECD	Organisation for Economic Co-operation and Development
PDD-NOS	Pervasive Developmental Disorder - Not Otherwise Specified
PTSD	Post-Traumatic Stress Disorder
Q & A	Question and Answer 'sessions': a form of bullying
SAC	Special Assessment Conditions
SENCO	Special Educational Needs Coordinator
TA	Teacher Aide
TCK	Third Culture Kids
ToM	Theory of Mind
WHO	World Health Organisation

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[1] CYFS is now known as Oranga Tamariki or Ministry for Children

Chapter One
Introduction and background

New Zealand: *country in the South Pacific, south east of Australia, consisting of North Island, South Island, and adjacent small islands: a member of the Commonwealth of Nations. 103,416 sq. mi. (267,845 sq. km). Capital: Wellington.*

(dictionary.com)

1.1 Introduction

The aim of this thesis is to explore the inclusive everyday lived experiences of senior high school students diagnosed with Autistic Spectrum Disorder (ASD) (or a variant) in mainstream high schools, Aotearoa New Zealand (NZ). There have been very few qualitative inclusion studies from autistic people's perspectives, so it seems students have very diverse experiences, with some experiencing forms of exclusion (Barnard, Prior, & Potter, 2000; Carrington & Graham, 2001; Humphrey & Lewis, 2008a; Osler & Osler, 2002; Watson, 2009). NZ schools are considered inclusive, and the curriculum operates under the 'inclusion principle', which states that "the curriculum is non-sexist, non-racist, and non-discriminatory; it ensures that students' identities, languages, abilities, and talents are recognised and affirmed and that their learning needs are addressed" (Ministry of Education, 2020a). There is an urgent need now however, to explore the perceptions and experiences of NZ autistic high school students to understand how well or not, this applies to them.

This chapter begins by summarising my Honours research, and the findings pertaining to 'heterogeneity', which was the initial impetus for this research. The characteristics of autism are then introduced, from an historical perspective. The remainder of the chapter is dedicated to contextualising the sociocultural and political milieu of NZ, as well as the development of education, its governance, and expectations for achieving New Zealand's National Certificate of Educational Achievement (NCEA). This contextual orientation is important because each country presents unique challenges and curriculums for autistic students. The theoretical frameworks and philosophical assumptions underpinning this qualitative project, assumes students' perceptions and experiences are known through their being embedded within a *particular* socio-historical-cultural milieu. Assumptions about this milieu must therefore be evident and interpretable to international readers, given the paucity of comparable research.

1.2 Heterogeneity: Honours degree research findings

In my Honours degree research, I initially took as my starting point a lack of co-ordinated autism services evident in the then recently published NZ Autism Spectrum Disorder Guidelines (Ministries of Health & Education, 2008), and the troubling, documented journey of one NZ family (‘the Murray’s’) to obtain a diagnosis and support for their son (see Murray, 2006). The Murray’s, like others at that time, had experienced multiple referrals, had travelled internationally seeking an autism diagnosis and subsequently, experienced varying, if not contrary, degrees of support and assistance for their son, within the NZ education system.

A research opportunity arose to pilot a methodology to develop a screening and tracking tool, which might be informative for teachers and interested others wanting to garner insight into autistic traits in general, but specifically in relation to each individual student. One of the forms of oppression that minority individuals face, is being stereotyped and treated as though they are all the same. Individual profiles, similar to that generated in attachment research (e.g., Kirkland, et al., 2004), would provide a comprehensive summary of individual abilities or lack thereof, important for stimulating ‘home-grown’ tailored interventions and for making a difference at the individual level, which would have implications for students’ personal experiences of ‘inclusion’.

I assembled a list of 150 semantic items pertaining to everyday observable experiences relevant to children and young people aged 5-18 years, diagnosed with Asperger’s Syndrome (AS). ‘Autistic’ symptoms and abilities are usually ordinary responses to everyday challenges, albeit with varying degrees of severity and developmental relevance. The method used to ‘map’ semantic taxonomic data has previously been offered in detail (e.g., Harvey, Bimler, Evans, Kirkland, & Pechtel, 2012; Kirkland, et al., 2004).

Forty adult participants from a range of caring and teaching professions used custom sorting techniques to map the semantic items resulting in a 3D spatial map (see Figure 1).

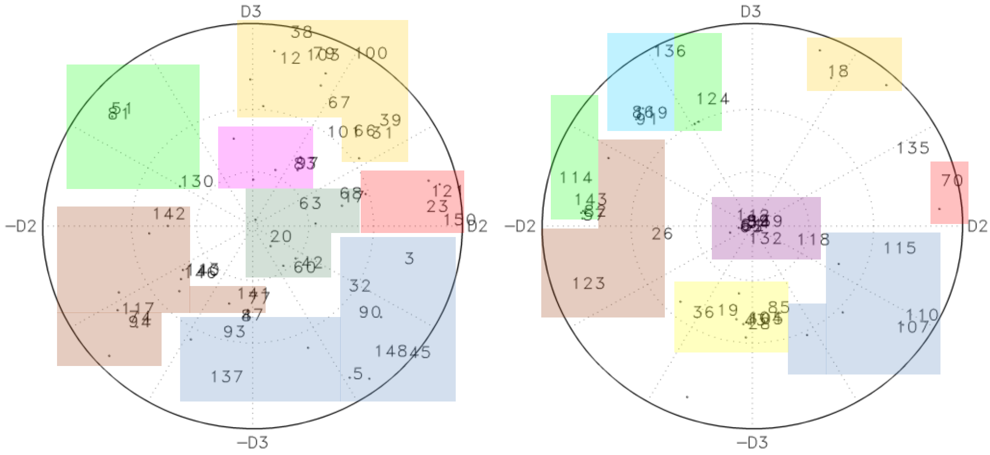

Figure 1. *3-D ‘mapped’ AS landscape*

(Shown from a split hemisphere perspective, with D1- negative dimension [left] and D1+ positive dimension [right]). Key: 🟩 Cognitive profile 🟨 pragmatic language 🟥 emotional ability 🟦 ‘emotional profile 🟫 rigid fixed interests 🟩 Social profile 🟪 ‘Theory of Mind’ 🟦 narrow interests 🟧 Sensory sensitivities 🟪 Motor co-ordination

In a subsequent phase of this pilot study, 238 parents of young people aged 5-18, diagnosed with AS or High-functioning Autism (HFA) were invited to sort the items online in terms of relevance for their child, thereby generating individual profiles (see Figure 2). Statistical analysis suggested a lived experience of high autistic heterogeneity.

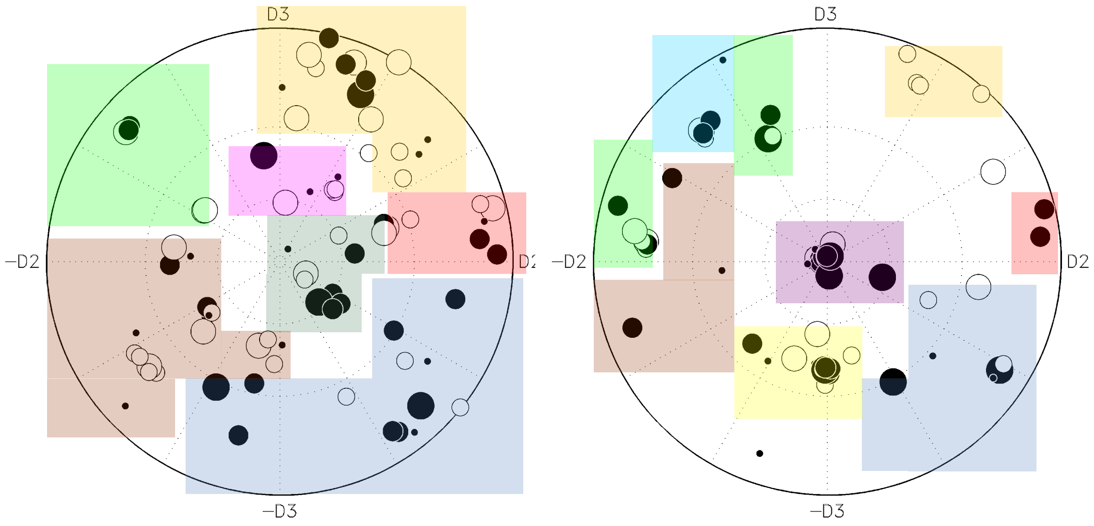

Figure 2. Profile showing characteristic and uncharacteristic symptoms and abilities

(Split D1- negative hemisphere on left and positive D1+ hemisphere on right).

Key: Open circles refer to ‘characteristic’ behaviours and black indicate ‘not characteristic’. Circle size emphasises relevance. (This is actual profile of participant ‘Chris’, generated in 2011).

I initially set out, as a PhD candidate, to develop this intervention tool further, however, there are ethical dilemmas associated with placing young people under the scrutinising gaze of the other, as *something* to observe and not *someone* to engage with. I rejected the notion, from my pilot study, that autistic people[2] were mostly savant-type, detached, a-social characters like 'Rain Man' (MacLeod, Lewis, & Roberston, 2013) and turned my attention to consider adolescents' perceptions and experiences of daily struggles, successes, needs, desires, goals, and their notion of what was meaningful to them regarding school experiences and their identity.

Reliance on behavioural descriptions, to *understand* autism and therefore autistic peoples' experiences, fails to address 'responsibility' for behaviour. It is assumed that symptoms and abilities are the result of being autistic as opposed to being autistic in a context. Without an intermediary step of listening to the nuanced lived experiences of autistic students in their everyday lived context, it would be impossible to illuminate how and where transformation of services and policy is needed to support their education experiences and well-being. The existing literature was in its infancy, resulting in more diversity than convergence of inclusion experiences; there has been no NZ contribution to the literature.

1.3 Characteristics of autism: historical understandings and current descriptions; prevalence, and co-morbidity

'Autism' was initially derived from the Greek word 'autos' (which means 'self') and according to Grinker (2007) was first used by Eugen Bleuler in 1912, in reference to individuals thought to have schizophrenia, in addition to an unusual internal focus on self. In te reo Māori autism has been translated 'Takiwātanga', derived from "tōku/tōna anō takiwā" being "my/his/her own time and space" (Altogether Autism, 2020). Autism researcher, Uta Frith (1989) suggests that although literary examples point to universal truths and oral traditions about autism, especially fairy tales and 13th century religious genres, most modern accounts of autism began with the work of two Austrians, Leo Kanner (1894-1981) based in

---

[2] Goffman (1963) suggests that by adhering to the principle of placing the 'pronoun before the noun' ('autistic' before 'person'), we can avoid using language in ways that mars one's identity by conveying negative connotations about the person (person with autism). Identity first language (autistic person) is consistent with the predominant desires of autistic people who believe that autism is entwined with identity (Sinclair, 2013). Throughout this thesis, I use identity first language, however, for brevity, I also adopt the 'slang' or colloquial term 'autist', using it interchangeably for 'autistic person'. The term 'autist' is more commonly used in on-line settings in an endearing and self-identifying manner to denote one's struggles as neurodiverse as opposed to 'disordered'. Many diagnosed autistic people (Aspergers, PDD-NOS, or ASD) typically also appeal to their location on the autistic 'spectrum' as being 'high-functioning' commensurate with having high level of intelligence. I have incorporated these terms in a way that I believe is contemporary, light-hearted, and yet meaningful to a diverse population by referring to participants in this study as 'high-functioning autists'.

the USA, and Hans Asperger (1906-1980) in Austria. Both men became psychiatrists and were keen observers of children. Asperger simultaneously described a milder variant of Kanner's classic autism, which became eponymously known as AS (Wing, 1981).

In 1981, Lorna Wing introduced AS to the English-speaking academic world, whilst Director, Barry Levin, introduced autistic savant, Raymond Babbitt ('Rain Man'), to the lay world, in 1988. Babbitt became the face of the autistic stereotype, aided by six million admissions to the movie in West Germany alone (IMDb.com, 2016).

Psychologist, Bruno Bettelheim, was one of the earliest and most prolific writers on autism, impacting how Americans, and eventually, the English-speaking world came to understand autism. He was a holocaust survivor who found employment in a residential school for children with mental illness, and despite his lack of psychoanalytic qualifications, opined that autism was caused by similar 'extreme situations' arising from maternal deprivation (Severson, Aune, & Jodlowski, 2008). He wrote 'The Empty Fortress' (1967), referring to mothers of autistic children as 'refrigerator mothers'. This gave him exposure in popular media through magazine contributions. Despite Kanner's assertion that autism had a genetic component, he believed that babies were born with an inborn defect (Folstein & Rutter, 1977) to parents who exhibited similar, but less pronounced traits. His work was sometimes interpreted as providing support for Bettelheim's 'mother blaming' theory.

Concordance studies (e.g., Hallmayer et al., 2002; Rutter, 2005) suggest high heritability of autism, with a high degree of phenotypic traits in first degree relatives (Papandreou, 2014). Papandreou (2014) suggests that from three-to-fifteen genes are involved, ruling out Mendelian inheritance, whilst others (e.g., Arnett, Trinh, & Bernier, 2019; Muhle, Trentacoste, & Rapin, 2004) suggest that the identity and quantity of genes involved remains speculative. Nonetheless, a significant cultural repercussion of this historical period was that mothers of autistic children fought back, speaking out regarding child development and actively 'constructing the autistic child' (Stace, 2010).

Others have since speculated that autism is caused by environmental conditions including measles-mumps-rubella immunisation (Rutter, 2005), since discredited (Hviid, Hansen, Frisch, & Melbye, 2019), and internal dysfunction such as a deficient mirror neuron system (Iacoboni et al., 2005; Oberman & Ramachandran, 2008). Without a 'proven' cause though, it is often concluded that autism is a multifactorial disorder, therefore diagnosis is behaviourally-based. It is considered a lifelong and "devastating developmental disorder" (Happé, 1999, p. 216), though evidence suggests that individuals experience improvements in symptoms with age (Ballaban-Gil, Rapin, Tuchman & Shinnare, 1996; Howlin, 2005; Matson & Horovitz, 2010; Shea & Mesibov, 2005).

Autism is characterised by impairments spanning three developmental areas, namely communication, social interaction, and thinking (cognition) or behavior (Ministries of Health & Education, 2016). At one end of the autistic spectrum, individuals may be non-verbal and have intellectual impairments, retreating within themselves. At the other end of the spectrum, high-functioning autists may be verbal, cognitively able, and active members of schools and communities. This is of particular significance during the adolescent years because on one hand studies have suggested that some adolescents show marked improvement in communication and social interaction by late adolescence (Levy & Perry, 2011), whilst other studies have shown that adolescence is a time when autistic symptoms and behaviours can deteriorate (Ballaban-Gil et al., 1996; Howlin, 2005; Levy & Perry, 2011).

Because ASD affects one's social and communication skills (Howlin, 2004), especially deficits in social-emotional reciprocity and nonverbal communicative behaviors, autistic children and adolescents struggle to develop and maintain social relationships appropriate to developmental age (American Psychiatric Association, 2013; Carrington, Templeton, & Papinczak, 2003; Linton, Krcek, Sensui, & Spillers, 2014). This restricts friendships due to outward appearances; autists are often perceived and constructed as 'odd', 'inappropriate', and 'cold' (Church, Alisanski, & Amanullah, 2000).

Many autistic people also experience restricted, repetitive behaviors and narrow interests (American Psychiatric Association, 2013; Attwood, 2007; Lai, Lombardo, & Baron-Cohen, 2014; Linton et al., 2014). Whilst this can result in a fixation on routine and firm resistance to change (American Psychiatric Association, 2013; Ashburner, Bennett, Rodger, & Ziviani, 2013), it occasionally leads to some autists becoming 'specialists' in limited areas. Additional characteristics and traits such as sensory sensitivities and repetitive speech (echolalia) can leave children and adolescents also appearing as 'odd' (Frith, 1989) and misunderstood (MacLeod, et al., 2013).

In addition to core autism characteristics, there are also an array of 'associated features' comprising impeded language development; motor abnormalities including coordination deficits, gait, and balance (Dewey, Cantell, & Crawford, 2007; Manjiviona & Prior, 1995; Wing, 1981); and a proclivity toward attention to detail (Lai et al., 2014). Many autists also report experiencing sleep deficits (McLay, Hansen, Carnett, France & Blampied,

2020) and hyperactivity (Lai et al., 2014), as well as gastrointestinal problems (Mannion & Leader, 2013).

Autistic characteristics are typically expressed as a deficit, concealing positive characteristics (Connor, 2013; Grinker, 2015). These can include superior skills and abilities leading to exceptional talents, particularly if recognised and nurtured (de Schipper et al., 2016). de Schipper et al. asked recognised ASD 'experts', including three from NZ, to describe the skills of individuals they had worked with. In addition to 'attention to detail', it was suggested that autistic individuals have a strong sense of morality (honesty, lack of judgmental attitude etc.); a preference for work on repeated or monotonous tasks, expertise in a specific areas, mathematical abilities, creative talents (can look at the world differently), artistic skills (music, drawing, visual arts), visual perception, intellectual functions (good memory), technical abilities (computer skills, engineering); and, a high degree of trustworthiness, loyalty, and kindness.

Examples of potentially 'contrived representations of autism' are evident in the now 'taken-for-granted' psychological concepts and cognitive stereotypes, which are applied to autism. Autistic people are generically described as 'lacking empathy'. In the cognitive neurosciences, those lacking emotional empathy and cognitive empathy (Theory of Mind) are believed to have greater propensity for violence and psychopathy (Blair, 2005). In the beginning of autism research, neither Kanner, Asperger, nor Wing placed any emphasis on the fact that autistic individuals lacked empathy, however in 1991 it was called a 'disorder of empathy' (McDonagh, 2013). Many autobiographies contest this assertion (e.g., Higashida, 2013; Jackson, 2002; Robison, 2008; Williams, 1998), with biographers complaining they have too much (e.g., Birch, 2003). Similarly, Baron-Cohen proposed a stereotypical 'extreme male-brain' cognitive profile of autism, based on the idea that autists have low empathetic and high systematising abilities (the ability to analyse and control non-social taxonomies). However, it has been argued that this 'gendered' perspective obscures detection of ASD in women and girls (Cridland, et al., 2015a; Stewart, 2012).

Attwood (2007) believes that the signs of AS become most obvious during adolescence as social and academic demands increase in complexity and a lack of essential responsive characteristics becomes conspicuous. Whilst much of the autism research involving symptoms focuses primarily on children, by drawing on a selection of autobiographical literature written by autistic adults, Causton-Theoharis, Ashby and Cosier (2009) 'reframed' autism to suggest that autistic individuals have a deep need for connecting to others and a need for predictability. They have unconventional responses to sensory stimuli and as a result of their social and communication disorientation, they have a need to retreat and turn inwards when interactions exceed their receptive and connecting capacity.

Cashin (2008) suggests that whilst autism does not affect temperament or personality, temperament may affect ones' experience of autism. Some autistic individuals will be passive and others active; some loud whilst others are quiet; and, some may internalise, whilst others may externalise their problems, all of which comes to the fore in everyday experiences, including coping strategies. The environment may accommodate and reduce anxiety, or it may exacerbate it and make coping with autism difficult. Thus, from a broader ecological perspective, Arnold (2012, p. 3) suggests that the so called 'triad' of symptoms can seem as though an 'occamist simplification'.

There has been a lack of diagnostic instruments useful for ascertaining presence of comorbid 'disorders', in individuals whose primary diagnosis is ASD (Mannion & Leader, 2013). Comorbidity refers to the presence of two or more disorders in the same person (Matson & Nebel-Schwalm, 2007). The most common secondary diagnosis pertains to the mood disorders, with depression being the most common (Ghaziuddin, Ghaziuddin, & Greden, 2002). Attwood (2007) suggests that up to 65% of teenagers with AS suffer from mood disorders, primarily anxiety disorder, followed by depression. Depression increases the likelihood of exhibiting aggression and increases likelihood of suicide (Portway & Johnson, 2003). Others, like Mannion and Leader (2013) suggest that anxiety overlaps with ASD and depression, with communication difficulties increasing anxiety.

Some comorbid forms of anxiety (such as phobias) have rarely been studied (Kerns, Newschaffer, & Berkowitz, 2015; Matson & Nebel-Schwalm, 2007) despite the suggestion that traumatic events may be experienced by autistic individuals more traumatically (Kerns, et al., 2015). Several participants in this study expressed pervasive 'social phobia', whilst one participant experienced seismophobia. All of these comorbid secondary 'symptoms' can lead to increased irritability evident in aggression, tantrums, and self-injury (Attwood, 2007). In sum, the array of traits, characteristics and experiences of autism now documented, support the notion that it is phenotypically heterogeneous (Arnett, et al., 2019).

Data depicting prevalence of ASD in NZ has been lacking, however Bowden et al. (2020) have tentatively identified a rate of prevalence for 8-year-olds as being one in 102. This is consistent with the Ministries of Health and Education's (2016) estimation of prevalence being 1 in 100, or 40,000 individuals in NZ. However, these statistics potentially fail to account for prevalence of ASD in Māori and Pasifika populations given lack of equitable access to health care in NZ (Bevan-Brown, 2004). In the space of 40 years, epidemiologists have gone from estimating that autism effected 1 in 2,500 individuals in Europe, to 1 in 68 American children, aged 8, in 2010 (Mandell & Lecavalier, 2014). More recently, ‘The Centers for Disease Control and Prevention’ (2020) suggested a prevalence rate as high as 1 in 54. Fluctuations in prevalence rates are also thought to be due to enhanced detection (Meanner et al., 2020), through development of diagnostic instruments, and increased general awareness (Lai, et al., 2014). Lai, et al. (2014) however, recommend caution is needed when reading into these prevalence rates because it would be premature to rule out increased exposure to environmental risk factors as accounting for the changing epidemiological data.

1.4 Obtaining a diagnosis of ASD in NZ

A diagnosis provides a ‘common language’; service providers can co-ordinate support, interventions, and treatment for a specific category of people (O’Connor, Kadianaki, Maunder, & McNicholas, 2018; Perkins et al., 2018). The process of obtaining an autism diagnosis in NZ is well-known to be a difficult and confusing one with multiple referral points and a lack of a single service taking responsibility for managing assessments (Ministries of Health and Education, 2008. p.38; Murray, 2006). In the United States, a diagnosis of ASD is typically sought in order to access health care funding and insurance whereas in NZ and Australia, a diagnosis is predominately sought by parents and others, to access special education services (Attwood, 2007). In NZ it is not uncommon for Special Education Needs Coordinators (SENCOs), Resource Teachers of Learning and Behaviour (RTLBs), or Ministry of Education (Special Education) to recognise developmental problems and refer students to suitable services for assessments. Prior to 2010, it was also not uncommon for NZ citizens to travel abroad, especially to Australia in order to obtain an assessment and/or autism diagnosis from Tony Attwood’s psychology clinic in Brisbane (Murray, 2006).

A diagnosis in the public health system in NZ is typically gained through an initial consultation with a local GP (general practitioner, usually a family doctor) who then refers to a pediatrician or Child, Adolescent and Family Mental Health Services (CAFS). As an interdisciplinary provider for mental health, alcohol and drug assessments, CAFS provides services to children, youth, and families through social workers, clinical psychologists, psychiatric nurses, psychiatrists, pediatricians, and occupational therapists. The ‘common language’ of the Diagnostic and Statistical Manual of Mental Disorders (DSM) therefore, is particularly relevant in interdisciplinary contexts. CAFS services are provided free to NZ youth; however, because of high demand, there can be lengthy delays, both in regard to initial consultation and accessing follow-up services (MidCentral District Health Board, n.d.). In order to be eligible for follow-up services in the first instance, an official diagnosis is required.

Funding for these services comes from Government allocations for health, which is managed by District Health Boards (DHBs). DHBs purchase necessary services in order to meet healthcare objectives for citizens in their area. These objectives include "effective care or support of those in need of personal health services or disability support" (Ministry of Health, 2020). At the time of writing, NZ has 20 DHBs, which are geographically arranged throughout the country.

1.5 Context: Historical, cultural, and economical

Being Australian born, I have lived just over half my life in NZ. I therefore completed my primary and [some] secondary schooling in Australia, gaining tertiary qualifications in NZ. My neurotypical daughters, now young adults, have completed all their education in NZ. Despite our proximity to Australia, NZ culture is significantly different, even from our other South Pacific neighbours. Without considering NZ's historical, socio-cultural context, alongside the growth of the psy-disciplines internationally and locally (Chapter Two), participants' perceptions and experiences, and my interpretation of them, would make little sense. ASD is not only a diagnostic category, but a lived experience, and as such, "shifts through different cultural contexts" (O'Dell et al., 2016, p. 174). The following section therefore provides a brief overview of the historical, social, and cultural milieu wherein lived experiences of autistic teens in this project transpired, illuminating something of our 'Kiwi' identity and culture, as well as educational system. It is beyond the scope of this project to make a detailed comparison of our educational and health systems in relation to other countries, suffice that by elucidating briefly here, international readers might be equipped to draw their own comparisons of salient differences.

1.5.1 Aotearoa, New Zealand: 'The land of the long white cloud'

New Zealand is a diverse nation of 4.6 million people, spread over two main islands, located in the southwest Pacific Ocean. For its size (approximately 1600km long and 268,000 square kilometres) NZ is incomparably beautiful, often referred to as 'the land of the long white cloud', green, and rural, with only five main cities (Oettli, 2004). Brad, a 16yo participant in this study said that NZ is "green":

> *green…it's what NZ is. It's part of the culture; it's part of the culture of NZ; green makes NZ beautiful…the grass, the bushes, the lands…the plants such as the koru – it makes it innocent – it makes it innocent and beautiful…and that's why people from all around the world love to visit this country (Brad [adol[3]], p. 2).*

Brad's enthusiasm for NZ is not an unequivocally accepted representation of NZ. More recent bloggers have suggested that NZ doesn't live up to the "100% pure" image (Tourism New Zealand, 2012) with up to 60% of our rivers now estimated to be un-swimmable due to the growth of our dairy industry and its effluent discharges into waterways (The Economist, 2017).

Nonetheless, we are a people of the land: *tangata whenua* (Oettli, 2004), founded upon the Treaty of Waitangi, signed on the 6th of Feb 1840. The Treaty comprises a preamble and three 'articles' which gave the Crown (then the British Sovereign) rights to buy land in return for providing Māori with the rights and privileges of British citizens. Indigenous Māori came to NZ from Polynesia about 1000 years ago (Tourism New Zealand, n.d.). The Treaty of Waitangi paved the way for partnership and collaboration between the indigenous people of NZ, Nga iwi Māori, translated as 'the ordinary people' (Williams, 1971) and Pākehā, the 'pale people', predominately of European decent (Sibley & Liu, 2004). The term 'Pākehā' denotes "an empty category as it does not represent an identity but merely means 'not-Maori'" (Urry, 1990, p. 20); it signifies the existence of a relational identity in NZ between Māori and non-Māori (Matthewman, 2017) through processes of colonisation.

NZ is therefore referred to as a 'bicultural' nation, as though reflecting equal partnerships between Māori and Pākehā (Liu, 2005). However, the two versions of the Treaty (Māori and Pākehā) represent two different settlement views and underlie ongoing tensions in NZ. Historically, Pākehā placed less emphasis on the Treaty and established trade and education in NZ, assuming that their 'common sense' approach was no different from Māori. This has been significant in NZ's history because it highlights, as Kirton (1997) alludes to, the relationship between groups deemed privileged and at-risk, and has little to do with a democratic society, but rather the existence of ontological "blindness"[4]. Through the

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[3] [adol] refers to adolescent participants, distinguishable from [ter] for 'tertiary' autistic participants. Additionally, [adv] refers to advocates and [par] refers to parents. To aid the reader, this 'key' will be used throughout this thesis each time a participant is referred to in the first instance within a paragraph and following every quote.

[4] Just as many Māori now look back as though having passed through a schooling system in a mono-cultural context (Webber, 2008), so too autistic people describe their education as being designed for one class of

normalising processes of dominant groups, their invisible ‘norms’ become the standards against which others might or might not measure up to (McIntosh, 1988).

The Māori sense of belonging is particularly significant for all aspects of life in NZ. Māori *whānau*, loosely translated as ‘family’, has a different set of meanings and connotations compared to Pākehā conceptions of the term. The lived experience of whānau binds members tightly to each other in order to bring about a deep sense of unity so that whilst Māori individuals conceptually ‘exist’ in their own right, their individuality might best be expressed within the context and proximity of whānau (Walker, 2017). With respect to this aspect of our biculturalism, all participants in this study were ensured freedom to have whānau or ‘family’ present and one gratefully accepted.

In the post colonisation period, increasing numbers of Pasifika (Pacific Islands nations including Fiji, Samoa, Tonga, and Rarotonga) and Asian individuals began migrating to NZ. In 1971 the then NZ Prime Minister, Norman Kirk, affirmed that the future of NZ lay not with its British immigrants, but with Asia and the wider Pacific giving NZ, by the 1980s, a sense of being a nation within the Asia-Pacific region, stimulating immigration and thoughts on our nationality. New Zealand’s resident population now identifies with more ethnicities than countries in the world (Statistics New Zealand, 2019) though we are predominately a mix of European (74 %), Māori (15%), Asian (12%), and Pacific Island (7.4%). The ethnicity of students in NZ secondary schools also reflects considerable diversity with 48% of students being European, 20% Māori, 14% Pacific, 12% Asian, and 6% ‘other’ (Clark et al., 2013).

Our dominant language is English, however our official and ‘legislated languages’ are Māori and - from 2006 - New Zealand Sign Language. For a long time, Te Reo Māori was banned in NZ schools, deemed irrelevant for getting along in a colonial settler society. According to the NZ census in 2013, 160 different languages are now spoken in NZ with almost one fifth of the population multilingual (Statistics New Zealand, 2013).

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people: the neurotypical. The taken-for-granted assumptions about the availability of cognitive and executive functioning processing skills have led to the development of only one curriculum with no alternative options available for those whose frames of reference differ. Thus, just as Māori have been called upon to make many more adaptations than Pākehā in order for us to become ‘one’ nation (Webber, 2008), autists have argued that it is they who are repeatedly being called upon to make all of the adaptations to ‘fit’ within schools. The term ‘ontological blindness’ is also taken up and contested in critical autism studies. From this perspective, there is not simply one way to ‘be’, but multiple.

1.5.2 Identity and culture

Despite NZs diverse population, we tend to have a common identity and a strong sense of what it means to be ‘Kiwi’ (eponymously given to citizens, representing the unique flightless long-beaked brown bird, not found elsewhere, and deemed a *taonga* or treasure by Māori). Although the academic study of national identity is relatively new in NZ (Liu et al., 2005), from the 1970s onwards, NZers have seen themselves as less British and more ‘Kiwi’. We tend to agree that icons like the All Blacks, the haka, pavlova, and the pohutukawa tree accurately depict our nation’s identity (The New Zealand Herald, 2014a).

Anthropologists, Rita Denny and Patricia Sunderland from the anthropological research group, ‘Practica’, explored ‘Kiwi’ characteristics (Clifton, 2011). They suggested seven distinct and defining characteristics as typifying ‘Kiwis’. These include having an affinity with the land which we are highly, if not ‘spiritually’, connected to; a love for freedom and independence; a preference for masculine characteristics and expressiveness without being anti-feminist (for example, our DIY - do it yourself - ‘can do’ mentality is highly valued and embraced by all irrespective of gender); our tendency to elevate sport to a cultural code, with success and failure affecting our collective psyche; being mate-orientated through our strong friendships; a ‘she’ll be right’ attitude and easy-going nature; and, a good sense of humour.

Our ‘can-do’ entrepreneurial attitude grew out of the harsh period of colonisation when most resources were scarce and difficult to obtain (Kennedy, 2007). Sheep farmers in remote, isolated, and difficult to access regions were wont to purchase a specific gauge of fencing wire (8-guage) in bulk. ‘Number 8 wire’ as it was colloquially termed, was then used ingeniously and resourcefully as a substitute for more appropriate, but unavailable resources, particularly in relation to mechanical or structural items. Later, the ‘number 8 wire’ mentality became an approach to life by the ordinary suburban ‘Kiwi bloke’ and thereafter became a cultural archetype (Kennedy, 2007). It now refers to someone who can turn his or her hand to ‘fix anything using whatever is available’ (Oettli, 2004).

This approach to problem solving continues to form part of the ‘Kiwi’ psyche and functions like a mode of subjectivity that influences our sense of obligation to ‘dig deep’ whilst persisting in finding our own solutions. As a result, we tend to persevere in silence as we exhaust our own ‘home-grown’ remedies to apply solutions in unique ways (Kennedy, 2007). The onus for resolving problems is individualistic. This ‘mentality’ is evident in the outcomes we assumed associated with the type of autistic ‘profiling’ developed in my Hons research: that it would equip teachers with short-hand notations so they could produce 'home-grown' interventions and accommodations, tracking effectiveness through a reduction in negative characteristics or 'symptoms'.

Good 'kiwi's' often acquire the label 'good sort'. When applied to someone in a position of authority, such as a teacher, it would be assumed that they are going the 'extra mile' for their students (Jones, 2017). Indifference is likewise 'framed' idiomatically too, referring to someone who fails to 'step outside the box' and go beyond their designated role to help those in need. Applied to a governmentality, enablers would ensure one could 'step up' and go the extra mile, whilst constraints might inhibit action, leaving one to simply 'tick the boxes'.

1.5.3 Neoliberalism and the economic conditions of NZ

In 2019, NZ had a gross national income of approximately 292.9 billion dollars (Statista, 2019), being the 51st largest national economy in the world. The economy in NZ has been driven by three primary industries: agriculture, construction, and tourism. Prior to the Covid-19 pandemic, the economy was growing, though productivity was below other leading OECD countries, which affects living standards and well-being (Nolan, Pomeroy, & Zheng, 2019). Employment was relatively stable; however, there was a growing demand for high-skilled occupations, predominately digital technologies and Artificial Intelligence (OECD, 2019) and an expectation that automation would substantially impact the labour force in the future. Some business analysts believe that there is a general over-reliance on the agricultural sector in NZ and suggest we sit on top of an untapped resource of natural energy, having substantial levels of green energy per head of population in the world.

New Zealand is no longer considered an egalitarian nation, given the stark divide between the nations' rich and poor (Rashbrooke, 2014). Under the guise of improving social equality, NZ adopted neoliberalism in 1984, (known in NZ as 'Rogernomics' after the Minister of Finance Roger Douglas), which encouraged private creative freedoms that could foster increased development of intellectual ideas to enhance economic growth and private enterprise. Between 1984 and 1990, the economic implications of neoliberal governance caused tension for the Labour Party's social agenda, particularly in the areas of deregulation, liberalisation and privatisation. However, by 1990, NZ social reform was deemed considerably more 'neo-liberal' (Humpage & Craig 2008), with only minor shifts in public attitudes around perceived governmental responsibility for social issues between the years 1987 and 2005 (Humpage, 2011).

In this thesis, neoliberalism is taken up as ‘governmentality’ and not ideology or specific political technologies, but rationalities that give rise to certain discourses and ways of understanding, following Larner’s (1997) definition. This was taken up by Nairn and Higgins (2007) a decade later, in their analysis of identity construction in the lives of NZ school leavers.   Underlying a neoliberal governmentality is the belief that individuals will assert themselves, seeking that which is in their best interest (Crawshaw, 2015); citizens would take responsibility for their individualism (thus education), using to their advantage, freedoms conferred through an open market place (Harvey, 2006). Sociological implications of neoliberalism means that arbitration and collectivism is replaced by volunteerism and individualism (Humpage, 2011). This has implications for autistic people in NZ seeking education and support. Thus, it is not the overthrow of capitalism at the heart of the issue, but the excesses of capitalism leading to large scale social and educational inequality (of opportunity).

For some, neoliberalism presents a cold and calculating framework that restricts participation and contribution within a community; there are too many hurdles. Those who cannot contribute to the economy are considered fiscal liabilities, whilst strict criteria functions to restrict access to social support, which has implications for people with autism and their family. In summary, neoliberalism can hold individuals responsible, and accountable, for their own health.

1.6 NZ high schools: then and now

NZ s first Education Act was passed in 1870 to provide state funded, secular ‘compulsory’ primary education to children aged 7-13. Subsequently there have been several significant attempts to transform education and ‘reform’ it, with four major reforms occurring in the last 28 years. In 1870, the first Education Act was founded on the ideology of ‘social equity’, being premised on the belief that education should be available to all. However, state funding was not extended to secondary schools until 1902-3. Up until this time secondary schools were predominately for the ‘upper class’ and intellectually gifted and in the year 1900, there were only 25 secondary schools in NZ, exhibiting Victorian British influences and providing education to less than 3,000 students (Murdoch, 1943).

The prevailing social ideology of equity seemed to be the driving force of education, however, so too perhaps was assimilation into western education. In 1935 the Labour Government reviewed its restrictions on access to secondary education, abolishing the Proficiency Examination in 1936. This gave all students the right to enter mainstream secondary education if they had satisfactory grades. In 1939 the Minister of Education, Peter Fraser hinted at 'inclusion':

> *The Government objective, broadly expressed, is that every person whatever his [sic] level of academic ability, whether he be rich or poor, whether he live in town or country, has a right as a citizen, to a free education of the kind for which he is best fitted and to the fullest extent of his powers. So far is this from being a mere pious platitude that the full acceptance of the principle will involve the reorientation of the education system* (Renwick, 1986, p. xxii, cited in Clark, 2004).

Secondary school rolls drastically increased thereafter so that by the mid-1940s there were 38,810 secondary students and 20 years later, 149,063 students (Swarbrick, 2012). The Second World War reinforced the idea or 'myth' (Alcorn, 2007) that education was a necessity for all, if not a key strategy for preventing future conflict and ensuring security. By the 1970s, there was growing social unrest in NZ due to a downturn in the economy, resulting in high unemployment, inflation, and general fiscal insecurity. Social commentators criticised the government for its education reforms, noting that they had not raised the standard of educational opportunities *for all* after all, evidenced by the sheer number of school leavers lacking qualifications.

The Government's economic advisors, the Treasury, capitalised on this during the 1980s to advance their new market-orientated ideology of individual choice, applying it to schools and education, thereby altering not only the direction of education in NZ, but the ways in which we now think about education as 'consumers' in a market place (Wylie, 2009; Clark, 2004). This ideology was also reflected in Treasury's advice to government on issues of health, social welfare, and our research agendas (Clark, 2004).

The first of the four most recent reforms were therefore pivotal in providing the framework for relinquishing government of responsibility and enabling private and entrepreneurial management of schools, which underlies the ideology of individual choice. 'Tomorrow's Schools', instituted by Labour Education Minister, David Lange localised responsibility through the implementation of the Board of Trustees (BOTs). Wylie (2009, p.6) comments, that divulging government of its responsibility is "still thought of as radical by many overseas visitors." She notes we are the only Western country that "bases its *entire* public system on stand-alone schools, each with their own parent-led BOT, responsible for the school's direction and staff employment, and operating without being part of a school district, or local authority" (p.6).

A standard BOT is comprised of the school principal, a staff representative, co-opted trustees (usually parents of pupils), and up to four proprietor’s representatives in ‘integrated’ (typically, Catholic) schools, for example, a nominated Bishop’s representative and member(s) from the local parish community. In high schools, the BOT also comprises one elected high school student. Parents and community members therefore take greater responsibility for negotiating the overall direction of NZ schools, including employment of staff, and daily operation.

It was expected that this type of governance would bring to the fore, the ‘flavour’ of the local community (Wylie, 2013), providing students with greater fluidity between the social and cultural mores of community life and the lived experience of schooling. According to Wylie (2000), there has been no evidence that this type of governance has led to better outcomes for students; autistic students often present challenges beyond the proficiency of school staff (Tippett, 2004) and the BOT. Nonetheless, a small number of schools have developed expertise in developmental disorders like autism and dyslexia (Potter & Tiso, n.d.) when they are supported by a BOT member with expertise in this domain (Potter, personal communication), creating diversity between schools regarding specialist niches of knowledge and ‘expertise’.

The Department of Education was dismantled and a much smaller Ministry of Education (MoE) was established reflecting reduced governmental interference (Haque, 2014). Contrary to expectations however, the MoE has since increased its support over the last decade, nevertheless NZ schools have considerably “far wider powers and responsibilities than most overseas jurisdictions could conceive of” (Haque, 2014, p.77).

‘Tomorrow’s Schools’ led to three additional reforms, including the development of the New Zealand Curriculum, NCEA, and National Standards (Haque, 2014). The ‘outcomes’ focused curriculum of 1992 came under scrutiny and in 2000-2002, was reviewed, leading to the development and adoption of the ‘New Zealand Curriculum’ in 2007. In her forward to ‘The New Zealand Curriculum’, the Secretary for Education, Karen Sewell says the framework:

> *takes as its starting point a vision of our young people as lifelong learners who are confident and creative, connected, and actively involved. It includes a clear set of principles on which to base curriculum decision making. It sets out values that are to be encouraged, modelled, and explored. It defines five key competencies that are critical to sustained learning and effective participation in society and that underline the emphasis on lifelong learning* (Ministry of Education, 2007, p. 4).

The principles of the curriculum provide its foundation, and reflect the principles of the Treaty of Waitangi, acknowledging the bicultural nature of NZ as well as cultural diversity. It is 'future focused' preparing students for enterprise and globalisation. Students learn *how* to learn and are encouraged to connect with their whānau, families, and community. Schools are to have high expectations of students, and are expected to be inclusive by advocating a non-sexist, non-racist, and non-discriminatory curriculum which ensures that the "students' identities, languages, abilities, and talents are recognised and affirmed and their leaning needs are addressed" (Education Review Office, 2012a, p. 3).

In addition to 'respecting themselves, others, and human rights', the values or beliefs which are to be modelled encourage students to aim high and pursue excellence; be curious and creative; to respect diversity and cultural differences; contribute and participate in community for the common good; be ecologically aware so as to care for the environment; and, to show integrity and honesty, acting ethically. The key competencies include thinking, using symbols and texts, managing self, relating to others, and participating and contributing. These principles, values and competencies are therefore embedded into the national curriculum, to produce a certain type of student: one who is "equipped with the knowledge, competencies, and values they will need to be successful citizens in the twenty-first century" (Ministry of Education, 2007, p. 4). The import of these background factors cannot be overstated when considering the lived experiences of autistic adolescents within mainstream NZ schools; they are explicitly and implicitly pervasive throughout the entire curriculum.

The New Zealand Council for Educational Research has recently appointed a task force of five people, with extensive experience in mainstream education and educational policy, to review 'Tomorrow's Schools'. Their purpose is to ensure that "…the governance, management and administration of the schooling system is fit for purpose to ensure that every learner achieves educational success" (New Zealand Council for Educational Research, 2018, p.1). The review contains four key features of the Government's vision for education and expresses five objectives. The key features of the Government's vision include outcomes of an education system as the means for enabling individuals to engage 'fully in society' to lead 'rewarding and fulfilling lives'. Whilst the Government's vision suggests that a greater degree of flexibility will be purportedly built into 'education and learning' so as to cater for diverse learners, 'diversity' seems to be questionable and the vision seemingly already constrained if the goal of reforms is to produce a 'flexible' person with skills to work individually *as well as* collaboratively. These are among the many threads that may need to be unravelled when considering the everyday experiences of autistic young people in mainstream NZ high schools.

1.6.1 Today's high schools

Today the NZ government provides free education for its citizens and permanent residents aged 5-19 years, in state owned schools, with schooling compulsory for those aged 6-16. In addition to the 50 independent, privately funded schools, comprising preschool, primary, and secondary schools with day and boarding options, there are four types of funded schools in NZ providing education to approximately 788,000 students in 2016 (Education Counts, 2020a):

(1) 'State Schools' are dominant, secular, fully state owned and funded, and teach the national curriculum.

(2) 'State integrated' or 'Special Character' schools are state schools, receiving partial funding and reflect the special philosophical or religious character of the school. Most state integrated schools are Catholic with 189 primary schools and 49 secondary schools in 2016, catering for 66,460 students or 8.2% of the country's student population; 78% of all eligible catholic students (Wanden, 2016).

(3) The third type of state school is called 'Designated character' and these are schools that have a *particular* philosophy or culture, for example, Islamic or specialist schools for disabled students.

(4) The fourth type is Māori-medium education (Kura Kuapapa Māori): immersion schooling adhering to the philosophy, principles, and practices of Te Aho Matua (Ministry of Education, 2020b).

Children aged 5-12 years typically complete years 1-8 of their education in primary school, whilst adolescents aged 13-17 complete years 9-13 in high schools. The actual configuration of NZ schools varies widely, however. In 2016 there were 1068 'full primary' schools catering for years 1-8; 766 'contributing' primary schools catering for years 1-6; and 117 'intermediate' schools for years 7-8. Secondary schools typically offer years 9-13; however, some high schools cater for students in years 7-13. A lesser number of high schools offer education for years 7-10 or 11-13 and these are typically referred to as 'composite' schools. A few 'special character' schools also offer a complete education catering for years 1-13. Students in years 7-10 within a larger school are typically referred to as being in

‘Middle school’ or ‘Junior High School’ whereas students in years 11-13 are typically referred to as ‘Senior High’[5] students.

The exact configuration of schools is determined by the needs of the community and is therefore constructed according to its ‘special character’ and/or geographical location. Regional NZ communities are less likely to have an intermediate school, so are more likely to offer full primary schooling and high school from year 9, whilst provincial centres and cities are more likely to have intermediate schools, so predominately have contributing primary schools, but could also have high schools, especially ‘special character’ which start at year 7.

Some high schools in NZ have a government funded Student Support Centre (SSC), based on their school being decile rated 1-3. Schools are decile rated according to five indicators that include the percentage of households in the lowest 20% of income earners, percentage of parents in lowest qualified occupations, percentage of parents without educational qualifications, percentage of parents on an income support benefit, and the number of residents within a dwelling (Ministry of Education, 2017). Schools with a rating between 1 to 3 are called ‘low decile’ schools. It is assumed that economically disadvantaged people require more educational and behavioural support, thus qualify for a government funded ‘support centre’.

Research suggests that students who access learning support facilities are at increased risk for being rejected by their peers (Humphrey & Symes, 2011) and that this is more pronounced for students with milder autism deficits (Humphrey & Hebron, 2015). It is unknown how many high-functioning autistic young people in NZ access student support, or their perceptions of it. Autistic young people might attend all regular classes, or a mixture of regular classes and time in a learning support facility to suit their needs (e.g., Bevan-Brown et al., 2008). Two participants in the current study had regular access to the SSC, however no participants qualified for special education funding (Ongoing Resourcing Scheme [known as ‘ORS’] funding), whilst one student had access to a teacher aide.

Finally, the MoE maintains a Home-schooling database that indicates that as at July 2019, some 6573 children were being home-schooled (Education Counts, 2020b), up from 5837 in 2016. Most of these children were European and just under 70% were aged 12 or below. Anecdotally at least, it appears that autistic youth in NZ, especially those with

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[5] Autistic adolescents in this study are all in their ‘senior years’ referring to Years 11-14. Year 14 is an additional, optional year for students who either have not achieved the educational level they desire or lack options for alternative tertiary or workplace placements.

behavioural challenges, are being home-schooled as government resources fail to meet their needs (e.g., The New Zealand Herald, 2015a).

1.6.2 The New Zealand curriculum

NZ high schools base their academic learning programmes on *The New Zealand Curriculum*. In the senior years (years 11 to 13) of mainstream secondary schools, students aim to achieve three levels (Levels 1-3) of NCEA which, in 2018, began its fifteenth full year of implementation (New Zealand Qualifications Authority, 2015). NCEA is a standards-based assessment, meaning students are assessed against a standard rather than each other, in order to achieve credits. Each subject offers a range of units worth 2-6 credits based on complexity, via a mixture of internal assessments and external assessments (examination and externally examined work). There are over 50 NCEA subjects available, however not all schools offer all subjects, though they are available via correspondence (New Zealand Qualifications Authority, n.d., a).

In the 2018 academic year, 80 credits were required to attain Level 1, 60 at level two (plus 20 from any level), and 60 credits at Level 3 (plus 20 credits from Level 2 or above, in addition to numeracy and literacy credit requirements) (New Zealand Qualifications Authority, n.d.,b). Schools need to balance out their discretionary offering of credits per subject in order to allow students to produce ‘quality’ work (aiming at Excellence and Merit grades), rather than quantity (amassing a large number of Achieved credits); it is ‘quality’ credits which determine university scholarship and placement in more prestigious degrees.

Whilst the average student gains one level certificate per year, there is no requirement regarding how long this takes. A slower student may therefore work towards Level 1 over two-to-three years. Likewise, a student can engage in multi-level study taking a mixture of subjects from multiple levels, based on ability and commensurate with logistical abilities of each school. Attainment of enough Merit and Excellence credits can result in subject and year level endorsements. This becomes particularly important at Level 2, for those seeking university scholarships and residential placement on campus. The minimum level of achievement needed to enter university is 14 credits in three approved subjects at Level 3, plus 10 literacy credits at Level 2 or higher, and 10 numeracy credits at Level 1 or higher (New Zealand Qualifications Authority, n.d., c).

The NZ Government proclaims to be committed to good schooling outcomes, yet there are more young people, aged 15-19, out of work and not within education or training programs than the OECD average (Ministry of Education, 2016). The NZ Government has repeatedly articulated aims of educational attainment over the years, hoping for example to have 85% of 18-year-olds achieving Level 2 NCEA by 2017. However, in 2017, 76% of 15-year-old school leavers left without achieving a minimal Level 1 qualification (Education Counts, 2020c). It is unknown what portion of these students might have been on the autistic spectrum. Likewise, there have been no statistical data collected (or qualitative studies conducted), which considers how well or not high-functioning autistic students are doing in their NCEA subjects, nor what their plans are beyond high school. Despite the high percentage of students dropping out of high school, it is expected that NZ adolescents will emerge from high school increasingly competent and independent (Pearce & Forlin, 2005).

The NZ Education Review Office (ERO) is tasked with evaluating and reporting on the calibre of education in NZ schools and education centres. Their reports inform government, policy, schools, and communities. They have reported that competent schools “had high quality approaches supporting priority learners, especially for Māori students and those with special needs” but in some schools “students had very few opportunities to set goals, develop self-awareness, make decisions about their future and actively explore relevant opportunities” (Education Review Office, 2013, p.6). In other words, just over 90% of NZ schools were identified by ERO as having a narrow NCEA focus.

There are two specific desired outcomes of NCEA: University Entrance (UE) and Vocational Pathways. ERO has previously reported on Careers Information, Advice, Guidance and Education (CIAGE) in secondary schools to suggest that four out of the 44 high schools reviewed (9%), provided regular opportunities within the context of the NCEA curriculum, for students to develop ‘career management competencies’ (ERO, 2013), indicating a lack of vocational exploration.

1.6.3 The learning environment

NZ schools comprise a mixture of learning, sporting, and cultural spaces with most having open fields, some sealed turf, culture and arts centres, technology blocks, and a school hall, in addition to classrooms, library, ‘tuck shop’, and SSC. Special character schools might also have a church, chapel or marae, being associated with sacred liturgies, rituals, and celebrations. The learning environment has changed substantially in the last decade, to become increasingly ‘digital’ and fluid. There is a greater emphasis on technology, with many schools having access to ultra-fast broadband enabling them to provide free high-speed wi-fi for students. Many classes require students to have access to devices that support applications like ‘Google for Education’ and many students have access to teachers through email, thus now blurring the boundaries of teaching and class time.

The learning spaces are increasingly fluid with a return to ‘open classes’ re-labelled the ‘modern learning environment’. These provide larger teaching spaces, contain more people, and have potential to be noisier. Spaces are typically filled with a broader array of formal and informal furniture, including ‘break out spaces’ for small group work and consultation. Some NZ high schools have replaced ‘home rooms’ and ‘home room teachers’ with ‘learning coaches’ who are more like advocates and mentors. Student contact time with learning coaches is an allocated class period or two per week. These ‘vertical’ classes might comprise students from a range of year levels. The purpose of these classes is to motivate students and aid their goal setting abilities, providing opportunities to hone metacognitive and reflective skills, with the aim of transferring these skills to other subject areas aiding success and instilling a sense of being a ‘life-long learner’ (ERO, 2016b). Additionally, time is allocated to preparing students for life beyond school, teaching skills such as preparing a curriculum vitae and filling out loan applications, reflecting ‘life’ in our neoliberal economy.

Most secondary schools offer six learning periods per day, however there is a growing trend to reduce this to three 90-minute classes per day. Senior students move between classes, experiencing varying compositions of teachers and students as well as unstructured periods. A high school day is therefore typically busier and more chaotic than primary or intermediate school.

1.6.4 Inclusion

Since the 1960s, there has been an international movement towards including children with disabilities into mainstream schools. This grew out of ‘integration’ policies (Vislie, 2003) aimed at ameliorating discrimination (Ainscow & Miles, 2008). Although education is widely recognised as a ‘human right’ (Kaur & Gupta, 2014), a moral imperative (Baglieri & Knopf, 2004), and a social justice issue (Kearney, 2009; Saggers, 2015), disability studies have illumined the political foundation of education as privileging ‘majority’ students who experience the education ‘system’ (learning and structure) in similar ways, marginalising those with ‘differences’ (Baglieri & Knopf, 2004). Later, international conventions leading to the Salamanca Statement and Framework for Action on Special Needs Education (UNESCO, 1994) and the Convention on the Rights of the Persons with Disabilities, explicitly supported the development of inclusion. In its Framework for Action, the Salamanca Statement calls for a specific type of action aimed at meeting diversity. Since then, additional legislation has been developed commensurate with the needs of each country, for example the Special Education Needs and Disabilities Act 2001 in the UK and Education for All Handicapped Children Act 1975 in the USA.

Vislie (2003) calls ‘inclusion’ a *global descriptor,* indicating that in inclusive education, all members belong (Kearney, 2013). However there remains political and ethical implications, whereby some members may be deemed more worthy of belonging than others (Slee, 2011). This highlights an important notion about inclusion related to its ‘roots’ in ‘integration’. Whereas integration did not eradicate marginalisation and the experience of oppression for certain groups of students (Vislie, 2003), ‘inclusion’ is a “deliberate approach in education that involves particular values, and applies to all learners, to all barriers and to all forms of marginalisation, exclusion and underachievement” (Ainscow et al., 2006, cited in MacArthur, 2009, p.14). It is considered to be the biggest challenge faced by schools (Ainscow & Miles, 2008).

Inclusive education in NZ was also founded on the NZ Education Act of 1989 which remained unchanged until it was reviewed in 2015, and more recently legislated under the Education and Training Act 2020 (Ministry of Education, 2020c). This legislation was supported by the 1993 Humans Rights Act and culminated in several predominately administrative and management-related amendments under the Education Legislation Act 2016. The ‘Education and Training Act 2020’ (MoE, 2020d) has now legislated that all students, including those with disabilities and special needs, have the right to attend school full-time. This, too relates to *equality of access* to mainstream education institutions, not ‘inclusion’ per se. Previously NZ schools have denied students full-time schooling if they have lacked essential support services to meet their needs: “Some parents and whānau find that some schools only allow students with learning support needs or disabilities to attend part time, or else encourage them to attend another school” (MoE, 2020d). In the same Act, ‘special schools’ are now required to be called ‘specialist schools’; the discursive construction is an attempt to bring out the positive nature of ‘disability’.

1.7 Wellbeing: ‘health’ in secondary NZ school

In 2012 the MoE launched The Youth Mental Health project as a means for improving wellbeing of youth aged 12-19. The concept of ‘wellbeing’ was defined by stakeholders and adopted to suggest that:

> *a student’s level of wellbeing at school is related to their satisfaction with life at school, their engagement with learning and their social-emotional behaviour. It is enhanced when evidence-*

> *informed practices are adopted by schools in partnership with families and the community. Optimal student wellbeing is a sustainable state, characterised by predominantly positive feelings and attitudes, positive relationships at school, resilience, self-optimism and a high level of satisfaction with learning experiences* (Education Review Office, 2016b, p.4).

ERO (2015a, p.7) concluded that to ensure optimal wellbeing, students in NZ secondary schools should

- have a sense of belonging and connection to school, whānau, friends and the community
- experience achievement and success
- be resilient and have the capacity to bounce back
- be socially and emotionally competent, be socially aware, have good relationship skills, be self-confident, be able to lead, self-manage and be responsible decision-makers
- be physically active and lead healthy lifestyles
- be nurtured and cared for by teachers at school, have adults to turn to who grow their potential, celebrate their successes, discuss options and work through problems
- feel safe and secure at school, where relationships are valued, and expectations are clear
- be included, involved, engaged, invited to participate and make positive contributions
- understand their place in the world, are confident in their identity and are optimistic about the future

When ERO sampled 68 high schools to investigate student wellbeing, they found that only a minority (16%) were thought "well-placed to promote and respond to student wellbeing" (ERO, 2015a). Their report highlighted that one third of schools faced major challenges in their promotion and response to student wellbeing (26%) and were too overwhelmed to promote wellbeing at all (5%). These statistics are problematic for the disability community in NZ, whose vision for the coming decade (2016-2026) embraces key areas of education and wellbeing, where it is envisaged that the disabled community will access "… an excellent education…" and attain the highest standards of "…health and wellbeing" (Ministry of Social Development, 2016, p. 7).

1.8 Chapter summary

In summary, the New Zealand Human Rights Commission has called for inequalities to be addressed for people diagnosed with disabilities. NZ has responded to this through the establishment of inclusive mainstream schools. However, there has been no research to further our understanding of how successful or not this is for autistic young people, particularly for those completing the NZ curriculum NCEA, which spans the final three years of high school and determines the nature and quality of transition to tertiary study or workforce opportunities and contributes to wellbeing in adolescence. 'Inclusion' aims to value all students, and pertains to the culture, curriculum, and 'community' of the local schools, aiming to restructure "the cultures, policies and practices in schools so that they respond to the diversity of students in the locality" (Booth & Ainscow, 2002, p. 3). Ecological theory posits that it is the healthy adaptation to the various demands of our environment and settings that determines personal growth and optimal development (Bronfenbrenner, 1979). As such, there is an urgent need to gain a comprehensive understanding of the perceptions and experiences of autistic adolescents in NZ mainstream high schools, especially from an ecological perspective, the influences of which have been detailed from an historical socio-cultural perspective, in this chapter.

1.9 Thesis structure

This thesis comprises ten chapters and has begun by painting, with broad brush strokes, something of NZ's demographic, including its political and educational system. Chapter Two is the first of two chapters informing the literature review. Chapter Two explores the historical development of a 'medical model' understanding of autism. This chapter invites the reader to consider that "for positivists, there was only one kind of knowledge about the world" (Rouse, 1990, p. 180), which has had consequences for how we can know, perceive, experience, and challenge what is 'taken-for-granted'. Chapter Three introduces key qualitative autism studies and reviews those themes most pertinent to the lived experience of autistic adolescents in mainstream high schools. Chapter Three concludes by justifying the present study. Chapter Four introduces the philosophical, theoretical, and epistemological attributes supporting the methods used to answer the research questions.

Chapters Five is the first of five analysis chapters exploring the lived experiences of participants in this study. It begins with parents' experiences of the 'autism journey', including 'the diagnostic process', and their expectations of what this provides. These experiences provide an insight into the complex process of navigating 'mental health' services for a diagnosis of autism in NZ. This Chapter then explores autistic students' understanding and experience of being diagnosed and their understandings of 'being autistic'. Chapter Six investigates how students experience and make sense of structures, technologies, and forms of governance pervading their high school. Chapter Seven explores autistic students' perceptions and experiences of participating and achieving in the NCEA curriculum, whilst Chapters Eight and Nine explore participants experiences of 'being supported'. Support pertains to academic, social, and familial support. Finally, Chapter Ten summarises and discusses the findings and methodological issues. This chapter concludes with a reflection on the processes of doing research and the strengths and limitations of this study. Within this discussion chapter, the implications for the findings are considered and opportunities for future research are proffered.

Chapter Two
Literature review (part 1)
Knowledge, authority, and ‘expertise’

I came that you might have abundant life (John 10:10). In this, “John distinguishes between biological life [βίος, ου, ὁ] (bios) and the fullness of life [ζωή, ῆς, ἡ] (*zoé)*

(Ratzinger, 2007).

2.1 Introduction

In order that autists begin to ‘identify’ with their diagnosis, concepts such as ‘disorder’, ‘disability’, and ‘difference’ have specific and assumed meanings; the concepts come to be accepted and challenged as they constrain and enable understandings of self and others. Our understanding of autism has grown out of a medical model framework of understanding, predominately via the psy-sciences (psychology and psychiatry) through the legitimation process of scientific ‘experts’; the antithesis of the phenomenological participant/consumer diagnosed ‘disordered’ and lacking a voice in the research process. Exploring the development of autism knowledge within the context of a developing scientific field is essential for understanding autistic identity and what it means for being integrated and included in a mainstream high school, alongside ‘neurotypical identities’ who comprise the ‘normal’, majority student body.

Historical, political and sociocultural contexts demonstrate proliferation of certain forms of knowledge about development and disorder, which subsequently influenced how we can understand (ab)normal development. It could be argued that scientific progression has been functionally kaleidoscopic in nature, narrowing our visual field, constraining and restricting alternative, broader ways for understanding the array of symptoms called ‘autism’; the dominant scientific and thus, medical model ‘narrative’, stresses a *particular* understanding of what it means to be ‘autistic’.

Whilst this thesis draws from philosophical psychology through its consideration of phenomenology and application of phenomenological analysis, it recognises that our everyday understandings of autism predominately come down to us through the practical disciplines of psychology, namely empirical and clinical psychology. The DSM arose out of certain historical conditions to emphasise the role of biology in mental health, which has wide ranging implications, including classification and categorisation of people, and production of the commodities of mental health. Such commodities include pharmaceuticals and diagnostic test kits, as well as policies that result in privileging funding for biogenetic research, as opposed to qualitative, phenomenological research.

The DSM is a “handbook used by health care professionals in the United States and much of the western world as the authoritative guide to the diagnosis of mental disorders” (American Psychological Association, 2020). It contains descriptive criteria, which provides researchers, clinicians, social workers, and other health-professionals, a means for communicating in a common language about patients, aiming for ‘reliable’ and ‘consistent’ diagnoses, interventions, and ‘treatments’. As an ‘authoritative’ source of knowledge about autism and autistic people’s experiences, it has been generated almost exclusively by non-autistic people and is criticised for its political resistance to acknowledging psychiatric patients as ‘experts’ (Faulkner & Thomas, 2002, p.2).

Autists cannot be diagnosed and ‘introduced’ to autism without reference to autism as a ‘disorder’, within the context of a medical model framework. These discourses are therefore taken up, often without critical reflection, and are used to make sense of a new ‘identity’. This chapter will therefore review the evolution of our current medical model understanding of autism, rather than ‘taking it for granted’. This provides the context for understanding the assumptions, experiences, and challenges pertaining to, and presented by, participants.

2.2 The privileging of function and form in (scientific) enquiry

Science has no specific known origin (Boring, 1929). Likewise, psychology also has no known official starting point, however, philosophy, physics and biology, all contributed to the discipline of psychology, as we know it today. Assumptions about reality, thought, and mind, began with the work of Pythagoras in 550BC and unlike all subsequent philosophers, Pythagoras had no known peer influence (Benjafield, 1996); he stands alone as an original contributor to the field, most notably for his thoughts on rationality and irrationality. Plato (427-347BC) extended these ideas, which influenced Aristotle’s thinking on the role of the psyche in knowledge production. Later, science became less interested in the role of spirituality in functioning and focused instead on medical explanations. Historically this began with the work of Hippocrates’ (ca 460-370B.C.) who provided a medical context for understanding the human being, writing 87 treatises, including gross classifications on temperaments.

It was not until the 15th and 16th centuries that medicine and philosophy became legitimised and revered for their findings and treatment. In 1506 Marco Marulik introduced the term ‘psichiologia’ and in 1524 published his first volume on ‘The Psychology of Human Thought’ (Lawson, Graham, & Baker, 2007). By the 18th and 19th centuries, the human body increasingly came under the gaze of scientists as a site of experimentation and when the human body failed for practical purposes, animals became the focus. This can be seen in Russian-born Ivan Pavlov’s work around 1850, when he attempted to understand behaviours by integrating philosophical underpinnings with objective scientific procedures in his biological laboratory he shared with his canine subjects.

The form of modern science as we now know it, started to become as though it was ‘fixed’ by advances in physics from around the seventeenth century onwards (Boring, 1929). However, Pavlov’s work had a salient impact on the development of authoritative ways of knowing because whilst he was attempting to isolate basic from complex behaviors in the name of ‘objective science’, his experiments took on the ‘form’, which subsequently shaped future experimentation and bridged two eras in science. It gave science its mathematical basis and predilection for a deductive orientation to knowledge acquisition.

It was assumed that the ‘true’ processes of knowledge acquisition depended upon the scientific method of hypothesising and deducing truths known as the ‘hypothetico-deductive method’. An alternative to the deductive method, an inductive line of research emerged in the work of German philosophers, most clearly culminating in the work of Edmund Husserl. However, whilst Husserl’s philosophy was to become, methodologically speaking, the ‘poor cousin’ for now, it was noted that observation and subjective experience produces rich descriptions, and thus logically precedes experimentation (Boring, 1929). The phenomenological method was the antecedent to the development of Gestalt psychology in Europe, but it was the normalisation processes involving the mimicking of the natural sciences that substantially shaped the development of what are now commonly referred to as the ‘psy disciplines’. This stemmed primarily from advances in the natural sciences, which increasingly moved towards taxonomic organisation of Botanical systems; thus, the leap into nosology *could* be conceptualised (Weiner, 2008). This increased the status afforded natural scientific methods, which subsequently influenced what was studied and our understanding of human development, subordinating lived experience and phenomenology, as well as other alternative, especially indigenous methods of knowledge production.

2.3 Epistemological ‘openness’

Whilst there is evidence of some epistemological ‘openness’ a century ago in the field of psychiatry, it was limited and marginalised. Bleuler, for example, theorised about schizophrenia, persistently querying conventional expressions and raising epistemological doubt through his use of terms like “probably”, “perhaps” or “possible” (Stotz-Inglelath, 2000). Rose (1996, p.11) noted that typically, ‘experts’ were perceived as providing us with certain truths through their objective conceptualisations and attributions of the human person. The classification of deviant characteristics into ‘disorders’ was becoming increasingly legitimised through the publication and sharing of information among those with authority to pronounce such truths. The consequence of this ‘state of the field’ was that in 1942, when German-born psychiatrist, Leo Kanner described a set of so-called *autistic* ‘organic traits,’ he drew almost exclusively on his medical training. In rejecting subjective experiences, his medical knowledge and observation objectified the *disorder* of autism (Mackay & Parry, 2015).

When Leo Kanner’s classic paper on autism, was published in 1943, it provided new ways for understanding autism through more comprehensive behavioural descriptions that gave way to checklist categorical criteria, making it easier to diagnose. Kanner’s descriptions were transformative in that they initially removed the oft-used labels of ‘feeble-minded, retarded, moronic, and idiotic’ (Fischbach, 2020), nonetheless, ‘madness as mental illness’ continued to be a contested throughout the 1960s and 1970s. As new categories and labels for the ‘mentally ill’ emerged, some autistic people were assigned ‘schizoaffective disorder’ and then prescribed a long list of psychotropic drugs whilst institutionalised, all of which they failed to respond to (Szalavitz, 2012). Some may have even been discharged re-diagnosed as “schizophrenia in remission” (Rose & Abi-Rached, 2013, p.113).

2.4 The purpose of classification of mental disorders

In the USA, the first attempt to gather information about mental disorders was in the 1840 census, when one category was assigned for this purpose: idiocy (Kirk & Kutchins, 1992). In 1880, seven categories were recognised; however, at this stage statistics were not particularly relevant; they were not being used to plan how to treat psychiatric problems, and treatment was nonspecific at the time (Kirk & Kutchins, 1992). By the middle of the twentieth century, numerous classification systems had been devised, with some quickly running their course and others being used prolifically by psychiatrists (Stengal, 1959).

Around this time, the World Health Organisation (WHO) compiled the International Statistical Classification of Diseases, Injuries and Causes of Death (ICD) and began advising affiliated countries to adopt this system. Few countries did, with NZ (initially) being an exception. It was thought that valid classification systems formed the foundation upon which science would grow, particularly regarding future research and treatment (Kendell, 1975) and its promulgation did much to enhance the careers and prestige of psychiatry and psychology (Kirk & Kutchins, 1992).

By the time World War II was over, the need for classifying mental disorder was less motivated by practitioners and more by governmental needs to 'track' the mental well-being of the population. During the 1930s, Catholic priest Fr Moore, identified 40 symptoms from data gathered on 367 psychotic patients (Blashfield, Keeley, Flanagan & Miles, 2014) to which he applied, by pen and paper techniques, factor analysis that yielded eight factors. This statistical application set the wheels in motion for the process of fathoming the dimensions of psychopathology. Overall, prior classification systems had been chaotic (Blashfield, et al., 2014). This, however, gave impetus to development and emergence of the first Diagnostic and Statistical Manual: Mental Diseases (DSM-I). Thus, DSM-1 arose out of a milieu elevating biological and objective methods of 'science', raising the status of 'scientist'.

2.5 DSM-I to DSM-5

In 1952 when the first DSM was released, 128 disorders were prosaically offered as characteristic behaviours and traits; these were hierarchically arranged between organic and functional disorders that were typically described in 200 words or less, spanning 132 pages and costing $US3.00 in paperback (Blashfield et al., 2014). The word 'autism' appeared only once to describe a type of psychotic reaction called "Schizophrenic reaction, Childhood type". Between the first and second edition of the DSM, research continued to generate descriptive data with special consideration given to reliability of the classification system outlined in the DSM.

Every country continued to rely on its own classificatory system with European countries retaining multiple systems; thus it became the goal of the American Psychiatric Association (APA) (then named American Medico-Psychological Association) to proceed with one conceptual system for use throughout the world (Blashfield et al., 2014). The WHO, however added a psychiatric section to their medical manual of disorders, the

International Statistical Classification of Diseases and Related Health Problems (ICD-6). Additionally, they attempted to establish an international committee aimed at a general consensus of psychiatric disorders with the result being a revised edition of the ICD (ICD-8) and a new edition of DSM (DSM-II) which, though not identical, were now highly similar (Blashfield et al., 2014).

In the second edition of the DSM (DSM-II), some 14 years after the publication of the first edition, the word ‘Autism’ again only appeared once, but this time to describe schizophrenic behavior under the diagnosis ‘Schizophrenia, Childhood type’. Sixty-five additional diagnostic categories were offered, retaining a hierarchical organisation of classification. The manual however shrunk in size to just 119 pages and rose in cost to $US3.50 for paperback copy.

The development and promotion of the DSM and ICD reflect broader political agendas. Firstly, the problems of ‘life’ and ‘living’ were legitimately being taken up as the ‘problems of mental illnesses’. There was not only an expectation of betterment for mentally ‘ill’ individuals - what is labelled ‘ill’ is destined to be a target for ‘fixing’ and making well or ‘normal - but it legitimised the processes and raised the status of those deemed suitable for ‘fixing’ the ‘ill’, namely psychiatrists. Through legitimisation processes, psychiatrists were thereby gaining an equality of professional status, by moving away from the defamed psychoanalytic techniques of their earlier years, towards the more highly esteemed, medical physicians (Szasz, 1974).

Secondly, it appears that certain ‘problems’ were made salient (especially apparent prior to publication of DSM-III), for which specific solutions were ‘needed’ (Kirk & Kutchins, 1992). That is, the DSM and ICD provided a common diagnostic language but now the most pressing problem was diagnostic *consistency* and this was touted as a ‘serious matter’ and one of ‘urgency’ (Bradley, 2006); thus ‘the establishment’ now had a ‘job to do’. Through political positioning, the psy-disciplines were needed; mental health was becoming an economic and political business.

Between the second and third editions, the field of psychiatry was turning to its medical roots and establishing a ‘specialty’ field of practice. Robert Spitzer was a key figure in shaping the DSM-III through the establishment of taskforces that predominately shared his view that psychological behaviours were fundamentally of a medical or biological origin (Reznek, 2016). In this way, DSM-III reflected what some consider being the American Psychiatric Association’s ‘revolution’, whereby it morphed itself from being associated with a subjective Freudian approach to diagnosis, to an ‘a-theoretical’ medical and empirically based scientific diagnostic criteria (Bradley, 2006). This change aligned psychiatry with roots to Hippocrates and earlier scientific taxonomic tendencies, thus further legitimising mental health diagnoses and (perhaps) creating an illusion of an ‘a-theoretical’ approach to mental disorder, due in no small part to the claims of an objective science that had deemed neutrality in the areas of bias, emotion, ethics, culture, politics and economics.

These changes also occurred in the context of a prolific theory-era in the humanities and social sciences resulting in researchers and clinicians on the one hand, having access to diagnostic checklists of mental disorders, and on the other hand, a significant number of new conceptual theories, which together provided a shared understanding of ‘normal’ human development. Previously, psychoanalysts suggested that unconscious conflict was the principle cause of mental illness; this was now being replaced by theories touting that mental health problems in adulthood, if not biological and ‘organic’, were the result of poor parenting and early childhood trauma and stress. But, just as importantly, it was the emphasis on diagnostic classification which was to play the largest role in shaping the future direction of mental health research. Robert Spitzer was instrumental in ensuring that the DSM-III adopted what became well-known, as the ‘Feighner approach’ to classification, calling it the ‘specified diagnostic criteria’ (Rose & Abi-Rached, 2013). This required a general description, as well as a checklist of symptoms and stipulations regarding the number of required criteria for diagnosis, a time-related scale regarding onset and trajectory, as well as implications in relation to existing psychiatric conditions.

Given the flurry of research and theory production at the time, the DSM-III grew to contain 228 categories. It provided lengthier descriptions and a multiaxial system with supplementary material that enabled clinicians and researchers to match categories in the DSM-III to the ICD-8, swelling it to 494 pages at a significantly increased cost of $US31.75. This edition generated significant revenue for the American Psychiatric Association, to the tune of $US9.33million. Diagnosing mental health was becoming big businesses. By the time the text revision of the fourth edition was published in the year 2000, sales of the fourth edition had generated $US120 million (Blashfield et al. 2014). However, the economical spin-off of the DSM was the medical-industrial complex of the pharmaceutical industry, which by 2002 had become “the most profitable industrial sector on the planet” (Scull, 2011, p.119) with a large proportion of their profit derived from mental health medications.

By 1980, when the third review of the DSM was complete, Wing’s translation of Asperger’s work (Wing, 1981) had revolutionised our understanding of ‘Autism’ and it was formally distinguished from schizophrenia with ‘Infantile Autism’ being categorised as a form of ‘Pervasive Developmental Disorder’ (PDD) in DSM-III. ‘Infantile Autism’ comprised four major groups of symptoms with the absence of schizophrenic symptoms including early onset (before 30 months), a lack of responsiveness to others, deficits in language development, speech peculiarities such as echolalia, and odd reactions to the environment including opposition to change and peculiar interests. When the third edition was revised in 1987 (DSM-III-R), ‘Infantile Autism’ was replaced with Autistic Disorder and criteria changed so that in addition to early onset during infancy or childhood, children needed to exhibit eight out of the 16 items listed under three additional themes: a) impairments in reciprocal social interaction; b) impairments in (non)verbal communication and imaginative activity; and c) restricted interests.

Despite resistance by researchers and clinicians regarding the speed at which each version of the DSM was now being revised (Blashfield et al., 2014), DSM-IV was published in 1994. Changes between DSM-III and -IV came about as working groups reviewed the published scientific literature available at the time to determine the most contentious diagnostic categories in need of reviewing (Blashfield et al., 2014). This resulted in a burgeoned edition containing 383 categories over 886 pages of descriptive criteria, selling for $US48.95. There was a significant change made regarding the diagnosis of autism. DSM-IV enabled clinicians to determine subtle variants of autism including HFA, AS, and Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS).

A text revision (TR) of DSM-IV followed in the year 2000, with minor adjustments only. This resulted in the DSM-IV-TR being 57 pages longer and costing $US74.95. DSM-IV-TR (APA, 2000) retained ‘Autism Spectrum Disorder’ (ASD) with relatively minor modifications to criteria. It was not until preparation for the fifth major revision of the DSM, that the APA sought to conduct an overview of the, by then, ‘prolific’ field of *quantitative* autism research. This review occurred in the context of widespread internet access, which made the construction of the DSM-5 observable, thus discussable and contestable in ways that earlier updates had not been (Blashfield et al, 2014).

Drafts of the DSM-5, having been made available on the APA’s website came under scrutiny from the autism community, which had a well-established on-line presence (e.g., WrongPlanet). The anticipated collapse of previously established categories (AS, HFA, and PDD-NOS), were debated (Ozonoff, 2012) with detractors homing in on two main criticisms. The first being that the removal of AS ‘robs’ individuals of their autistic identity (Giles, 2014), highlighting that a significant cultural shift in the perception of the diagnostic category of AS had already taken place; there was stigma attached to a diagnosis of ‘plain’ autism.

Secondly, it was thought that by removing the autism sub-types, this would jeopardize sensitivity and specificity of an autism diagnosis, failing to capture all who would otherwise be diagnosed under DSM-IV-TR (Tsai, 2012).

As a result of the 13 working groups (comprising more than 500 health professionals who were domiciled as part of the review process), the latest edition of the DSM (DSM-5) ballooned to 991 pages and costs $US210. DSM-5 differs significantly from DSM-IV-TR regarding its dimensional approach and lifespan perspective, with greater attention paid to developmental differences regarding presentation of symptoms. Like the DSM, the ICD has undergone a significant review. Now in its 11th edition, ICD11 is fully electronic, and available free online (World Health Organization, 2019). The ICD11 and DSM-5 differ slightly with reference to autism. Both refer to social communication difficulties and restricted interests, but ICD11 recognises loss of early competencies, and instead of drawing attention to the type of play children engage in, focuses on the underlying rules, catering for cultural diversity (World Health Organization, 2018).

2.6 Postulating 'why' the DSM privileged biological research

In 1852, an assistant physician, Heinrich Laer, working in an asylum in Halle said, "insanity is nothing else than a disease, and only medical treatment will prevail against it" (Shorter, 1997, p.262). Today, neuroscientists continue to assert that through understanding brain chemistry and anatomic pathology, we can understand 'mental health'. The DSM-III was a pivotal point in the history of science and specifically in psychiatry and has even been called a "watershed moment" (Bradely, 2006, p.97). Psychiatry had lost public credibility; its legitimacy and authority were in jeopardy, because of its reliance on psychoanalytic techniques for the treatment of mental health. Rather than bow out of the mental health arena, it turned itself to the task of addressing the technological problem of diagnostic reliability and pharmacological interventions, thereby reviving the discipline as a legitimate source of knowledge and authority in the medicalised diagnosis and treatment of mental health (Bradley, 2006).

It has been said, "in a world without psychiatry, rather than being tolerated or indulged, the mentally ill were treated with a savage lack of feeling. Before the advent of the therapeutic asylum, there was no golden age, no idyllic refuge for the supposedly deviant…" (Shorter, 1997, p. 4). And so with the establishment of the asylum and advances in biological psychiatry and the pharmaceutical industry, precision manufacturing of antipsychotic drugs has led to major biological interventions, which initially seemed like a key which could unlock the chains binding the mentally ill to their inner torment. It was thus expected that the DSM would become legitimised through the advancement of biological and 'objective' research, specifically in relation to the isolation of biological markers that could then be mapped onto the disorders.

Of the 450 million people diagnosed with a 'disorder' (out of seven billion people in the world), approximately one quarter, or 100 million people receive medication (Cohen, 2016). Historians of psychopharmacology believe that drug companies became increasingly competitive throughout the 20th Century and trillions of dollars have now been invested in the pursuit of pharmaceutical interventions for 'mental illnesses'.

Shorter (1997, p.319) suggests that "in trying to create for themselves market niches, drug companies would balloon illness categories" and thus they began to play a role in distorting psychiatrist's perceptions of diagnosis. As Healy (n.d. cited in Shorter, 1997, p.319) points out "as often happens in medicine, the availability of a treatment leads to an increase in recognition of the disorder that might benefit from that treatment." Thus many (e.g., Cooper, 2014; Reznek, 2016; Rose, 1990) have suggested that mental health is a lucrative venture; one that dubiously attempts to demarcate a 'normal' human being as desirable; segregating the 'pathological', and 'undesirable' for 'treatment'.

This is achieved according to governance in science and the potentials existing in the industrial, neoliberal marketplace. Governance of people is therefore chained to, and obtained by, legitimating and privileging certain types of knowledge and 'authority' (Rose, 1990), favoring neoliberal trade. Science and by implication, the generation and legitimisation of knowledge, can therefore be discerned as a practice, which can be contested regarding its political and economic ends (Pykett, Jones & Whitehead, 2017).

This critical perspective has direct implications for autistic individuals, particularly when 'differences' are understood in terms of a medical model; where conditions are identifiable by their deficits (Kapp et al., 2013). Whilst a diagnosis is at times highly desirable in order to gain understanding of symptomology, thus providing insight into 'self', it has also been deemed essential for accessing services and in some countries, is necessary for insurance purposes (Attwood, 2007). However, a diagnosis also has potential to pathologise and de-humanise; it can 'mark' individuals by stripping them of their dignity, distinguishing 'them' from 'us' (Brosnan & Mills, 2016). This occurs when undue hope is placed in biogenetic research to achieve 'normalisation'; and when the diagnosis impacts identity by focusing on deficits, obscuring strengths and giftedness (Nadesan, 2005), thus de-legitimising the voice of the ‘mentally ill’.

2.7 Dominance and contestation of the DSM

Dominance of the DSM in making sense of mental health can be discerned from the APA’s (2012) observation that it provides “a common language” for clinicians, including mental health and social workers (Corcoran & Walsh, 2010) and is therefore widely used in the western world. It has been criticised as an artifact that reflects the ‘culture of science’ in the West and as such cannot now be pinned to a specific institution or person (Harding, 1991). Rather, it presents one version of reality. Nevertheless, critiques of a medical model suggest that a reductionist framework renders ‘mental illness’ as ‘madness’ or a ‘damaged mind’ (an abnormality within the individual); that it “feeds into the medicalization of deviance” (Bradley, 2006, p.109). The DSM has been contested on the basis that it stereotypes, stigmatises and ultimately limits our understanding of variance in human beings. It is ‘naturally’ used to make sense of ourselves and those around us (Lafrance & McKenzie-Mohr, 2013). At no time has this been more obvious that in the period leading to the release of DSM-5, whereby the taskforce proclaimed that the PDDs like AS would be subsumed under the broader autistic spectrum, ASD. As noted, those with AS were particularly vocal, criticising the move as one which would ultimately strip them of their ‘aspie’ identity (Giles, 2014).

The medical narrative has also been contested for obstructing alternative ways to make sense of, and support the holistic well-being of, the individual. Critics like Bradley (2006) suggest alternative frames for understanding mental health (including feminist, religious, disability studies, or phenomenological frameworks), have been veiled off, being neither ‘natural’ or ‘ordinary’. He asked the DSM task force: “why choose one particular rhetorical framework for the manual and disregard all others?” This question points to the narrative and culture of science, and political agendas; to the milieu in which knowledge is incubated, perpetuated and then legitimated.

Current conceptual systems of mental health in the affluent ‘west’ therefore, have an umbilical cord to ancestral medicalised roots that cannot be easily severed. DSM nomenclature is privileged and reinforced as ‘dominant’ through the legitimisation of ‘expert’ and subordination of its ‘object’: the subject. In relation to autism specifically, a diagnosis on one hand can be positively perceived and received by autists (Billawala & Wolbring, 2014), as necessary in order to obtain support and gain self-understanding, and as stigmatising and stereotyping on the other hand (MacLeod, et al., 2013). A medicalised approach has also led to significant (mis)understandings of autistic individuals for whom there has been no medical treatment. As a 'model' or framework, it has influenced the appropriation of energy and funding for garnering alternative ways for understanding autistic differences and this has resulted in limited interventions (Howlin, 2010), with most being based on the therapist's interests rather than individual's needs (Mills & Wing, 2005, cited in Mills & Marchant, 2011).

A focus on the diagnosis itself has rendered the broader context of the autist invisible; they are biological beings, as opposed to social, cultural, relational, spiritual, and ethical beings. Our biological nature has eclipsed the fact that we are body and soul, living embedded, embodied, contextual lives, animated by spirit, or 'essence'[6]. Whilst the DSM does not omit contextual factors, it has limited our vision to the technologies of diagnosing and treating mental health at a predominately biological level, failing to take into the account the myriad of data which actually suggests for example, that it is the therapeutic relationship which has the greatest benefit for those seeking treatment; a lack of relationships often compromises mental health (Timimi, 2013).

In NZ, like other neoliberal western societies, we have privileged biomedical knowledge, having been influenced by naturalistic scientific methods, limiting alternative frames of reference for understanding mental health. Unlike many other western societies however, NZ does acknowledge the value of alternative frameworks. For example, Te Whare Tapa Whā provides scaffolding for understanding the spiritual dimensions of mental health experience (Ministry of Health, 2017). To date these alternative frameworks have not been sufficiently explored or applied specifically to autism but could be.

2.8 Implications of a medical model of illness.

One of the implications of drawing on a medicalised biological framework to inform the DSM is that autists are positioned as having a "mental illness", or more bluntly, the DSM constructs autists *as* mentally ill. Connor (2013) for example highlights that the DSM-IV has

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[6] In Edith Stein's 'trinitarian ontology', she constitutes the person as being body, soul, and spirit. According to Maskulak (2015, pp. 274-275) Stein's "tri-partition means to convey that the soul is the medium for the meeting and intertwining of 'spirituality and bodily sentient being…In the human being, the soul which 'draws from its own sources and moulds itself in body and spirit' images the Father. The body as the 'circumscribed expression of the essence' images the Son, and the spiritual life images the Spirit."

succeeded in characterising autism only in dysfunctional or in ‘deficit’ terms: ‘abnormal’, ‘disturbance’, ‘failure’, ‘inflexible’, ‘lack of’, ‘non-functional’, and ‘persistent preoccupation’; thus, making a ‘disease’ out of traits (Grinker, 2015). Given that these traits are typically distributed in the general population, this objectification renders autists homogenous and ‘objectified’ and consequently stereotyped. The construction of a check-list criteria may have been an efficient method for clinicians working with the large cohorts, such as WW2 soldiers in need of treatment funding for PTSD support services and interventions (Corvalan & Klein, 2011); however, it has now led to a form of tunnel vision when applied to autism, blocking alternative ways of understanding autism and the lived experiences of autists.

In summary, a medical framework posits that mental illness is biologically determined, as opposed to something socially constructed within the knowledge economy. Autism therefore became a biological ‘puzzle’ to solve (Grinker & Mandell, 2015) with significant funding being funnelled towards discerning its genetic markers, including heritability (Durdiaková, Warrier, Banerjee-Basu, Baron-Cohen, & Chakrabarti, 2014; Durdiaková, Warrier, Baron-Cohen, & Chakrabarti, 2014). Pathologisation of autistic spectrum differences, however, has not led to development of specialised genetic treatment (Nadesan, 2005). We need to ask, like Halasz (2003) did, why was it that psychiatry reduced our humanity to objective measures, at the expense of subjective experience, if not purely for recognition in the field of science and for financial reward? Medicalised characterisations have functioned to frame autistic individuals as in need of a cure at worst, or in need of an intervention to approximate socially acceptable norms at best, whilst simultaneously failing to acknowledge diversity of unique strengths, gifts and talents (Mogensen & Mason, 2015). In the name of scientism, parents in the past have generally supported the medicalised view of autism because they too ‘want’ a ‘cure’; they want to ‘recover’ their lost, mentally ‘disordered’, child (Nadesan, 2005) and as such, this background, alongside their views and experiences, are important for understanding the lived experiences of their children.

2.9 Use of the DSM in NZ

According to the New Zealand Psychological Society (NZPsS) (n.d.) “the delivery of mental health services in Aotearoa New Zealand have been more heavily influenced by the Diagnostic and Statistical Manuals (DSM) of the American Psychiatric Association than any other diagnostic and classification system.” In NZ, there is widespread and sometimes mandatory use of the DSM, which according to the NZPsS (n.d.) has given it the power to really 'shape thinking' about mental illness in this country. The NZPsS (n.d.) criticised the homogenous implications of the categorical adjustments in DSM-5, suggesting that it will result in a failure to see the 'complexity and uniqueness of the individual.' This echoes the view of critical autism researchers who acknowledge benefits of having a common language in the DSM for management of complex 'objective' data; however, they also recognize the limitations of a medical framework which functions to homogenize diversity of experiences (e.g., Orsini & Davidson, 2013). The implication of the process of homogenisation is, as mentioned above, the grounds upon which potential misperceptions and misunderstandings may arise and be perpetuated as stereotypes and stigma (Link & Phelan, 2001; MacLeod, Lewis, & Robertson, 2014), thus have implications for autists in inclusive schools.

NZ psychologists are required to include more holistic conceptual models of well-being, such as the principles outlined in Te Tiriti o Waitangi. This requires cultural responsivity and recognises that "cultural mores are not restricted to ethnicity but also include (and are not limited to) those related to gender, spiritual beliefs, sexual orientation, abilities, lifestyle, beliefs, age, social status or perceived economic worth" (New Zealand Psychologist Board, 2014). New Zealand psychologists are therefore required to draw on models, theory, and practices that are culturally and individually sensitive (NZPsS, 2017). This suggests that in theory, whilst the DSM in NZ fundamentally influences our understanding of mental disorders, there is a general recognition for the need to bring more than one model or framework to bear on our understanding of mental health for NZ citizens. This does not mean that these ideals have penetrated education services or influenced educational policies.

2.10 Social model

A social model of disability developed much later than the medical model and primarily grew out of the work and writing of Mike Oliver in 1976 (Mertens, Sullivan, & Stace, 2011). Unlike the medical model, which foregrounds and thus, maintains individual responsibility for impairment (Grenier, 2010), the social model aims to eliminate attitudes, structures, and features of social organisations and political institutions causing barriers to participation and inclusion (Barnes & Mercer, 1996; Grenier, 2010). Politically, this helps others to accept diversity and perceive 'difference' in more positive ways (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013), removing the onus of responsibility from the individual for their disability.

The social model is relevant to this thesis given that schools and support communities are social environments where autistic youth may experience exclusion through social practices, including attitudes, structures (governance), and the general demands and operations of the organisation. This can result in oppressive conditions, especially when individuals are excluded through a lack of appropriate individualised support and environmental accommodations (Mertens et al., 2011). Ideally, society would provide structures and environments which do not hinder disabled peoples' participation (Orsini & Davidson, 2013); schools would *aim* to accommodate differences by ensuring that social and material environments met the needs of all students. To move beyond an 'aim' within school, however, teachers must have some understanding of the disorder and the impact of social structures and governance to 'disable'; they then require resources to accommodate and support one's individual needs.

A criticism of the social model is that sometimes theorists fail to attend to the individual experiences of those impeded by social structures (Morris, 1991). This seems counterproductive to transformative change however, given that disabled people have been discursively tainted by stigma and silenced (Goodley, 2001), and are often regarded as illegitimate sources of expertise regarding their own experiences.

2.11 Chapter summary

In summary, this chapter has traced the growth of an industry intent on classifying 'difference' and labelling mental 'disorder'. Labels have potential to change "interpretations of […] behaviour, […] identities and hence the meaning of the label itself" (O'Dell, et al., 2016, p.171). Just as each new edition of the DSM provided new understandings of mental illness and disorder, so too did it have an array of consequences for those labelled, though few studies have investigated what those consequences were for autistic individuals. Nevertheless, social, cultural, historical and political contexts function to govern and sanction outcomes of diagnoses, including service provision (Miller & Rose, 2008). There have been significant changes in regards to the problematising, diagnosing, and intervening in the lives of those constituted with mental health 'problems' (Miller & Rose, 1990), with each edition of the DSM having potential to shape perceptions of an 'othered' self as well as shaping the expectations that others hold for those so labelled.

Chapter Three
Literature review (part 2)
Autism: a diagnosis and a lived experience

I mean autistic people, people with my disability are just…usually don't get a lot of help from other people. I mean the other people don't care do they?
(Chris [adol], p. 22).

3.1 Introduction

This chapter introduces the reader to key factors concerning inclusion research, especially as it pertains to autistic students in mainstream high schools. This chapter differs from the last, in that it is derived more from the insights of those with ASD, as opposed to those writing about ASD. However, qualitative autism literature typically takes a multi-perspective approach to augment what autists offer, and this chapter begins discussing this aspect of research. It then defines inclusion and introduces three studies of *particular* relevance to this project, before drawing on a more general body of qualitative literature exploring the themes pertinent to inclusive experiences and understandings of autists in mainstream high schools and special education units. Salient themes include the diagnosis, identity development, peer friendships, anxiety, student-teacher relationships, academic and general school challenges, and support. This review provides the rationale for the current study and the research questions guiding it are offered at the conclusion.

3.2 Multi-perspective studies

Multi-perspective autism studies have typically included students, teachers, and parents. Humphrey and Lewis (2008a) for example, used a range of data collection techniques including semi-structured interviews to investigate the meaning of inclusion for autistic high school students in four UK high schools. In addition to giving voice to autistic students, teachers, learning support assistances, SEN coordinators (SENCOs), and senior management, parents also participated.

Psychology and education researchers, have begun to increasingly value parent's insights regarding their autistic children (Brewin, Renwick, & Schormans, 2008; DePape & Lindsay, 2015a; Posavad, 2009). Parents are often key informants for gathering historical information, including diagnosis, and information regarding school and social activities

(Marks, Schrader, Longaker, & Levine, 2000), general student wellbeing (Harper, Dyches, Harper, Roper, & South, 2013), and, access to services (Altiere & Von Kluge, 2009; Carborn, Behl, Azor, & Murphy, 2010), especially school, health, and community services (Montes, Halterman, & Magyar, 2009). They gain an in-depth knowledge of autism and become primary advocates for their autistic children, developing 'expertise' (Feinberg & Vacca, 2000; Nadesan, 2005; Tippett, 2004); parents can cover a broad array of issues and understandings (e.g., Hay & Winn, 2005). Parents can also identify factors that contribute and detract from quality of life, at home and school (Brewin, et al., 2008), including implications of the diagnostic experience, availability of support, and perceptions regarding teacher autism knowledge. They have a pivotal role liaising with schools, especially where autism may not always be understood (Portway & Johnson, 2003), mediating between autistic individuals and their schooling experiences (Hebron, Humphrey, & Oldfield, 2015; Muus, 1996). Nonetheless, very few studies have enriched the empirical literature by explicitly seeking the voices of parent and autist (Cridland, et al., 2015b; DePape & Lindsay, 2015b; Diener, Anderson, Wright, & Dunn, 2015). This can make comparing findings difficult.

Young autistic adults can also broaden how we understand inclusive experiences, through retrospective accounts (Baric, Hellberg, Kjellberg, & Hemmingsson, 2015); similarly, there have, as yet been few attempts to seek their perspectives. Whilst autobiographical memories are typically information rich in all areas (memory involving location, people, and actions), they are considered less absolute regarding dates and times (Brewer, 1994). For the purpose of recollecting high school experiences, absolute dates and times are less relevant than memories involving actual experiences, relational or solitary, and overall perceptions of high school. In Baric et al.'s (2015) study for example, older participants may have benefited from the passing of time, enabling rich reflections and the development of insights perhaps not otherwise available about inclusion and academic success, whilst in the setting.

3.3 What has diagnostic experiences got to do with 'inclusion'?

The aim of inclusive education was to 'overcome marginalisation' and "to empower students and their families, and to influence policy and practice with the view of realising a goal of inclusion" (Selvaraj, 2014, p.60). However, Lord and McGee (2001), along with others (e.g., Allik, Larsson, & Smedje, 2006; Sivberg, 2002), describe it as challenging to have a family member on the autistic spectrum. An autism diagnosis is often experienced as a turning point in familial life and can take a long time to obtain. Howlin and Asgharian

(1999) posited that it takes eight years for AS to be diagnosed, however, a survey involving 1200 patients in the UK, suggested families experienced diagnostic delays spanning 5-32 years (Howlin & Moore, 1997). A diagnosis facilitates understanding, co-ordination of support, and is usually the impetus for parents to seek interventions, (O'Connor, et al., 2018; Perkins et al., 2018). It can therefore bring needed clarity to move forward in life with direction and purpose (DeGrace, 2004).

Exploring the diagnostic experiences of parents and autists sheds light on the complexity of identity development and family life. These are processes taking place between people and their ecological settings, which influence perceptions and experiences of inclusion as well as the development of relationships between home and school (Muus, 1996) that might support or hinder inclusive experiences. For example, some parents have looked back at the diagnostic experience as a hellish journey and an epic battle (Nadesan, 2005), whilst others have experienced emotional trauma in receiving the diagnosis and need time to adjust (Midence & O'Neill, 1999). The experience of emotional trauma has sometimes been profound (Phelps, Hodgson, McCammon, & Lamson, 2009), including periods of grief, as well as ongoing worry about what the future holds for someone diagnosed ASD (Corcoran, Berry, & Hill, 2015). Emotional trauma can be due, at least in part, to behavioural and communication difficulties resulting in "high levels of anxiety and depression" (Phelps et al., 2009) and this can have implications for how supportive parents can be towards their adolescents, including their ability to liaise with school and advocate for services. When parental support has been lacking for a long time, in extreme cases, it has led to filicide (the murder of one's own child) (Palermo, 2003), highlighting 'complexity' and 'interconnection' between circumstances and systems of influence.

3.4 Defining 'inclusion'

According to the ERO (2015, p.7), being inclusive means that education "is about the full participation and achievement of all learners. In fully inclusive schools, children and young people with special education needs have a sense of belonging as they participate as much as possible in all the same activities as their peers". This definition is consistent with international literature (e.g., Booth & Ainscow, 1998; Farrell & Ainscow, 2002) that depicts inclusiveness as referring to the *presence* of the individual, their *participation*, *acceptance* by others, and their *achievement,* not limited to academic achievement, but personal, social, and the emotional domains (Humphrey & Lewis, 2008b).

‘Inclusion’ can also have different meanings for different people (Huag, 2017) and has a tendency to be used ubiquitously, often describing pedagogy, which according to Goodall (2015, p. 306) “in reality is exclusionary at worst, or at best assimilationist or integrationist”. Yet, in educational literature, inclusion typically relates to one’s ‘rights’ to receive an education in a milieu that functions to meet the needs and abilities of all students. From the perspective of students, ‘inclusion’ has been related to feelings (Goodell, 2018). Falkmer, et al. (2012, p. 191) have previously noted that ‘participation’ is “a subjective feeling of belonging to, and being active in, a specific context”. ‘Inclusion’ has therefore also been considered as having an ‘ethical’ dimension (Allan, 2005), being shaped by ‘attitudes, values, and beliefs’ (Mentis, Quinn, & Ryba, 2005, p.121), all of which lead to something ‘felt’.

What is meant by ‘inclusion’ in the context of education, is also evident in the way qualitative studies consider ‘barriers’ preventing ‘inclusion’ for those with diverse learning needs, particularly ASD. Humphrey and Parkinson (2006) have suggested that barriers are related to: the school’s general ethos towards inclusiveness; communication, including the appropriate distribution of information and knowledge throughout the school and between the home and school; difficulties teachers have in regards to implementing elements of Individual Education Plans (IEPs); and the distinct needs of the students. Tippett (2004), like others (e.g., Baric, et al., 2015; Carrington & Graham, 2001; Humphrey & Lewis, 2008a; Saggers, Hwang, & Mercer, 2011) has suggested barriers exist regarding the curriculum (especially around numeracy and literacy); the environment, impacting and exacerbating sensory sensitivities; the lack of academic and social support for autists; and, the repercussions associated with teachers’ lack of autism knowledge. Stack, Symonds and Kinsella (2020) have understood barriers like this as inhibiting the school’s ‘goodness of (person/environment) fit’.

The aim of the next section is to therefore review the ‘inclusion’ literature from a predominately qualitative perspective, privileging the voice of autistic adolescents in the first instance, augmented by parent perceptions. This review will establish the need for further research exploring the lived experiences of autistic adolescents in mainstream schools, especially local research, where conditions present a unique curriculum, challenges, and opportunities for autistic students.

3.5 Adolescent autism research: lived experience of inclusion in inclusive mainstream schools

Davidson (2010) highlights the value of insider accounts; it is a valuable means for assessing inclusion experiences. Yet, qualitative studies involving adolescents with disabilities have generally been lacking (Maxey & Beckert, 2017), including those involving autistic students (Harrington, Foster, Rodger, & Ashburner, 2013; Jones et al., 2007; Preece, 2002). Consequently, little is known about the 'inclusive' and general 'lived experiences' of cognitively able autistic adolescents in mainstream high schools (Connor, 2000), including support and how best to accommodate their needs. Researchers have therefore postulated that there is a need to continue obtaining first-hand accounts from autistic individuals, to understand what life is like for them (e.g. Bagatell, 2007; Cridland, et al., 2015; DePape & Lindsay, 2015a; Jarman & Rayner, 2015; Marks, et al., 2000; Poon et al., 2014; Preece & Jordan, 2009; Tobias, 2009).

Many autistic adolescents believe they should be given opportunities to participate in research and tell their stories (Carrington, Templeton & Papinczak, 2003; Hurlbutt & Chalmers, 2002) and their knowledge is needed to progress and guide program and curriculum development. This is important because autistic high school students have some of the poorest post-secondary education outcomes (Roux, et al., 2015). Over one third of young autistic adults in their 20s report being 'disconnected' (Roux, et al., 2015). Additionally, the inclusion of more young, autistic adolescent women in educational research is needed. It appears that whilst there are gender similarities regarding sensory sensitivities and peer relationships, girls are more socially motivated but are also more inclined to hide their social difficulties, masking and concealing their 'identity' (Tomlinson, Bond, & Hebron, 2020). This has been related to poor mental health outcomes (Cook, Ogden, & Winstone, 2018; Moyse & Porter, 2015).

The lack of studies is most notable when considering country of origin. For example, in Hong Kong, China, Wong (2017, p. 377) wanted to learn about inclusive experiences of Chinese autists, recognising the benefit of drawing on first-hand accounts. They had to settle for reading the self-portrayals of 17 young people in a single book, published by Hong Kong Autism Awareness Alliance.

Inclusive autism studies are also limited in our neighbouring countries. In Singapore, Poon, et al.'s (2014) research is the only research to seek the inclusive perspectives and experiences of high-functioning autistic adolescents (three male and one female aged 12-17 years) in mainstream high schools. In Australia, Saggers, et al. (2011) considered the lived experiences of younger high school students (seven male and two female students, aged 13-16), all of whom attended an “extensive special education support program” (p. 175) within a mainstream high school. Whilst other studies from neighbouring countries are of interest like Hay and Winn’s (2005), participants were in their ‘junior’ years (years 8 and 9) as opposed to ‘senior’ years.

In 2015, two meta-syntheses were published related to the lived experiences of autistic people, from the perspective of autists (first person accounts) (DePape & Lindsay, 2015a), and from the perspective of parents who care for a child with ASD (second person accounts) (DePape & Lindsay, 2015b). These thematic syntheses integrated qualitative evidence, which Erwin, Brotherson and Summers (2011) suggests provides a greater appreciation of a topic of research, more so than the findings of any single study. Of the 33 peer-reviewed, first person studies identified by DePape and Lindsay (2015a), published between 1980 and 2014, only 15 included high-functioning autistic adolescents (as opposed to children or adults), representing the experiences and perceptions of 152 individuals aged nine to 21 years. However, only eight of these studies (Browning, Osborne & Reed, 2009; Carrington & Graham, 2001; Hughes, 2012; Humphrey & Lewis, 2008a; Humphrey & Symes, 2010; Marks, et al., 2000; Penney, 2013; Saggers, et al., 2011) were specific to high school experiences, comprising the views of 90 students.

Whilst this literature review draws on a range of qualitative autism studies, three will be introduced as particularly relevant to this thesis. The first is Humphrey and Lewis’s (2008a) study, based on data collected between 2005 and 2006, comprising the perceptions and experiences of 20 adolescents, from four mainstream schools in England. The primary aim of the study was “to develop an understanding of (and subsequently to inform practice around) the inclusion process for pupils with AS” (Humphrey & Lewis, 2008a, p. 25).

Humphrey and Lewis (2008a) found that autists wanted to talk about their diagnosis and make sense of their autistic characteristics in order to interpret what this means for ‘being different’ in the context of daily school life. They constructed understandings of themselves by pathologising autism as ‘disorder’, “consistent with a medical model approach” (p. 31). However, some students also accepted autism as part of a positive sense of their identity. The problems autists experienced in school varied considerably depending on their autistic characteristics and ‘fit’ within the school’s environment. Some students were esteemed for their characteristics, whilst others were bullied and exploited for being socially naïve. Most of the autistic students experienced bullying and teasing to varying degrees; one to a severe and worrying degree.

Although bullying and teasing increased students' experiences of anxiety, environmental factors also seemed to invoke stress, including noise and a lack of predictability. It helped when schools offered quiet spaces, like the library (Humphrey & Lewis, 2008a). Some students benefited from adult support. Support was perceived of in terms of academic and social support, alleviating anxiety and reducing occasions for being bullied. Some students received academic support, whilst others did not want it. They believed 'hovering' teachers detracted from their goal, which was to be perceived by their peers as 'normal'; teacher support meant illuminating their 'differences' (Humphrey & Lewis, 2008a).

A lack of teacher knowledge about autism meant that teachers found it difficult to cater for individual needs; autists believed teachers knew little about 'people with special needs' (Humphrey & Lewis, 2008a, p. 39). This lack of knowledge was deemed a barrier to the school's ability to be inclusive; some schools were "inadequately equipped" to meet the needs of autistic students (p. 42). Without autism knowledge, meaningful forms of support were lacking, contributing to the conclusion that students constantly grappled with ways to negotiate 'difference'.

Although Humphrey and Lewis's (2008a) study is small, it has become something of a 'gold standard' on 'inclusion' experiences, being cited prolifically and influencing subsequent 'interpretations' of data. For example, it led Saggers (2015) to reinterpret previous findings pertaining to Saggers, et al. (2011), which was already a worthy contribution to the autism inclusion literature.

The second study with specific relevance to this thesis is Saggers, et al. (2011), read in conjunction with Saggers (2015). Saggers et al. (2011) investigated the lived experiences of nine high-functioning autistic adolescents in a single inclusive mainstream school in Brisbane, Australia. The focus of the study was to "examine current inclusive educational practices for students" (p. 184). Unlike many high schools however, this school was renowned for its special education support program. Students were aged 13 to 16 and attended mainstream classes, whilst also having access to additional support, based upon individual needs. This level of ASD expertise is uncommon in typical Australian high schools.

Saggers et al. (2011) revealed six effects in relation to learning and participation, similar to the findings in Humphrey and Lewis's (2008a) study. These were, (a) the importance of teacher characteristics for learning, listening, and enjoyment; (b) curriculum-related issues pertaining to workload, problems with handwriting, and fathoming solutions; (c) support mechanisms, relating to attitudes towards support, types of support, and the manner in which it was received; (d) friendships, especially perceptions towards friends and friendships, as well as attitudes regarding socialising and solitude; (e) environmental considerations, especially noise, crowding, and cramped spaces; and, (f) teasing and bullying, including frequency, severity, and reporting problems (Saggers et al., 2011).

Saggers et al. (2011) concluded that whilst the needs of some students were being met within the school, ‘gaps’ existed, especially around teacher knowledge of ASD. A lack of knowledge caused a chain reaction impacting adaptations, for example, failing to understand one’s strengths impacted how the curriculum might be flexibly adjusted. Saggers et al. (2011) concluded that a lack of understanding may also mean that the physical environment is ill-suited, or homework and workload too stressful.

The third study of interest is Goodall’s (2018) research. This study differs to others in that it is retrospective and pertains to the perceptions and experiences of 12 participants (aged 11-17 years), all of whom had previously attended mainstream high schools and had left due to overwhelming difficulties. Seven students were attending the Alternative Education Provision and five were being home-schooled and were attending a ‘study hub’ run by a voluntary group.

This study, like Saggers et al. (2011), is of interest because NZ autistic participants attend a mixture of mainstream classes and time in their SSC. One participant in this current study dropped out of high school due to distress, another opted out for long periods in year 13, and another attended school but was not ‘participating’ in the curriculum per se.

Similar to Humphrey and Lewis (2008a), Goodall (2018) considered a range of options for data collection, beginning with semi-structured interviews, but also adding additional activities including drawing, a ‘beans and pots’ activity, and a diamond ranking activity with the aim of fleshing out and helping participants elaborate on identified key in/ex-clusive themes. These themes included the aspects of schooling deemed important and the “potential worries about school that could act as barriers to accessing education in mainstream schools” (p. 8). From these diverse methods of data collection, Goodall suggested ‘inclusion’ was experienced as a general ‘feeling’ and thus pertinent to any type of school or unit within a mainstream school. Participants’ feelings of inclusion stemmed from being wanted; having a place where one felt they belonged, were valued, recognised, respected, and understood by teachers, thus having their individual needs met.

Barriers to inclusion were perceived as resulting from interactions with teachers who lacked autism knowledge; the school's 'mentality'; and, the lack of support available within the school. Barriers like the 'school's mentality' may refer to local or distal forms of governance, attitudes, beliefs, and values functioning to make the student feel excluded. One student in the study concluded that "mainstream and autism do not really go together" (p.16).

It is clear from these three studies that autistic students have valuable insights to offer regarding their lived experiences. Based on their insights, it could be expected that 'senior students' and tertiary students looking back, might also be able to opine as to how or why 'school mentality', or 'governance' presents 'barriers'. This suggests that students are not content to look within as the cause of all their problems, but are looking to the setting, context, and structures functioning to oppress, 'disable', or 'other' them.

3.6 General autism literature

Because adolescent inclusive research is limited, it is necessary to draw on studies that may include participants from a broader range of ages. Tippett's (2004) NZ study for example included three boys aged 12, 8, and 6 years; Humphrey and Lewis's (2008a) participants were aged 11-17; and, four of the nine participants in Hay and Winn's (2004) study were in Years 8-9 (the equivalent of 'intermediate' or 'junior' years in NZ). These studies and others like them, elucidate on dominant inclusion themes. These pertain to the diagnosis, identity development, peer friendships, anxiety, teacher-student relationships, academic and general school challenges, and support.

3.6.1 An autistic self: a diagnosis and an identity

Narratives pertaining to autism lived experiences often begin with experiences of the diagnosis. This is because the diagnosis speaks to experiences of 'difference', identity, and being understood. Most parents obtaining a diagnosis of ASD for their child have experienced frustration, delays, and multiple referrals (Howlin & Moore, 1997; Gould & Ashton-Smith, 2011), and few qualitative studies have sufficiently explored this issue (Midence & O'Neill, 1999). There has been an extensive focus on diagnostic instrument sensitivity in the literature (like DSM-5) (Huerta, Bishop, Duncan, Hus, & Lord, 2012; Mayes, Black, & Tierney, 2013; McPartland, Reichow, & Volkmar, 2012), but few studies have attempted to understand the lived experiences of being diagnosed, or investigated the barriers parents encounter *en route* to a diagnosis (Elder, Brasher, & Alexander, 2016; Gordon-Lipkin, Foster, & Peacock, 2016; Russell, Steer, & Golding, 2011).

Elder, et al. (2016) have reported that the most common barrier to an earlier diagnosis is a lack of professional education around ASD and disregard by professionals for parental accounts of atypical development (Elder et al., 2016), despite observations of something amiss early in their child's life (Young, Brewer, & Pattison, 2003). Whilst it is rare for a diagnosis to be given below the age of three (Fletcher-Watson & Happé, 2019), NZ parents have reported barriers including professionals taking a 'wait and see' approach, whilst seemingly dismissing parental wisdom (Bevan-Brown, 2004). Fletcher-Watson and Happé (2019) highlight that the diagnostic manuals are not the barrier to obtaining a diagnosis, rather, it is the "variability of presentation in the autistic population" that make diagnosing difficult: the same feature "may be manifest in dramatically different forms between individuals" (p. 33).

The literature suggests that parents seek a diagnosis to remove self-blame (Midence & O'Neil, 1999), especially the stigma of 'bad parenting' that is associated with children having challenging behaviours (Calzada, Pistrang, & Mandy 2012; Ryan & Runswick Cole, 2009). Additionally, parents believe a diagnosis will alleviate confusion, provide insight into behavior (Calzada, et al., 2012) and increase their ability to accept and support their child (Midence & O'Neill, 1999).

Parents believe that a diagnosis will increase teacher understanding and provide access to appropriate support services (Calzada et al., 2012; Ryan & Runswick Cole, 2009), improving the quality of life for their child and family. Parents expect that teachers will be empathetic towards their child, also improving quality of life. For some students, this has been the case. Adolescents have felt others were more sympathetic towards them following declaration of a diagnosis; they have perceived being treated better because they were understood (Mogensen & Mason, 2015), highlighting a link between ASD knowledge and 'inclusion' experiences. The diagnostic 'journey' therefore is part of a broader narrative around knowledge acquisition, identity acceptance, and the search for support.

The experience of being diagnosed, for children and adolescents is also an under-researched area (Huws & Jones, 2008). However, when the diagnosis comes at a critical period of development in one's life, it can impact one's self-concept and social identity. If communicated poorly, a diagnosis can compromise self-understanding and lead to social isolation and stigmatisation (O'Connor, et al., 2018). Few studies have attempted to investigate how being diagnosed with autism impacts adolescent's self-understanding and negotiation of identity (Mogensen & Mason, 2015). The few qualitative studies to date, suggest that the diagnosis has led to feelings of liberation from oppression; feelings of relief at discovering a shared common identity (Hurlbutt & Chalmers, 2002; Mogensen & Mason, 2015); and, feelings of pride and being happy with an autistic identity (e.g., Carrington, et al., 2003; Humphrey & Lewis, 2008a; Poon et al., 2014; Saggers, et al., 2011). These experiences of 'self' may be bi-directionally influenced through inclusion/exclusion experiences. Thus 'inclusion' studies by nature, must account for an embedded being; someone who is shaped by their diagnosis and their lived experience in the construction of a personal 'identity'.

In a simplistic way, the term 'identity' refers to domains and groups which we believe best captures our sense of self (Renninger, 2009), for example, a 'kiwi', an 'aspie', a teenager, a Catholic. Erikson proposed that adolescents are engaged in the psychosocial conflict of *identity development* versus *role confusion* (Erikson, 1994; Santrock, 2020). The main question of this period is 'Who am I?'

Adolescence is generally perceived as a time when adolescents also experience key challenges which "includes adjusting to the increased academic, social, and cognitive demands of high school; exposure to, and participation in, a broader range of social roles', as well as learning how to manage sexual urges in socially appropriate ways" (Cridland, et al., 2016, p. 3). Some adolescents have reacted negatively to 'discovering their impairment' and decry "make me normal" and "I'm a freak" (Humphrey & Lewis, 2008a, p. 31). They characterise themselves adversely: "It's like I have a bad brain; I'm mentally disabled, well partly mentally disabled", and "I told them it's a mental syndrome and they think 'Ah, he's a retard'" (Humphrey & Lewis, 2008a, p. 31).

The information received at diagnosis about autism has sometimes differed from what individuals experience; some want to speak out about these differences to demonstrate the problems of being compared to stereotypes (MacLeod et al., 2013; Mogensen & Mason, 2015). Other students believe that the autism label obscures who they are (MacLeod et al., 2013) and see it as failing to communicate anything about the problems they experience. Many want to conceal their diagnosis, and hide their differences, 'masquerading' to appear 'normal' in school, especially in front of peers (Carrington & Graham, 2001; Humphrey & Lewis, 2008a; Mogensen & Mason, 2015). Some 'high-functioning' autists have distanced themselves from other ('lower functioning') autistic individuals in schools, referring to them as 'people *with* autism' (MacLeod et al., 2013). Thus, adolescents not only demonstrate an awareness of their own differences and what this means to them within a social context, but they draw on normative discourses about the 'spectrum' positioning themselves 'higher' (thus better positioned) compared to those less able, at the lower, less desirable end. In summary, high-functioning autistic adolescents grapple with their ‘autism identity’.

A specific limitation of existing literature (regarding autistic people’s diagnosis and identity development) stems from there being a bias toward what is known about the experiences of male adolescents (Sproston, Sedgewick, & Crane, 2017; Stewart, 2012; Tomlinson, et al., 2020). Gould and Aston-Smith (2011) suggest that male biased diagnosis ranges from a ratio of 2:1 up to 16:1. It is thought this is due to Kanner’s original observation of autistic boys.

Autism has therefore gone underrecognised in girls for decades. Aside from biographical offerings from women ‘on the spectrum’ (e.g., Cook O’Toole, 2018; Grandin, 1995), the lived experiences of girls and female adolescents have rarely been specifically sought (Cridland, et al., 2014; Dean, Harwood, Kasari, 2016; Moyse & Porter, 2015; Sproston, et al., 2017). When Tomlinson et al., (2020) reviewed the autism literature on the school experiences of autistic girls and adolescents, all eight qualitative studies meeting criteria for inclusion revealed a lack of understanding about autism in girls, and the subsequent effort required of them to achieve. A lack of knowledge negatively impacted the array of accommodations that could be made for them. It seemed that girls experienced more positive relationships with school staff, impacting their overall educational experience in positive ways. This thesis expects to include a larger contingent of female autistic participants and thus contribute to this limited body of knowledge regarding the lived experiences of female adolescents on the autistic spectrum, in mainstream schools.

3.6.2 Peer friendships

From an ontological and ‘western’ perspective, adolescence has been socially constructed as *the time* to pull away, but not disconnect with parents and as *the time* to engage with more peers, through a range of culturally appropriate activities (Santrock, 2020), leading towards the acquisition of a ‘mate’. It can be a time that is especially distressing for autistic adolescents who experience social exclusion due to social communication difficulties (Carrington, et al., 2003; Greenlee, Winder, & Marcovici, 2020; Howard, Cohn, & Orsmond, 2006).

There have been too few investigations into the development of friendships for autistic adolescents (Chamberlain, Kasari, & Rotheram-Fuller, 2007), despite parents and autists reporting that friendships are more important than ‘physical or academic skills’ (Ryan, Coughlan, Maher, Vicario & Garvey, 2020). It is thought most autistic children have fewer friendships (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011) due to difficulties establishing and maintaining relationships (Daniel & Billingsley, 2010; Bauminger & Shulman, 2003).

Negative social experiences can lead to a reduction in social confidence (Griffin & Pollak, 2009) and fear of rejection, which decreases one's ability to instigate friendships (Humphrey & Lewis, 2008a) and leads to social avoidance (Daniel & Billingsley, 2010). Lacking social skills however, does not equate to a lack of 'social desire' (Grinker, 2007). Most autistic people want friends, (e.g., Bauminger & Kasari, 2000; Carrington & Graham, 2001; Connor, 2013; Hebron, Humphrey, & Oldfield, 2015; Humphrey & Hebron, 2015; Humphrey & Lewis, 2008a; Humphrey & Symes, 2010; Locke et al., 2010; Saggers, 2015; Saggers et al., 2011) and even crave social contact (Causton-Theoharis, et al., 2009). There is therefore diversity of social experiences and social expectations among autists; not all autistic people lack friends (Bauminger et al., 2008; Calder, Hill, & Pellicano, 2013; Sedgewick, Hill, & Pellicano, 2018).

It appears that autistic adolescents understand the concept of a 'friend' (Carrington et al., 2003) and that shared interests form an integral component of friendship (Daniel & Billingsley, 2010). Freeman and Kasari (1998, p.341) describe friendships as providing 'companionship, mutual support and affection'; however, Brownlow, Betilsdotter Rosqvist, and O'Dell (2015) contend that dominant discourses contain assumptions that friendships must exhibit certain elements such as emotional expression to constitute the full measure of a friendship. Parallel play for example, is a type of play which normally developing young children grow out of relatively early in life, but which autistic teens may continue to value, and by engaging this way with others, they believe it constitutes friendship. Thus, the literature posits that alternative ways of defining 'friendship' and communicating are needed (Brownlow et al., 2015) and these must be explored from an autistic adolescent experiential perspective (Brownlow, O'Dell, & Taylor, 2006).

Most studies suggest that social deficits present "the greatest life challenge" for autists (Church, et al., 2000, p.19). They are more likely to be on the periphery of peer networks, leaving them lonelier than typically developing peers (Bauminger, et al., 2003; Falkmer et al., 2012). This leads to a lack of integration into both academic and social activities (Locke et al., 2010). For example, in classroom observations, autistic students were more likely to spend significantly longer alone, either engaged in an activity on their own, or being unoccupied (Humphrey & Symes, 2011). Outside of school, they tended to spend less time with peers, more time alone or with their mother, as well as more time engaging in solitary discretionary activities like watching television and using a computer (Orsmond & Kuo, 2011). Locke, et al., (2010) found that the consequence of having fewer friendships is increased isolation and marginalisation.

Some adolescents report being self-conscious about their social incompetence and aloneness and they attempt to hide this (Carrington & Graham, 2001; Humphrey & Lewis, 2008a; Saggers, 2015). Mothers have reported that social incompetence leaves their autistic daughters highly anxious (Sedgewick, et al., 2018), leading to the desire to increasingly control aspects of their day-to-day lives (Mogensen & Mason, 2015). Social anxiety seems heightened during high school and stems predominately from perceived escalation of social complexity (White & Roberson-Nay, 2009). Alongside social isolation and loneliness, social anxiety can also lead to depression (Marshall, 2002) and suicide ideation (Attwood, 2007; Humphrey & Lewis, 2008a).

Being the target of bullying can lead to similar negative outcomes for autists and impact their grades (Rettew & Pawlowski, 2016). Autistic people are more likely to report being bullied than neurotypical students and there is potential for the consequences to become cumulative (Hebron, Oldfield, & Humphrey, 2017). Bullying is a problem in almost every school and is one of two indicators thought to be indicative of in/ex-clusion experiences, with the other being support (Humprhey & Symes, 2010; Saggers, 2015). Whilst some NZ studies have ‘mirrored’ international findings regarding prevalence of bullying in NZ schools, other studies have indicated a significantly greater bullying problem in NZ secondary schools (Carroll-Lind & Kearney, 2004). There has been a lack of qualitative research pertaining to the lived experience of autists in this regard (Carrington & Graham, 2001). To date, most studies on autistic bullying have been quantitative in nature, with few from an ‘experiential standpoint’ (Hebron, Humphrey & Oldfield, 2015).

Humphrey and Lewis (2008a) have reported that bullying occurs with ‘alarming regularity’ for autists; it can be persistent and long lasting (Cappadocia, Weiss, & Pepler, 2012; Humphrey & Symes, 2010; Poon et al., 2014; Rowley, et al., 2012;). All students in Saggers et al.’s (2011) study for example, reported being recipients of some form of bullying. Whilst it is thought that prevalence of bullying is higher for boys than girls (The National Autistic Society, 2006), the impact on mental health might be worse for girls (Greenlee, et al., 2020).

Autistic adolescents have reported that bullying predominately occurs outside of class, when teacher supervision is lacking (Connor, 2000). Having protection, a safe space within school, and supervised transport to and from school have been considered protective factors. Poon et al. (2014) found that teacher and peer knowledge of autism protected some individuals from feeling bullied. Having friends is also generally perceived as having protective value from bullying (Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Locke et al., 2010), as is good student-teacher relationships (Baric, et al., 2016; Humphrey & Lewis, 2008a; Krieger, Kinebanian, Prodinger, & Heigl, 2012; Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012).

Whilst in-vivo interactions pose many problems for autists, online communication has been revolutionary, allowing autistic adolescents the chance to communicate and socialise in new ways (Jordan, 2010). Online communication enables autistic teens to converse without the normal obstacles of posture, facial expression and tone of voice (Arnold, 2012). Many autistic individuals have claimed to form strong connections with other autistic members in chat rooms and on social media groups like Facebook and Twitter, embracing neurodiversity and incorporating autism into their construction of identity (Arnold, 2012).

Pinchevski and Peters (2016) suggests that social media may afford autistic people an opportunity to redefine what it means for them to socially communicate. One adolescent in Mogensen and Mason’s (2015) identity study suggested that being able to communicate online was important to their experience of being autistic. However, there have been few, if any studies investigating online ‘friendships’ among NZ autistic teens. It is also unknown how influential social media use is in its role in the formation and ongoing experiences of ‘friendships’, including how this carries over into school to potentially contribute to inclusive (or exclusive) types of experiences.

3.6.3 Anxiety (and depression)

Anxiety and depression have been well-documented problems for autistic youth (Bellini, 2004; Edirisooriya, Dykiert, & Auyeung, 2020; Ghaziuddin et al., 2002; Russell & Sofronoff, 2005); it is thought more than half suffer from anxiety (Lugnegård, Hallerbäck, & Gillberg, 2011). Kanner (1943) first noted that children with ‘classic’ autism suffered anxiety problems, congruent with current research reporting higher levels of anxiety being reported for those with lower intelligence quotient (IQ) (Edirisooriya, et al., 2020). It remains speculation as to the relationship between anxiety and ASD; whether it is comorbid or co-occurring (Attwood, 2007; Kerns & Kendall, 2013; Lilienfeld, Waldman, & Irael, 1994; Regier, Narrow, Kulh, & Kupfer, 2009); the result of structural brain anomalies, neurochemical disturbances (White & Roberson-Nay, 2009) or a genetic association (Piven &

Palmer, 1999). Edirisooriya, et al. (2020) suggest that autists with a higher IQ (as opposed to 'classic' autism), report higher levels of depression, concluding that anxiety *and* depression are causes of concern for the entire autistic population of adolescents.

The focus on the phenomenon of depression and anxiety in autistic people has sometimes failed to consider broader ecological influences, due to the dominance of nosological, and epidemiological studies (Fisch, 2012; Volkmar & McPartland, 2014). However, parents of younger children with autism have noted that anxiety is triggered in relation to "sensory experiences, academic expectations, social demands, and uncertainty" (Simpson, Adams, Wheeley, & Keen, 2020, p. 572). These 'triggers' seem to persist into adolescence and their impact on learning remains unknown (Goodall, 2015). Participant perspective studies reveal that high-functioning autistic adolescents attribute anxiety to environmental influences, including excessive noise, bright lighting, chaos in movement between classes, and crowding (Ashburner et al., 2013; Ashburner, Ziviani, & Rodger, 2008; Dillon, Underwood, & Freemantle, 2014; Goodall, 2015; Griffith, Totsika, Nash, & Hastings, 2012; Hay & Winn, 2015; Hebron et al., 2015; Humphrey & Lewis, 2008a; Pellicano, 2013; Saggers, 2015), as well as to disruptions to routines (Carrington & Graham, 2001), uncertainty generally (Adams, Clark, & Keen, 2019), specific changes to the environment (Carrington et al., 2014), academic workload (Connor, 2013) and social difficulties, especially for those whose ASD characteristics are more marked (Settipani, Puleo, Conner, & Kendall, 2012).

There is also growing evidence that autistic young people face added stressful challenges disproportionately, compared to neurotypical people of the same age. For example, interacting with strangers (Penney, 2013) or experiencing gender dysphoria (Cooper, Smith, & Russell, 2018). A disproportionate number of natal autistic females have been thought to experience incongruence between assigned gender and experienced gender (Cooper, et al., 2018) and this intersection between two forms of marginalised identities is associated with increased stress, depression, and anxiety, over and above that which is typically experienced by autists (George & Stokes, 2018). This significantly reduces personal well-being and compromises mental health, all of which has implications for school life.

The immediate consequence of excessive anxiety is a lack of focus and participation in academic learning opportunities (Hay & Winn, 2005; Humphrey & Lewis, 2008a; Penny 2013; Saggers et al., 2011). However, some students mask anxiety and stress at school (Carrington & Graham, 2001), only to spend prolonged periods in isolation at home, reflecting on the problems they were experiencing (Clark & Griffin, 2014; Tomlinson, et al., 2020). This impacts time for homework, study, and hobbies and is consistent with the notion that autistic people experience poorer quality of life, due to ‘living with’ excessive anxiety (Smith, Ollendick, & White, 2019).

Long-term, persistent anxiety and a lack of resolutions can lead to more serious consequences, which can become forms of ‘exclusion’. These include academic problems, behavioural difficulties, and high school drop-out (Penny, 2013). Personalised strategies are therefore needed to help students overcome anxiety triggers, however these are only possible when strategies are personalised across settings (Clark & Adams, 2020), so are dependent on communication. This form of communication needs further investigation, given that parents often complain that they are not taken seriously by school staff (Azad & Mandell, 2016; Zablotsky, Boswell, & Smith, 2012) and have reduced access to high school staff compared to one’s primary school teacher.

3.6.4 Teacher-student relationships

Pianta (1999) highlights the importance of quality teacher-child relationships for children’s optimal functioning within school. It is thought that “supportive teacher–student relationships are a critical factor in creating and maintaining a sense of school belonging that encourages positive academic and behavioral outcomes” (Mason, Hajovsky, McCune, & Turek, 2017, p. 177). This theme therefore has relevance for inclusion experiences.

Students who experience good quality relationships with teachers typically demonstrate better behaviour, exhibit social competence, achieve academically, and are more likely to be generally well-adjusted (Quin, 2017). Autistic children however have been thought to have poorer quality relationships with teachers compared to neurotypical students (Blacher, Howell, Lauderdale-Litten, Reed & Laugeson, 2014). All the students in Saggers et al. (2011) study considered their relationship with teachers as essential for having a voice and ‘being heard’; this led to sharing problems and working toward solutions.

The centrality of teacher-student relationships in inclusion experiences was evident in studies like Brede, Remington, Kenny, Warren, and Pellicano’s (2017) investigating perceptions and experiences of successful re-integration of autistic students previously excluded from mainstream schools. Their findings revealed four key factors that autistic students believed helped their previously un-met needs to be overcome. Having strong staff/teacher-student relationships was deemed essential because it enabled students to make their needs known, increasing the potential that they would be responded to, resulting in more ‘inclusion’ experiences and an overall sense of being included.

Despite mainstream teachers having received minimal ASD training (Church, et al., 2000), their attitudes toward ASD students is thought to play a critical role in successful inclusion education. Teachers’ negative attitudes towards autistic students has been associated with negative effects for these young people (Park & Chitiyo, 2011), including barriers to learning and participation (Li, Wong, Sum, & Yu, 2019). Attitudes can be influenced by contact with autistic students as well as availability of knowledge about ASD; those “with more contact and knowledge about students with ASD tend to have more positive attitudes toward them” (Li, et al., 2019, p. 151). Parents often push for a diagnosis with the aim of increasing teacher knowledge, expecting it to impact their attitude and thus make a difference in the daily life of their child. Many parents find however, that teachers lack ASD knowledge (e.g. Goodall, 2018; Penney, 2013), resulting in inappropriate responses toward their child (Connor, 2000; Howlin, 1998), contributing to exclusion experiences.

Teachers who have taken individualised approaches to understanding ASD students have been viewed positively and held in high regard by autists (Krieger et al., 2012). When Baric et al. (2015) asked high-functioning autistic individuals, then aged between 20 and 29, to look back on their British education, they found that it was the alignment of two key experiences which were critical to the person’s experience of feeling as though they ‘belonged’ and were successful: individual academic support and psychosocial support. Individual academic support requires a flexible curriculum and at times an individualised programme of study for attainment of essential numeracy and literacy, whilst psychosocial support necessitates that someone in the school has a good rapport with you, makes you feel understood, and as though you belong. Baric et al. (2015) concluded that participants’ relationships with teachers influenced their overall academic success and happiness.

Positive and negative teacher characteristics impact quality of relationships as well as motivation. Teachers characterised by yelling and authoritarianism negatively influenced student’s experiences, whilst positive characteristics were considered crucial for achieving and being motivated (Penney, 2013; Saggers et al., 2011; Sciutto, et al., 2012; Tobias, 2009). Teachers who exhibit positive characteristics tended to share their humor and warmth, imbuing the ambient environment with an atmosphere conducive to learning whereby learning became ‘fun’ (Saggers, 2015). This is not too different from the autobiographies of autistic individuals who attribute their good outcomes to those teachers and individuals who demonstrated a high degree of care and interest in them; those who were prepared to the go ‘the extra mile’ (Grandin, 1995; Lawson, 2000). Roberston, Chamberlain, and Kasari (2003) found that positive teachers positively influenced younger autistic children in their class, reducing behavioural problems and increasing social exchanges, suggesting that quality of teacher-student relationships impact outcomes throughout one’s education.

Similarly, parents of younger autistic children in Bevan-Brown’s (2004) NZ research felt that teachers who understood autism and showed the greatest care, made the biggest difference in the lives of their autistic children, and this outcome was perceived to carry forward into subsequent years. Whilst Murray (2006) found teacher understanding relatively poor in NZ, Tippett (2004) noted that teachers’ attitudes were generally positive; they were mindful of their student’s needs and wanted to learn more about autism and they “felt there was more they should be doing” (p. 15). The importance of this for inclusion seems understated in the literature (Florian, 2017); it is in this area where the onus for ‘success’ and ‘inclusion’ shifts away from the individual as being ‘the problem’, to a focus on the *interaction* as contributing to, or resolving problems. This current study seeks to contribute to the limited body of research by exploring adolescent’s experiences of, and perceptions around teacher-student relationships, especially its impact on learning, and thus participating and achieving in the curriculum.

3.6.5 Academic and general school challenges

Academic outcomes are important for all students. There is pressure upon students to ‘succeed’ and this has increased over time (Fisher, Cavanagh, & Bowles, 2011). Recently, Nash, Naylor, Manandhar, Stubbs, and Penten, (2020) found that pressure contributed to poorer mental health outcomes for ‘senior students’; those studying for their ‘A-Levels’ aged 16-18 (in the UK). There had been no prior studies exploring the lived experiences and perceptions of ‘A-Level’ students to draw on (Nash et al., 2020), though outcomes for autists are considered comparatively poorer (Roberts & Simpson, 2016).

Nonetheless, some autistic students do succeed academically, and their successes have enabled them to overcome otherwise crippling social deficits to find meaningful employment and success in a specialised field (Grandin, Duffy, & Attwood, 2004). Autistic students in mainstream schools are usually required to engage in the same curriculum as neurotypical students; curriculums have not been pedagogically considered and developed from the perspective of ‘types’ of learners (Imray & Colley, 2017; Lewis & Norwich, 2005). When the curriculum is flexible or oriented around individual interests and abilities, autistic students describe being motivated to learn (Carrington & Graham, 2001). However, many teachers claim that they are unprepared and ill-equipped to cope with ASD students in their class; they consider themselves insufficiently trained to accommodate the needs of autists (Hay & Winn, 2005; Roberts, 2015; Soto-Chodiman, Pooley, Cohen, & Taylor, 2012).

In their studies, Humphrey and Symes (2013), Carrington and Graham (2001), Saggers, et al. (2011), and Poon et al. (2014) suggest that mainstream schools therefore pose unique academic challenges and opportunities to autists stemming from demands of workload, curriculum suitability, and practicalities like handwriting.

'High-functioning' refers to 'cognitive ability' (Assouline, Foley Nicpon, & Dockery, 2012). It is assumed high-functioning autistic individuals have average-to-above average cognitive development. This assumption has often meant that others have high expectations of them (Estes, Rivera, Bryan, Cali, & Dawson, 2011), leaving students distressed when they cannot achieve. Some adolescents end up having very low expectations for themselves (Poon et al., 2014). Being unable to meet expectations may be related to asynchronous development of cognitive and executive functioning skills. For example, high-functioning autists typically have well-developed rote memory, but impaired higher-order skills, like problem-solving, abstraction and conceptual thinking (Meyer, 2002). Difficulties can also be observed in "tasks involving creative writing, reading comprehension, making inferences, and having to organise material in a novel way to solve problems" (Meyer, 2002, p. 30). Approximately 90% of students in Saggers et al.'s (2011) study reported academic-related stress as a result of their academic workload, their inability to write fast enough, and being unable to complete assignment work within the allocated timeframe.

Poon et al (2014) have suggested that certain curriculums also present unique challenges and opportunities. For example, the Singaporean curriculum enables students to 'fit' within various 'streams'. These range from challenging academic 'express streams' to technical streams, which are less challenging, and potentially more enjoyable for students whose interests and abilities align. A significant challenge of the academic (express) stream is that four years of study terminates in national examinations. Autistic students tend to suffer more exam distress compared to neurotypical students, also potentially compromising outcomes. It is expected that this current study will contribute to an understanding of students' nuanced experiences of another form of curriculum (NCEA), which also poses unique challenges and opportunities and a mixture of internal and external assessments.

3.6.6 Support

Parents have typically informed research regarding autistic students' experiences of school support, resulting in a need for more research from the perspective of students (Baric et al., 2015). 'Support' in the context of schooling, is oftentimes assumed to refer to 'academic support' as opposed to social or emotional support. Teacher perceptions differ from that offered by parents and students. Teachers have deemed the needs students have for support as 'demanding', suggesting that multi-teacher frameworks are problematic (Embich, 2001; O'Shea, Hammitte, Mainzer, & Crutchfield, 2000). Many high-functioning autistic students do not receive any support (Attwood, 2007), despite having parents who advocate for it (Murray, 2006). As a result, when autistic students have a 'bad day', parents are often expected to drop their plans and collect their adolescent (Fong, Wilgosh, & Sobsey, 1993), causing additional familial stress and indicating that not all schools have the facilities or expertise to enable 'inclusion' for all students all of the time.

So far, high-functioning autists have highlighted that they might need support for a range of challenges. These are related to behavioural challenges, social difficulties (Carrington & Graham, 2001; Saggers et al., 2011), environmental and sensory stressors (Penney, 2013), as well as academic challenges (Saggers et al., 2011) and the need to navigate the 'hidden curriculum' (Carrington & Holm, 2005). For some of the students in Humphrey and Lewis's (2008a) study, support in class provided a natural form of protection from bullies and this seemed more of a priority for the student than academic supports assumed to be the primary benefit.

Not all high-functioning autists have wanted to be singled out to receive academic support, especially support offered in front of peers in mainstream classes (Saggers, 2015; Saggers et al., 2011). Some students have therefore reported that they have benefited from support in class when it has been offered in a more subtle form (Humphrey & Lewis, 2008a). Whilst ASD students in 'fully inclusive' schools are thought to have higher levels of social support, broader social networks, and more forward-thinking education goals (Eldar, Talmor, & Wolf-Zukerman, 2010; Lindsay, Proulx, Scott, & Thomson, 2014), Baric et al. (2015) found that most participants were unsatisfied with the high levels of support they had received. This was because students deemed their academic performance to be of less value than their socio-emotional needs. Baric et al. (2015) therefore concluded that receiving support had been a fragmented experience, dependent upon specific teachers having essential qualities in order that academic support was offered in the context of psychosocial relationships. Cribb, Kenny, and Pellicano's (2019) findings converged with this, in that parents and young autistic adults perceived that 'deep connections' to others were more highly valued, despite not being sufficiently recognised by school management. For example one parent recalled the principal at her son's school saying "if you want social skills maybe you should take him out and home school him because we don't have time to do that here" (Cribb et al., 2019, p. 1775).

Although the prevailing medical model of disability can translate into low expectations for learning (Linton, 1998), teachers may be unable to envisage imaginative ways to reach these students and to teach them according to inclusive education principles (Grenier, 2010). Canadian parents believed this flexibility to be lacking (Penney, 2013). Whilst teachers and schools might be committed to inclusiveness, without sufficient training and knowledge, they may lack discernment regarding the needs of students and find it difficult to provide the appropriate level of support or the right type of support for each autistic student (Robertson et al., 2003). Although there have been several studies assessing and evaluating various programs of support, like TEACCH (e.g., Tutt, Powell, & Thornton, 2006), fewer studies have sought the lived experience of students 'being supported'. When inclusive schools have provided autists with support, it is typically through Teacher Aides (TAs). NZ has 22,000 TAs working in state and state integrated schools (MoE, 2020e). Many TAs however, report having no teacher training or classroom experience prior to taking on their roles (Gibson, 2015).

It is assumed that exclusion is the natural consequence of mounting demands that cannot be met by support (Brede, et al., 2017). Support is therefore relevant to overcoming the obstacles to exclusion experiences and it is expected that a broad phenomenological investigation (like this study proposes) will help to further current knowledge regarding 'needs', 'mounting demands', and perceived utility of support for academic and social success.

3.7 Conclusion

In NZ, the 'inclusion principle' is now embedded as a key principle in the Curriculum. According to the MoE (2020f) "it is about creating an inclusive school culture for everyone where the contributions of all students and their whānau are valued, barriers are minimised, and learning supports, and flexibility are built into the environment from the outset". Based on a sample of 152 schools in 2014, the report *Inclusive practices for children with special needs in schools* by ERO, highlighted that 78% of schools self-reported as being ‘inclusive’ (ERO, 2015b). External inclusion assessments, however, only provide observations about inclusion; it cannot determine how successful inclusion is without considering the lived experiences of those included in a *particular* school, or learning environment (Davidson, 2010). Walmsley and Johnson (2003, p. 16) reiterate, inclusive research must relate to those to whom it concerns. Barnard et al. (2000) likewise suggests that even if a school appears to be inclusive and provides support, what matters most is the quality of inclusiveness and support and this can only be assessed by the recipients of that support.

Whilst there is a dearth of literature on ‘inclusion’, very little research has focused on the lived experiences of autistic students in mainstream schools (Carrington & Graham, 2001; Connor, 2000; Harrington, 2014; Humphrey & Lewis, 2008a; Penney, 2013; Poon et al., 2014; Saggers et al., 2011). It appears as though no studies to date have specifically sought to listen to the voices of autistic students in their ‘senior years’ of high school.

Because of the small body of literature, the literature reviewed is comprised of diverse ‘inclusive’ experiences, making conclusions difficult to draw. This is compounded by the limited cohort of students whose experiences of autism are heterogeneous, giving the impression of diversity of experiences. However, whilst students have very differing needs, it seems that schools have varying knowledges and resources pertinent to supporting autistic students, constraining curriculum adaptations, social and environmental support, and influencing well-being. It seems the educational milieu provides opportunities and experiences that make autists feel valued, respected, accepted, and included (or not), which influences participation and subsequently the contribution they could make to academic and school life.

There have been almost no identifiable studies pertaining to inclusion schooling experiences of autists over time. Hanson et al. (2001) considered the very early years of education, whilst Harrington (2014) interviewed Australian parents and autists aged 11-15 investigating the ‘turning points’ “in children’s participation over time” (p. 57). Harrington concluded that exclusion-type experiences were on-going and persistent over time, with parents constantly ‘vigilant’ regarding promised accommodations (p. 210).

It seems that one’s understandings become shaped over time, not only the result of being diagnosed, but because we are always embedded within ecological niches, with their ebb and flow of bi-directional influences. The component of time is therefore a natural contextual proposition in any phenomenological project because ‘the present’ is deemed to be understood in relation to ‘the past’ and one’s aspirations for ‘the future’. This is consistent with Bronfenbrenner's theoretical framework comprising the chronosystem (development over time) and compatible with Heidegger's notion of 'being and time', which provides the philosophical basis for this present study. By the 'senior' years of high school, NZ autistic students may have had many similar salient experiences as those described in this 'inclusive' literature review. With age 'senior' students are more likely to not only tell their story and experiences, but their insights into 'why' they have experienced what they have. By looking back to make sense of the present, senior students are more likely to consider the influences coming to bear on experiences, constraining and enabling 'inclusion': participating, contributing, finding acceptance and feeling as though belonging. These more sophisticated and nuanced insights and understandings are epistemologically essential for challenging and developing policy, impacting curriculum development, pedagogy and praxis, all of which constrain and enable inclusion experiences and impact lived experience and well-being.

3.8 Present study

Some countries have contributed little to the international literature on inclusive experiences of autistic students; no study has limited its focus to a *particular* era of high school, like the 'senior years', using an ecological framework. This has resulted in 'gaps' regarding identity negotiation, unique curriculum challenges, and perception of causes for in/ex-clusion. A study that focuses on the 'senior years' of NZ high schools, for example, provides an opportunity for autists to draw on cumulative experience (social and academic) to provide insights into the unique opportunities and challenges that NZ students must navigate, including a unique curriculum and potentially higher-than-average rates of bullying in high schools.

Several 'inclusion' studies have been multi-perspective and similarly, this present study proposes to incorporate the views of autists (high school as well as tertiary), parents, and advocates. Whilst parents can provide a context for diagnosis, and insights regarding academic and social experiences and support, advocates have accumulated 'expertise' derived from diagnostic, clinical, community, and educative support; they carry the collective story of NZ autistic adolescents. Nonetheless, the aim of the present study is to privilege the voice of autistic adolescents and explore their inclusion experiences in mainstream NZ high schools. This thesis therefore poses to answer the following research questions:

1. How do senior students with (high-functioning) ASD, in mainstream NZ high schools, understand and experience in/ex-clusiveness (belonging, acceptance, achievement, participation, and contribution);

2. How do every day in/ex-clusive schooling experiences contribute to perceptions of (autistic) identity and wellbeing; and,
3. How do the co-articulated autism discourses of strengths, problems, and tensions, experienced by adolescents, converge or diverge from that understood and experienced by parents and advocates?

Chapter Four
Methodology: doing the 'Unstrangering'

And she bore him a son, and he called his name Gershom:
for he said, I have been a stranger in a strange land.
Exodus 2:22

4.1 Introduction

This chapter introduces two scientific paradigms of relevance, namely constructivist/interpretivist and the transformative paradigm and considers their philosophical challenges. Two theoretical frameworks that underpin the method used are also introduced. These include a Feminist Epistemology and Bronfenbrenner's bioecological framework. Interpretative Phenomenological Analysis (IPA) is a suitable method for use in the constructivist/interpretivist paradigm. It's philosophical and historical origins are introduced and its use in this project, outlined. Ethical challenges are considered, and 'quality' as a process in qualitative analysis is explored.

I am a devout Catholic who has been highly influenced by secular science and secular psychological theories. As this project progressed, I sought ways to find a balance between Catholic and secular psychology and to that end, have decided to take as my example St Thomas Aquinas' position. Aquinas borrowed from pagans and atheists (Trabbic, 2011), being wont to use only that which he believed was the truth. To that end, in this research I use relevant aspects of theory or philosophical schools of thought without necessarily adopting all the underlying tenets whole and undigested.

4.2 Quantitative vs Qualitative Research Methods

Epistemologically the scientific method, coined 'positivism' by Auguste Compte (Bogdan & Biklen, 2003) held that the 'pure' scientific method was the only legitimate means for establishing truth in studies of the social world and human behaviour. Empirically, this is a strict quantitative approach which advances the notion that reality can be apprehended through well-designed methods; where things exist and have meaning regardless of our awareness or consciousness of them (Crotty, 1998). From a pure quantitative position, qualitative approaches have been rejected because they are deemed to lack objectivity, as well as reliability and validity, on the basis that 'measurement' is no longer controlled and central to the entire process, leaving research designs fundamentally lacking scientific rigour.

There is an ideological shift for the ‘pure’ qualitative researcher that argues that the scientific method described above, leads to a corruption of power, specifically in regard to the power-subject relationship (between researchers and researched), contributing to distorted conceptions of reality. In comparison, qualitative researchers, especially those considered constructivist, hold that reality is something that is constructed by individuals in their social location, thus is subjective and open to interpretation, allowing for multiple socially constructed realities to exist. On these grounds, I reject sources of authority like the Diagnostic and Statistical Manual (DSM) of Mental Health, as *the only* or superior means for understanding ASD. It is from this position, that I take up qualitative research methods and adopt theoretical frameworks as a means for guiding this project.

Qualitative research methods are typically chosen as the means for illuming personal and subjective experiences. This requires fewer participants and enables greater exploration of the topic and in-depth analysis of the phenomenon, with options for analysing and interpreting the data in relation to the explicit account or the implicit, unconscious facets outside of awareness; for example, in relation to the function of power and subjugation. Qualitative methods are suitable for answering the questions posed in this research because the goal is to develop an in-depth understanding of daily lived experiences for autistic teens and to develop an understanding of the ways in which autistic young people may experience exclusion and oppression, or marginalisation, through a process of subjugation in mainstream education.

Qualitative methods can be understood in terms of fitting one of four paradigms: namely postpositivist, constructivist/interpretivist, transformative, and pragmatic (Mertens, 2015) with the constructivist/interpretivist and transformative paradigms being of relevance to this project. The term ‘paradigm’ comes from the Greek word *paradeigma,* which was first used in Greek literature to refer to the ‘pattern’ used to create the cosmos. In scientific terms, a paradigm denotes the pattern, or type of framework, whereby underlying philosophical assumptions come to guide our thinking and action. These are the particular “commitments, beliefs, values, methods, outlooks, and so forth shared across a discipline” (Schwandt, 2001, pp. 183-184). The underlying philosophical assumptions characterising each of these paradigms can be considered under the following categories: axiology, ontology, epistemology, and methodology. These categories therefore provide the paradigm with its ‘shape’, ‘model’, or ‘pattern’ and is used to guide all aspects of the research project, from conception to maturity.

On the surface, it may seem that most research projects fit neatly within a single paradigm. However, closer examination of the research question(s), philosophical underpinnings, and ontological assumptions, suggests that paradigmatic boundaries are not always ‘black and white’ and are often permeated, being more fluid than fixed. This can be seen for example when Mertens (2015) highlights that ethical principles of constructivism are creeping towards aligning with those of a transformative paradigm. Kuhn (1962) for example, whose work on scientific paradigms continues to influence our understanding on these frames of reference, never held that the boundaries were impermeable or incommensurable, like they are often portrayed (Mertens, 2015).

I gravitate towards a philosophical school of thought called ‘Personalism’ and it is from this position, which I will attempt to justify why researchers should (and do) draw from multiple paradigms and theoretical frameworks to inform their ‘work’. Personalism is grounded in the ancient, Christian, notion of the ‘person’ and it is a return to the experience of “being a person and of encountering other persons” (Burgos, 2018, p. 32). Although its influence has waxed and waned over the years, Personalism was a response to the 20th Century social, cultural, and philosophical questions of that era. It arose in Europe and was instrumental in “influencing the UN Declaration of Human Rights, the constitution of European states after the Second World War, and the Second Vatican Council” (Burgos, 2018, p. xiii). Its application in psychology and bioethics waits to be fully explored.

Personalism, not individualism, elevates human dignity and freedom whilst acknowledging our relational capacity and innate need for connecting to others through intersubjective engagement (Acostas & Reimers, 2018). In his pre-papal role, Polish scholar Karol Wojtyla (now St John Paul II), made as his starting point, the notion that “Man [sic] ‘never experiences something outside of himself without, in some way, experiencing himself” (Burgos, 2009, p.110). Thus, vital to Wojtyla’s understanding and that of others, like German phenomenologist Edith Stein (also known as St Teresa Benedicta of the Cross), is that the philosophical study of the person is a ‘cohesion between person and action’ (Stein, 2000; Stein, 2009). This dynamism has been achieved through the methodology of phenomenology, which is used in this project.

I am driven by what might politically be referred to as ‘an Ethics of Compassion’. At its broadest sense, an ethics of compassion is based on the ‘Golden Rule’, namely “do unto others as you would have them do unto you” (Matthew 7:12), or in research terms: “one’s own desires can serve, by analogy, as a standard for how one is to treat others” (Reilly, 2008, p. 7). Such an approach means assessing situations and the problems people face, not by reason alone, but via connecting emotion with rationality (Tallon, 1997). Compassion differs from empathy and “does not imply an emotional commitment with the other person” (Úriz-Pemán, Ballestero, & Idareta, 2013, p.353). It leads directly to action and thus philosophically “…is a bridge between the individual and the community…” (Nussbaum, 1996, p. 28). Having a highly developed sense of compassion is prerequisite to aspiring to the highest level of ethically guided care in professional intervention (Úriz-Pemán et al) and thus is a motivating factor in both work and research.

Wojtyla was also motivated by an ethics of compassion, advocated for the vulnerable, and furthered social justice causes. He rejected Nazism and the Communism of his day, as well as the Marxist underpinnings now often associated with a transformative paradigm. He gave primacy to our spiritual nature, taking up and letting go of that which holds the greatest relevance to the researcher and is of the greatest good for the most vulnerable. In this way, he too demonstrates the benefits of traversing paradigmatic boundaries, without violating philosophical tenets.

4.2.1 Constructivist/interpretivist and transformative paradigms

A constructivist paradigm based on Husserl’s phenomenology enables the researcher to derive a greater understanding of lived experience from the perspective of those living it. A transformative paradigm, however, seeks to disrupt what we often take-for-granted; it seeks to alert society to the need for radical change, increasing potential for social justice (Mertens, 2012). It requires awareness of issues related to discrimination and oppression, including oppressive conditions; thus, it “promotes the principles of respect, beneficence, and justice on several fronts” (Mertens, Holmes, & Harris, 2009, p.49). These paradigms differ however, in several important ways, best explored in terms of their axiological, ontological, epistemological, and methodological differences.

Axiological assumptions relate to the nature of ethical behaviour (Mertens, et al., 2009). Axiologically, constructivists acknowledge that research is not value-free, meaning that we are prejudiced by our values, bringing them to bear on the project as researcher and participant alike. This value-laden nature of the research also affects interpretation of the data and therefore what is deemed important (Chilisa & Kawulich, 2012). To overcome this, constructivist researchers attempt to remain transparent and explicit regarding these value-laden influences. In a post/positivist paradigm emphasis is given to the rights of the person’s privacy, their informed consent and the minimisation of harm (Mertens, 2015); however, little attention is paid to the role of power and privilege imbalance between researcher and participant.

In comparison, constructivists increasingly - and transformative researchers especially - deem that "every person must be treated with dignity and respect and that the avoidance of harm must be the primary principle" (Mertens, et al., 2009, p. 89). Thus, ethics of care and justice are guiding precepts taken up in a bid to build rapport and respect in the transformative project. The ontological position of the researcher reflects their view on the nature of reality (Willig, 2008). This necessitates a declaration like that provided above regarding Personalism and a penchant for traversing paradigm boundaries for the overall good of the project. Similarly, from a broad constructivist perspective, multiple realities from the various stakeholders are expected and these too, may defy being easily categorised.

Whilst post/positivist researchers believe that there is one reality that can be known, constructivist and transformative researchers accept multiple realities which are socially constructed (Mertens, 2007); that 'truth' is contextual to 'being and time', thus relevant to sociocultural and historical contexts. Transformative researchers also recognise however, that one version of reality is often privileged over another, which sometimes has consequences, particularly for the less privileged (Mertens, 2015) and most vulnerable (Mertens, et al., 2009). What may seem 'real' and be *taken* 'as real,' may be the result of taken-for-granted and 'normalised' oppressive social and political structures (Mertens, 2015), as well as the methodological and disciplinary practices, for example, the production of categories of people through its 'scientific' narratives (Hacking, 2006). It is attention to these differences that most separates the constructivist research project from the transformative.

Epistemology refers to knowledge, including ways the researcher establishes relationships with participants in order to build trust and understand how power differences might influence what is shared (Mertens, 2007). In a post/positivist paradigm, it is key for the researcher to remain objective and distanced from the participant, whereas in a constructivist paradigm, objectivity gives way to confirmability, where knowledge is constructed in an interactive process, resulting in multiple perceptions of 'reality' (Mertens, 2015). In a transformative paradigm, multiple versions of 'reality' are also acknowledged. However, it is thought that by accepting differing perceptions, there is a risk of ignoring the factors which underlie the privileging of certain realities: "what is taken for real needs to be critically examined via a critique of its role in perpetuating oppressive social structures and policies" (Mertens, 2015, p.32).

Methodological differences likewise reflect differing underlying assumptions between the various paradigms. Post/positivist methodologies utilise quantitative designs, whilst constructivist and transformative paradigms typically utilise qualitative designs. Constructivist theories can therefore include naturalistic, phenomenological, hermeneutic and ethnographic modes of research, whilst methodologies typically include the use of interviews, observations, and document and diary analysis. Transformative researchers prioritise dialogical methods too, but may also utilise mixed methods, depending on the nature of enquiry and relevance of contextual factors, such as historical situated-ness and oppression (Mertens, 2015).

There are a wide range of theories that could be utilised within a transformative paradigm and these include critical theory, feminist theories, disability theories and Human rights or equity focused theories (Mertens, 2015). A transformative paradigm enables researchers to form a partnership with those who are marginalised or vulnerable, like those with ASD, in order to explore inequalities that lead to the experience of being socially excluded. This is achieved by exploring other dimensions of diversity, such as access to power or knowledge (Mertens et al., 2011). In this project ‘inclusion’ could be as simple as having equal access to resources enabling equal participation and success in the school curriculum (Orsini & Davidson, 2013).

4.3 Theoretical Frameworks

Scholars such as Guba and Lincoln (1994) and Starks and Brown-Trinidad (2007) suggest that there should be an explicit link between theories drawn upon, and the methods and analytic strategies used. I will consider two theoretical frameworks here, which inform my research, beginning with a note regarding narrative approaches.

4.3.1 Narrative approaches

A narrative is an individual’s story, recounting events and experiences, which are not only temporal, well-ordered or disjointed, but are often interjected with descriptions, explanations, and interpretations of thoughts and feelings (Breakwell, 2006; McAdams, 1999). Through their narratives, people seek to make sense of their lives by recounting and positioning their experiences. Experiences are often fraught with tensions that are navigated and understood in the context of day-to-day moments; in living a particular life, in a particular place, at particular point in time, with their tensions and successes, wrestles and struggles, and diversity of challenges. Some narratives are of a collective nature in that they tell the story of many stories heard. For example, advocates in this research project tell a collective story about autism and autistic peoples' experiences, based on their interaction with many autistic individuals and their families over a long period of time.

Seeking the 'missing voice', of young autistic people through their storied understandings, is a quest to therefore broaden our autism knowledge and challenge in-grained assumptions. A narrative approach seeks to fill out limited understandings through richer, more complex accounts. Psy-scientists (psychologists, psychiatrists, and psychoanalysts) have provided us with two dominant narratives of autism in the current literature. The first is in relation to their efforts to construct, test, apply and expand their finite categorical systems in order to 'describe' others. And the second is in relation to their sleuthing efforts to seek out bio-genetic explanations to predict and explain autism. Consequently, the psy-disciplines have produced an autism narrative that now perpetuates stereotyped understandings of autism and influences expectations based on a deficit model of medicine. In turn, autistic people may also come to interpret their own lives in a limited way, through contact with this narrative. Without taking up a narrative approach for furthering our understanding of autism, we may miss not only the rich, complex, and multifaceted aspects of their life, but the reasons why they believe they face the types of challenges they do.

4.3.2 Feminist standpoint epistemology

A feminist standpoint epistemology is a term originally used to explain the organisation and outcome of feminist research across various disciplines including sociology and political philosophy (Harding, 2009). It emerged in the 1970s and initially functioned to bring to the fore women's lived experiences, taking their standpoint and 'voice' as legitimate sources of knowledge. It has since grown to become an approach to doing research, involving a broader array of topics and marginalised participants. Standpoint epistemologists are committed to producing knowledge of the struggles, needs, and desires of various, often-marginalised groups, whilst fleshing out the forms and locations of oppression, which position them as 'other'. Solomon (2009) says it is like having "…attitude on behalf of an oppressed group" (p. 233) which brings political awareness, explicit or implicit because it analyses injustices from the perspective of the marginalised.

Feminist standpoint epistemology is intrinsically ethical and political. Out of it comes the means by which we can challenge dominant methods of *doing* research, including who can participate and the roles of emotion vs reason, and objectivity vs subjectivity; the 'value free' nature of the scientific method is brought into consideration as part of the research process (Riger, 1992). Feminist standpoint epistemology informs an array of academic disciplines about what life is like for a *particular* group holding a *particular* position in the world. It has as its focus the collective (Harding, 2009). Yet the individual voice and storied narrative is imperative because it is people's shared, lived stories of similar goals and desires, which 'tells' of the ways they experience exclusion and oppression (Harding, 2009).

On reflection of my Honours research project, I concluded that autistic people's lives are important enough to hear about first-hand; they may share similar narratives of experienced oppression within mainstream schools, rendering my 'short-hand' profiling 'intervention' premature. A standpoint epistemology is thus committed to deeper considerations, challenging the researcher to grapple with underlying tensions that might 'hold' oppression(s) in its place for a *particular* collective. In this case, it can help in the discernment and understanding of potential barriers to participating and achieving in education.

Through rigorous research and dynamic forms of analysis, feminist standpoint epistemologists may discern how power might be exerted by dominant groups, subjugating the dis-ordered or 'othered'. This type of qualitative research becomes transformative because it enables critical theorising. Done well, critical theorising potentially leads to a standpoint, which resists notions that neutrality exists in both science and politics, positing that the personal is in fact political (Hundleby, 1997). Research like this can challenge biases and mainstream discourses, such as those surrounding inclusive education and normative development as well as notions of 'mental illness'. To assist in this 'challenge', I will use Bronfenbrenner's bioecological contextual theory for direction regarding oppressive influences; the ways in which power and oppression might be 'enacted' and understood at multiple levels by autistic 'senior' students, embedded as they are within a particular milieu and era.

As a research framework, feminist standpoint research is contextually oriented or 'situated', being relevant to a point in time and as occurring within a specific location in the social hierarchy. Like feminist enquiries that take women as their starting point (Kourany, 2009), this project will take autistic young people in their senior years as the starting point, exploring lived experience within a mainstream setting at a time when participation in the 'national curriculum framework' (NCEA) is expected.

4.3.3 Bronfenbrenner's bio-ecological theory

Urie Bronfenbrenner's theory is described as having shattered "barriers and forged bridges" in social science, education, and policy formulation (Ceci, 2005; Ceci, 2006). Bronfenbrenner saw teaching as 'a way of life,' rather than a vocation, viewing it as the act of "doing God's work" (Brendtro, 2006). He esteemed children and young people and promulgated two related maxims: that "every child needs at least one adult who is irrationally crazy about him or her"; and that every caregiver "should also have the support of another adult". Bronfenbrenner viewed the student-teacher relationship as truly collaborative and relational and drew on Vygotsky's theory, 'scaffolding' learning opportunities to ensure salience for the individual. He accorded students as 'worthy' of his full attention, once saying to the then Vice President of the United States on an incoming call, that he'd have to call him back because "he was with a student" (Steinberg, 2005). Thus 'schooling' for Bronfenbrenner, is relational as well as educational; there is more to it than mere academic attainment.

Bronfenbrenner also envisaged the good of society as being contingent upon the well-being of the whole family and not just the child. This means considering the broader context of the whole family with the end goal in mind of making research 'transformational'. 'Locating oppression(s)' is therefore only one-half of the task; the other is to fathom opportunities for speaking out in an advocacy role.

Tudge, Mokrova, Hatfield, and Karnik (2009) have noted that the principle omission researchers make in taking up Bronfenbrenner's theory is failing to articulate the specific aspect of his theory used, referring to his earlier or later (and more mature) theoretical framework relabelled 'Bio-ecological theory'. However, I would add, that almost all applications fail to consider these other 'maxims' as underlying philosophical aspects, with potential for steering transformative research outcomes.

Several propositions underscore Bronfenbrenner's theory. Firstly, development is deemed to occur predominately through proximal processes of increasing complexity. Proximal processes are dynamic, emerging out of reciprocal interactions between an individual and others, as well as objects and symbols (Muus, 1996). 'Development' is therefore considered a joint function of biological givens and environmental circumstances, across time, and in a sociohistorical period (Bronfenbrenner, 2005). Secondly, ecological transitions occur during upheavals in daily life, such as parental divorce, moving from primary to high school, or from high school to tertiary or workforce (Muus, 1996). During these transitions and challenges, individuals are required to adjust to new roles and environments.

Bronfenbrenner's four ecological levels, the microsystem, mesosystem, exosystem, and macrosystem, provide the means for considering the organisation of sociohistorical and ecological influences, which constrain or enable optimal development leading to perceived success, well-being, and flourishing. The fifth level of influence is called the chronosystem and refers to the influences pertaining to the passage of time (Muus, 1996). When these systems are rich and favourable, development should proceed positively. However, when impoverished, or incumbent with obstacles, adaptations to these ecological hurdles may lead to 'arrested development' resulting in a failure to thrive and a perception of self as a 'failure'. Change, adaptation, and therefore 'ecological transitions', are organically difficult for autistic young people (Attwood, 2007).

Phenomenology philosophically underpins Bronfenbrenner's theory, so emphasis is on the individual's subjective interpretation of experiences. Brofenbrenner often quoted Thoman and Tomas (1928, p. 572, cited in Muus, 1996, p.321) who said, "if men [sic] define situations as real, they are real in their consequences." What shapes optimal development or one's sense of 'inclusion', is not what is outwardly 'observable', but inwardly meaningful. A narrative approach therefore aids individuals to make sense of their experiences.

During his later years, Bronfenbrenner re-considered the role of our biological nature as a salient feature of development. Although researchers have not yet found any specific biological markers which set autistic people apart from ordinary developing individuals, it is commonly accepted that neural systems are implicated, accounting for a 'neurological' and psychological 'disorder', giving rise to diverse symptoms (Just, Keller, Malave, Kana, & Varma, 2012). Bronfenbrenner's bio-ecological theory however diverges from psychology's focus, if not obsession, on the individual as being primarily responsible for their behaviour and developmental outcomes. He gave significant weight to the environment noting that we are biological beings in a social milieu and what happens within that context - the transactions and the interactions - has a bearing on development (Rutter, Champion, Quinton, Maughan, & Pickles, 1995). Hence, providing a contextual backdrop in Chapter One will aid the reader in making sense of the four 'levels of influence' comprising Bronfenbrenner's theory.

Microsystem

At the microsystem level, individuals are embedded in settings, roles, and personal relationships that affect achievement, identity, psychological development, and positive perceptions of everyday lived experiences. Rich and favourable microsystems are deemed optimal for healthy development, whereas sparse, and impoverished relationships and settings fail to provide the necessary support and spectrum of rich experiences necessary for well-being and development (Muuss, 1996). Typical adolescent relationships at the microsystem level involve peers, parents and family, teachers, and coaches, all of which are embedded in one's settings. These settings typically diversify during adolescence, moving beyond the home and school to the wider community, particularly in relation to the pursuit of personal interests and part-time work (Muuss, 1996).

Mesosystem

Bronfenbrenner's mesosystem refers to the overlapping relations between members of the individual's microsystems, such as parent from one microsystem relationship and teacher from another. It is therefore the links and connections between various contexts such as home and school, or primary school and high school, that are of importance (Muus, 1996). For autistic people this may also be between school and autism support workers, however the focus is "on the synergistic effects created by the interaction" (Bronfenbrenner, 1993, p. 22). For example, high quality regular interaction between teacher and parent may be favourable in the early years of a child's schooling career, but crucial for an autistic young person in high school. Where there are impoverished mesosytem connections, the individual's life may seem disconnected and become compartmentalised (Muus, 1996). It is therefore at this level that Brofenbrenner's philosophy became policy and advocacy directed, because fewer meaningful connections can lead to disenfranchised, delinquent, or unproductive adolescents (Muus, 1996).

Exosystem

The exosystem level contains the broader, or more distal community settings in which the individual is embedded. Decisions made in these settings do not seek the developing person's input, but the outcomes affect what they can participate in and have access to, or conversely, determine what they cannot do, or have access to (Muus, 1996). Decisions and events that take place at this level, can therefore profoundly affect individual development either directly, or indirectly. Decisions in local community settings may favour normally developing individuals, which have significant consequences for autistic young people, leading to social injustices and oppression(s). For example, the BOT may ratify school policy underpinning inclusive practice. Inclusive policy, however, may not lead to inclusive practice so individual needs, even if discerned, may not translate to plans that can be implemented with current resources (e.g., McLaren, 2013; Osler & Osler, 2002), compromising the lived experience of inclusion, whilst leaving the educational setting, appearing ‘inclusive’.

Macrosystem

The macrosystem is the broadest level of Bronfenbrenner’s ecological systems theory. It is often described as the level containing the ‘blueprint of society’ which permeates all other levels, thus impacting our subjective perceptions of experience and human development, containing as it does, our attitudes, values, and culture, as well as policy that impacts all citizens (Muus, 1996). According to Bourdieu (Harker & May, 1993), the dominant culture is transmitted or reproduced in schools and similar institutions, hampering social mobility, and favouring social reproduction. This happens when dominant culture values are ‘naturally’ embedded in the attitudes, rules and expectations of the institute and perpetuated in its curriculum by assuming what is most valued. Our macrosystem values are part of our internalised national identity, growing up out of our historical roots.

4.4 Phenomenological enquiry

The founding father of phenomenology, Edmund Husserl, was interested in how people discerned the essential qualities of their experiences (Smith, Flowers, & Larkin, 2009). He believed that certain qualities of the experience would transcend the circumstances so that by ‘returning to the things themselves’ we might rise above what is taken for granted to bring out the essence, and therefore bring about ‘meaning’ for others. Husserl used ‘intentionality’ to relationally link the object in mind with the process, for example, ‘remembering’, or ‘judging’, in order to illumine this orientation of the phenomenological experience or consciousness of it (Smith et al., 2009).

Also relevant to phenomenological experience and consciousness of experience, is the process of intersubjective engagement. Husserl grappled to ‘locate’ this and eventually he included the notion of a Divine Being (in Section 58 of Ideas I), where his annotations point to what lies beyond ‘the sphere of lived experiences’ to a ‘teleologically structured world’ (in Section 51 of Ideas) (Bello, 2005). For Edith Stein, his student, created ‘beings’ are relational and unitive in body, soul, and spirt, being patterned ‘in the image’ of a Trinitarian

God, who is both self-contained as Creator and self-giving, in the going out of self, to the Son and Spirt without loss to self (Valiquette, 2018). In this phenomenological sense, the essence of human 'being' is found in its needing to go forth from self (Bello, 2018).

From a phenomenological perspective, Husserl has noted that the 'objective outer world' is experienced intersubjectively, that is, through engaging with others; with individuals who can 'relate' (Haney, 2013). Therefore, when meanings are constructed and re-constructed intersubjectively, acquired understandings emerge in a fundamentally 'relational' act, as "a process in which one mind explores a second" (Dant, 2015, p.46). For example, "intersubjectivity precedes subjectivity; humans can only understand themselves and others in terms of how others respond to and interact with them" (Crawford, Kippax, & Waldby, 1994, p. 573). This is a significant philosophical 'straw' worth grasping in a project such as this.

4.4.1 Heidegger's phenomenology

Martin Heidegger was born to poor Catholic parents in 1889. He was considered a promising theology philosopher, exhibiting an interest in Husserl's refutation of psychologism, which includes "the attempt to found logic and mathematics on the psychological makeup of the human mind – as a form of empiricism and relativism" (Caputo, 2006, p. 327). Heidegger was opposed theologically to modernism as a "form of historical relativism that threatened to undermine ageless theological truth" (Caputo, 2006. p. 327). This led him to consider another side of medieval philosophical tradition that embraced the 'living' aspect: the study of medieval mysticism. From this, Heidegger acknowledged that medieval theologians' theories grew out of their "concrete experiences of life"; and from the mystical notion that 'the soul is all God's'. This aspect of Heidegger's early studies was pivotal in the development of that one core tenet of his phenomenological approach, in which 'spirituality' comes to be denoted as 'being' (Heidegger, 1962, p. 27), and which he emphasises repeatedly: that 'thinking 'belongs' to being' (Caputo, 2006).

Heidegger's ontological focus of 'being' refers to being grounded and embodied in the world; inseparable from the world, thus in 'being there'('*Dasein*'), one encounters others (other *Dasein*) or objects of the world, such as language and culture. An underlying assumption is that *Dasein* comprehends 'their being' in terms of possibilities discerned in the ordinariness and everydayness of encounters. *Dasein* is thus relational, concerned not only with 'Being oneself' but 'Being with others' and 'Being alongside the world' (Heidegger, 1953/2010). Notions of 'selfhood' and 'worldhood' (world apprehended), can therefore be explored ‘in relation to’; that is, the entity (‘the who’) is explored in relation to the everydayness and ordinariness of existence or ‘being with’ others (Heidegger, 1953/2010), where what is implicit, becomes, through ‘interpretation’ explicit (Horrigan-Kelly, Millar & Dowling, 2016, p.3). This assumes *Dasein’s* pre-existing understandings, or their ‘fore structure of understanding’, necessitating ‘interpretation’ as opposed to pure apprehension, yet demanding that the researcher’s preconceptions and assumptions be explored and kept in check (Smith et al, 2009; Horrigan-Kelly et al, 2016).

In addition to the concepts of ‘being’, ‘being in the world’, and ‘being with’, four additional Heideggerian concepts are relevant to this thesis. These are *Dasein’s* encounters in the world, the care structure, spatiality, and temporality. This thesis takes up *Dasein’s* encounters in the world, predominately in relation to in-vivo encounters pertaining to peers, teachers, and support agencies, whereby needs and desires are negotiated intersubjectively; where (mis)understandings arise. Heidegger’s concept of the ‘care structure’ is also relevant and parsimoniously defined by Horrigan-Kelly et al (2016, p. 3) as “exposing what is of most consequence or importance to the human being” including “future aims, goals, desires, or ambitions”.

‘Temporality’ is taken up in this thesis to reveal something essential about *Dasein’s* existence: what matters now, before, and in the future. Temporality “…is a notion showing how time is subjectively experienced differently depending on the situation” (Tutty & Hocking, 2004, p. 5). This is most evident regarding the ways in which autistic people reflect on their pre/post diagnosis and later, negate ‘identity’.

Finally, spatiality provides another means for revealing Dasein’s existence (Heidegger, 1953/2010); ‘being in’ a particular ‘felt space’ (van Manen, 1997a). For example, at home I can ‘be’ what I am (van Manen, 1997a); at church I feel small and cool in the large space, and ‘caught up’ in the transcendental nature and spirit of the Liturgy; I am what I am in relation to the space I am in. The primary space pertaining to this research project is mainstream high school, and as such it also affords opportunities for discovering ‘being’, in relation to the affordances of mainstream classrooms, special need facilities, and other designated learning and socialising spaces.

4.3.2 Interpretative phenomenological analysis

Whilst phenomenology is a form of philosophy, interpretative phenomenological analysis (IPA) enables researchers to study how “something appears or manifests itself” (King, 2001, p.109). German literary historian and philosopher, Dilthey, was instrumental in developing the hermeneutical method (the method of interpreting text). Hermeneutical methods were typically associated with biblical or literary exegesis (Eatough & Smith, 2008); however, Dilthey argued that it was also the most relevant 'art and practice' for understanding 'recorded expression' of lived experience (Tappan, 2001).

Heidegger followed Dilthey's application of hermeneutics, asserting that 'being in the world' can be approximated, interpreted and best explained using language: words and text, most commonly interviews (Heidegger, 1953/2010). Phenomenology (in the way Heidegger used it) brings meaning and sense-making into the light; it brings latent things out from obscurity, including that which has been disguised (Smith, et al., 2009). This occurs when the researcher takes in the following two hermeneutical approaches: firstly, standing in the shoes of the participant and standing back from them; and secondly, questioning things and musing over potential meanings. These two hermeneutic processes are called the hermeneutics of empathy and the hermeneutics of suspicion (Ricoeur, 1970, cited in Smith et al, 2009).

The hermeneutical approaches enable researchers to seek clarification and develop an understanding of how people make sense of their experiences in specific contexts. Broader than this though, the hermeneutical cycle helps researchers to not only make sense of their participant's interpretation of their experiences within a given, often situated context, but provides the means for illuminating how this is being 'framed' through the eyes of the researcher (Tierney, Burns & Kilbey, 2016). This is called the 'double hermeneutic' meaning that as the participant is making sense of the world, the researcher attempts to make sense of the participant making sense of the social world (Smith, 2004).

The hermeneutical method used in IPA, in psychology, contains a number of important assumptions about lived experience relevant to this study. Firstly, in order to understand 'lived experience' it must first be 'expressed'. Dilthey notes that an 'expression' is not merely the overflow of feeling, but an 'expression of life'; a narrative, story, poem or piece of music (Tappan, 2001). The expression pertains to the three psychological dimensions of thinking (cognition), feeling (emotion), and acting (volition) all of which may come to be expressed in varying degrees by participants as they make sense of their lived experience.

It is assumed that people with ASD have difficulty communicating their thoughts and feelings, or they will communicate them in odd ways (Attwood, 2007). Therefore, a common limitation in studies involving people with ASD is due to speech, language, and communication difficulties, restricting depth of self-expression. I chose to include a second group of students in this study, tertiary students. Being older and more experienced, tertiary students may be more capable of articulating and expressing their high school experiences, retrospectively. With the addition of time, they may also look back at their high school days with increased insight.

Some younger students with ASD did experience difficulties communicating their thoughts, feelings, and actions, but they also found ways to overcome these limitations, if I gave them enough time. For example, ‘Chris’ [adol] demonstrated his thoughts, feelings, and actions, with difficulty in relation to anxiety, but given additional time to pause, it was not an impossibility:

> *My main anxiety at the time was “holy crud I’m in college now, and I have to start thinking about my future and that is where one of my anxieties of now come from…thinking…Just thinking about my future yesterday made me just feel funny…(pause)…I just felt like…I don’t know how to explain it but…I just felt like “what do I do, what do I do?” I just felt like I wanted to run…And I did run away from college a few times* (Chris [adol], p. 6).

For the lived experience to be expressed, participants must enter a relationship with the researcher. Like Personalism, IPA is also relational; being in the hermeneutical cycle, requires being present and focused, with the other. This ‘with-ness’ in dialoguing underpins the intersubjective nature of constructionist approaches. In a study with young autistic people, building relationships takes time. It requires patience and perseverance and sometimes it means taking time to ‘be with’ each other, sharing food, stories, and silences too. This process can be furthered through adherence to key principles.

Firstly, knowledge of ASD and the adaptation of my expectations was an important pre-requisite. I needed to be flexible regarding meeting when it suited the participant, terminating the interview and taking it back up on their terms. For example, Taylor [adol] tired quickly, but was not done with what she had to say, so we met for several weeks for shorter periods of time, beginning each session with an ice-cream of her choice. Similarly, Grace [ter] had computer problems that distressed her and it meant she was not able to meet, but this ‘putting off our meeting’ enriched our next meeting, as she was able to provide an example of what happens when distressed. Being accommodating and rescheduling, conveyed understanding and enabled friendship building through respect.

Secondly, the nature of the relationship was salient in this project. For example, all three parents saw me as someone who wanted to listen despite the fact their stories were, as Danny [par] put it, part of "an horrendous journey". Participants deemed my relationship as non-threatening, thus different to those they had previously experienced, when trying to obtain professional help. In these interviews, participants did not need to 'perform' to access something of need, rather it served as an opportunity to speak out against a 'system' that had silenced and oppressed them. However, divulging so much anguish was predicated on trust through development of relationships that were open and friendly, and yet set the conditions enabling a sense of it 'being safe to talk'.

The third assumption of the hermeneutical method is that 'understanding' is positional, meaning "an interpreter understands by constant reference to her own perspective, which shapes her understanding of the world based on her expectations, preconceptions, biases, and assumptions" (Tappan, 2001, p.49). Whilst it might be the 'ideal' in qualitative designs to bracket one's experiences and assumptions in order to become immersed in the text (Bogdan & Biklin, 2003), IPA does not require this. Instead reflexivity and thus transparency is required, where preconceptions can be discovered throughout the analytic period. The cyclical nature of bracketing and detective work are essential for bringing forth meaning, thus together they function like two sides of the same coin, bringing currency to the project (Smith, et al., 2009).

For example, the researcher acknowledges their preconceptions if they cannot 'bracket them off', then lays their concerns aside, to listen again to the participant's story. In doing so, the researcher is actively engaging in the tasks aiding the 'appearing' as Heidegger termed it, where the phenomenon, there, but yet obscured, is unearthed; where by coming into the light, and 'seen', is made sense of (Smith et al., 2009). It may also mean returning to the participant and dialoguing with them about my interpretation of their interpretation (Smith, 2007). Given the varying communication difficulties assumed to face all people with ASD (Attwood, 2007), I believed it was important to return to participants and discuss my interpretation of their now textual account. I sought further clarification, dialoguing, building trust, and enabling a new cycle of interpretation by laying aside newly realised assumptions. This enabled additional fresh ideas, and emerging understandings to come to the fore, whilst moving from being a stranger to becoming someone who participants could trust with their 'story'.

This was a valuable means for garnering additional expressions of the lived experience from all participants, parents and advocates included. Thus, I found myself repeatedly entering in to the stories told, listening, being captivated, and then facilitating discussions, where I sought to open ideas ‘up’ like fissures, lost in the ‘art’ of letting the ‘heat of the matter’ rise, aware only afterwards, on reflection, how I had also become entangled in the construction. Then, back at home-base, as Smith describes in Smith et al (2009), I was free to return to my assumptions about autism, communication and relationships, education and inclusion, professional practice, and human rights issues.

Looking back, I would argue that the hermeneutical cycle also enables researchers' opportunities to demonstrate relationality, ethical care and compassion as painful moments are again relived, revisited, and *re* re-constructed. This revisiting in IPA does not necessarily mean that it is ‘more’ or ‘less’ valid research. IPA is embodied and embedded and thus subjective, so ‘truth’ and ‘validity’ need to be addressed in ways relevant to qualitative paradigms.

4.4 ‘Quality’ in qualitative research

Validity and reliability are concepts crucial to quantitative methods; studies that fail to demonstrate these constructs are typically considered, rightly or wrongly, flawed. Quality in qualitative research however has a different set of connotations and expectations and many of these have been considered above. Following Yardley (2000), Smith, et al., (2009) considers the importance of four ‘broad principles’ as a yardstick for measuring ‘quality’: sensitivity to context; commitment to rigour; transparency and coherence; and, impact and importance.

Sensitivity to context refers to the overall level of sensitiveness at all stages of the research process. I have highlighted earlier that an understanding of the community and broader context of the study is important, as is knowledge of the topic (the current academic literature), and the nature of the data gathered. However, sensitivity is also demonstrated relationally with participants through acts of empathy and care, recognising difficulties and fathoming ways of overcoming these (Smith, et al., 2009).

In this study, sensitivity was demonstrated when I provided autistic students with ample time to respond to questions and develop their thoughts; when I provided their favourite foods as snacks; and when I met them in those places they were most comfortable, taking into consideration sensory sensitivities such as light and noise. During the early analytic stage, I demonstrated sensitivity by returning transcripts to participants for further dialoguing with them regarding my interpretation and being open to their re-interpretation. In the analysis to come, sensitivity will also be evidenced through ‘listening’, demonstrable when enough quotes are drawn upon to establish depth and quality of the account. Being sensitive, in some respects, overlaps with commitment and rigour, the second principle related to quality. This refers to the researcher's degree of investment into the project and thoroughness with which the project was carried out (Smith et al, 2009).

The greater the degree of consideration given to commitment and rigour, the more chance there is that the project will be robust and thus of high quality. In some projects, this may necessitate the honing of certain skills, such as interviewing, listening, knowing when to listen and when to probe, or the development of knowledge relevant for interacting with certain populations, such as autistic students. Without this type of commitment, those fissures mentioned earlier will not open, making it difficult to extract those expressions that have potential for changing the landscape of knowledge commensurate with ideographic designs.

The third principle related to quality is transparency and coherence. Transparency occurs when researchers give enough attention to describing each facet of the project. Coherence however, can be assessed from several vantage points, including the degree which the philosophical and theoretical underpinnings cohere; the manner in which contradictory constructions are managed and converge around central themes (Smith, 2011); and finally, coherence of the overall write-up (Smith et al, 2009). Transparency and coherence have been at the forefront of my mind from the outset of this project, in that my Catholic worldview is often at odds with secular psychological positions. Thus, ensuring transparency and coherence regarding the philosophical and theoretical underpinnings, has been a salient consideration.

Finally, how well I convey my research and tell the story of (un)strangering the stranger in a strange land; how interesting it is to you, the reader; and, how important the contribution of this project to the existing knowledge base of autistic adolescent experiences in mainstream high schools, constitutes achievement of the fourth principle of quality in qualitative research: impact and importance.

In summary, Smith et al. (2009, p.184) suggests that whilst assessing quality is important and can be gained by adhering to the four broad principles outlined here, IPA is more of a 'creative process' than a recipe-book approach. van Manen (2017, p.777) opines that "there is no step-by-step model that will guarantee phenomenological insights and understandings." As such, they advise new researchers to focus on 'getting the balance right', by which they mean "…the balance between pushing for work to be of very high quality and recognising when something is 'good enough.'" With this in mind, I will briefly highlight three limitations or criticisms that Willig (2013) has noted in regards to IPA and then I will begin delineating how I have pushed for a high quality research project, by trying, then rejecting the recipe-book approach, letting the creative process take hold and be my guide.

4.5 Limitations of IPA

Increasingly, proponents of IPA have provided detailed consideration regarding evaluative criteria: ‘what makes a good IPA paper’ (Smith, 2011) with limitations being predominately focused on its ideographic nature (Willig, 2013). Nonetheless, Willig (2013) also asserts that IPA “…does suffer from several conceptual and practical limitations” (p.94). The conceptual and practical limitations she refers to regard ‘the role of language’, ‘suitability of accounts’ and ‘explanation versus description’. Firstly, she describes language as the means for constructing differing versions of reality and as such, argues that the text (transcript or otherwise) “tells us more about the ways in which an individual *talks about* [emphasis in original] a particular experience…” (Willig, 2013, p.94).

However, Heidegger, in following Dilthey only asserted that ‘being in the world’ can be best approximated using language, not completely apprehended. Additionally, the claim that IPA ‘brings things into the light’ does not in any way suggest that we can only bring things into the light of noonday, where shadows are least likely to be cast over the ‘thing’. Thus, full, or complete ‘apprehension’ is not implied in phenomenological analysis. Linguistic constructions are simply considered the ‘best approximations’; the storying of meaning-making, thus constructions remain subjective but illuminative; shadows may still loom large.

Willig (2013) acknowledges that IPA is ‘modest in its claims’ about the suitability of accounts. By ‘suitability of accounts’, Willig refers to how well positioned participants are at communicating, noting one project specifically that required ‘vivid’ descriptions in relation to thoughts, feeling, actions, people, places, situations and events, in order to capture the full ‘essence’ of the phenomenon. She concludes that this method might not therefore be “suitable for the study of the experiences of those who may not be able to articulate them in the sophisticated manner required by the method” (p. 95). She does not however disregard alternative communication methods, such as visual methodologies. Nonetheless, this is relevant to this research project with a supposedly communicative impaired population.

Smith et al (2009) has advocated repeatedly that IPA has costs and benefits and these need to be weighed up. Humphrey and Lewis (2008a) among others (e.g., Poon, 2014; Stace, 2011), have demonstrated the transformative nature of their autism research using IPA, whilst Harding (2009), advocating a feminist epistemological standpoint, would argue that unless missing voices are included (irrespective of sophistication in articulation), the majority and powerful will continue to oppress and undermine the marginalised, whose voice is so often lacking in research *about* them. Additionally, by adhering to IPA practices deemed to improve ‘quality’, limitations like this can be minimised.

Thirdly, Willig (2013) highlights that in phenomenological studies the focus is on description of perceptions and experiences, not explanations: “phenomenological research *describes and documents* [emphasis in original] lived experience of participants but does not attempt to explain it” (p.95). She suggests IPA provides no way to close the gap of ‘why’ something occurs. I believe this underestimates the power and flexibility of the ‘interpretive’ nature of IPA. I acknowledge it could be more relevant to specific types of phenomenological studies, such as physiological-oriented ones on pain or other medical conditions. In this study, I have used IPA within Bronfenbrenner’s ecological framework to advance opportunities for exploring potential reasons ‘why’ certain experiences or perceptions might occur and have taken into consideration how essential a good knowledge of community is, for moving beyond description.

Finally, a more widespread and acknowledged limitation of IPA research is its lack of generalisability beyond the immediate participatory community, being ideographic. Ideographic studies, however, provide a degree of depth and insight otherwise un-obtainable in social science. Thus, there is a trade-off and purpose (Eatough & Smith, 2008); specificity is intended. This makes IPA a particularly appropriate method when a phenomenon is under-studied (Smith & Osborn, 2007) as is the case in qualitative autism studies involving adolescents lived experiences of ASD (Humphrey & Lewis, 2008a; McLaughlin & Rafferty, 2014); their voices are ‘missing’ (Ministries of Health and Education, 2008), so IPA renders the unheard, heard; it has potential for (un)strangering the ‘stranger’.

4.6 Research method

In this next section I describe how I conducted this study. I discuss the people who participated, including their characteristics and interests, and describe the various stages of the study, including gaining ethical approval; informed consent; confidentiality; withdrawing from the study; cultural sensitivity; minimising risk; recruitment of participants; the interview; data collection; transcription; data analysis and development of themes.

4.6.1 Participants

I am based in Palmerston North, a city located in the Eastern Manawatu plains of the North Island, NZ. Participants were recruited from a broad geographical region taking in towns and cities 400km north, 250km northwest, and 160km south. There were four groups of participants: ‘high-functioning’ adolescents and tertiary students, parents, and advocates. Participants were purposively selected commensurate with homogenous samples typical of phenomenological research, where understanding and experience of the phenomenon of interest is essential (Smith et al, 2009). Autistic participants in this study (had) attended a combination of independent or private schools, state and special character (Catholic) schools.

Participants were recruited using a combination of common qualitative techniques (Springer, 2010), namely referrals, opportunistic recruitment (personal contacts), and snowballing (referrals from recruited participants). Sampling anomalies also occurred. Two participants approached me to participate, one as a result of attending a university talk on this proposed study, and one during an informal discussion of my research proposal. A third participant, Rachel, was ‘recruited’, being present when I interviewed her ‘advocate’ husband. Both met criteria for participating as advocates and as parents, however, they predominately spoke in their roles as advocates and only occasionally referred to the lived experiences of their16yo daughter, diagnosed AS.

Whilst there were no Māori participants in this project, I acknowledged our bicultural identity through consultation processes with Māori and Pasifika representatives on campus. I considered the importance of *tikanga*, or customs, particularly *manaakitanga*, or hospitality. I offered to bring food to share with participants during interviews, seeking to provide those things most desirable and fulfilling specific requests when asked. It was a condition of this study that participants speak English to aid interpretation, primarily, because people with autism can use language literally (Attwood, 2007) and draw on puns. Being sensitive to its nuanced application was deemed important and my command of Te Reo Māori would compromise interpretation of their understandings and perceptions.

4.6.2 Saturation of data

Fewer participants are needed in qualitative studies in order to obtain saturation of data (Guest, Bunce, & Johnson, 2006). Mason’s (2010) investigation into saturation and sample size in qualitative doctoral studies demonstrates that a large proportion of studies appear to have a premeditated sample size with a statistically significant number of studies containing a multiple of ten participants. Therefore, I chose not to premeditate the number of participants for this study but remain cognizant of the quality of data I was obtaining as I progressed from participant-to-participant, noting that diminishing returns, or new insights, would normally be expected.

Preece (2002) acknowledges little guidance for the methodological issues facing researchers choosing to interview young people with ASD. Most have difficulty communicating; some may offer scant responses, whilst others may be verbose. I felt it was important to avoid generic expectations and assumptions regarding 'deficits' and opted to remain open to the possibility that some participants will offer more than others, necessitating greater on-going consideration of 'saturation' throughout the data gathering process.

Adolescent participants

Adolescent participants were recruited if they met the following criteria:

- ✓ Were aged 16 years and over
- ✓ Attended a NZ mainstream high school (state, private, or integrated)
- ✓ Were enrolled in years 11-14
- ✓ Were English speaking with reasonable verbal skills
- ✓ Had a diagnosis of ASD, AS, HFA, or PDD-NOS, based on Diagnostic and Statistical Manual of Mental Disorders (4th ed.; DSM-IV) or DSM-5
- ✓ Resided within the defined geographical boundary

Six adolescent participants were initially recruited, with one participant (Roman) withdrawing, leaving five participants aged 16 to 19 years; three males and two females, in years 11 to 14 NCEA (see Table1). On recruitment, participants were provided with an information sheet about the research (see Appendix 1). Three of the five participants were unaware of the year level they had achieved in NCEA, despite this information being available to all NZ high school students on-line. Four of the five participants were diagnosed with AS, whilst one was diagnosed with ASD, reflecting a more recent diagnosis and change of nomenclature in DSM-5. Students' transcripts ranged from 10,000 to 19,000 words.

Table 1 *High school students' participant characteristics*

Pseudonym	*Age*	*Gender*	*Ethnicity*	*Diagnosis*	*Year Level*	*NCEA level*	*Educational arrangements*	*Family living at home*

Brad	16	M	Euro	AS	11	1	Mainstream classes	Mum and Dad
Catherine	16	F	Euro	AS	12	2	Teacher aid in mainstream classes	Mum and Dad
Taylor	17	F	Euro	AS	13	?	Special needs unit and limited mainstream classes	Dad
Chris	18	M	Euro	AS	14	?	Special needs unit and mainstream classes	Mum and Dad
Liam	19	M	Sth African	ASD	14	?	Mainstream classes	Mum, stepdad, sister

Adolescent participants' interests:

Hans Asperger's suggested that autistic people are characterised by their strong and narrow interests (Wing, 1981). Interests pertain to one's disposition - a psychological state. As such, interests are usually enduring, but can have peak moments, and lulls. Thus, they can be picked up and engaged in repeatedly (Renninger, 2009), or become dormant over time. Baron-Cohen (2009) theorised that autistic people were prone to exhibiting advanced skills in systemising where "systemising is the drive to analyse or construct systems" (p. 71). Thus interests are predominately thought to be 'rule driven' and pertain to a range of 'systems', namely bodily (for example, digestive, renal, circulatory etc.), collectable (stones, seeds), mechanical (trains, planes, wheels), numerical (pi), abstract (colour), natural (storms, rain), social (hierarchical), and motoric systems (like trampoline bouncing). Autistic people's interests have rarely been framed in a positive light, but rather, as being 'narrow'; the result of 'rigid' or 'obsessive' thinking, and as such autistic obsessions and narrow interests have been postulated as a form of 'autistic deviance' (Brownlow, 2010). In this pathologising of interests, there has been little recognition of how strong interests at one point in life, can become useful in another, for example, concerning a future career, especially in specialising in a 'narrow' field to develop 'expertise' (Molloy & Vasil, 2002).

Adolescents in this study had broad and ordinary interests that spanned looking after pets such as chickens, cats and dogs; playing X-Box, Candy Crush and computer games in general; writing fan-fiction; learning how to speak Te Reo Māori from YouTube; watching movies; drawing; and, using the computer to learn about animals in general, NZ wildlife, and natural disasters. Other interests were more active such as training to get fit, swimming, doing yoga, and going on outings. Some interests came and went. Liam [adol] for example was interested in animals and used to volunteer at the SPCA, although he lost interest over time and quit; Chris [adol] went through a phase of watching disaster movies; and, Catherine [adol] used to have a special interest in flags when she was very young, but can no longer recognise them. Taylor [adol] enjoyed part-time work delivering papers and suggested that this can also be counted as a genuinely enjoyable activity.

Adolescents had specific interests that were comparatively less common and involved imagination and fantasy. Chris [adol] liked to parody TV shows in his spare time and make up worlds; "whole creatures, whole factions, whole peoples; I even made my own little force of nature of sorts," positioning himself as the "Mary Sue" in these worlds (p. 4).

Participants believed some interests might need justifying, failing to fit cultural norms. Chris [adol] liked to learn about various firearms and their manufacturing and enjoyed constructing lists of these. He was careful to emphasise that this interest, was 'only' an interest, and not a reflection of a sinister character:

> *well I'm just interested, that's all; just interested. I'm just interested - there's so much variety. It's also… It just feels like they're so numerous. You could have numerous amounts of firearms in gaming but in real life they are very… I mean they are rarely manufactured in real life. It's not as common…I mean everything is just not as common as it would be in gaming* (Chris [adol], pp. 3-4).

Some teens also had interests that were decidedly academic but were pursued for pleasure in their spare time. These included the study of biology, ancient history and ancient Greece; and the study and drawing of dinosaurs. Catherine [adol] for example, **loved** reading biology textbooks and had done so for years in her spare time:

> *I like reading the textbook. I read the textbook.* ***I mean I read the Campbell's textbook…the big one, the big one, the big textbook, the University textbook.*** *I used to read it in the bath when I younger (laughing) and then once I dropped it in the bath (laughing) and mum had to take it outside to dry it in the sunshine and turn all the pages*

> *and I wasn't allowed to read in the bath since then (still laughing).* ***I like reading biology textbooks!*** *I like reading in general* (Catherine [adol], p. 17).

Catherine [adol] wasn't sure if she would pursue a career studying biology; it was something she was considering; interests can contribute to shaping identity, especially when this leads to career opportunities (Krieger, et al., 2012) and she'd already been part of a biology Olympics team. At present she was combining her interests in creative ways, writing fan-fiction to draft five paragraphs on 'speculative alien genetics'; the piece being selected for use in a science fiction novel.

Digital platforms played an important role for participants. Liam [adol] was recognised for being one of the top players in an online game, whilst James [ter] connected with his friends through gaming, which led to more in vivo social encounters with this group (see Chapter Nine).

A number of these and other interests, were also taken up as group activities in high school and as recreation outside of school. Catherine [adol] belonged to a competitive biology team and had been a member of the Archery club. Similarly, Brad [adol] belonged to a social cricket team with school, played in a competitive touch rugby team, belonged to a squash club, attended organised yoga classes, and in the 2016 academic year, had been a cast member in two major productions staged at local theatres. Thus, it seems some participants had interests that were well-supported across a variety of contexts.

Some interests were confined to home, like playing computer games or hanging out with siblings. Thus, whilst relationships and family dynamics may have changed over the years as siblings grew, family remained important, particularly for Brad [adol] and Catherine [adol]. Brad felt his relationship with his older brother had changed recently: "…we've got sort of different lives now" (p. 23), but nevertheless some interests remained shared and companionship was important.

> *He [brother] is sort of more into mythology and stuff and I am like more into all of the Cinematic Cannons, such as the Marvel Cinematic Universe or the Star Wars Trilogy or Middle Earth … [and] … me and him used to play with each other when we were little - that's what brothers or siblings do to each other …[now]… he talks to me, he teaches me the stuff he knows, such as he is more into Star Wars than the Marvel Cinematic Universe so he tells me about all [that] stuff (Brad [adol], p. 24).*

Brad [adol] placed a heavy emphasis on family life in general. He loved travelling and holidaying with his family who lived in a remote European country. He was attempting to learn their native language in order to communicate better with them. Brad also enjoyed travelling with his immediate family to international sporting events where his brother was a regular international competitor. As a result, Brad's passion for planes and flying was satiated and he continued to pursue his interest via YouTube, watching planes arriving and departing from international airports and learning about their features.

Overall, high school participants shared a diverse array of interests, pursued in multiple contexts for enjoyment, interest, relaxation, and stress management. Some students like Brad [adol] and Catherine [adol] had particularly rich microsystems through a high degree of family support and schooling opportunities; whereas other participants like Taylor [adol] had little family support and limited environmental opportunities to pursue what interested her. Taylor liked going to different places and swimming; however, these interests remained predominately unexplored, or rarely indulged.

Tertiary participants

Tertiary students were included in this study, if they had previously been diagnosed with ASD or one of its earlier variants and…

- ✓ Were enrolled in a tertiary program of study (1-4 years)
- ✓ Had attended a NZ mainstream high school for part or all of years 11-14
- ✓ Were English speaking with reasonable verbal skills
- ✓ Had been diagnosed AS, HFA, or PDD-NOS (DSM-IV)

Three tertiary students were included in this project, two of whom had completed University Entrance (Level 3 NCEA) at high school (see Table 2). One participant had dropped out of high school towards the end of year 11, before making their way back to tertiary study at age 20. I was initially reluctant to include this participant given their limited experience with NCEA; however, he met the criteria I had initially presented and on further reflection, I decided that his contribution could be potentially valuable in terms of why he left high school when he did. Tertiary students were more articulate compared to adolescent students, producing transcripts ranging from 9,500 words to 28,000. All tertiary students still lived at home. On recruitment, tertiary students were provided an information sheet about the research (see Appendix 2).

Table 2 *Tertiary students' participant characteristics*

Pseudonym	*Age*	*Gender*	*Ethnicity*	*Diagnosis*	*Tertiary Programme*	*Level of NCEA achieved*	*Family living at home*
Emily	20	F	Euro	AS	BA degree 2nd year	3	Mum and dad
James	20	M	Euro	AS	Technical degree 1st year	N/A	Step mum and dad
Grace	23	F	Euro	PDD-NOS (initially, then ASD)	Post Grad degree 1st Year	3	Mum, dad, and younger brother

Tertiary students' interests

Tertiary students were interested in computer gaming and Facebook, looking in shops, going to the movies, eating McDonald's, and spending time in town with friends. Looking back on their high school years, tertiary students recalled that their dominant interests then included team sports like croquet and learning (in general), learning about current events, military life, firearms, and military equipment, cats, and astronomy. Grace [ter] felt like she was able to incorporate her interest in organisation with running the tuckshop during school interval periods, recalling how much she enjoyed this, giving break times purpose.

Some interests spanned the high school years and continued into the tertiary years. James [ter], for example, progressed from enjoying the sound of trains, to being able to identify car types by their sound. He particularly loved music and especially enjoyed guitar. One of his most enjoyable experiences in his older teen years was attending an intimate guitar concert given by a well-known artist whose band was touring. He had trouble describing the sheer pleasure of this particular sound, as though mellifluous and therefore ineffable and beyond the realm of joy possible for someone without a similar sound sensitivity.

Grace [ter] loved singing and enjoyed reading. She used to like reading books on cat care in primary school and carried this through to high school, reading every book the library had related to her beloved felines, more than once. Other reading topics in high school included astronomy and encyclopaedias for gaining general knowledge. However, in the tertiary years, she added to this repertoire of favourite reading genres, non-fiction. She particularly enjoyed authors like Jodi Picoult, who she says, provides autistic people like herself, with social skills 'lessons' through a narrative device enabling her to explore dominant themes from multiple character perspectives.

Parents and advocates

Whilst phenomenological research aims for an in-depth understanding of lived experience, qualitative research in general aims for an in-depth understanding of the issues involved in the study (Springer, 2010). I therefore chose to interview parents and advocates as two types of participants who might extend understandings of the issues young people with ASD currently face, thus adding rich contextual data.

Parents were recruited if:

- ✓ Their son or daughter was already participating in this study
- ✓ Their son or daughter gave verbal consent that I could talk to their parents
- ✓ They were English speaking

Three 'parents' participated in this project; two mothers of high school students and one father of a tertiary student (see Table 3), bringing the total number of participants to 18. Parents and advocates had overlapping roles, with most advocates having someone 'high-functioning' in their family. Information sheets outlining participating were offered to parents (see Appendix 3), however, I liaised verbally and by email with advocates.

Table 3. *Parent characteristics*

Pseudonym	*Gender*	*Son/Daughter participant*	*Occupation*
Danny	M	James	Pastoral/ministry/education
Kym	F	Liam	Stay at home mum
Victoria	F	Chris	Stay at home mum

Advocates are 'experts' in their professional roles and carry a 'collective' (autism) story (Pallicano, Dinsmore, & Charman, 2014). They have historical knowledge, knowledge of the DSM, and long-term work experience that may both converge and diverge from other ‘insider’ perspectives (Waddington & Reed, 2006). Advocates can also play a major role in regards to the diagnosis of autism, implementation of interventions, provision of general support for families, and assistance in helping families to navigate the autism system (Heidgerken, Geffken, Modi, & Frakey, 2005). They often work to empower parents, and help them in their role of moving forward with an autistic member of their family, and thus share similar goals (Brewin et al., 2008).

Advocates are often involved in family life at critical stages and play a salient role in reducing familial stress (Bradford, 2010). Thus, they have relevant lived experience, particularly given the paucity of information regarding the quality of life for those with disabilities in general (Renwick, Fudge Schormans, & Zekovic, 2003). They also often have connections with schools, which are not always equipped to accommodate the needs of all students (Bradford, 2010), advocating for the autistic individual, but working alongside parents, helping and empowering them to take on these roles. Further, whilst advocates may come from varying professional backgrounds, their understandings have potential for intersecting at pertinent junctions, commensurate with expertise and interests. By drawing on this collective ‘mind’, advocates can provide salient ‘sign posts’ in unchartered, or unexplored ‘territory’.

> *People who are interested in Asperger’s and working like me, we are all on the same page; none of us are in conflict with each other; we are all saying the same thing and identifying the same needs. It’s not like I’m out on a limb somewhere* (Karen [adv], p. 43).

Advocates were recruited if they:

- ✓ Had five or more years’ experience working with autistic young people aged 15 and over in NZ
- ✓ Were English speaking

Advocates represented four professions: community advocacy, education, social work, and psychology (see Table 4). They provided almost 100,000 words of data with interviews ranging from 8,800 to 28,000 words. Three of the six advocates had children with an official diagnosis, whilst two others mentioned family members who were ‘on the spectrum’. One advocate had not received an official diagnosis; however, he had suspected he met DSM criteria for AS and ADHD.

Table 4. *Advocates' participant characteristics*

Pseudonym	*Gender*	*Years as autism 'expert'*	*Family diagnosis*	*Professional field*
Grant	M	8	Son (AS)	Community
Nellie	F	8		Education
Michelle	F	20+		Psychology
Pamela	F	20+		Social Work
Karen	F	20+	Son (AS)	Education
Paddy (referred to himself as 'autistic' and ADHD)	M	30+	Daughter (AS)	Education
Rachel	F	6	Daughter (AS)	Education/Psychology

4.7 Ethics applications and approval

In 2012, the scope of ethics review applications by the NZ Health and Disability Ethics Committees was reduced to exclude studies involving participants who were functioning in a capacity other than consumers of health and disability services. An institutional ethics approach was therefore taken.

Whilst the importance of including ASD participants in research is no longer contested, I deliberated regarding the need for a low, versus high risk, ethics application. I consulted the literature, my supervision team, and several autism experts', as well as a young adult with AS. I considered that this research explores the ordinary and every day and that three-quarters of our schools have been rendered 'inclusive' (ERO, 2015b); research highlights that autistic people want to participant in research projects (e.g., Muller, Schuler, & Yates, 2008); that autistic individuals are typically rendered 'disabled' in dominant autism literature (e.g., Baron-Cohen, 2002; Hurlbutt & Chalmers, 2002); and, that autistic autism researchers contend that "autism per se is an aspect of normal human difference" (Chown, 2014, p. 2). I weighed up the risk/benefit that conversational research presents problems too, including delving into topics in much greater depth, thus causing distress (Wassenaar & Mamotte, 2012).

Because participants were all over the age of 16, verbal and ‘high-functioning’, I deemed a ‘low risk’ application appropriate for speaking about every-day lived experiences and this was peer approved. I used precautionary safety measures for myself including alerting my family and supervisors of house visits for interviews. However, I failed to envisage the ways in which ‘everyday’ research can impact researchers and consider the implications of this in Chapter Nine,

4.8 Informed consent

The most fundamental ethical principle in research pertains to informed consent (Langdridge, 2007). In phenomenological research, this is considered relatively easy to obtain as there is no risk of deception. Informed consent involves divulging all that the research entails, including time commitments, expectations, method of interview, the type of information being sought, and the risks and benefits associated with participation (Springer, 2010).

In this study, my initial contact was with parents via email or phone so that they might first of all provide consent, for all bar two autistic participants. I engaged directly with a tertiary student aged 23 from the outset by email and engaged with an educational advocate regarding an autistic student who had conveyed an interest in the project after they had mentioned it.

Consent was not considered a one-off acquirement but an ongoing process to be monitored and negotiated at all phases of data collection and analysis (Smith et al, 2009). Jordan (1999) has highlighted that although participants with ASD might be able to provide consent, they may not be aware of all the implications this has regarding participating. I considered using a Social Story (Gray, 1994), which is a common technique to convey expectations to someone on the autistic spectrum. However, in consulting an autistic adolescent and a tertiary student, I decided that it would be enough to have a copy of the information sheets couched in concrete language, un-cluttered and thus appropriately structured and available for consultation at the start of the interview, along with the informed consent forms (see Appendix 4 for adult informed consent).

On the autistic students’ informed consent form (Appendix 5) I placed a prominent ‘stop sign’ and reminded participants they only needed to point to it to conclude the conversation; no explanation was needed. No student used this option; however, Catherine [adol] reiterated salience of pictorial representations for autistic people in distressing situations, even if they can give clear verbal consent at one point:

> *Sharon: So, if you feel overwhelmed by anything…*
>
> Catherine: I can point to the stop sign
>
> *Sharon*: *and you don't have to tell me why you want to stop. I can text your mum [who was on campus waiting] and ask her to come and get you.*
>
> Catherine: and I don't have to say 'STOP' aloud, which is fine with me, but it's actually a really good idea because lots of autistic people go non-verbal on distress (Catherine [adol], p. 1).

In addition to initial consent and the provision for ongoing consent with the 'stop' sign, I also used secondary indicators of consent (Preece & Jordan, 2009). Prior to the interview, I considered that these might include a lack of desire to engage, evident through body language. One participant, whom I met after school, began yawning profusely, with sudden onset about 30 minutes into our interview. She confirmed she was tired when asked and said: "can we stop now?" She asked if I would bring another ice-cream to share the following week, highlighting an overall interest, sense of engagement in the process, and a desire to continue, but not in that moment. I returned on two subsequent occasions.

Finally, 'consent' was also 'tested' in returning transcripts of interviews to participants and discussing these, asking more questions, and checking my interpretation of their meaning. Once participants were satisfied regarding accuracy of their first transcript, I added the additional comments and returned the completed version, requesting they sign a 'release of transcript' form (Appendix 6). I ensured participants understood what I meant by using their stories and including their voices in "reports and publications arising from the research".

Consideration was given to the need for ensuring participants had appropriate access to care following interviews should they need it. All participants were provided with the contact details of a psychology researcher in the event of wanting to discuss matters arising from the interviews. Additionally, a list of potential service providers was made available for parents and autistic participants and offered at the conclusion of the interviews. However, participants were either 'connected' with service providers, such as personal psychologists, or educationalists, or had had repeated negative experiences with agency providers and declined additional contact information.

4.8.1 Withdrawing from the study

Participants were also informed of their right to withdraw from the study at any point, including having their transcript removed. One high school participant, 18-year-old Roman, provided informed consent at the beginning of the interview, with ongoing secondary consent seemingly evident. At the end of the interview when I asked him how he felt about me talking to his mum, Roman seemed reluctant to give permission. This was the first clear secondary indication that he was not consenting. On further questioning, Roman commented that he did not want me to contact his mum. He revealed feeling as though 'pushed' into participating because his mother wanted to 'tell her story'. I asked Roman if he would like me to withdraw his interview transcript and he affirmed his wish.

4.8.2 Confidentiality

Participants were informed that their consent forms would be securely located, stored in a locked filing cabinet for five years on campus, and then destroyed according to university protocols for document destruction. The information sheet clearly highlighted that tape recordings would be deleted after transcription and that all data files would be stored on the researcher's fingerprint protected, laptop. Additionally, pseudonyms were used[7], whilst high school names were withheld, and towns and cities were un-named. This is particularly important in small countries like NZ.

4.9 Interviews

Interviews are particularly useful in ideographic studies seeking in-depth sense-making (Smith, Hollway, & Mischler, 2005). Semi-structured and open-ended or conversational interviews are one of the most common forms of interviews in qualitative research (Krogh & Lindsay, 1999). They have the benefit of being flexible to enable the participant to talk about what is most meaningful, as opposed to the constraints of closed-interview techniques that are more likely to elicit standard or expected responses (Cridland, et al., 2015b). A flexible approach is well suited to exploring day-to-day lived experiences, where a wide array of possible topics could arise. In this study, my aim was to talk about things that mattered to participants, so 'interviews' were 'participant led'.

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[7] All names in this report are pseudonyms. Most were electronically generated via 'pseudonym generator' (https://www.namegenerator.biz/pseudonym-generator.php). In hindsight it would have been more prudent to ask participants, especially autistic participants, if they had a preferred pseudonym.

This functional feature of dialoguing is relational and authentic and, I would argue, of superior 'quality' (Reddy, 2008) in qualitative research. The 'risking' required to 'listen', facilitates an encounter leading to a genuine sharing from the heart. I noticed this most strikingly when I 'interviewed' Victoria, mum of adolescent Chris. On three occasions, over the course of three hours, she shared how she reached a point, through lack of support, whereby she wanted to murder Chris's older sibling, who was more profoundly autistic. The details were comparatively 'bare' to begin with, but with each subsequent cycle of returning to this story, details emerged as trust was built.

There are additional considerations in interviewing an individual with ASD (Cridland et al., 2015), particularly in relation to negating preference topics and discomfort topics. To minimise the chance of causing unnecessary discomfort, I asked parents if there were topics or words that I might stumble upon that could cause discomfort. This proved salient as Chris [adol] could not tolerate the word 'pride'. I therefore not only refrained from using this word during the interview but avoided 'autism pride' originally used in the title of this thesis and therefore on the consent and information sheets. Nonetheless, he and other adolescent participants expanded upon 'off limit' topics themselves, including 'pride', earthquakes and girlfriends.

Autistic people can have slower processing speed, needing more time to respond (Lewis, 2001). In her doctoral research, Harrington (2014) suggested that up to 11 seconds was required for participants to process the question and fathom their answer. This calls for patience and restraint.

Whilst typical teenagers may baulk at the idea of having a parent present in an interview about their daily life, this could not be assumed for autistic students because they rely on parents to a much greater degree. Liam [adol] and Kym [par] were the only dyad present for each other's' interview. They were comfortable in each other's presence, sharing banter and laughter, and often finished each other's sentences. This meant what one forgot the other remembered. Kym had one issue to discuss 'in private' and emailed regarding this. Chris [adol] thought it was a good idea to have his mum, Victoria, nearby during the interview in case he forgot something or didn't like me. She worked in an adjacent room, providing assurance of accuracy of information when Chris requested it from her.

4.9.1 Autistic participants as informants and 'experts'

The dominant belief reflected in the psychological literature suggests that autistic people lack a 'Theory of Mind' (ToM) (Baron-Cohen, Leslie, & Frith, 1985; Frith & Happé,

1999) and are therefore unable to recognise other people's mental states (they suffer 'mindblindness') (Baron-Cohen, 1997). It is believed that this "extends to difficulties in reflecting on their own mind" too (Lombardo & Baron-Cohen, 2010, p.395), thus, compromising how we (non-autistic) can accept how they (autistic) could 'know what they are talking about' specifically in relation to self-knowledge and self-representation.

To support this theory, it has been proposed that autistic people have a weak central coherence; they lack a neural mechanism that prevents them from seeing the 'forest for the trees'; the whole for its parts (Frith & Happé, 1994; Happé & Frith, 2006). Historically, it has been hypothesised that autistic people would be unable to make sense of a cohesive sense of self; their self-representation would be impaired and fragmented (Lombardo et al., 2010, p.620). It was thought that theories like ToM "provides the ability to predict relationships between external states of affairs and internal states of mind" (Frith, 2003, p. 77), thus provides an explanation for impairments in social functioning (Frith, Morton, & Leslie, 1991).

Given that the dominant literature suggests that autistic people generally evidence difficulty in attributing and recognising mental states in others, it is therefore implied that they cannot make sense of their behaviour (Wellman, Cross, & Watson, 2001). It was thought that in time research would lead to interventions increasing non-autistic understanding of autistic people and thus be an aid to help autistic people to make sense of themselves (Chown & Beardon, 2017). This implies that autistic self-expression is well-nigh impossible. Autistic people would be considered only able to express other people's ideas, by 'miming' them (Bustion, 2017; Williams, 2010), as in echolalia (Prizant & Duchan, 1981). Autistic people have typically been positioned in the dominant autism literature as having a 'disability' in self-expression; in thinking, knowing, and articulating first person experiences and by extension of their impairment, categorically, are rendered incapable of connecting with, and understanding other minds, regardless of 'where' on the spectrum one might be.

The dominant narrative and the rhetoric of 'mindblindness' and other delimiting theories about autistic communication has been contested by autistic people (e.g., Sinclair, 1992; Williams, 1992) and others including Bustion (2017). They believe it has contributed to the silencing of autistic people through the promulgation of a circulatory argument that renders 'listening' to autistic people as authoritative sources of their own understanding, oxymoronic. The problem with this argument is that it subsequently delegitimised all they say (Yergeau, 2013).

The dominant narrative of 'mindblindness', further privileges those with the power and authority to define 'normal' and make assumptions about fundamental things like 'communication', which then casts and positions others (Holland, Lachicotte, Skinner, & Cain, 1998). This 'positioning' can lead marginalised people to view themselves and the world from the perspective they have been cast into. This perhaps explains why autistic people like Amanda Baggs have felt the need to make a video presentation about something as innocuous as 'communication'. As a non-verbal autistic woman, she has been 'positioned' as one who *does not* and cannot, 'communicate'. However, her YouTube presentation 'In my language' (Baggs, 2007) has been viewed by more than 1.6 million people, who ironically understand that she is communicating her resistance to such a narrow definition for what it means to express oneself and exchange ideas with another!

Unlike cognitive psychological research, which suggests that ToM-type deficits were the result of dysfunctional or damaged biological mechanisms (Baron-Cohen, 1995, p.51), phenomenology does not reduce the mind "to the physical organ of the brain but describes it experientially as a seat of consciousness in which intention is directed towards things that take on meaning or significance for the person…" (Dant, 2015, p. 49). Philosophically, phenomenology poses that we have a conscious (not biological) 'mind' and we use our senses to bring into conscious awareness perceptions of the world. Thus, phenomenologists, like Edith Stein, suggests that our understanding of the 'I', is derived, to varying degrees, from our perception and understandings of how other people perceive us through consciously shared understandings, as well our lived, and bodily experiences (Baseheart, 1997).

IPA is not premised on having a certain type of participant, or having certain types of intersubjective skills, but rather, in having a participant that can make sense of, and communicate something of their own lived experience. In a study with verbal, high-functioning autistic participants, there may be more challenges to accommodate. It is expected that when 'on topic', participants will talk about those things of most interest and relevance to them *about the topic*. Instead of perceiving their 'topic of interest' as a hinderance, by asking participants about *their* interests, it demonstrated interest in them as people and was a means for building rapport.

In taking up a feminist epistemological standpoint, this research rejects prevailing notions that all autistic people have communication deficits so disabling that they are categorically inhibited from making sense of what is meaningful and of interest to them. This thesis acknowledges that autistic people are the 'experts' of their own experiences and accepts that even if they ‘see’ the trees and not the forest (Vermeulen, 2015), the ‘trees’ that hold the most significance to them are those we stand to learn the most about.

4.9.2 Privileging one voice over another

The loudest voices in autism research have often been parents and professionals (Davidson & Henderson, 2010). From a feminist epistemological standpoint perspective, it would be expected that I would privilege adolescent and tertiary students’ voices by interviewing them first, however, it seemed more pertinent to begin by interviewing advocates. This did not seem to render the autistic young person more silent, but functioned I think, to provide a better context for listening to adolescents’ lived experiences. Similarly, listening to parents talk about the ‘diagnostic journey’, which is a salient narrative in disability studies, provided a sociocultural and historical context for understanding autists perceptions of autism, especially their political responses to ‘being autistic’. During the analysis however, autistic voices were privileged. Where parents and advocates augmented understandings, or diverged, I continuously returned to the autists’ voices.

4.10 Reading transcripts and developing themes

The analytic phase begins with transcribing data and reading transcripts multiple times. Having done this, I began to code the transcripts using nVivo qualitative software. Whilst qualitative data analysis software like nVivo provides good data *management*, I struggled with the artificiality of the *analysis*. The biggest challenge was regarding coding to ‘nodes’. Node construction and the commitment to this level of coding seemed to create an artificial distance between the theme and its context, like that described by Zamawe (2015). I therefore opted for a simplified line-by-line analysis, loading the relevant data into a table, like Table 5. Some autists occasionally retold stories, so I chose the richest of any re-told story and omitted the skeletal versions, omitting also, deviations from the topic at hand, for example, elaborations on personal interest topics. The analysis continued through reading and reflection until superordinate and subordinate themes ‘emerged’. Superordinate themes included diagnosis, school governance, NCEA, and support. Whilst the autists’ voice was privileged it was a complex process given the various participant groups, and idiosyncratic occurrences of examples (or their omissions, creating suspicion).

Where the narrative is not ‘rich’ or ‘dense’, a ‘hermeneutics of suspicion’ enables one to consider meanings that are less evident, or are even disguised, within the text (Josselson, 2004). Thus, it is not only possible to consider and analyse what *is said*, but also to be informed by what remains taken-for-granted, and sometimes *unsaid.* A line-by-line manual analysis seemed a superior means for being 'suspicious'. Additionally, in hermeneutical studies, it must be remembered that the participant's understanding of experience is interpreted against a backdrop of knowledge and ideas about what they think is experienced. Thus, new understandings emerge and get, as it were, developed (Denzin & Lincoln, 2011).

Table 5. *Sample of IPA coding process*

Transcripts	Interpretation - developing themes	Emerging theme
I remember after I found out that I got a 'Not Achieved' for my Algebra test, I just went away and I just started (pause) I just started getting upset and emotional	Disappointed with result. Expected to achieve Pressure to 'achieve' Strong reaction for adolescent Emotional reaction	Emphasis on credit attainment Managing emotion
the last period was science and we were all just watching a movie and I just decided to have some down-time, just playing games on my laptop, though I had homework, I still had to have down-time… because having "Not Achieves" that's what made me have down-time.	Takes time to recover from these academic disappointments High expectations dashed Needs recovery time	Strategies for managing emotion Impact of emotion on focusing; Learning opportunities compromised
So, I remember struggling in my Māori exam and that made me have down-time. It stopped me from studying Māori for a while. But now I've just got to let go of that and I just want to move on.	Difficulties across subjects with literacy basis? Exam stress? Stress and anxiety inhibiting relaxation. Lack of practical strategies Taking personal responsibility	Emotional impact of NCEA Support for student Positioning of 'responsibility' Academic and social support
If I have homework…so if I've got…If I just found out 'oh, I failed at my favourite subject, ohhhh' or this friend has upset me, I'm just going to have downtime, or the teacher has upset me and all that and I'm just going to go away and have time alone and all that.	Failures are painful The school day is filled with events and experiences that need time to process. Multiple factors (academic, social, and teacher characteristics) impacting attainment. Downtime is needed for 'making sense' and restoring equilibrium; coping	Reflections Teacher characteristics Teacher understanding of autism Support Personal responsibility

4.11 Chapter summary

In summary, this research project draws on the philosophical phenomenological traditions that have their origin in Wojtyla's philosophical 'method' (Personalism) and Husserl's philosophical phenomenology, especially that which came to be understood, explored, and critiqued, by his students Edith Stein, and Martin Heidegger. To guide the interpretative 'act' of 'doing' qualitative phenomenological research, the method is derived and adapted from Smith, et al.'s (2009) application called IPA.

By adhering to the methodology proposed, this research analysed participants' meaningful experiences, perceptions, and concerns within the social and academic domains of 'education' in the hope of contributing to a small, but growing body of inclusion literature exploring 'being', 'being autistic' and 'being autistic in mainstream high school' (albeit a predominately 'normal' or 'neurotypical' milieu). In these 'spaces' it was expected forms of oppression would be illumined and unexpected themes would be brought into the light during the act of phenomenological analysis.

The theoretical frameworks guiding this thesis are applicable and compatible with the philosophies and the methodologies introduced in this chapter, minimising internal structural conflict. Phenomenological enquiry tends to provide a certain liberty that enables the researcher to be guided by its philosophical underpinnings throughout all stages, personalising the project and giving it its 'shape'.

Chapter Five
Discovering autism and 'being autistic': butt-burgers and ice cream sundaes

"I am on the high levels of autism, you know Asperger's Syndrome or 'Ass-burger's' as Americans call it, so I am a 'butt-burger'."

(Chris [adol], p. 12).

5.1 Introduction

For the participants in this research, the diagnostic journey was a diverse experience. It began for parents and some autists with a period of confusion, marked by frustration resulting from referrals, lengthy delays, misdiagnosis and medical experimentation. Parents and advocates believed that the diagnosis was needed to access support. Autistic participants believed it 'made sense' and explained 'them'. Autists immersed themselves in the autism literature, gauging accuracy in relation to lived experiences, and over time, realised limitations to categorical understandings. Three participants, two tertiary and one high school, believed that the medical model narrative had limitations. They considered alternative narratives to the DSM, and these are explored at the conclusion of this chapter. This chapter suggests that some autists have arrived at an 'identity' and have come to understand themselves in less derogatory ways, having a mixture of symptoms and abilities. They used the interview to advocate for a broader understanding of autism, promulgating alternative narratives.

Whilst this chapter provides insight into the diversity of NZ autistic peoples' experiences and understandings of 'being autistic' derived from their diagnostic experiences, reflections on self and identity are entwined understandings derived from 'in/ex-clusion' experiences. This chapter therefore needs to be read considering the entirety of one's lived experiences; 'being autistic' intersects with experiences and affordances within home, community, and school contexts and is not simply about a 'diagnostic experience'. For ease of reading, parents' diagnostic experiences are explored first, followed by autistic participants' perspectives, resulting in some overlap. However, this is also commensurate with a chronosystem perspective, whereby the diagnosis is often pursued by parents first of all; it is only when left undiagnosed that young people begin to seek answers for themselves regarding their functioning.

De Pape and Lindsay (2015b) conducted a metasynthesis of parents' lived experiences of raising an autistic child. They found this limited body of literature could be broken down into six salient themes. These include: the pre-diagnosis phase, which is a search for answers to a-typical development; the diagnosis, resulting in various reactions ranging from relief to devastation, as well as guilt and blame; the adjustment to the diagnosis as a family, resulting in adaptations to daily life, including additional financial pressure, the need to take on more work, and emotional adjustments that may also result in parents medicating to manage stress; learning to navigate the autism 'system', including accessing support and liaising more with school; becoming empowered, including a search for solutions that provide coping strategies and additional control in daily life; and, moving forward, by incorporating 'autism' into a new normal, becoming aware of the benefits of looking after an autistic child, and navigating concerns regarding the future.

In this study, similar themes were also evident. I have temporally arranged these according to the pre-diagnostic phase, characterised by confusion, noticing 'difference', and self-blame; the diagnostic phase, characterised by referrals and delays; and, the diagnosis, received quickly for some and after a 'battle' and 'long journey' for others. Parent perspectives are augmented by advocates' perspectives, as well as autistic participants, especially when speaking on behalf of their parents' experiences.

5.2 Secondary perspectives: Parents and advocates tell their story of the 'diagnostic journey'

In NZ, the 'norms' by which infant, child, and adolescent development is measured, is derived from the steady growth of research into normative development taken up in western social science research, through the disciplines of Human Development and Developmental Psychology. These measures and milestones, derived from the calibrated psychometric findings in the physical, cognitive and socioemotional domains of development became, as Rose (1989) argues, a matter of sameness and difference which is now so well-disseminated as to have become assimilated into the fabric of normative 'growing up'. As such, they have veiled alternative ways of understanding 'childhood'. We now share a collective understanding of 'normal' childhood development; we have internalised what it constitutes and therefore what is deemed most desirable in our culture. Knowledge of measures and milestones have increasingly become incorporated into the warp and weft of how we parent, and it contributes to our common-sense understanding of childhood developmental expectations.

Our Plunket books[8] are among our first 'gifts' from the state after the birth of a baby. This is a government-funded initiative to monitor child progress. Whilst our Plunket books testify to the legitimacy of medicalised standards for monitoring child development in NZ, their initial aim was to improve the health of babies by helping mothers to be *better mothers*. Founder of the Plunket Society, Dr Frederick T. King, otherwise known as 'Truby King', "believed the family incapable of fulfilling its functions unless the wife-mother had been trained and supervised by scientific experts" (Olssen, 1981, p.22). Infant and child 'surveillance' therefore increased commensurate with a mother's dependency on the patriarchy of medical professionals to tell her how to do 'her job' (Weiss, 1977). This was a global westernised phenomenon. Between 1914 and 1978, Dr Spock's pamphlets on 'Infant Care', and his 'Pocket Book of Baby and Child Care' became recognisable sources of mothering authority and subsequently internalised as socioemotional support. Fifty-nine million copies of the pamphlet and 28 million copies of the book were issued with many mothers writing in from all over the world to the managing Bureau that the rules and expectations conveyed therein were essentially their 'bible' (Weiss, 1977).

The implicit assumption was that 'good mothers' are vigilant mothers. Their cue was no longer in following other women as sources of authority. Infant and child development were academic knowledges. Over time, mothers became increasingly indoctrinated into the process of monitoring 'normal' development, recording attainment from their children's earliest days of life against lists of specified 'developmental norms', including more recently, social comparisons on popular media. The function of the state to monitor children's health was transferred to the natural, taken-for-granted function of a responsible citizen and is one of the first measures of being a 'good mother' (Blum, 2007; Hays, 1996).

The onus on parents to judge their children's behaviour has increased substantially in the last decade as neuroplasticity discourses have increasingly circulated in the public domain. Authorities and service providers reinforce this sense of responsibility and 'urgency' in order to promote the necessity for 'early intervention' regimes that aim to capitalise on what is thought to be the peak period of the brain's neural malleability (Rose & Abi-Rached, 2013). There is an expectation that 'early intervention', in whatever biological, behavioural, cognitive, or psychosocial form this might take, has potential for compensating an otherwise inevitable trajectory of ever greater and irreparable 'losses' or deficits. Autism

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[8] Plunket books (The Well Child/Tamariki Ora Health Books) have been freely given to NZ parents, predominately mothers, since the 1920s to record the growth and development of a baby from birth to five years of age.

is no exception (Bryson, Rogers, & Fombone, 2003; Nadesan, 2005). Thus, early detection of disorders is thought to maximise the ‘window of opportunity’ available in early childhood development for interventions in a bid to promote or compensate for ‘normal’ development; “our most vulnerable” (as our young, disadvantaged, and ‘mentally ill’ are typically referred) (Gee, 2018; Vause, 2017) ‘need’ every opportunity to develop according to the desired ‘norms’ of our culture.

5.2.1 Confusion: there’s ‘something not right!’

Parents have therefore shown themselves to be adept at noticing when ‘something isn’t quite right’, even if they cannot pinpoint exactly what is wrong (Frith, Soares, & Wing, 1993; Portway & Johnson, 2003). Midence and O’Neill (1999) believed parents sought a diagnosis for their child after they noticed a disordered or a-typical pattern of behaviour in early development. Parents in this study reflected on their own experiences to suggest that whilst ‘differences’ were evident almost from birth, they were difficult to articulate, perhaps the result of baby’s lack of agency and ability to act on the world in more specific and complex ways, leaving parents initially with only a sense that ‘something wasn’t right’. Over time, this general notion gave way to specific concerns, evidenced by concrete examples and an intensification of vigilance against comparative norms:

> *The things that stood out to me for Chris [adol] from the time he was born [...] like he’s the first depressed baby I’ve ever come across […] that I’ve noticed. Just before he went to school [...] he was, very self-involved and isolated [...] he was quite happy to play with his siblings, he never smiled, he never drew a happy picture of him smiling – everyone else was. And he always came across as slightly depressed, which I thought was quite strange in such a young child so that was in the back of my mind. So, as we progressed, I said to (husband,) ‘I’m going to start writing down what I have observed with Chris [adol]’… I observed him and every day after school, he ran around the garden and he started making noises and I thought “Ohhhh!” That put me in a panic* (Victoria [par], p.2-3;18).
>
> *I always knew there was something different about him. I’ve always known it… before school, maybe even at school… The first year I would have picked it up already …because I kept thinking ‘what the heck is this child’s…’ you know?* (Kym [par], p.5; p.9).

> *There was something not right and (long pause) I think in time some of the adults, particularly teachers exacerbated it sometimes out of ignorance, but in the same way I did. Was it just a matter of making the boundaries firmer? […] because we didn't know what we were dealing with and that was the thing - was this kid mad or bad?* (Danny [par], p.4).

Curiosity and confusion that marked the earlier years, became markedly obvious and increasingly distressing as the seemingly 'abnormal' became in-explainable:

> *There was a couple of incidences in primary school where he has had a fight in the playground, where he has ripped a chunk of hair out of a kid… And they were odd incidences . . . it's 'oh what's going on?'* (Danny [par], p.3).
>
> *But as things got on, chairs would get flung across the room – and again it's 'oh what's going on'? We were visiting a friend once and he's smacked some other kid in the face and he's just gone BANG and we're going…* (Danny [par], p.3).

Over a protracted period, parents, wider family and one teacher with links to an autism community centre, all noticed the emergence of behaviours that signalled developmental deviations; a-typical development.

> *His Omar here, she said "I'm telling you it's Asperger's"* (Kym [par], p. 3).
>
> *Within a couple of months of being there (Integrated Catholic High School), the Guidance Counsellor said to my mum and dad "we think you should… it's probably worth getting her assessed." Um, and so I was referred to CAMHS*[9] *through the DHB* (Grace [ter], p. 6).
>
> *Then one of the teachers whose brother ran [autism organisation] said 'I think your son has Asperger's' and I was like 'what the hell is that?'*
> (Victoria [par], p. 2).

Grace ([ter], p. 28) reflected that prior to her diagnosis, her extended family attempted to make sense of her confusing (autistic) behaviour. She perceived that this added to the burden her parents were experiencing. She recalled how she would often cry and experience

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[9] CAMHS: Child and Adolescent Mental Health Services

seemingly illogical tantrums (what she now knows as autistic ‘meltdowns’) and how responsibility for these episodes were often unfairly projected upon her parents as though they were to blame for her actions, which they were powerless to control.

> *I tended to get upset and cry a lot and it was … Mum and dad were often quite criticised for poor parenting …* (Grace [ter], p.28).

The result of concern over a-typical development resulted in parents navigating ‘self-blame’.

> *He’d throw himself down and scream at the top of his lungs and people would come past and…that used to bug me…well, I used to…I used to let it… you know… God I’m a bad parent and it wasn’t until he was actually diagnosed with autism that some stuff started to…oh well this is called a ‘meltdown’; it is not a tantrum* (Victoria [par], p.23).
>
> *I had nurses tell me “no, well actually I don’t have these problems with my kids” so the parent was to blame* (Danny [par], p.1).
>
> *I kept thinking ‘what have I done to cause my kids to be like this?’ I felt like a bad parent because of the tantrums, which we later learnt were ‘meltdowns’* (Victoria [par], p. 2).

Whereas as a ‘tantrum’ signalled a potential ‘parental problem’, a ‘meltdown’ has no such societal attribution.

Kym [par] (p. 10) also grappled with self-blame. However, she negated responsibility by placing this in God’s Hands.

> *I am a born-again Christian, so that is my whole life, not just Liam - my marriage and my everything revolves around God, so I think that has been hugely important for me because I had that piece of ‘no this is not actually me’ and I didn’t own it.’ Like, because he’s not like…because then I’ve heard mothers say, “oh but I made him” but ‘no’* (Kym, [par], p. 10).

Kym believed in Divine Providence, accepting that our innermost being is not an arbitrary arrangement of DNA, but one specifically ‘knit’ together by God (Psalm 139:13). By accepting that God’s mode of stitching may include a genetic pattern that results in an autistic phenotype, she rejected what she understood to be a prevailing assumption about ‘mothering’.

5.2.2 Seeking understanding: searching for a diagnosis

There has been a long history of parental dissatisfaction regarding diagnostic processes, particularly because delays increase parental stress (Quine & Pahl, 1987). The metaphor of a 'journey' is typically used in mental health narratives to convey the depth and breadth of the experience traversed, covering all the phases of the diagnostic process, from curiosity, to distress, referrals, diagnosis, interventions and 'treatment'. It is often used by families to convey something epic (Muhlbauer, 2002, p. 1076).

Parents generally looked back to this period of actively searching for answers, as the most treacherous part of their 'journey'. Whilst this time was characterised by diagnostic delays, referral difficulties and significant frustration and distress due to a lack of 'answers', diagnosing clinicians have noted that the complexity of diagnosing and the comprehensive nature of assessments, requires time (Perkins et al., 2018) and therefore patience.

> *…he [specialist] just would not diagnose; he would not say 'yes' and he would not say 'no'. He just said come back in two years' time, which is the worst thing you can tell a parent who had been waiting for 18 months on a waiting list to come back again, you know and go away empty-handed. In my personal case, that is why I flew to Brisbane to go and see Tony Attwood[10], yeah, not to put up with all this nonsense* (Grant [adv/par], p. 19).
>
> *Now I knew he had Asperger's syndrome three years before that, but there was no one diagnosing and then I managed to get Tony Attwood to diagnose . . . to have a session with him and, I paid for it, and he gave the diagnosis* (Karen [adv/par], p.24).

Danny's [par] experience of 'the journey' was frustration, isolation, misunderstanding, and distress. He repeatedly felt as though he was not listened to or taken seriously, which had repercussions for his physical and mental health. As a solo dad, the process left him feeling at times as though he "was shattered" (p.15), which he repeatedly re-articulated as a 'trauma' stemming from the experience of violence inflicted by 'the system'. Danny's transcript stands out as one heavily punctuated by excruciating adjectives conveying a diagnostic journey that was: "horrendous…all consuming… lonely…. exhausting… painful… very frustrating… a nightmare… really hard…[traversing] heavy stuff… of

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[10] Tony Attwood is a clinical psychologist known world-wide for his writing and 'expertise' in Autism, especially AS.

becoming overwhelmed." Danny's journey, like other parents have indicated (e.g., Corcoran et al., 2015), was an all-consuming one; taking all his resources, including fiscal and emotional.

> *I think while the story of James [ter] and his journey and our discovery of him being on the autistic spectrum, there is a larger picture, but that became the all-consuming picture [...] in the meantime, we have been shafted from one place to another and then there is actually no accountability [...]we didn't fit anybody's boxes - no one wanted to know* (Danny [par], p.1-2).
>
> *...so we had CYFS[11]; we had YJ[12]; we had Work and Income[13]; we had Education; we had Mental Health; we had GPs; we had Open Home[14]; we had other youth services; we had...; And you know, within each of those there was subsections; we had Skylight;[15]...Skylight were pretty good...; Numerous counsellors - because each time you are saying 'this kid ...we're not making progress'... and I think that was, part of the thing was [lack of diagnosis]* (Danny [par], p.26).

By the time Kanner's paper appeared in the vernacular in 1980 (Wing, 1980), there had been significant worldwide reduction in the use of institutionalisation. The disability sector has long since advocated for human rights including non-institutionalised forms of support. Compared to 1900 "when Kraepelin and Freud were putting forward the ideas that would shape modern psychiatry, by 2000 there had been a fifteen-fold increase in rates of admission to psychiatric wards" (Healy, 2002, p. 329). NZ continues to carry remnants of this dark past forward, casting more than a mere shadow over the lived experience of participants in this study. Danny [par] was told that a period of 'institutional care' would lead to 'insights' into James's [ter] behaviour. He was 'advised' to admit James into psychiatric care for a period of three months "for observations". The goal of 'care' was to

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[11] CYFS: Child, Youth and Family (New Zealand). In 2017 this became known as the Ministry for Vulnerable Children and is now known as Oranga Tamariki or Ministry for Children.

[12] YJ: Youth Justice. Youth Jusitice was used in this context to refer to services instituted to support offending children.

[13] 'Work and Income' refers to a government-funded department under the Ministry of Social Development, dedicated to financial assistance and job-search.

[14] Open Home refers to the Open Home Foundation, which is a Christian family support service whose work now aligns with Oranga Tamariki.

[15] Skylight support children and young people specialising in grief support, trauma and loss.

enable the ‘expert’s gaze’ free reign, to ‘look into the mind of another’ to discern *why they* could not ‘cope’, barring them from ‘everyday life’ in the process (Rose, 1990).

Danny [par] had limited contact with James [ter], including access to essential information regarding ‘care’ and ‘progress’. Given how ingrained and internalised parental responsibility is, this was particularly painful for Danny. He reflected with remorse over his failure to ‘take care’ of James [ter] who was 13-14yo at the time. Danny believed James’s confinement to a psychiatric ward was ‘involuntary’[16]. O’Hagan (2003) suggests that remorse is a common response to any type of force used in mental health services: “Many users believe there should be no compulsory treatment because it violates an even more fundamental right than the right to freedom of movement. Compulsory treatment sets out to control who you are, whereas compulsory detention merely controls where you are” (p.4).

> *Danny: that was involuntary - and I wish I hadn’t. I was given advice ‘they [institution and psychiatrist] will help.’*
> Sharon: who gave that advice to you?
> *Danny: The psychiatrist […very long pause gathering his composure…]* ***and James hated it*** *[…] and he wasn’t believed and […] they were all two or three years older than him, he was frightened […] he would tell me “dad there are drugs in there and there are kids sleeping together.” So here I am, trying the best to care for my son and the systems and the people are blocking that. I couldn’t get plans; I wanted to know information: ‘what’s happening; what are you going to do?’ ‘Oh, let someone else worry about that.’ And you couldn’t get it. […] But you know, there is a lot of ‘I wished this had been different’; sometimes I wish I had done things differently* (Danny [par], p.10; 28).

The lived experience for Danny [par] is one of subjugation, followed by self-blame: of the unrivalled dominance of the ‘expert’ and unrivalled diffusion ‘within the system’ of any responsibility for quality of care. The goal was framed as being a time for observing and looking into the ‘workings of his mind’ with ‘disorder’ being innocuously ‘located’ within; where the body is *the* site and object ‘to be watched and explored’ as though it will give up its secret workings with enough vigilance.

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[16] He possibly felt it was ‘involuntary’ because duress and coercion have been common factors in voluntary confinement (Stone, 1999).

Danny [par] experienced the power of the ‘system’ and his powerlessness and oppression bodily in the form of personal regrets, anxiety, and distress. In his failed attempts to pin down and locate responsibility for his son’s experiences whilst institutionalised, he arrives at the conclusion that he alone ‘should’ have made different decisions and thus has no other option than to ‘accept’ ‘accountability for care’ himself, internalising and justifying it as his own failings. As a parent he reflects that he could have (and should have), prevented the abuses that ‘the state’ enacted and threatened.

Kym [par] also experienced ‘the system’ as a long and protracted ‘journey’, with Liam [adol] remaining undiagnosed until his last 6 months of high school. Kym perceived the pre-diagnostic phase as being marked by blame, misdiagnoses, and experimental medicating:

> *I mean even when he was put on those antidepressants, he was about eight, he was a zombie and I phoned the doctor and I said, “I’m not even coming back in; I’m taking him off the pills.” He was just a zombie you know – “go and clean your room” “***okaaaaay***”, “come and eat” “***okaaaaay***”. It was just… He was so drugged up. […] I am like ‘nah’ “I am taking him off right now”. And the Ritalin too - that was in New Zealand when they put him on Ritalin. I mean, and later I discovered that they do that to try. That’s a dangerous game to be playing. ‘Let’s put him on Ritalin and see if that calms him down’. That is a very dangerous game to be playing because it is brain altering* (Kym [par], pp. 11-12).

In a neoliberal climate it is expected that all people in a transaction will be benefited by the transaction (McGregor, 2001), thus to ‘miss autism’ is to have leave the ‘transaction’ without ‘satisfaction’ of insight, or a money back guarantee. This contributed to parent’s perception of the ‘cost’ of the autism journey. The actual diagnosis was the ‘commodity’ they deemed valuable; they anticipated it would bring clarity and direction. Parents like Danny and Kym felt neglected and dismissed within the mental health ‘system’, as though no one would go the extra mile to listen long enough, similar to parents in other studies (e.g., Hall & Graff, 2010; Russell & McCloskey, 2015;).

5.3 Being diagnosed:

To date the literature is sparse regarding “… the impact of political variables on health policy and on health outcomes” (Navarro, 2008, p. 354). However, according to Sugarman (2015), neoliberal governance constrains time for relationship building, impacting health and well-being. Danny [par] believed that the politics of economics in health were evident. He believed it not only impacted the diagnostic process but contributed to the cause of a ‘system’ that is now complex, multifaceted, difficult to navigate, fragmented and effectively directing ‘blame’ away from ‘experts’, and firmly placing it on the shoulders of parents, suggesting “ there is actually no accountability” (p. 1).

Stace (2011) concluded in her PhD, that if you can find the ‘right person’ in the ‘right place’, good diagnostic outcomes are possible in NZ for autistic parents and their children. The ‘right person’ was someone willing to go the extra mile, to listen, and not give up without resolution, support, and understanding. For Danny [par] and Kym [par], meeting such a person was transformational. Kym had first taken Liam [adol] to a psychiatrist at age five and had not relented in seeking ‘answers’ thereafter. After years of delays and referrals Kym and Danny believed their diagnosing psychologists were more oriented toward elevating their child’s needs above the limitations of a mental health system, which had hitherto functioned to otherwise constrain good outcomes.

> *…and sometimes you just get the right person in the right placement and she was passionate about the outpatient work… She [diagnosing psychologist] had been ‘refused’ [perhaps ‘castigated’] within the system…. You know she is only supposed to spend so long doing this - she refused, and she just stayed, and stayed, and stayed until they knew… I mean she did so much outpatient work and she said ‘I want to do this’ and she took us to [City 150+ km’s away] for a week and they put us up in a motel, yeah and every day we went in and they just did test after test after test, not just around autism, but around IQ, where they were getting great results here and then they would get “I can’t even give you an answer on this one because he just doesn’t function there”, you know* (Danny [par], p. 12).
>
> *Sometimes you have to step outside. Would not be outside my… I wouldn’t do anything outside what was, you know, I was supposed to do really. But it might be going, taking an extra step, you know…well, just spend extra time really…* (Pamela [adv], p. 22).

For two families the diagnosis was quick in coming. Victoria’s [par] oldest son was ‘profoundly’ autistic, so she was ‘vigilant’ with her second son, Chris [adol]. She took notes and discussed them with her GP and then Pediatrician, obtaining a diagnosis of ‘mild autism’ (AS). Catherine’s [adol] diagnosis, however, came as a surprise:

> *I was going to the doctors (for Chronic Fatigue) and [he]was like "Oh, she's oversensitive because she's on the spectrum." And we're like (laughing)* ***"ahhhhhhh …what spectrum?"*** *We [mum and I] got a bit confused. I had Chronic Fatigue issues but then I had medicine for it and that helped* ***and then I had the autism diagnosis*** (Catherine [adol], p. 25).

Looking back, parents and advocates believed the diagnosis was 'needed' for personal understanding and was transformative when it came. This is consistent with the belief that an autism diagnosis has explanatory power; potential to explain someone's thoughts, feelings, and intentional behaviours (O'Connor, et al., 2018). It has profound consequences, different from those touted by early interventionists:

> *…well, we're not calling the police every other day; we are not having violence…I think it was probably a lightbulb moment for him (James [ter]). He's probably been bashing around in this dark room going over stuff and getting frustrated and someone has turned on the light and he's gone 'is this what the world looks like? I can walk over here, and it is safe' and I think it must've been like that for him. He took responsibility for it and he would read stuff* (Danny [par], p. 19).

Kym [par] believed the diagnosis 'opened doors' to knowledge and support, for her and her son. This converges with advocates' experiences, suggesting that access to educational services is one of the primary reasons why it's necessary to pursue a diagnosis for students in NZ. Without this, in a system set up for 'normally developing' students, failure is imminent, and blame difficult to shift.

> *So, I think in NZ particularly, without a diagnosis you cannot access any resourcing and there are very few resources anyway, so you need that* (Karen [adv], p.33).
>
> *If you don't have the diagnoses or a problem, you don't have an IEP*[17] *do you?* (Karen [adv], p.23).

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[17] IEP: Individual Educational Profile

Parents assumed that if teachers knew the diagnosis too, the label would 'speak for itself'. They expected that teachers would have similar reactions to theirs: compassionate understanding, and supportive accommodations.

> *So if, say we got a diagnosis when James was 11, so went into high school and the teachers were aware that we have a kid on the autistic spectrum - be aware that he will be overstimulated in a noisy classroom for example, so again providing those ways out* (Danny [par], p. 24).

> *Without a diagnosis there is very little that they* ***can*** *do, which is sad because I think with a diagnosis, Liam could have at least had Level 3 NCEA by now* (Kym [par], p.2).

> *…they didn't know what they were dealing with… yes, that [diagnosis] would have been key* (Danny [par], p.11).

Parents and advocates also thought that a formal diagnostic label would curtail informal labelling, such as 'naughty' or 'lazy'.

> *The only reason we ever got [daughter] diagnosed in the first place was because the teachers …you know they…it was always about her being naughty or about her doing this. . .* (Paddy [par/adv], p.45).

> *Nobody understood him* [an as yet undiagnosed teen], *he was clearly in major distress and all that happened was he got labelled as bad, different, wrong, mentally ill, all that kind of stuff* (Michelle [adv], p.16).

Parents continued to carry the scars of their diagnostic journey. Reflections were tear-filled; their deepest anguish inexpressible in words. Transcripts were punctuated with moments of anguish and filled with silent voids. Heidegger rather poignantly notes: "in order to be silent, Dasein must have something to say, that is, must be in command of an authentic and rich disclosedeness of itself" (Heidegger, 1953/2010, p.159). For some parents, silences were augmented by embodied reactions; tears were occasionally held at bay whilst the body contracted, or they flowed, and we waited patiently for them to pass.

> *I have realised now that we are in a relatively stable part of the situation, that there is no place to kind of reflect on what has been a horrendous sort of 10*

> *years or so[…] And when I do sometimes stop, I think some of that is really, really painful* (Danny [par], p.1).

The sample of parents and advocates in this study make generalisations difficult. However, advocates believed that the diverseness of diagnostic experiences reflects growing knowledge regarding autism and autistic peoples' experiences:

> *Eight years ago, they didn't [diagnose]. As I say the level of ignorance was incredible. I'm talking about people like psychologists and paediatricians and that, even then. I was arguing with a lot of people back then; they just didn't know, and I mean it was quite shocking. And, parents were giving me the same feedback, it wasn't just my opinion* (Grant [adv], p. 1).

> *What I am happy to say is I think there has been an improvement over the years. I mean, I've been working as a Clinical Psychologist for 30 years and I've seen a really big shift in the whole thinking about autism, from nobody even knowing what autism or Asperger's was to now, you know - now it almost seems like everybody wants to get themselves or a family member diagnosed* (Michelle [adv], p. 8).

As a solution to diagnostic problems resulting from heterogeneity, Danny [par] suggested that there needs to be a better balance between checklists derived from strict, diagnostic criteria and lived experience, commensurate with autistic people's developmental stage, thus phenotypic expression. Exploring these types of checklists was the point of my Honours degree research outlined in Chapter One.

> *…but the problem is we go there's 37 features and you've got to have eight of them or whatever the combination is, so one child has got features a, k, l, o, w and James has got these ones and each one needs some slight variations* (Danny [par], p. 24).

> *...have any tests been done around autism; I wonder…?' That's pretty simple. 'Where could I start… even a little checklist.' When we get a child at whatever level, I think even at 13 or 14, a kind of a checklist [so we can rule out] 'has this been explored?'* (Danny [par], p. 30).

Autistic participants recounted similar diagnostic experiences. This is not surprising given that there were three parent-adolescent dyads. However, autists' experiences also diverged in important ways too, particularly in considering the consequences of 'not knowing' they were autistic and the desire they had to challenge others to consider the limitations and implications of categorical identity, in getting to know them.

5.4 Autistic participants' perspectives of the 'diagnostic journey'

The interviews with autistic students' (high school and tertiary) began by asking if they could recall the diagnosis they had received and at what age they learnt about it. Beginning with these types of questions helped to 'break the ice' and functioned to provide young autistic people with a chance to begin sharing something factual and potentially easy to discuss. It was assumed that all participants, being 16 and over, would understand what the words 'diagnosis' or 'diagnosed' meant, however one participant had to stop and think about the meaning:

> *mmm [...] 'diagnosed'? I've forgotten what that word even means!* (Brad [adol], p. 1).

He may have forgotten in that moment what the word 'diagnosis' meant, but a few moments later he demonstrated his understanding, commenting that he had been diagnosed:

> *my mum has told me that* ***I am Asperger's****... since like I was an 8-year-old* (Brad, [adol], p. 1).

5.4.1 Prediagnostic period

Like parents (including advocates who were also parents of an autistic person), some autistic participants demonstrated recognition and insight into their differences prior to their autism diagnosis. Except for Liam and Catherine [adol's], high school participants had been diagnosed prior to age ten. Of the tertiary participants, Emily was diagnosed young and had no recollection of being undiagnosed, whilst James and Grace were both diagnosed in their teens (15 and 13 respectively) and reflected on the time leading up to the diagnosis.

James [ter] and Graces'[ter] recollections of 'being undiagnosed' coalesced around delays, recognising differences and being confused by them, receiving false diagnoses, and acting out in violence as a result of being misunderstood. Grace [ter] recalled delays in being able to obtain an appointment with CAMHS following a heightened period of angst, whereby she knew she was fundamentally different, but not why. Eight months was spent waiting for an appointment, with follow-up appointments also being delayed. This seemed to her as though a very long time to be left wondering, as a teen, why you are 'different'. She recalls this period of waiting as one marked by feeling depressed and anxious. These are two common comorbid diagnoses for autistic teens.

> *…so I was referred to CAMHS through the DHB in May, I think, of my year nine and it wasn't until February of the next year that I even got a first assessment, so it was that long… It was an eight-month period from referral to actual, even first consultation and then another couple of months after that by the time I actually got a formal diagnosis* (Grace [ter], p.6).

It was around the age of 12 that Grace [ter] recalls noticing something regarding her way of 'way of being' that was 'fundamentally' different from the 'way of being' of others. She muses that *their inner world* must contain something that *her inner world* lacked; whilst 'they' were able to apprehend the world and make sense out of the ordinary, for her, the 'ordinary' always seemed to remain 'extra-ordinary' and in-apprehend-able. The desire for a diagnosis thus increased.

> *I knew I was different. I knew that! I knew that there was something* ***fundamentally*** *different because all these other people seemed to be doing this stuff and it all just seemed to come so naturally to them; to talk to each other and to know these things and there seem to be all these* ***things*** *that everyone knew that I didn't and I had no idea* ***how to learn them*** *and it was like "where did you get all this stuff from?" But as a concept 'autism', or 'Asperger's' or whatever, was never on my radar at all until diagnosis* (Grace [ter], p.29).

> *It's so integral in the way that I think, in the way that I act, in the way that I react and all of that is like, who would I be without that [...] but it means that I see the world in a very different way* (Grace [ter], p.8).

Amid the confusion regarding her self-identified 'ontological differences', Grace [ter] also demonstrates engagement in the ordinary developmental tasks of adolescence: separating self from the other; a natural process that is confusing. It is thought that in the task of gaining independence (in preparation for unity in adult relational partnerships), there is an increased awareness "…of the ultimate isolation of one's inner world from the inner worlds of others" (Van Noorden & Bukowski, 2017, p.604). By making social comparisons between herself and others, she is engaging in the ordinary task of self-evaluation typical of adolescence (Heckhausen & Krueger, 1993) and perhaps no less important for autistic adolescents (Huws & Jones, 2015). In order to arrive at this notion, she must engage in theorising about her mind as well as other minds.

The benefit of knowing *why* she was different outweighed the 'cost' of a diagnosis for Grace [ter]. Her parents [not interviewed] considered that a diagnosis would come with a 'price tag': the cost of 'being marked', or labelled for life as 'mentally ill':

> *I can remember arguing for a diagnosis because I got frustrated and not being able to explain why all these things happened to me.* ***Why*** *- I need to be able to say* ***why*** *this is causing so much trouble and it was something that was very important to me. Whereas mum and dad were a bit more, not unwilling, but were a bit more concerned about the idea of being labelled and then having a label that will follow you for the rest of your life and my perspective was, well my life is already pretty sh#t so surely a label is not going to make that much of a difference and any way to help explain this is going to be better than this* ... (Grace [ter], p. 19).

Grace's reflection assumes that the cause of her 'differences' is biological, resting entirely 'within her'. She looked back and made sense of her experiences as though all her peers were 'normal', positioning herself as the opposing binary: 'abnormal'. She simply wanted to know why she was 'abnormal', not *just* 'different'.

James' [ter] interpreted the period prior to his autism diagnosis, primarily in terms of 'being violated' and 'being violent'. He recalled being labelled 'naughty' in school (something that parents in this study believed would stop with a diagnosis) and reflected on his myriad of referrals investigating his 'being' (different). His mother had died several years earlier, and this became the focus for his behaviours. On reflection, James understood his reaction to her death as typically autistic (e.g., Robison, 2008) and logical. Therefore when "every other counsellor or psychologist" said "so tell me about your childhood and how did that make you feel?" in hindsight, it left him feeling as having been violated (pp. 11-12), particularly as these types of repetitive 'investigations' did not increase self-understanding or provide insight.

During the pre-diagnostic period, James [ter] also recalled feeling 'forced' into psychiatric care to be gazed upon. He recalled this as a very dark period, marked by a regime of enforced 'experimental drug use', as a kind of 'elimination' approach to fathom why he 'operated differently'.

> *I signed it. Unbeknownst to me, I had signed "hey um, you've given up all rights to say you could go out on your own free will or whatever. I wasn't allowed to leave. I was in prison basically; a self-imposed prison"* (James [ter], p. 17).

> *James: I guess the worst time of my life. I was put into a psychiatric ward… There was a psychiatrist, psychologist, one of them, the ones that prescribes medicine*
>
> Sharon: psychiatrist
>
> *James: yeah, I don't know why, he just seemed to make my life like a living hell for some reason, I don't know. Yeah, so I was in a Psychiatric Ward for like three months.*
>
> Sharon: Ok, did he say what he thought the problem was?
>
> *James: "I don't know, I don't know. I think we need to have a look closely at your life, or something". It was weird* (James [ter], p.5).

James's repeated return to this topic to re-re-construct, re-emphasise, and re-recount it, particularly the pain associated with 'being a subject' of 'investigation' through intense observation and 'experimentation', adds to his conviction of having 'been violated'. He understood this 'treatment' as not only a violation of his rights, but ultimately perhaps, considering his diagnosis, as a violation of being a *normal* 'autistic' person:

> *…it was the worst experience! That was when they [CAMHS] sent me to the psychiatric ward after trying me on a trillion different drugs – I hated it! I absolutely hated it! […**long pause**…]* (James [ter], p.24).

Whilst this echoes assertions that in a neoliberal governmentality, we are each positioned as responsible for our own 'madness', James's [ter] experience is highly reminiscent of the literature of a century ago where asylums mustered the 'mad' and 'deviant' for communal living to be gazed upon for classificatory purposes. The period that followed this admission was not one of increased self-understanding and insight, but rather one of increased volatility and violence, at home and in school whereby his feelings of frustration were enacted upon, directed at his dad and his environment as a form of communicating that something was terribly wrong:

> *And so, I just… I've never wanted to hurt anyone, but I guess my… The reason I was violent, basically always was 'would someone who was feeling okay, do this?' […] That was my way of explaining how I was feeling; and how serious it was* (James [ter], p.7).

> *…he was throwing, pointing knives, you know. I've got knives pointing at my… at me, you know, and this sort of stuff […] I had knives going through*

> *doors and things like that so we are talking potentially quite…* (Danny [par to James], p.13).

The police became an everyday and ordinary presence in their lives during this period:

> *we had this thing which was to always call the police. Because we didn't know what we were dealing with…* (Danny [par], p. 4).

In saying that he didn't know "what we were dealing with", Danny [par] separates the 'thing' from the person, distancing whatever it is that is causing James [ter] to act this way, from the heart and soul of the child he loves. The separating is an attempt to impose distance between the behaviour that the police were called to respond to, and the intuition that something just wasn't 'right'. In some respects, police involvement was problematic because the focus became the events, and not their underlying causes.

The prediagnostic period was, for James [ter], a volatile period, where the yearning for self-understanding and the desire to be understood by others rises and is hampered by an inability to articulate one's state verbally. It is a period marked by the lived and bodily experience of rage rising and spilling over in frustration. As social beings, this desire to be understood is 'at the heart of any dialogic moment' and therefore, authentic encounter (Penman, 2014). It would seem that the lived experience of have someone 'gazing upon you' and yet still being unable to 'connect' or provide understanding, not only runs counter to the natural inclination autistic people have to be understood, but heightens one's sense that their inner world is not shared or 'felt'. Thus, James's experiences of 'being misunderstood' had escalating ramifications and consequences.

When a diagnosis was not forthcoming for James [ter], violence became *as though* the *only way* to communicate intense feelings of anger and frustration. Whilst developmental psychologists might suggest that emotional expression is often reported to increase during adolescence, it is also well-documented that hormonal fluctuations influence emotion considerably less than environmental experiences (Santrock, 2010). James recalls having a growing dossier of pathological labels that didn't explain his 'being'. He says he had a "raft of false diagnoses" (p.1), which failed to lead to a sense of self-understanding:

> *I was being diagnosed first of all for things like PTSD, um Oppositional Defiance Disorder...I've got a massive file full of stuff* (James [ter], p. 4).

It was not until his autism diagnosis was received that his frustration level receded, and he was able to make sense of himself in a new light. The actual diagnosis signalled the moment when violence stopped.

> *James: But yeah after my autism diagnosis, I have been violence free ever since.*
>
> Sharon: violence free?
>
> *James: completely! Once I understood 'hey there is a reason why I'm doing this', I stopped completely and yeah. And obviously with the autism diagnosis, it has changed my life completely.*
>
> Sharon: for the better?
>
> *James: yeah, I just wish it happened earlier!* (James [ter], p.8).

The frustration James [ter] experienced thereafter during ordinary life didn't stop; however, he took control and chose alternative ways to physically display his feelings, which he still lacked words to convey. When he was angry with his stepmother who hated cupboard doors being left open, for example, he waited until she was out of the house for an opportunity to open every drawer and cupboard. This reduced his frustration via a physical act that was non-aggressive (or at least non-confrontational in the 'heat of the moment').

> *I opened every cupboard and door. Other times like, I've closed every door in the house kind of thing, and it brings me emotional comfort, displaying my feelings. I definitely have tried to use words more, but my vocabulary is rather small* (James [ter], p. 11).

That James 'knows' his mind is evident given that his affective state has as its objective correlate (Zúniga, 2015) in the 'open doors'. That he chooses to do this whilst his step-mum is not home, further suggests he 'knows' something of her mind too, using willpower to manage affect until the opportune moment for 'venting'. Phenomenologically, it seems James knows his mind and in estimating the potential reactions that his 'display' might evoke in the mind of his step mum, he demonstrates theorising of other minds, or as 'science' frames it, he is using a 'theory of mind'.

5.4.2 The process of 'being diagnosed'

The diagnostic experience from the perspective of parents, has received considerably more attention than from the perspective of those with autism (Huws & Jones, 2008). For two participants (Catherine and Liam [adol's]), the process was remarkably unremarkable, whereas for James [ter], the actual process was significant in the ways that differed from all previous encounters with mental health that had led to the 'raft of false diagnoses.'

Catherine [adol] (as mentioned earlier), was diagnosed with autism 'by chance', having gone to her GP for Chronic Fatigue Syndrome, coming away with a prescription related to that *and an 'autism' diagnosis*, which she understood as the GP's justification for her 'after school exhaustion: "Oh, she's oversensitive because she's on the spectrum" (Catherine [adol], p. 25). Taylor [adol] also explicitly supported this connection, whilst research has previously suggested that autistic people find social engagement exhausting (Stewart, 2012).

Although Liam's [adol] mother, Kym [par] recalls a long drawn out process of seeking answers, Liam recalls the diagnostic process as relatively simple. When he was in Year 14, his mum contacted Autism NZ as a 'last resort', who initiated contact with a diagnosing psychologist. According to Liam, his encounters were brief: the psychologist "did a whole lot of stuff", referring to the tests she administered at school and later at her clinic. Whilst Liam admitted that he didn't like talking to strangers, he commented that he found the process "a little bit in between [difficult and not so difficult]". Liam was the only participant diagnosed ASD according to DSM-5. He recalled receiving his official diagnostic report in the mail and thought it accurate.

In comparison to Catherine [adol] and Liam's, [adol] experiences, James [ter] had a long history of encounters with mental health professionals. His father (Danny [par]) recalled having contact with at least a dozen different agencies and their sub-agencies, over the years. James informed me that he was dubious about the referral leading to his actual diagnosis of AS. It was initiated by his new GP, following relocation. The GP's referral was to a 'visiting psychologist' who attended the regional health service periodically, whilst working out of the Health Board's mental health facility 200km away. The diagnostic process required one local consultation followed by a week of 'testing' 200km away.

James's [ter] experience of *this* Health Board was significant. He believed he experienced the process 'how it should be', contrasting it against his earlier experiences within a 'flawed system'. He described this Health Board as being "really, really, really good" (p. 6), giving emphasis to the fact that 'their' approach to mental health demonstrated a degree of respect for him as a person, something he doesn't recall of other encounters he had experienced under the jurisdiction of a different Health Board. At some point, James was able to apprehend the autonomous nature of District Health Boards in NZ, which function to shape service delivery in their specified regions by allocating funds according to perceived demographic needs. His reflection alludes to a broader story of the politics of health in NZ.

> *the [regional] Health Board - they came up from [city] - and yeah, they were really, really, really good. There was 'Dr Kuro' [pseudonym], she, I don't know how to explain this, but basically talked about a lot of things. Eventually*

> *she said, "hey come down for a week of tests". I was like 'well this sounds familiar' (laughing) [referring to his time of 'testing' in a psychiatric facility]. But no, it was really good. Dad came down with me and we stayed in motels and stuff and for a week, they did a whole lot of psychological tests on me - some intelligence tests and aptitude tests. Not quite physical tests, but you know the old, put a whole lot of things on the table and see how your hands work or whatever. I've forgotten what the test is called, but yeah, and so then the next week they said, "How would you feel if we told you, you were diagnosed with autism and so and so?" "Actually, it kind of makes a lot of sense"* (James [ter], pp. 6-7).

What was significant for James [ter] is that this experience, in no way violated his sense of dignity, but rather, it affirmed it and he felt listened to. The motel accommodation provided a sense of safety and freedom, something previously restricted and compromised in the psychiatric ward, where he felt trapped, and violated, witnessing other kids 'sleeping' with each other and being experimentally medicated 'on', like he was. Dr Kuro spoke to him, explained things to him, and looked to him for confirmation of her assessment, including the diagnosis. This relational approach was empowering, being a stark contrast to his previous dehumanising encounters that left him feeling as though he were an object of the psy-gaze and a subject to be experimented on.

5.4.3 Officially 'autistic': the label's 'goodness of fit'

Advocates believed that the diagnostic label is typically well-received by adolescents when it is offered sensitively, for example in the way James [ter] recalled Dr Kuro offering it.

> *Generally, done sensitively, they're [autistic teens] not traumatised; they are actually strengthened by having that diagnosis, but the parents are very worried and the parents are often going "if somebody was going to tell me that I had a mental illness, I would be devastated [...] it seems like all of the parents worry about how do I tell my child that they've got autism and quite often I will be the person who tells the child or teenager that they have got autism and I find it really easy to do that because when you are telling an autistic person that you're autistic, they look at it very logically and go "yeah that makes lots of sense! [They] see a logical response to the diagnostic issue whereas with the parents, I see an emotional response* (Michelle [adv], p. 10).

Unlike parents who have reportedly considered the diagnostic label as mental illness, dysfunction, and abnormality, autists experienced the diagnosis in terms of how well or not it explained their experiences and perceptions about themselves. Overall, they believed it explained a lot; it was metaphorically speaking, the ‘missing piece of the puzzle’. Although Grace [ter] objected to PDD-NOS, the remaining autistic participants in this study believed their overall diagnosis was accurate, even if they perceived the diagnostic label as having limitations.

Huws and Jones (2008, p. 99) highlight that initial reactions to being diagnosed ‘autistic’ can vary broadly, ranging from being very relieved to wanting to die; participants old enough to recall their reaction were predominately satisfied with the diagnosis. It gave them a sense of control and a sense of group membership, even if they didn’t get to know other autistic people immediately. It was as though in being diagnosed with autism *Daesin* was awarded, for the first time, a sense of freedom and liberty for ‘being normal’; the *authentic* ‘autistic self’ is autistic-ally ‘normal’. It makes sense! It is logical *and* it is ‘communal’; it is a ‘type’ of ‘being’!

James [ter] was diagnosed one week after being expelled from high school and said it was “the most helpful information I have ever had” (p. 29). It was helpful because the diagnosis provided personal insight into the problems and experiences he was having and as such he could ‘fix’ things: “You can’t really fix anything if you don’t know what the issue is” (p.29). On the surface it appears that James considers autism in terms of medicalised terminology, however it can also refer to the benefits derived from accommodations and protection from an environment that ‘disables’.

Being officially diagnosed didn’t ‘fix’ the fact that James [ter] had been expelled from high school for lashing out at a teacher who prevented him from reaching ‘safety’ when overwhelmed. Nonetheless, the diagnosis meant James could ‘fix’ his reaction to ‘being different, confused, and highly frustrated’. Being 'officially autistic’ became the defining moment in which he could put an end to his ‘disordered’ responses to ‘being frustrated’ because of his ‘being different’. In this sense, being diagnosed ‘autistic’ meant ‘being normal’; someone had recognised that his ‘symptoms’, or behavioural patterns and experiences, were a legitimate categorical identity. It meant James was no longer ‘alone’; he was like other (autistic) people after all. James resonated with the general nature of the autism diagnosis and found relief in sharing a categorical label in common with others, at least initially.

‘Being like’ other people, was something James [ter] and others possibly craved and so, as James ‘digested’ the diagnosis - that he ‘fit’ this category known as ‘Aspergers’ - his craving to ‘belong’ to a ‘normal’ group was not only instantly satiated, but the epiphany left him as though ‘transformed’.

> *James: But yeah after my autism diagnosis, I have been violence free ever since.*
>
> Sharon: violence free?
>
> *James: completely! Once I understood ‘hey there is a reason why I’m doing this’, I stopped completely and yeah. And obviously with the autism diagnosis, it has changed my life completely* (James [ter], p. 8).

James’s ‘relief’ was echoed by advocates’ experiences and converged with his dad’s (Danny [par]) perception that the label has *explanatory power*, which gave ‘them something to work with’.

> *I’m not saying it’s a gift to have autism but I’m saying it’s the fact that you know what you’re dealing with is ‘the gift’* (Karen [adv], p. 22).

The diagnosis provided insight; a means for Danny [par] to now approximate James’s [ter] desires and intentions and this led to more accurate predictions and interpretations of his behaviour and possibly contributed to improved intersubjective engagement. The diagnosis improved their microsystem relationship by easing tensions leading to violence; it empowered Danny to help James by accommodating his needs. Similarly, the diagnosis gave James the *power* to understand himself in new ways; his differences were no longer a *threat* to his personhood and wellbeing.

Not all participants were as explicit as James [ter] in regard to expressing their reaction to being ‘officially autistic’. However, they did sometimes offer reflections or episodic memories providing glimmers of insight into their perceptions. Brad [adol] recollected a time when he realised that autism was the ‘thing’ that set him apart and he no longer wanted to be autistic:

> *I remember on my 16th birthday, I was in Hong Kong. I just wanted to upload some video pictures on Facebook about my journeys in Europe and my mum said we’ve got to go “I’ve got to post these” and she’s like “you don’t want to have a birthday on your own?” and I’m like ‘that’s just so rude’ and I’m like…I just look over what I did and I’m just like “oh, that’s what Asperger’s is” and I want to change from being Asperger’s!* (Brad [adol], p. 22).

For Chris [adol], being autistic also resonated with being ‘retarded’. He made a ‘play on words’ to define what it meant to be ‘officially’ diagnosed, using his best American accent to say ‘Asperger’s’. He declared he’d been diagnosed a butt-burger: ‘Azz-Buuurrrrgah’ - “I am a butt-burger” (p. 12). His pronunciation was ‘spot on’ and we laughed but on reflection this early quip veiled off the seriousness of what he was really trying to convey: how sh#tty life actually can be when *all you are* is officially a ‘butt-burger’; when you resonate with being autistically ‘stupid’. Throughout the interview, Chris digressed back to the meaning of ‘being autistic’, waxing and waning between wanting a full cure and a partial one, whilst coming closer and closer to the realisation that he was as though ontologically[18] set apart from the neurotypical person in the most derogatory way; he was ‘retarded’.

> *Chris: I don’t work like everyone else, I’m too retarded.*
>
> Sharon: in what way?
>
> *Chris: I’m autistic. Honestly, I’m just waiting for someone to smack me …I mean autistic people, people with my disability are just retarded* (Chris [adol], p. 22).

‘Retarded’ comes from the Latin word *retardare,* meaning ‘slow’. It is synonymous with ‘handicapped’ and whilst a more politically correct word than ‘imbecile’ or ‘moron’, it has historical use in ‘legitimate’ medical contexts, describing ‘slow children’. Today though ‘retarded’ is taken up and used colloquially to refer to people deemed stupid and outside the ‘norm’, and hence is usually considered an offensive and derogatory term. This self-reference suggests Chris [adol] perceives himself as a sum of ‘deficits’ making him not just ‘ontologically different’ but abnormal. His response is like autists in Humphrey and Lewis’s (2008a, p. 31) study who referred to themselves as being ‘a freak’; having ‘a bad brain’; being ‘mentally disabled’; and, ‘retarded’. Even though Chris may have denigrated the label ‘Asperger’s’ by aligning it with the ‘butt’, he never declares any good attributes and focuses entirely on how his life as a ‘retard’ resonates with being autistic.

Kym [par] and Liam [adol] grappled with ‘location’ on the spectrum; how they could ‘locate’ one *in relation to* the other ‘on’ the spectrum of high and low functioning autism. In this way, the spectrum was predominately conceived of in a linear capacity, with polar ends indicating ‘more’ or ‘less’ autistic’; ‘low’ or ‘high’ functioning. Kym considered the breadth

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[18] In taking up their interpretation of ‘being fundamentally different,’ I have opted to refer to autistic participants as being as though ‘ontologically different’; however, as will be evident, many of the perceived ‘differences’ that they experience are the result of the milieu in which they are embedded, thus the term is used as a subjective (not objective) interpretation of how autists feel.

of categorical membership and conceptualised a way to distance her son from their long-time non-verbal autistic neighbour, Bryce [pseudonym], in order to accommodate her schema of autism and the recent news that her more comparatively ‘able’ or ‘normal’ son, was autistic.

> Sharon: what did you think about autism beforehand?
> *Liam: basically, what everybody else thinks about it*
> Sharon: what is that?
> *Liam: uh, I don’t know…*
> *Kym: just say it*
> *Liam: that they were stupid and stuff*
> *Kym: or crazy*
> *Liam: Yep crazy*
> *Kym: can’t function… Unfortunately, the mother he has got is useless (referring to herself) because…*
> *Liam: you keep comparing me to that bl##dy…*
> *Kym: to Bryce. There was this boy up the road from us; this little kid and he was like high needs; like really high needs… Crazy… And I kept telling Liam “if you don’t write, they are going to think you are like Bryce. Are you like Bryce, Liam?”*
> *Liam: yes!!! (laughing)*
> *Kym: so yeah, I did more damage than good […] Nobody wanted to be like Bryce. I mean he drooled; he was just crazy… He couldn’t look at something… he had…everything had to be close like this (demonstrates) and, I don’t know, he was just very high needs*
> *Liam: yeah* (Liam [adol]; Kym [par], pp. 13-14).

Catherine [adol] thought that the DSM-IV labels could never really be a ‘good fit’. She believed that AS and HFA were more about having at your disposal, a ‘politically correct’ way to politely ‘position’ particular people, primarily those who are predominately verbal compared to those who were not. She thought autistic nomenclature was somewhat arbitrarily chosen to avoid stigmatising people, assuming that it was less stigmatising to be diagnosed AS or HFA than ASD.

> *I thought they were the same thing but the high-functioning autism is kind of irrelevant like Asperger’s was usually given to people because of the stigma against autism and then high-functioning is generally used to describe people…um sometimes people… it’s based around some of the things… it*

> *doesn't really accommodate…Someone can be really good at some things and really bad at others. I like a better description of that involving like an ice cream bar* (Catherine [adol], p. 21).

When Grace [ter] discovered she'd been diagnosed PDD-NOS and had had time to reflect on this in relation to the other possibilities, she rejected PDD-NOS believing it was a poor 'fit' given her symptoms. She believed that because she was a girl, it obscured the diagnosing practitioner's ability to recognise classic tell-tale signals.

> *It was 'you do match this, but we don't think you match this because of this' and all of that and it's like…yeah. They say you didn't match the routines, but it's like really – 'someone who can't stand things changing and gets so stressed when things change, and you don't think that matches routines?'* (Grace [ter], p.8).

This provided the impetus for Grace to think about how she differed from the dominant diagnostic criteria to challenge dominant assumptions and current limitations concerning how autism is understood as a 'gendered' condition. Grace's challenge, like Catherine's [adol] (that autism is like an ice cream bar), is taken up and explored below. Grace experiences a form of resistance to being defined by 'experts' lacking understanding of autism in girls and women.

Receiving a diagnosis of PDD-NOS, contributed to Grace's [ter] sense of being *more different* than 'different'; as though conveying an added degree of abnormality, where you do not 'fit' the 'normal' box of Asperger's. For Grace, the label 'Asperger's' was highly preferable and even desirable to PDD-NOS. This is not surprising given the online digital presence of large autistic communities who identify with being 'aspie' (Giles, 2014). It is this lack of identification that meant apprehending 'not otherwise specified' as a seemingly additional 'abnormality' or difference, which functioned to situate her out on a limb; as though her differences could not be quantified or qualified in the 'ordinary' way, highlighting stigma and increasing her sense of not 'belonging' to a legitimate autistic community.

> *It's like you're abnormal but you still even abnormal among the abnormal people because… It's like, it's not just like… Because again when you are diagnosed it is very much deficit based; it's very much […] yeah, 'there's something wrong with you but you still don't even fit into the normal wrong boxes, you fit into this weird one on the side', which as someone who very much likes things in a row, to not fit into the lovely little Asperger's box drove me nuts!* (Grace [ter], p. 8).

When the diagnostic criteria changed, Grace recalled her psychologist confirming that she definitely "met criteria for ASD". In their analysis of changing criteria, Huerta et al. (2012), Kent et al. (2013), and Dickerson Mayes, Black and Tierney (2013) felt that most children would remain eligible for meeting ASD criteria if they were diagnosed PDD-NOS using DSM-IV criteria. The matter was of sufficient concern for Grace that she followed this up with her personal psychologist later on, highlighting a lasting interest in staying abreast of autism research and the importance of receiving a diagnosis that resonated; that seemed like a 'good fit'.

In summary, in reflecting on the quotidian of daily life, participants apprehended that they had things 'wrong' with them that autistic people 'have'. Their symptoms and abilities, generally 'made sense'. Nonetheless, some adolescent and tertiary participants also acknowledged that they do not fit 'criteria' or common stereotypes as parsimoniously as they are described and therefore challenged existing notions that autistic people are 'as though' homogenous. This is consistent with Ho's (2004) findings, which posit that the pathologising of difference has typically led to treating those so labelled, as though the same, having implications for 'being educated'.

5.4.5 Disclosing and 'coming out' autistic

> *Should parents tell their autistic children that they are autistic? I think so. If the children notice words at all, they already know the word is being used about them. But be sure to tell them what it means. I was told that it meant, among other things, being dumb, crazy, malicious, uncaring, and unmotivated"* (Sinclair, 1992, para 6).

Whilst parents typically pressed for a diagnosis with the view of disclosing it to teachers and staff at school so that more could be done to assist their child, not all parents were as inclined to disclose the diagnosis to their child/teen. Victoria [par] felt that the diagnosis would lead to a deterioration in Chris's [adol] behaviour.

> *... it took a long time before we told him because we had to work out how we tell him because we didn't want him to use it as an excuse, because he was intelligent enough to do that* (Victoria [par], p. 18).

When James [ter] realised that some parents occasionally withhold disclosing an autism diagnosis, he chided that this is a 'normy problem'. It suggests he is aware of the tensions between 'sameness' and 'difference' where 'being authentic' and 'being autistic' should be more highly prized than wanting 'in-authentic' and 'sameness' for a child. Thus, James perceives parents who withhold the diagnosis from their child as buying into a normative ideology, privileging those beneath the ‘bell-curve’ of normative development.

> *[the diagnosis] …it was the most helpful information I have ever had. They don’t want their kid to be different or something? That’s a terrible ‘normy’ problem isn’t it! I guess the pros are knowledge so you can actually do things about it* (James [ter], p. 29).

Participants who found out they were autistic quite young were more likely to disclose it whilst young; but with age, grew in their sense of shame about being autistic. This seemed to peak in high school and to subside once in tertiary education. For example, Brad [adol] discovered he was on the autistic spectrum at age eight but with growing understanding regarding the negative connotations associated with difference now regretted that decision:

> *Well when I found out I had Asperger’s, I started telling people… I wish I did not tell them because that just embarrasses me and they could have made my life worse* (Brad [adol], p.24).

Emily [ter] was likewise too embarrassed to tell anyone about autism in high school and says she “felt really embarrassed” (Emily [ter], p. 23). Chris [adol], suggested he would disclose his diagnosis if need be, in order to *warn* others about his ‘retardation’so they could lower their expectations! However, Grace [ter] couldn’t see the point in disclosing her diagnosis to peers, as they were a ‘bunch of outcasts’ with their ‘own problems’ and ‘autism’, as a label, wouldn't mean anything to them.

Advocates were not of one accord regarding their advice to disclose. Whilst Michelle for example, noted that things have changed in NZ over the last two decades resulting in less shame and stigma, Karen had quite the opposite opinion:

> *So, going back 20 years ago, if the person was diagnosed with autism, they wanted to keep it a secret, or diagnosed with Asperger’s, they’d keep it a secret, you know nobody should know. Lots of issues about whether to disclose it or not - those are still there, but they actually seem to be, more for the parents than for the person themselves* (Michelle [adv], p. 8).

> *And, I think that's one of the main things that the kids who don't want people to know that they are diagnosed with Asperger's, don't want to be categorised, as having all of the things wrong with them that kids with autism have, you know* (Karen [adv], p.2).

It was this rigid, derogatory, and sometimes 'deficit view' of autism that three participants explicitly challenged.

5.5 Challenging assumptions: about autism and autistic people

Whilst the diagnosis seemed 'about right' when autistic participants reflected, a number challenged the implications of a medical model explanation of autism, suggesting it constricts how others 'see' them. Autists were interested in autism research and posed alternative narratives that others could use, building on from categorical taxonomy they had come to internalise as capturing understandings of ASD. These counter-narratives were constructed over time as they grappled with 'identity', encountered others, and grew in autism knowledge. Tertiary students especially, had a good understanding of the autistic literature and a well-developed interest in autism generally. Their constructions shed light on the way autists not only want others to 'see' them, but how they saw themselves at the time of the interviews.

5.5.1 An interest in autism; challenging 'models' and frameworks.

Unlike most of the high school-aged participants in this study, tertiary students demonstrated an interest and an active involvement in the field of autism, primarily through attending 'talks', speaking to others, or in relation to mentoring younger autistic people. Grace [ter] was preparing to complete her Master's thesis with an emphasis on exploring a particular autism perspective, in relation to her chosen field of research. Tertiary participants therefore seemed to have a 'vested interest' in autism as a result of their diagnosis and 'hellish' high school experiences. Phenomenologically, their interest in autism and 'being autistic' suggests that they had achieved *Daeisin* as *authentic self*; that is, as having achieved an understanding of autism and an acceptance of the phenomenon of 'being autistic', or more specifically, of '*being an autistic person in the world*'. This suggests that the 'I' has integrated a general understanding of autism, including how it is lived and experienced bodily, as well as how autism and the 'autistic self' is perceived and experienced by others. Thus, as Renninger (2009) notes, developing 'identity' occurs over time through regular and ordinary interactions.

One-way tertiary participants' 'interest' in autism was evident was regarding participating in this research project. Emily [ter] attended my 'PhD confirmation event' having seen it advertised on campus. She actively engaged with me during the question and answer session. She was the first to speak when the 'floor' was opened, declaring her willingness to participate. Similarly, James [ter] was invited by an agency to speak about how, as an autistic young adult, he had sourced funds to access services enabling him to advance his tertiary studies. He enjoyed speaking about autism. Grace [ter] also took a keen interest, attended autism conferences and talks at university campuses, including lectures by Hillary Stace, who presented her doctoral findings on the topic of autism (see Stace, 2011). Grace drew on those findings to make sense of her own lived experiences:

> *There's a PhD person called Hillary Stace. I went to one of her lectures and she said that, good outcomes in autism tend to be down to two things: love and luck and I think I got both* (Grace [ter], p. 35).

Grace [ter] also took an active role in discussing autism with others and provided moral support and advice for autistic teens in high school. Grace's interest in mentoring other autistic teens stemmed from a range of difficulties she encountered in high school:

> *It is interesting, because now as an adult [23yo] actually I have email correspondence with a couple of girls in high school on the spectrum, because … I hated that I seemed to go through the journey of high school and puberty as a person on the spectrum, as a* ***girl*** *on the spectrum, completely alone with only really professionals on the outskirts* (Grace [ter], p. 19).

Tertiary students also described a distinct period of becoming aware of the constructions of autism and began grappling with these to reflect in more sophisticated ways about autism. Prior to tertiary, like high school students in this study, they were shaped in their understanding of autism by medicalised narratives. Tertiary students contended that the social model of disability was something they did not discover until they entered the tertiary setting. When they discovered this, it 'opened up a new world' of understanding for them.

Medicalised constructions of autism have become our stereotypical (and often stigmatising) understandings of autism (Baron-Cohen, 2002; Molloy & Vasil, 2002); they are used in our everyday lexicon to describe autism and autistic people. As such, an autism narrative communicates pathology over normalcy, sickness over well-being, and at its core is the "examination of the nature and aetiology of presenting problems" (Lewis, 1999, p. 45). These conceptualisations pervade parents' and young peoples' experience of autism (Mackay & Parry, 2015); epistemological constraints shape the autistic ontology of deficits, as opposed to differences.

> *When you're diagnosed with any condition it comes from a medical professional, who comes from a medical model of disability of 'you have something that's wrong with you that needs to be fixed so that you can fit in*

> *with everyone else' and unfortunately that in some ways kind of gets passed on to the parents as well because they are hearing what it is from that* (Grace [ter], p. 46).

Adolescents in high school, who were diagnosed the earliest, seemed to have the greatest difficulty in apprehending themselves in ways that were not commensurate with dysfunction, disability, or deficit. Catherine [adol] and Liam [adol], diagnosed much later, did not refer to themselves with the same ferocity of negativity that Chris [adol], Taylor[adol], and to a lesser degree, Brad [adol] did. Chris and Taylor seemed to lack any other discourse for making sense of their identity.

> *Taylor: I think that must be different with me.*
> Sharon: why do you think that might be?
> *Taylor: I think it is my disability or something* (Taylor [adol], p. 4).

A social model of disability has rarely been explored in relation to the lived experience of young people with disabilities (Connors & Stalker, 2007), though it has been applied in research 'about' young people, especially in relation to exploring barriers to participation or in regards to service provision (Dowling & Dolan, 2001). As noted in Chapter Two, a social model of disability is fundamentally different to the medical model of disability (Drake, 1999) and posits that society creates barriers, and these barriers function to prevent 'disabled' people from participating. This takes away responsibility from the individual and places it elsewhere in a bid to fathom ways for removing obstacles that prevent participation, thus helping others to accept diversity and difference in more positive ways (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). It foreshadows attempts to eliminate attitudes, structures, and features of social organisations and political institutions that are the barriers (Grenier, 2010), by recognising that dominant social forces tend to influence subordinated ones (Drake, 1999) . From a social model perspective, 'disabled' individuals can be excluded by a lack of appropriate individualised support and environmental accommodations (Mertens et al., 2011).

When Grace and Emily [ter] moved into tertiary study they became increasingly aware of new ways to make sense of being autistic in comparison to how they made sense of being autistic in their senior years of high school.

> *whether you've got a physical, emotional, developmental, whatever impairment, you tend to be focusing on the same kind of medical-model - something wrong with you, you need to fix; we need to fit you in and then in university it's suddenly focusing on the social model and so I learnt this whole*

> *other language around disability that never appears in high school or anything like that and it became…it moved away from explaining the things that were wrong with me, to, this is…I think differently and shouldn't that be a strength; shouldn't that be seen as something positive, instead of 'she's the weird one in the corner who thinks differently and that's weird and we don't want her part of this.' University values you a lot more for thinking differently* (Grace [ter], pp. 46-47).

> *Emily: I felt like there was a lot of stigma at high school […]*
> Sharon: ok, how do you feel about being labelled 'autistic' now?
> *Emily: I feel fine about it now because I talked to Dan (pseudonym) in Disability Services […] [It's] something to be proud of really because it gives you a lot of things and it is part of your personality and who you are […] I think about things in a different way, which might be helpful* (Emily [ter], 20-23).

From the perspective of governmentality a social disability narrative equipped 'disabled' tertiary students with a 'clean slate'; they could renegotiate and reinterpret their 'disability'. Institutionally, the deficit narrative is no longer needed as the 'gate-keeper' in the production of a normative citizen (Rose, 2001); in tertiary institutions, success is predicated less on the production of normalisation and more on the exploitation of one's individual strengths to generate unique insights. Looking back and reflecting, tertiary autists imply that a medical model discourse in high school functions to place the onus on students for their disability, or inability to be included. They posit that a social model and strengths-based approach function to make them feel included, enabling them to incorporate the more positive aspects of their characters into their understanding of what it is to be autistic. In the process of learning about the social model, autists are engaging within a community which Stein might posit as enabling intersubjectivity, conveying 'understanding' (Zúniga, 2015).

Three autistic participants (two tertiaries; one high school) challenged assumptions about how we understand, and *could* understand, autism. They challenged autism as membership to a specific type of culture versus autism as a deficit; autism as gendered versus autism as 'masculinised'; and, autism as an individualised array of symptoms and abilities (weaknesses and strengths) versus autism as a categorical and homogenous 'spectrum' disorder. Participants provided 'alternative discourses' for considering autism. Alatas (2000, p. 4) uses 'alternative discourses' as "a descriptive and collective term" referring to discourses “that emerged in opposition to what is understood to be mainstream…”. Alternative discourses problematise mainstream epistemological and methodological underpinnings of ‘doing (positivist) science’ (Alatas, 2000). Alternative discourses can contribute to a genre of research advancing the voice of the autist (O’Dell et al., 2016).

5.5.2 ‘Being autistic’ is like being a ‘third culture kid’

Autistic advocate, Jim Sinclair (1992, p. 9) said “grant me the dignity of meeting me on my own terms - recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours”. He suggests ‘we’ (autistic and non-) need to get to know each other, acknowledging at some level, that fundamental differences separate us. It is not the ‘differences’ per se, that he contends that function to keep us alienated as ‘them-us’, but the lack of connecting bridges that unite us as ‘we’.

The metaphor ‘building bridges’ is typically used in the context of fathoming ways to ‘connect’ in a bid to improve relationships, by increasing knowledge and understanding. This is sometimes understood as occurring within the ‘third space’, that is ‘between the hyphen’ (Rutherford, 1990). It is in the ‘third-space’ that a conceptual notion of ‘hybridity’ emerges (Bhabha, 1994), which is in part, key to understanding the ideas considered below by James [ter]. Bhabha (1994, p. 211) suggests “the importance of hybridity is not to be able to trace two original movements from which the third emerges, rather hybridity . . . is the ‘‘third space’’ which enables other positions to emerge.”

James [ter] grasps the relevance of both hybridity and the ‘third space’ through his diagnostic and support experiences. Being misunderstood for a long period of time was an experience of ‘us’ (different; abnormal; autistic; deficit) versus them (normal; neurotypical). As he reflected on his experiences with his diagnosing psychologist, as well as current psychologist, Dr Carey [pseudonym], he realised that our ways of understanding autism enable and constrain how others can enter the hyphen and thus be in the ‘third space’ with him.

> *What I like about Dr Carey is that [she] definitely catered towards… [autistic people] ... basically every other counsellor or psychiatrist hasn’t helped at all really* (James [ter], p. 36).

James [ter] chose an alternative discourse as the means for ‘building this bridge’ enabling others to enter the ‘third space’. He believed that the medical understanding constrained, whilst a ‘cultural’ understanding of autism enabled. This troubles the traditional power relations that have functioned to elongate the hyphen, creating distance between autistic and neurotypical people; between abnormal and normal; different and same. To advance an alternative discourse, James drew on his knowledge and experience of 'third culture kids' (TCKs).

> *…so there is missionary kids, so people that have lived in Afghanistan, or Turkey or whatever and it's really good because they called themselves "third culture kids", because they don't know what culture they fit into and I feel like I can relate a lot to that; that just 'I am in my own culture almost'* (James [ter], p. 9).

Whilst raising her sons in the 1950s during a study of Americans in India, sociologist/anthropologist, Ruth Hill Useem, coined the term 'third culture' and not long afterwards initiated the study of 'third culture kids' (TCKs) (Useem et al., 1963). This term is best understood as referring to someone who has spent a significant period of their developmental years in a culture (or multiple cultures as is often the case when parents are missionary workers, soldiers, etc.) outside their parents' cultures, impacting upon their sense of belonging. However, it is not uncommon for TCKs to identify with others in a similar situation, as opposed to identifying with those in a similar 'place'. This can leave TCKs feeling marginalised; they might have a global sense of belonging, but a constant sense of "never belonging anywhere" (Fail, Thompson & Walker, 2004, p. 320). This is not dissimilar to how the autistic adolescents and tertiary students in this study seen themselves. Some identified with others who had 'problems'; felt like they 'belonged together', though not entirely, yet they knew they did not belong within mainstream school 'culture'.

> *I related more to the people who had problems, seeing as we were more in the same boat. We had problems and don't fit in with more normal people. So yeah, I felt more…I didn't really relate to them entirely, it was more just that you guys have the same problem as me – just having a problem, or problems and not fitting in with other people. So, I felt more comfortable around them than a 'normal' person* (Chris [adol], p. 25).

Third culture kids differ from bicultural or multicultural kids, in that these children and adolescents exhibit flexibility, adaptiveness, and an understanding that comes from being firmly embedded within two or more cultures, whereas TCKs have difficulty adapting to the social and cultural 'rules' that vary from culture-to-culture. Whilst some cultural differences are easy to discern, (being obvious like food and dress, music and art), others are 'hidden' and thus more difficult to detect, learn, assimilate, and employ, as though 'natural'. These include etiquette, courtesy, body language, personal space, and underlying expectations.

They inform the myriad of taken-for-granted assumptions that permeate interactions and 'knowing', governing our 'fit' and 'ease of movement'. Nowhere are these assumptions made explicit, yet they are constantly shared by those 'in the know'. In aligning himself as 'being like' TCKs, James [ter] implies that he is 'othered' and made to feel as though a 'stranger in a strange land'; a foreigner within the dominant school or community culture. He feels like he doesn't belong because the unspoken social rules remain elusive to outsiders like him.

> *Like I go 'why in one million years would you do something like that?'* (James [ter], p.9).

Similarly, though far less sophisticated, and lacking access to this discourse, Brad [adol] nonetheless also seems to sense something of the underlying assumptions. He says:

> *well you have a friend and you talk with them and socialise and then one day he just decides 'hey do this thing' and you think it is like rude and then what comes up in your mind is 'oh, this guy, I just have to understand' – that's what he does, maybe he's different to what I am, what I do.* (Brad [adol], p.5).

Whilst Brad [adol] has a lived experience of self as different to 'normal people' and seemed to feel as though 'alien' in a "culture ruled by normative versions of life" (McGuire, 2016, p.25), he lacked a broader discourse to draw on that would enable him to think about himself and his 'difference' in a more positive light. James [ter] however, evidences a different mindset as a result of taking up and trying out, an alternative discourse, enabling him to consider sameness and difference more positively.

> *And people go 'don't you know that's horribly rude, why would you do something like that?' And it's like "what (laughing)? I'm just leaning against the table" [whilst simultaneously shrugging his shoulders and raising his arms questioningly but with a deep sense of satisfaction and self-acceptance to highlight that the 'rules' are different in an 'aspie' culture]* (James [ter], p.9).

The TCK discourse enabled James [ter] to (re)consider 'belonging': to an 'autistic culture' through its cultural modes. Throughout his transcript, James subsequently refers to himself as a member of an 'aspie culture' with shared underlying assumptions that are culturally relevant. In regards to style of communication (on-line; *kind of introverted, withdrawn from society. . .can't communicate socially and that kind of stuff* [p.29]); clothing (*wearing greys and blacks - that's a very common thing* [p.29]); food (*having the same lunch every day - rolls and ham and a can of Coke* [p.10]); language: must be 'interpreted' (*give them the answer they want, not the answer that is correct* [p.14]); interests (*interested in* *computing*; *I love flying; I love planes* [p.12]); and, preferred disposition of its people: humble (*I don't like the whole 'I'm better than everyone else; or I'm very smart* [p.36]). Chris [adol] (p.25) put this preferred disposition this way: *Pride is feeling superior about something and superiority leads to…some of the worst people in the world felt superior to others. Something I don't want to be* (Chris [adol], p. 25).

James [ter] posited that his psychologist was so different from all others because she too understood autism as 'culture' whereby inherent assumptions were acknowledged, without ever being articulated to produce a 'feeling of being understood'. In this sense, Dr Carey was bilingual, speaking a language he 'naturally' understood, thus was standing in the 'third space' between 'them' and 'us', traversing the hyphen and thus, 'bridging the [intersubjective] gap'. Grace [ter] also had a similar experience of her psychologist:

> *Grace: She was my psychologist when I was in year 13 and my first year out of school so … best person I have ever seen in my entire life*
>
> Sharon: Is that right?
>
> *Grace:* ***by a mile!*** *Yep! I've had some good people and that since and even before probably as well but, I, even to this day, still use lots of the stuff we worked with. I think, just very much someone who I didn't have to explain anything to; she just 'got it' the first time around* (Grace [ter], p. 1).

James [ter] posits that autism is a 'culturally relevant lived experience' and in doing so, he sagaciously provides an alternative, non-deficit language for talking about autism, aiding understanding of people like him. Essentially, James [ter] apprehends that the lived experience of autism seems more like a cultural phenomenon than a medical one, thus invites a (re)interpretation of what it is like 'being autistic'. In his experience, the majority of professionals he encountered could not step into the 'third space'; they lacked access to the bridge, rendering his idea that the 'expert' is "not someone who [simply] knows *about* autism" but the one who definitely "caters towards" autistic people. "The rest were of no help" (James, [ter], p.36).

James [ter] draws on his experiences both before and after his diagnosis to postulate an alternative discourse as the means for helping others to 'build bridges'. He believes alternative discourses are needed for moving away from categorical notions of sameness and difference, politicised through the neurological frameworks (O'Dell, Rosqvist, Ortega, Brownlow & Orsini, 2016) leading only to ideas of 'what autistic people have wrong with them'. He notes he is not privy to the dominant culture's 'taken-for-granted' underlying structures; so acknowledges there are things that are wrong. However, even this is reframed; he is ‘almost’ his own culture: the alone-ness of ‘belonging’ to an ‘aspie’ culture’. A cultural discourse therefore enabled him to rework an otherwise devalued (Whyte, 2009), or spoiled identity (Goffman, 1963); it equipped him with a sense of power and control over his life, enabling him to unpack ‘autism’ on his terms. Thus, he could now be the ‘object’ of ‘the gaze’.

> *I guess it’s nice to feel a part of something…it’s kind of interesting…I guess it’s cool to say like “man you are really autistic!”…this is weird…this little community and now we are being studied or something. Or even saying, “I’m a part of this”…it’s kind of strange, but yeah, a lot of it is…autism is kind of an insult, but it’s kind of the whole autistic people versus the normal people, so there’s a…yeah, I guess, there’s like a certain imagery and stuff associated with each kind of side, so yeah* (James [ter], p. 28).

TCKs must learn to adjust again and again when moving from country to country and many lose their sense of personal identity when resorting to chameleon-like adaptations (Fail et al., 2004, p.323). In the same way, autists like James [ter] must learn to adjust again and again when transitioning from setting to setting. This is not easy work but having a psychologist who ‘got autism’ (as a ‘culture’) enabled James to be resettled into Tertiary education, highlighting that the ‘proof was in the pudding’. Nonetheless, it could be argued that ‘cultural’ autism discourses run the risk of perpetuating gendered, or male-biased assumptions. Grace [ter] took up this challenge.

5.5.3 (Un)gendering the extreme ([male] brain) in autistic people

The implications of positing autism as a male dominated category of disorder, has led to increased likelihood that females with ASD will go undiagnosed or misdiagnosed (Lai & Baron-Cohen, 2015). Baron-Cohen et al. (2009) having once postulated the ‘extreme male brain theory of autism’, suggests that whilst there is currently a higher prevalence of autism in the male population, it may be that diagnostic instruments require tweaking to be more gender sensitive, particularly regarding social and communication differences. The ‘extreme male brain theory’ influenced development of instruments now claimed to be insufficiently gender-sensitive, contributing to stereotyped understandings and misdiagnoses. They have led professionals to be on the lookout for ‘masculine’ autistic traits such as trainspotting through this normalisation of male bias.

The masculinised 'autist' has not been separated from the historical male-centred roots of scientific enquiry (Boring, 1929; Rose, 2008); autistic masculinity and femininity have been 'profoundly shaped' by (historical) political forces (Sherif, 1998). As a result, masculinised forms of autism are considered normative, whilst women are often positioned 'in comparison', as 'a-typical' (e.g., Bargiela, Steward & Mandy, 2016).

In direct response to Baron-Cohen's recent address at Cambridge University on the extreme male brain, the Disabled Student's Committee (DSC) staged an autism event by creating and publishing a zine[19] (CUSU Disabled Students' Campaign, 2018), titled 'In camouflage: a zine on the intersection of autism and gender'. It was developed to explore the lived experience of the 'genderisation of autism', and the gendered minds of autistic people. The zine enabled participants to challenge the legitimacy of 'his scientific autism research' through the sharing of contrary lived, gendered, autistic experience, in a 'Third Space' (Meredith, 1998). This enabled participants to straddle two 'cultures' (autistic and normative), and consequently, negotiate difference (Hoogvelt, 1997, p.158).

This zine directly challenges not only the dominant method of 'doing autism research' through exclusion of autistic people but highlights the implications for autistic women. Failing to acknowledge women's lived experience has obscured legitimate knowledge of autism, stereotyped the autistic (gendered) mind and therefore promulgated misleading 'norms' and expectations, which has culminated in the experience of difficult and/or delayed diagnostic experiences for women and non-men. Sophie (autistic zine contributor) writes:

> *My apparent gender/interest paradox has constantly been questioned, and my autism diagnosis was no exception – 'you clearly display autistic traits' says my psychiatrist after an in depth ninety-minute assessment, 'but you don't look autistic, you're fashionable, you have makeup on. It's not exactly trench-coats and trainspotting. I'll have to think about it.' After a lifetime of being deemed masculine because of my autistic traits, I was now too femme presenting to be autistic? (sic).*

Sophie highlights what Heidegger refers to as 'pre-existing understanding or fore-structure' of knowing, which in this case is our common, stereotypical understanding of the gendered nature of autism, despite more recent research to the contrary, suggesting that

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[19] Zines are self-published magazines, which according to Licona (2005) represent a 'third space' for opposing dominant academic discourses. They enable exploration of a lived experience in a primarily (but not exclusively) non-academic space for the purpose of exploring meaning-making and the merging of shared understandings.

autistic girls have gender appropriate special interests (Mandy, et al., 2012; Lai, et al., 2015). This same apprehension regarding a narrow gendered autistic type, caused angst for Grace [ter] whilst for James [ter] it conveyed self-understanding and highlights how culturally embedded the concept is, and as such, is simply 'taken-for-granted' as autistic knowledge, like Sophie's psychiatrist pointed out. The week following James' [ter] diagnosis, he met a woman working in public office who he disclosed his diagnosis to, and she impressed upon him her *understanding* and *knowledge* of autism by referring to her niece who was autistic *and* liked trains.

> *[The woman said:] 'I've got a niece who was autistic, and she is really interested in trains' and so she knew what it was about, and it was really, really cool* (James [ter], p.20).

In comparison, Grace [ter] looked back retrospectively to make sense of how her 'odd' behaviour had initially come to the attention of teachers early in primary school, yet it was not until she was in year 9 that she obtained a diagnosis. She believed the delay was due to circumstances that made her 'look normal'. With the sudden acquisition of a new friend part way through primary school, Grace perceived herself as though being 'thrown'[20] into a new state, an experience that gave her the appearance of looking relatively 'normal'. She'd been struggling in class and was without friends at school, having come to the attention of teachers 'as different', until suddenly 'being with a friend', albeit a 'selective mute' to all others except her, providing onlookers with a new illusory view of her 'normalness'. She believed that this sudden change veiled off her 'oddness' so that the onlooker's gaze simply glossed over the duo 'huddled together'; they did what *girls do.* On reflection Grace believes that she experienced persistent non-typical behaviours, consistent with a diagnosis of ASD, through the enduring 'deviation of her imagination'. She experienced a profound conflict between this inner world and the outward appearance it posed.

> *But what people didn't realise is that as we were playing imaginary games over in the playground, we played in the same 'world' for three years and as a child you don't construct a world like that, that you continue for that long. . . it was a magical world, witches and wizards and fairies and we ran a boarding school for witches and wizards and fairies, and we were the teachers… But we played it for* ***years*** *and again something pretty non-typical, but no one really*

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[20] Heidegger (1953/2010) suggests that throughout life, situations crop up and new opportunities present themselves. He terms this living in a state of 'throwness'.

> *noticed either, because you had two girls sitting playing and they were happy, and they were doing stuff together. Like it says, like I didn't have 'restricted and stereotyped behaviours' and the whole thing about imagination and they say well 'you have an imagination and you're fine' [during the diagnostic process resulting in PDD-NOS] and…but as an adult I'd go back and say well, 'yeah, but this whole thing about constructing a world' and that's that whole presentation of difference between boys and girls, so, I had an imagination and it ran wild and I built an entire world that I lived in for three years with a friend. That's kind of where your imagination deviated…* (Grace [ter], p. 5-6).

Looking back to that time when she (imaginatively) 'ran the boarding school', Grace [ter] challenged the legitimacy and accuracy of empirical science to know about autism in women and girls (as do others, e.g., Linton, et al., 2014). She believes that the emphasis is always on gazing upon the subject; giving accent to the 'realism' of the external world to the exclusion or insubordination of the rich internal world, where at least for (some) women and girls it is possible to imaginatively manage and systematically order; in this case, the running of a boarding school, enforcing routines, and arranging lessons and so on.

Grace [ter] also had an enduring obsession with cats. Cats and cat-care was more than a 'passing interest'; she believed it too served the same underlying drive as masculinised interests do. She supposed the 'signal' was missed because the *Felis catus*, regardless of actual gender has been feminised, thus causing an epistemological 'blind spot'. For 3000 years the home-loving, self-cleaning and domesticity-loving natures[21] of cats has shaped our feminine connotation of cats, making apprehending them in systematisation-friendly ways, difficult. This is not so with boys' 'backyard bugs'. When Grace developed the skills to systematise 'her' domesticated felines, the first thing she did was assign them to her Punnett squares in order to understand 'their genetic ordering'. Thus, whilst recent research highlights autism as presenting 'differently' in males and females (Lai et al., 2015), Grace's lived experiences have led her to believe that the 'experts' are again being fooled by stereotypes, failing to consider how gender-appropriate activities might be functioning to

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[21] Earl (1895, p. 155) says "the cat has been called the 'perfect pet,' and not without justice. Pussy has always had *her* friends and *her* foes; *her* ardent admirers and *her* extreme detesters. Faults *she* has, no doubt, but the lack of an affectionate regard for the person who befriends *her* is not, as has been alleged, one of them. Though less demonstrative than the dog, the quiet rubbing of *her* fur against one's person is no less indicative of supreme regard."

actually achieve the *same* underlying purposes, albeit with increased intensity (Gould & Ashton-Smith, 2011) .

> *…and my interest as a child was cats - but cats are something that are reasonably okay for a small child, or for a girl of primary school age to be obsessed with but, I can vividly remember being in primary school and being told by my parents that 'you're not doing another project on cats', so I did it on lions! I could pretty well explain to you how you got the different genetics of cat coats; how the colours… it was only at the start of year nine when we learnt the Mendel squares, but immediately I took that and took it straight back to the cats and it was like that's why the gingers are almost mostly male because it's ginger and that's why because it's X and Y and so it always came back to that, so, yeah, that whole thing about restricted interests…*(Grace [ter], p. 7).

Phenomenologically, Grace [ter] experienced the joys of continuously expanding her general knowledge of cats and applying her imagination to tasks befitting someone running a boarding school and keeping its lodgers in training for three whole years. Diagnostic and screening measures sympathetically aligned with theories like Baron-Cohen's (2002) 'extreme male brain' theory imply that autism is more aligned to a male-orientated phenotype supported by masculine-orientated interests (Tierney, et al., 2016). The leap required to postulate what a feminine autism phenotype may look like, remains fundamentally, unexplored. Baron-Cohen, (in for example, Hull, Petrides, Allison, Smith, Baron-Cohen, Lai & Mandy, 2017) has nonetheless continued to assess gender bias in adults, including women's tendencies to mask their behaviour, compensate for their differences and thus camouflage their social deficits. It could be argued that our biological 'givens' result in diversity of 'matter' and thus individuality of expression, but it is more than this which animates us and individualises us; it is at this level of the soul, that autists want us to keep an 'open mind' so as to not be so easily fooled by generalisations, or stereotypical understandings.

When James [ter] honed in on the gendered 'cultural' aspects of autism, including planes, trains, and dark clothing, it seemed ordinary. However, when women stand before the diagnostician, with their makeup and fashionable attire, or talk about their beloved felines, the epistemological weakness obscures diagnostic opportunities and experiences.

5.5.4 Autism: it is more like an ice-cream sundae

Catherine [adol] also challenged dominant assumptions about autism as an array of deficits, alluding to the idea instead, that autism is a 'bit of this' and a 'bit of that' – a bit like an ice-cream Sundae bar. In their bid to explain autistic heterogeneity, AuKids (AuKids Magazine Ltd, 2011-2018) pictorialised autism as a Sundae Dessert. They visually presented 'differences' by suggesting that a scoop of the three flavours comprising a tub of Neapolitan ice-cream (chocolate, vanilla and strawberry) represents the triad of autism impairments, with variations in the quantity of each flavour being akin to the individual differences children exhibit. This is served in a sundae glass; the 'vessel' serving as one's personality.

The addition of a 'flake' signifies behavioural difficulties that can be contingent on environmental contexts, thus can appear, or be withdrawn. Chocolate and strawberry sauces serve as toppings, one representing sensory sensitivities and the other, co-morbid conditions. Finally, sprinkles and a cherry finish the possible combinations, with the advanced skills 'sprinkled' and the 'cherry on top' being reserved for those few who operate at the level of genius; being 'savants'.

The Autism Sundae Dessert (AuKids Magazine Ltd, 2011-2018) is described as having been invented to "make autism sound palatable and not damage a little person's self-esteem" (Elley, 2018, pp. 28-29). It has been used as a teaching tool defining "autism in the modern age". It does not specifically challenge the DSM, but takes it up, highlighting in the process, why no two autistic children *could* be alike.

It is a truism that out of the approximate 7.7 billion human beings on the planet, no two are the same. Yet this trope is continuously paraded in autism literature in a bid to stem prevailing assumptions about the homogenous nature of people sharing a categorical identity. For example, the savant made famous by the movie 'Rainman' has resulted in a continuous defence that not all autists are savants, suggesting something prevalent in our collective thinking 'about autism' and autistic people (MacLeod, et al., 2013):

> *…and it doesn't bring to mind, um like everybody used to say "oh, it's a bit like Rainman", well, "No, we're not all like Rainman"* (Karen [adv], p. 33).

Catherine [adol] had no knowledge of AuKids' conception of the metaphorical ice-cream sundae, therefore her own account is privileged. Whilst metaphor "…constitutes an inherent part of thought, language and culture" (Naciscione, 2016, p.241) to enable new knowledge to be generated through 'seemingly incongruous juxtapositions' (Shibles, 1974), autists often use simile to advance ideas. A simile compares two unrelated things. James

[ter] for example used simile to *liken* autism culture to TCKs. Catherine [adol] uses the simile that autism is like a bit of this and a bit of that from the ice cream sundae bar, to challenge rigidity of categorisation and experience of autists. She wants to convey that the lived experience of 'being autistic' is not like having all things wrong with you (or, it is not like having all things wrong with you *all of the time,* or, *only* having things wrong with you). It is not that Catherine rejects the categorical conceptualisation of autism, but rather, she challenges how well this understanding conveys something about who 'she' is, including ways that specific circumstances might impact her and the lived experience she has in regard to the nature of autistic symptoms.

Whilst Smith, et al.(2009) suggest that good IPA happens when similar phenomenon is experienced by the majority of participants, proponents of the philosophy of phenomenology, upon which IPA stems from, paradoxically suggests that 'showing' and 'telling' (or illuminating phenomenon) is not predicated on psychological terms like 'quantification' or 'repetition' (van Manen, 2014). Their contention is that if this were the case, important phenomenological insights could remain concealed, lurking behind experiences and thus 'hidden' deep within the text. The in-depth exploration of simile, used by autistic people is possibly an important hermeneutical opportunity to consider in research with autistic participants, where communication might be difficult. By *likening* 'being autistic' (with its corresponding symptoms and abilities), to being more like an ice-cream sundae from an ice-cream sundae bar, Catherine [adol] attempts to reveal insights into the lived experience of 'being autistic', hampered in some things, but not in others.

> *Someone can be really good at some things and really bad at others. I like a better description of that involving like an ice cream bar. Like you could go and get whatever flavour ice cream you get and whatever toppings on it…then it was like autism spectrum is like this spectrum of possible ice cream sundaes you can get at* ***this*** *ice cream bar. It is not from more autistic to less autistic, it's more like the ice cream bar…* ***like a bit of this and a bit of that*** (Catherine [adol], p. 21).

This conceptualisation of the lived experience of autism will possibly resonate with many Kiwis, given NZ's dairy industry, high milk production, and the highest rate of ice-cream consumption per capita in the world (HDIP Inc, n.d.). Whilst there are more than 1000 flavours of ice-cream currently on the market including rice, bacon, and avocado, there are an array of possible cones to choose from too, including single, double, waffle, sugar, pretzel, gluten-free, cake, chocolate dipped, and jacketed, as well as toppings like hot fudge, brownie bits, sprinkles, caramel sauce, and gummy bears. One ice-cream bar might limit its range to 20 flavours and another specialising in desserts, may offer 36. On any day, an expert Ice Cream Server might fill single cones with the average 50-licks-per-cone whilst someone relatively new to the trade might consistently overestimate portion sizes, offering 10-to-15 additional licks per serve☺. Depending on the order, one cone might be single scoop with three gummy bears perched on top whilst another could be choc dipped and poorly rolled in sprinkles. No two of these 'frozen delights' could ever possibly be the same.

Catherine [adol] reigns in the boundary of the limits of difference and sameness, by specifically mentioning that her simile of 'autism being like an ice-cream sundae', applies to '***this*** *ice cream bar*'. This leads to a consideration that it is the ice cream bar 'owner', who gets to choose the flavours and toppings on offer. This can be likened to those who determine what constitutes criteria for autism. Autistic participants in this study suggest the 'array' makes sense in general, however the array has increasingly become our 'common knowledge' limiting how we can perceive autistic people.

Given that freezer fluctuations impact the consistency and texture of ice cream and thus the server's ability to form and fashion favourable scoops, perhaps what could be produced at 'this ice cream bar' is more variable than first envisaged. In this sense, Catherine's simile has more depth to convey than a simple challenge that autistic people can *only* be understood as though they were a *particular array* of ice-creams or deficits. Instead, she posits that being autistic is variable because it is always ecologically constrained. This means that under some conditions, people might be 'more or less' autistic.

> *I've gotten very good in what I would call the public sphere, talking to other people and working in an environment with other people and all of that, but at home, I am much more autistic I suppose you might call it, as in I have a lot of tics and, or I will repeat, or I will wander around after mum and I'm very much more like what you would expect of a* ***typical*** *person on the spectrum* (Grace [ter], p. 30).

> *There's this thing I remember seeing somewhere where people go non-verbal under distress. There are cards so if emergency services turns up they can show them the cards that says this is why I may act weird, this is why I am a not able to respond to your things. I am probably non-verbal, this is stressful,*

> *please word your requests clearly and let me get out my assistant device so I can type to you and their assistant device can be an ordinary phone that they could write a text on* (Catherine [adol], p. 21).

Catherine [adol] draws on the temporal element of being ‘nonverbal’ due to specific circumstances to demonstrate fluctuations in functioning, which is relevant to the bio-ecological nature of lived experience. By alluding to the implication of being ‘in distress’, she bolsters her claim that autistic people are not high *or* low functioning, but can be ‘some of the things’ from the ‘high’ functioning category *and* some of the things from the low functioning category, depending on not only biological conditions, but environmental circumstances. Thus, a ‘bit of this’ and a ‘bit of that’ is never ‘fixed’ but changeable, fluctuates, perhaps is even seasonal.

In phenomenological research, there is a need to consider the role of ‘self’, including preunderstanding and Gadamer’s notion that our prejudices can be “enabling and constraining” (Spence, 2001, p. 628). When prejudices ‘enable’, they help to open new understandings; however, when they ‘constrain’, our ability to develop new understandings is limited. My Honours Degree research, outlined in Chapter One, provides a case in point when trying to interpret Catherine’s pic ‘n mix approach. My research involved generating a taxonomy of items pertaining to autism, including physical and sensory characteristics. The array of items was the semantic representation of symptoms and abilities applicable to young people aged 5-18 with a diagnosis of HFA or AS. The individual’s profile, depicted in Figure 2, indicates the most and least applicable array of characteristics for a specific person; this being ontological and phenotypical. Open and filled circles represented personal applicability for each of the items. In this sense, the individual profile was like the ice-cream sundae, being comprised of only those items available at this ice-cream bar, being the taxonomy of items I semantically constructed as representative of autistic traits, taken from textual autism accounts, including autobiographies. The profile was like a ‘snap-shot’ of the individual’s lived experience of autism at that moment in time. Whilst it was generated by someone who shared their ecological niche, such as a parent or close relative, it could also be a self-generated profile or teen ‘selfie’. In this respect, an individual profile provided greater insight into the lived experiences of someone with autism than might the label of autism or someone’s stereotypical knowledge of autism, assuming that the semantic taxonomy was sufficiently broad and meaningful.

As providence would have it, Brad’s [adol] mum was a participant in that research project. She sorted the items in terms of relevancy to her son Brad at the time. His ‘profile’ is depicted in Figure 2 (Chapter One). Figure 2 comprises two parts with the purple rectangle on the right depicting physical characteristics as deficits. The larger size black circles indicate that Brad's mum deemed the array of physical deficits to be irrelevant to Brad. This makes sense, even some six-seven years later as Brad reflects on his lived experiences in high school. He is good at rugby and enjoys sport in general. In fact, 'rugby' is mentioned 19 times in his transcript. The purpose of phenomenological research is to transform lived experience into a textual expression to make us 'see' something (van Manen, 1997b); this repetition suggests that playing sport and following rugby are dominant interests in Brad's life. He says:

> *I've played cricket, touch, squash (I don't do squash anymore) and my favourite one, Rugby…I did Rugby union and it was a really good… I want to just play rugby all my life… and I got player of the day for that game. I scored a try* (Brad [adol], p. 3; 15).

In comparison to Brad [adol], Catherine's [adol] 'profile', if she were to select from the same semantic items on offer, would be like choosing an entirely different type of 'ice-cream' from the same ice-cream bar. There would be increased likelihood that Catherine's profile would be indicative of someone suffering sensory sensitivities as well as physical limitations, the implications of which remain poorly understood and scantily researched (Bodgashina, 2005). Whilst Catherine spends her days in physical discomfort due to her uniform (assigned students in this *particular* school), she might also not want to participate in the sporting life of the school, at least to the same extent Brad [adol] wanted to, or if she did, difficulties would be experienced.

> *Catherine: School also has a really annoying uniform. It has tights - in winter.* ***Tights hurt to wear!*** *so I wear very long socks but those still hurt to wear because of the band at the top of my leg still hurts and also sometimes they roll down and that is annoying.*
>
> Sharon: so you don't like the feel of the tights?
>
> *Catherine: I don't like the feel of the tights.*
>
> Sharon: what would you wear if you could instead of tights?
>
> *Catherine: shorter socks. Not short, short, but not over-the-knee. Because over the knee socks – it is really weird that they are the same length all the way down even though real people's legs get wider at the top.*
>
> Sharon: yeah, I know!

> *Catherine: Why do people design them like that? It's like real people's legs are wider at the top so socks need to be wider at the top so they don't just squash your legs* (Catherine [adol], p.4).

> *We went to the caves it was nice, but we went abseiling in the caves and the rope was very tight and it hurt. It was especially when I was going down the ladder - there was this really skinny ladder and you also had to have a rope tied around you and the rope didn't get let down properly at first so I ended up clinging to the ladder 'I'm about to die' [from pain]* (Catherine [adol], p.23).

One of the concerns regarding quality of research that phenomenologist van Manen (1997a) has alluded to, is our ability as researchers to probe for depth. This requires penetrating to the essence of participants' intentions, which according to Heidegger can at one time make an appearance and at another time be as though hidden in the background beneath the noise and kafuffle of all that covers and disguises the essence. This is a relevant contention because whilst this research privileges Catherine's [adol]voice, it then relies on multiple sources; a wide pool of people and positions who could add to the *eidos* (unique meaning) (van Manen, 2017). In this sense, Danny [par], Catherine, and Grace [ter] are all troubling the waters of 'difference' and the boundaries of (ab)normalcy through the medical narrative of autism, which has given rise to autism stereotypes. Being 'high-functioning' is more like 'being normal', but as will become increasingly clear, this also obscures genuine difficulties and tensions, including the need for support.

Paddy [adv] for example had recently attended a day-long presentation on autism, run by Tony Attwood, one of the world's most respected clinical psychologists in Asperger's Syndrome. Paddy's knowledge of autism had accumulated not only from his own experience of 'being autistic' and parenting an autistic daughter (aged 16 at the time of the interview), but over years of working closely with autistic adolescents, including those who came to him having been expelled from previous schools. He said:

> *They [autism 'experts'] still harp on about autism - you know kids with autism won't give you eye contact, they've got no sense of humor, you can't muck around with them, they take things literally, they do this and they do that, you know [...] You still get people like Tony Attwood [Australian Autism expert] for instance still saying this stuff and obviously he is well respected and everything but, you know, you actually... You know he's got a lot of valuable*

> *stuff to say and honestly, he's done a lot of great work and everything, but you know, you are perpetuating a myth* (Paddy [adv], pp. 1-2).

His frustration about the 'myths' is similar to Catherine's [adol] frustration that autistic people cannot be 'known' or understood if these first person, storied narratives are silenced and others are only being informed by the labels (high and low functioning), broad categories depicted in the DSM, minimalist taxonomies, or autistic stereotypes accessible in popular media.

In summary, research in cognitive psychology suggests we tend to prefer broad categories containing a larger number of items, versus narrow categories containing very few items (Pettigrew, 1958; Kogan & Wallach, 1964). And, whilst we have collectively shifted from categorising people into one of two very broad categories of 'being': normal or lunacy, we have not yet learnt *en masse* about the lived experience of autism in any detail. Whilst young autistic participants in this research believe that the diagnostic label was helpful and congruent with their lived experience, Catherine[adol], James [ter], and Grace [ter] also believed that it constrained how others could come to 'know them'. They believed we must move beyond the current constructed pathological boundaries of a medicalised narrative. In suggesting that the 'autism narrative' is not really that 'black and white', participants rejected the characterisations, arising out of the form of science and instead, moved towards framing autism along cultural and experiential lines. What is crucial for our understanding of their lived experiences, is that these new narratives lacked strictly derogatory ways in which others could easily 'other them' or reduce them to a deficient being.

The medicalised language of autism aided the construction of distorted representations of autism during high school. This is an important finding because it is through narratives, representations and discourses that cultures construct and transmit meanings. If certain meanings are privileged whilst others are unavailable within the high school setting, one's experiences of something pervasive like 'inclusion' will be implicated. As Hall (1997, p. 4) suggests "meanings also regulate and organise our conduct and practices – they help to set the rules, norms and conventions by which social life is ordered and governed. They are also, therefore, what those who wish to govern and regulate the conduct and ideas of others seek to structure and shape."

5.6 Chapter summary and transformative potential

Initially, at least, an autism diagnosis had a liberating effect for those participants who could recall being diagnosed during their adolescent years. It provided a broad framework from which autistic people could make sense of their previous thoughts and feelings about their ‘differences’. Previous research has suggested that the diagnosis provides self-understanding where there was previously doubt, worry, and suffering stemming from confusion (e.g., Mogensen & Mason, 2015). Whilst this thesis provides additional support for this, it also suggests that sometime following the diagnosis, participants began to grapple with how well or not, the diagnostic criteria and stereotypical understandings ‘fit’ their lived experiences.

Three participants in this study challenged stigma, stereotypes, and narrow constructions of autism, thus challenged *who* has the power to define autism and subsequently to define what *their* lived experiences were like. These participants had spent time reflecting on salient differences between what they experienced and encountered, versus what they had read and learned about autism, through encounters with health professionals and online blogs, or via various shades of literature, be that black, white, and/or grey. This suggests that there is a ‘gap’ in the autism narrative. It is not just that stories of lived experiences are ‘missing’, it is the insight and wisdom to think about autism differently, away from being a ‘medical’ condition, that is missing in mainstream.

From a transformative perspective, one way to consider this is in regards the way power and privilege is being renegotiated in NZ, in particular regarding Māori lived experience, through Māori indigenous research that ensures it is “by Māori, for Māori, with Māori” (Cram, 2017). This transformative approach provided not only the Maori community, but NZ society, with insight and wisdom that mainstream research had previously failed to (Mertens, 2009). Similar approaches are needed in NZ and elsewhere regarding autistic people’s lived experience.

From a Catholic standpoint, Matthew’s Gospel (13:43) provides a typology for how autistic people can provide insights into ‘being autistic’, and how we can learn from them, assuming epistemological humility. Jesus used simile as the means for teaching and expanding peoples’ knowledge, suggesting that *The kingdom of heaven is like leaven…*(13:33); *The kingdom of heaven is like treasure in a field…*(13:44); *Again, the kingdom of heaven is like a merchant in search of fine pearls…*(13:45); *Again, the kingdom of heaven is like a net…”* (13.47). He demonstrates that the search for truth remains puzzling unless we are prepared to also grapple with logic and our existing shared understandings to make sense of what is meant by ‘like’. Knowing what ‘Heaven’ is like, cannot be deduced by ‘scientific enquiry’. Likewise, ‘science’ cannot hope to ‘know’ what autism is really like by reducing it to broad categorisations, resulting in stereotypes. Whilst the diagnosis is a shared ‘language’ with legitimate value in the lives of autists, it is also experienced as a truncated one with limited positive utility for them and for how others could know them, communicate with them, and thus teach and accommodate them.

Chapter Six

Carving up space and time by ‘governance’: "it's all about the mainstream and 'everybody is going to do rugby!'"

Well, is croquet a sport? What is it?

(Rachel [adv], p. 10).

6.1 Introduction

In this Chapter, the superordinate theme of ‘governance’ is explored. Participants made sense of the structures and technologies of governance in the process of being ‘educated’ and ‘socialised’ within mainstream high school. Whilst there exists a growing body of literature regarding the characteristics of adolescents and young people with HFA, very little is known about the way in which these characteristics impact students in everyday settings (Brewin, et al., 2008); there have been very few studies regarding the role of the environment in the lives and experiences of autistic adolescents (Krieger, et al., 2018).

The phenomenological principles governing this thesis, postulate that we apprehend the world through our bodily senses (Stein, 1989). That is, we experience the concrete world, but we are not *in* the world in the same way that objects are; rather we are bodily acting *on* them and reacting *to* them (Heidegger, 1927/1962), or as phenomenologist Merleau-Ponty (1945/1996) highlights, we do this by ‘inhabiting’ the world.

Participants in this study alluded to a range of ways in which school governance explicitly and implicitly functioned to give them a sense of being included or excluded, through use of space, time, and the relevance of the dominant school culture. Thus, whilst experiences are diverse, the superordinate theme of the ‘problems of governance’ highlights ways in which in/ex-clusion is a lived experience and is made sense of through the meanings given to the spatial arrangement, cultural assumptions, and the way time is used and technologies of school, like rules, are promulgated and enforced.

‘Governance’ therefore determines where and how students are domiciled, gathered, separated, and re-united for teaching/learning and socialising opportunities; the ways time and space are ‘carved up’ (Rose, 1999). The ways of carving time and space, and its governance, become the normal way in which the ‘things’ that matter (values and meanings) can be defined and reproduced within the school space, as well as beyond its physical boundaries. The lived experiences of ‘being governed’ and the sanctions that result meant that autistic students perceived their ‘differences’ within the context of the ‘normative assumptions’ that dominated the school space. A range of ‘normative’, taken-for-granted school ‘structures’ were resisted, illumined, or rendered problematic by autistic participants, through what Heidegger (1927/1962) called their ‘encounters in the world’. However, some encounters were perceived to be enhanced too, for example, when senior autistic students were able to inhabit ‘common rooms’. Autistic young people likewise apprehended forms of power and privilege exercised through governance; through what (thus, who) got recognised. Therefore, governable spaces like high school, are not only spatially contingent, they are ‘socially malleable’ (e.g., Jampolsky, 2016, p. 87); they are permeated by dominant aspects of culture to ‘shape’ ways of ‘being’ to reproduce its citizens (Rose, 1999). Rugby is one specific cultural force or influence that ‘shaped’ the lives and lived experiences of NZ high school students and was a salient topic for adolescents, tertiary students, and advocates in this study.

One of the pitfalls of reducing lived experience to textual data is that it can appear, for a time at least, as though fragmented. In this thesis, fragmentation is perhaps more pronounced because ‘inclusion’ is “influenced by the contributions of the diverse range of people with whom they [students] work and play” (Annan & Mentis, 2013, p. 27); it is therefore fundamentally lived and experienced at all ecological levels (Muuss, 1996) reflecting that ‘education research’ must also remain conceptually multidimensional and fluid, like education itself.

This chapter begins by exploring the normative and taken-for-granted assumptions regarding the school’s ecological environment and what it affords students, including its ‘safe spaces’. It then explores the ‘embodied’ sensory battles autistic participants contended with, in relation to the spaces they occupied and the activities pertaining to those spaces. The school culture and its impact on autists’ sense of in/ex-clusion is also explored, whilst time is considered in terms of how it gets ‘consumed’ in self-management and the need for time out. The same causes for needing time out also implicates time for homework and time for leisure, however, these will be considered in the following chapters, in their proper context.

6.2 Affordances of the ecological ‘space’

From Gibson’s (1979) ecological perspective, schools, including classrooms, are spaces containing ‘objects’ designed to *afford* learning opportunities for those gathered for that purpose. From an ‘affordance theory perspective’, schools, classrooms and their objects, afford different things for different people; however, what they *potentially* afford autistic people are experiences considerably more diverse, given sensory sensitivities and preferences for order, structure, and routine. Whilst it has been commonly reported that sensory sensitivities pose a barrier to inclusion for autists (e.g., Saggers et al., 2015), their lived experiences have not been particularly well-detailed. There are implications for autistic people to be (differently) 'embodied' within the shared mainstream space. This analysis draws on three examples to highlight how assumptions about ecological 'affordances' has resulted, or could result in, exclusion experiences for autists.

Firstly, Karen [adv] highlighted ethical dilemmas for failing to conceptualise how the classroom, designed to cater for sensorial-normative individuals, can cause problems for students (autistic or not) with sensory sensitivities and for those who, like autistic people, typically desire organised structures (Mesibov & Shea, 2010). She draws on unspoken philosophical assumptions that educational space is arranged structurally as well as academically for learners who are similar in their perceptions of what structures afford; students who have similar goals; and similar learning styles (Baglieri & Knopf, 2004). Having someone in a class who is overwhelmed by the environment and expectations can pose problems not just for the autist, but for the whole class:

> *There is an assumption that what you are including them [autistic students] in, is this ideal world when in fact it's actually a classroom and often not an ideal classroom, with ideal temperatures, and ideal lighting and ideal noise and all that sort of stuff. Is that a good thing to include a sensor-ally disordered student in that, or is that a mean or cruel thing, you know? So many ethical things you've got a look at with inclusion* (Karen [adv], p.1).

As many NZ schools rearrange their classroom 'space' in response to the current trend of 'opening spaces', these environmental changes can render the space even less suitable for sensory-sensitive students. For example, two autistic students experienced decreased agentic capacity, with a corresponding increase in power being 'lorded over them' by teaching staff, in order to limit *their* movement and keep them paradoxically *more* confined. This is contrary to the assumption that by opening the learning space, students are *naturally* afforded more freedom to move, both through the space literally, and more figuratively, through the larger array of activities afforded them within the space.

> *In my experience, just very recently two boys with autism - both have ADHD as a comorbid diagnosis - that's very common - both of those boys have been limited to one part of the modern learning environment already because they*

> *can't manage on their own without an adult in proximity. So, their learning area has been limited to somewhere they are easily accessible by the teacher. So you know, already you've got this wonderful modern new learning environment in the concept of 'inclusion' and joining classes together and teaches co-teaching and all that sort of stuff, but it's already got limitations in the first couple of weeks because of autism* (Karen [adv], p.2).

Secondly, Paddy [adv] provided an example of how objects within ecological spaces afford different students different experiences. It is not uncommon for autistic students to experience objects affording experiences contrary to expectations, due to sensory sensitivities (Ashburner, et al., 2013; Leekam et al., 2007; Saggers et al., 2011; Williams, Gleeson, & Jones, 2019). Whilst sensory sensitivities (from autists perspectives) are considered further on in the chapter, they are considered a central feature of ASD (Hazen, Stornelli, O'Rourke, Koesterer, & McDougle, 2014; Kientz & Dunn, 1997); however, they are also prevalent in the general population. It is believed that these 'alterations' contribute to a student's sense of difference. This occurs when intentions, motivation, and reactions result from unexpected sensory-related processing in an environmental context that fails to stimulate others similarly. The interaction between sensory sensitivities and ecological affordances can lead to misunderstandings for autists, derogatory labelling, and disciplining. In this case, a student's intention to satiate her heightened olfactory senses, using what the environment afforded her, namely paper, led to her being expelled from several schools, and a dossier labelling her as 'violent' and 'destructive'.

> *Paddy: […] and she is sitting there calmly doing her ripping. Cos this is something she wasn't allowed to do because she destroyed schoolbooks and everything at other schools […] she would tear everything up.*
>
> *Rachel: she likes glossy paper!*
>
> *Paddy: [when she came to my class] you know I was supposed to "ahhh, your displays must be on the wall above this height; you can't have books out…you can't have this" and I'm going 'no' […] alright, we need to find ways that we can help her deal with this and cope with this. […] So with this girl, it's like I watch her and like yes, she is grabbing everything, but she'll grab it and she'll stand there and is about to rip and she is looking at the person, the teacher aide and the teacher aide takes three steps towards her and they're like one step away and it's 'scrrrrt' […] She likes the smell of the paper, so her sense of smell is so heightened you know. If you rip a colored magazine you can*

> *actually smell it if you stick your nose right on it, but she will just go 'scrrrt' and then she gives it a couple of waves like this [under her nose] and she gets rid of that one and*
>
> *Rachel: and [now]she puts it in the bin* (Paddy [adv]; Rachel [adv], p. 21).

As an 'autism expert', Paddy [adv] rejected autistic people as essentially violent and therefore studied the student's actions, noticing she passed the ripped paper beneath her nose quickly, after tearing it. Glossy paper can contain formaldehyde, a cheap preservative effecting the characteristics of paper in numerous ways, including shrinkage prevention and waterproofing (Jäppinen & Kanerva, 2000). It is possible that formaldehyde is released in minute quantities when glossy paper is ripped, thus could be smelt by someone with a sensitive olfactory system.

Paddy [adv] opted to accommodate her olfactory desires by providing two cardboard boxes, one either side of her desk (one filled with glossy magazines, the other for ripped strips). He emphasised severity of implications, including exclusion, for sensorially sensitive students who perceive the environment affording something different to that which it is assumed to be affording normative students. He also emphasised the ease with which accommodations can sometimes be made; the 'number 8 wire' solution. This student settled into her work, his paper resources remained on the periphery of the class, and she failed to live up to her demonising labels.

Nellie [adv] provides a third example. She apprehended that a high-functioning autistic senior student was using the main quadrant space of school, to enact certain dramatic imaginary scenarios, deviating from what a particular 'space' typically affords neurotypical students:

> *He carried out his own little fantasies in his head, which would see him scurrying from one corner of the quad to another - at a mad dash. You could see he was really into, into a story.* ***Fantasy unfolding!*** (Nellie [adv], p.5).

The space afforded this student a backdrop for imaginative performances, where angles, obstacles, structures, and buildings provided shelter, exposure, and elements enabling an embodied dramatic play. The same space afforded his peers a place to mingle, talk, and play ball games. During these moments of embodied participation in the quad, Nellie [adv] enabled freedom of expression, by keeping an eye on the student and ensuring his safety, thus accommodating his requirements in using this shared space to afford him something different.

The differences in perceptions of what space and objects affords ‘others’ has consequences for those who use it differently; Nellie felt she had to monitor the student, keeping him safe from bullies, whereas Karen [adv] had to stand in the ‘gap’, to interpret ‘affordances’ and Paddy [adv] had to defend and accommodate a student previously demonised because of others’ misunderstandings and assumptions. In summary, these advocates conveyed that whilst schools are not designed to cater for people with sensory sensitivities, teachers are not typically trained to ‘interpret’ or approximate how spaces and objects might be affording autists different opportunities and experiences, leaving their behaviours to appear ‘odd’ and them being poorly understood by school staff and by peers.

6.3 Safe spaces within school

From autistic people’s perspectives, having ‘safe spaces’ within school, was fundamentally important for ‘being’ in school. Whilst the route to and from school can be ‘hazardous’ for people who are bullied (for example, Grace [ter] was bullied en route; she believed she was an easy target, being ‘alone and exposed’), having safe and quiet spaces to retreat to within the confines of the school boundary was perceived as important.

Having a ‘safe place’ was apprehended as a critical strategy by advocates, if students are going to successfully ‘manage self’; a key competency of NZs educational system. It is not just how access to these ‘safe spaces’ was negotiated that is noteworthy, but adolescents’ understanding that safe spaces are essential for ‘self- management’. This also bespoke an assumption that ‘normal’ people cope in the ‘normal’ spaces. Autistic participants apprehended mainstream schools as having been designed, built, and governed, to predominately accommodate neurotypical students, with additional ‘spaces’ being as though ‘add ons’ and not a ‘normal’ aspect of an inclusive school. That is, schools were still learning how to let autistic (abnormal) people arrive at and use ‘safe spaces’, and thus accommodate them as part of ‘inclusion’ practices. For example, some students encountered obstacles along the route to entering ‘safe spaces’ and others assumed personal responsibility for the task of self-soothing and the management of ones’ problems when they arrived.

To begin, Catherine ([adol], p.1) noted “autistic people [can] go nonverbal on distress” (p. 1), therefore it is essential that plans are preempted and communicated prior to critical moments when they need to be enacted, with little verbalisation. Catherine highlighted that non-verbal didn’t mean no communication, but rather, indicative of potentially needing a digital device. Others highlighted that whilst they remained verbal, their ability to communicate and reason was compromised in the ‘heat of the moment’:

> *and I just didn't trust teachers during that time. It was in my early days. I wasn't thinking at the time, I was just thinking 'get to a safe place' and that was home* (Chris [adol], p. 20).

James [ter] left class feeling anxious, seeking a safe space. On route however, he became so overwhelmed so quickly, he couldn't verbalise his predicament.

> *James: I was told that I could go to the Administration Block and calm down when I felt overloaded. Another teacher called me out of the class for some reason and I just started to feel overloaded and so I started walking to the Administration Block and then the teacher stepped out in front of me and I tried to move to the side and then she stepped in again and so I pushed her out of the way and then I started walking faster and faster to the Administrative Block and then she ran up and tried to stop me again and said "Don't, don't walk away from me." I said, "stop following me, stop following me." Yeah… [long pause] … she wouldn't stop and so I pushed her to the ground and hit her a couple of times.*
>
> Sharon: ok, had she allowed you to go to the Administration Block, when you first felt overloaded…
>
> *James: That would never have happened hey.*
>
> Sharon: did you get the opportunity to explain that later, or were you able to explain that at the time?
>
> *James: no*
>
> Sharon: Were you stood down from school?
>
> *James: I was straight expelled* (James [ter], pp. 7-8).

Whilst this incident occurred just prior to James's [ter] autism diagnosis, procedures for managing the feeling of being overwhelmed, were none-the-less in place. Interpreting what had transpired between himself and his teacher like he did: as a form of 'violence' as opposed to self-perseveration, James "got on [his] bike and rode to the police station" (p. 8). Later, summoned to appear in the youth court, he was prosecuted for the assault, which left the teacher with a broken bone. Having spent the best part of two years home in bed depressed, he was forced, through the enacting of 'good (school) governance', to again return to *his* 'safe space'. James had enrolled in this school at the beginning of year 11 and was expelled in the third term. In being prevented from reaching his negotiated 'safe space', his inability to 'abide' by the 'normal' rules that govern 'good citizenship' (respect to elders, and courtesy), he was positioned as a specific *type* of 'abnormal': violent.

Looking back, James's dad, Danny [par] suggests inclusive schools should not be so rule-based and rigid (autistic) in their governmentality of students struggling with anxiety and sensory sensitivities (diagnosed or not). For example, if a greater degree of 'space' was given to students by caring and compassionate teachers to enable predetermined plans to be executed (thus, freedom, flexibility, and autonomy to 'discipline' their own body through access to, and use of, 'safe' spaces), students would self-manage and return to class more expediently.

> *So again, providing those ways out - don't follow - just trust him. And he knows where his safe places are* (Danny [par], p. 24).

'Pass out cards' have been one way in which NZ high schools have enabled students to leave class and get to their designated 'safe space' with few words. Some students therefore assumed an 'understanding' that they could seek safety when needed. At times however, this 'understanding' was neither enabled or enacted by all teachers and so the 'ordinary' conditions of governance prevailed to the detriment of the autistic (or overwhelmed) students' wellbeing. This ordinary style of 'governance' functioned as an experience of exclusion and conveyed their 'abnormality', whilst positioning the teacher as an authority figure, who demands a certain type of response from all subjects.

Homing in on the 'bio' in Bronfenbrenner's bio-ecological framework, James [ter] fled because he experienced over-arousal. His encounters with the teacher increased his arousal and with it, his 'need' for safety. What began as 'arousal' escalated to the point (perhaps) of fleeing as an automatically activated defense mechanism. Kozlowska, et al. (2015, p. 264) states that "whereas pain processing has been extensively studied, comparatively little is known about the detailed dynamics of sensory processing during defensive mind-body states," however they postulate from previous research, that both 'escape-focused cognitions' (flight and fright) and tonic immobility (freeze) are possible (normal) reactions. James [ter] was cognitive-focused and fled to safety. He treated 'obstacles' in his path, as 'objects' to avoid, keeping his mind entirely focused on his escape to safety. It does not take a 'quantum leap' to suggest that if an 'object' keeps coming 'at you' and you have been unsuccessful in avoiding it, in *this state,* you might defensively lash out at it, knocking it out of the way. Following the hermeneutic circle through, it seems as though James did not 'treat' the teacher as a 'subject' but experienced her as a 'hazardous object' at that critical moment when his defense mechanism was not simply cascading, but fully activated and automated.

As his thoughts on 'escape' gave way to what had transpired before him, he did recognise that he'd treated the 'object', the teacher, violently. He detoured to the Police Station to 'confess' 'his violence'. Had the teacher a better understanding of sensory processing and the possibility of excessive arousal activating defense mechanisms, then she may have been better equipped to foresee the futility of *forcing* a face-to-face encounter in *that* moment and done as Danny [par] suggested, letting him 'get to safety'. One might postulate that without a diagnosis, this is perhaps expecting too much. However, given that strategies were in place for James [ter] to leave class when needed, he had a right to be responded to with dignity; that is, with the right to use 'his strategy'. For 'governance' to be 'inclusive', Danny is perhaps alluding to not only issues pertaining to 'doing justice' but being guided by an ethics of care. In this case, Danny lamented that the incident had lasting consequences for him and James because thereafter his social milieu was as though stripped bare.

> *…now he's created a safe place and it is called his [bed]room and we're trying to make that room bigger and that is really hard work* (Danny [par], p. 29).

Grace [ter] contested normative-based assumptions about autistic people's alone-ness, by highlighting that when autistic high school students arrive at their designated 'safe-space', they are assumed to be effective self-soothers. Grace attended two different high schools and at both she had "a pass to leave the classroom if I needed to" and "a designated place to go" (p. 15):

> *It was a desk up by the Careers teacher [where] I could wait at the desk outside if she wasn't in her office and then she would often let me in when she came back and at [the other school] they had a little nurses area"* (Grace [ter], p. 15).

Grace sometimes used the 'safe space' for protection from the taunts of her peers as well as to de-escalate general arousal and extreme 'anxiety'.

> *I [would get] to the point…yeah, [of] crying, screaming meltdowns and my desk outside [the Careers teacher's office] - I spent quite a lot of time* ***under it*** *as opposed to* ***at it,*** *so…um, sometimes… Probably at that point, I wasn't at the point of calming myself down very well. I needed someone else to calm me down* (Grace [ter], pp. 32-33).

Like Catherine [adol], Grace [ter] also highlighted the importance of digital devices for accessing support when distressed. For Grace, ‘being distressed’ was not a fixed state, but a scale of intensity states with meltdowns being invoked in relation to sensory overload, environmental stimuli, or people. Despite the cause of her meltdowns, her parents proved to be the best source of help, in successfully deescalating arousal, though they need not be. Whilst this is something they had learnt to do over time, so too could trusted others, with enough insight.

> *if I get really upset somewhere […] I will still ring mum and if I can’t get hold of mum, I will ring dad and both of them know enough now to kind of even just manage to figure out what kind of meltdown it is. Whether it is a ‘routine’, or whether it’s a ‘sensory’ and because they can be quite different, or whether there is a people base. They can be quite different, but that tends to be breathing, always the breathing, or ‘where are you’ and always on the phone, always very simple questions, direct, single word answer questions, because I’m not at the point… They’ll ask the questions and if I am at the point of being able to answer, they will just keep going with single answer questions and distraction is probably the other big one. If I’m really not responding, they’ll start talking about something else - often my cats. I have two cats and so mum will start talking about one thing or dad will start talking about that and they will just keep talking and they will talk about something for a minute or two and then they will swap topics and they will keep kind of switching topics until there is something that I will respond to. And I’ve sort of described it before - when I was younger that sometimes when I am in a meltdown, it depends again on what sort of meltdown or why… It’s kind of like being in a little Perspex box in my brain and with them talking to me about it, it’s trying to find the little crack in it and, and it’s kind of like tapping on different sides of it and sometimes they can find the crack and I can get to that crack and hit it from the other side as well and get to the point where I can get even one word out and once one word is out it kind of all flows from there. Because, the kind of stages I get to are obviously stressed and tapping and that, into crying, like just stressed crying and getting quite upset, into very upset but still responsive, to completely unresponsive and screaming to the…, like, yeah… very, very, very unresponsive! And it’s the case of trying to move them back down through [the scale] …*(Grace [ter], p. 36).

Chris [adol] was another participant whose reactions were triggered quickly and so getting to safety was an imperative. Without plans in place for entering safe school spaces, he ran to the only 'safe place' he knew - home! In addition to a specific bullying episode of being 'jump scared' by his peers, it was his general anxiety that sometimes escalated quickly, triggering his seemingly abrupt attempt to 'escape' to safety, highlighting like James [ter] did, that he knows what he needs but has no capacity for entering into discussions. Chris [adol] would think:

> *holy crud I'm in college now, and I have to start thinking about my future and that is where one of my anxieties of now come from…thinking…. Just thinking about my future yesterday made me just feel funny…[pause]… I just felt like… I don't know how to explain it but…I just felt like "what do I do, what do I do?" I just felt like I wanted to run… And, I did run away from college a few times* (Chris [adol], p. 6).
>
> Sharon: where did you go?
>
> *Chris: home - that's the only place I could go!* (Chris [adol], p. 6).

Safe spaces were at times provided for autistic students who failed to act in 'normative ways' within mainstream classes and *had* to be removed for the threat they posed to teachers and students. Brad [adol] described episodes whereby he was sent to a 'withdraw' room in order to avoid conflicts with his math teacher. Other times, Brad opted to retreat to this quiet place himself, rather than encounter the math teacher again, until he was ready. Autists stressed their need for autonomy in biologically self-regulating and thus self-managing, desiring and demonstrating more agency over their environment (space) and their use of time.

> *like I got in trouble with my maths teacher and then my last two maths [lessons], I went to the [withdraw room] - it's a place where you can do work without like getting into any trouble and you're not struggling in class. The first time I went, I was sent there and then the second time I just went there by myself* (Brad [adol], p. 28).

Advocates also noted that at times it was necessary to withdraw autistic students to 'safe spaces' in order to 'contain' them until expertise or services might become available that could shed light on the cause of violent outbursts. In this case, a safe space was considered the *only* option for maintaining peace in classrooms and safety of other students, highlighting that specialist and individualised support is needed, though too often, unavailable, leaving some autistic students segregated 'for their good' and the greater good.

> *[the school] made available to him a flat which was on the school grounds in close proximity to the main school building, so he could work outside the classroom because he couldn't cope working in the classroom. He was just exploding all of the time* (Karen [adv], p. 30).

The use of safe spaces, time out, and seclusion, have gained much attention in the NZ media since 2016 (e.g., One News, 2016), when the more widespread issue of oppressive forms of 'containment' for autistic pupils became known. This led to significant discussions regarding how inclusive schools are for autistic pupils, and how equipped teachers and staff are, to respond to their needs. The autistic young people in this study highlighted that they were cognizant of when, and why, they needed 'safe spaces' in schools and that they were sometimes violent in reactive ways, particularly when provoked to the nth degree; the point at which verbalisation became an impossible expectation.

In addition to designated 'safe spaces', Williams et al., (2019) suggest that autistic students in high school also tend to seek out quiet places, to retreat to during break times. This may be to eliminate social anxiety, avoid bullies, or to pursue a solitary and desirable interest; thus, certain spaces were perceived 'safer' than other 'spaces'. Grace [ter] benefited from structured activities, like making milk shakes in a 'tuck shop' during sporting events or filing during lunch times. Other participants were more inclined to manage ongoing social anxiety by retreating within, sometimes remaining in the classroom, other times seeking a physical location that was quiet, as opposed to a designated 'safe place'. The determining factor was the perceived 'urgency' of regaining control over significant 'threats', versus managing and coping with low-level anxiety and social worry.

Typically, students have used the library for this purpose, often against school rules as Emily [ter] recalled doing. Catherine [adol] discovered an unused on-campus house, whilst Chris [adol] and Taylor [adol] retreated to the Student Support Centre (SSC), which they both attended, oftentimes in lieu of attending some mainstream classes.

> *well my favourite time in the SSC before it becoming computers was just doing my drawings, staying away from the other kids since I was too wary; I didn't want to run into bullies or anything or come across double-crossing friends. I've already had a bad experience with that kind of thing in my previous school* (Chris [adol], p. 5).

> *I like the SSC* (Taylor [adol], p.35).

> *There is this […] house. It's nice and it used to be a house and they brought it and they turned it into school rooms. And there's a microwave and a bathroom and a whole kitchen. Pretty much anyone I think [is allowed to go there], but most people just don't go there and so I go in there and I heat up my food in the microwave and then I…if it is a reasonable temperature and not raining, I go and sit in the sheltered area […] that's this deck thing but with stairs and it is quite wide so I can sit in the corner and it's got walls so I can lean against the walls, and eat my food there. There is also this area behind the drama room where a small group of students somehow got permission to sit there, even though it is right in front of a door, because if it is wet, that area is dry because there is a roof over it. So, they got permission to sit there and I prefer to sit there so I just go and join them* (Catherine [adol], pp. 9-10).

> *…and [I]snuck into the library at lunchtime when I wasn't supposed to* (Emily [ter], p. 2).

6.4 Common rooms and mainstream 'spaces'

Whilst some autistic students wandered during breaks or spent time isolated, others spent time with groups in mainstream spaces. For Grace [ter] the underlying common denominator of her group was that they were 'odd bods'; for Liam [adol] it was being part of a 'gaming group' of peers, sharing a likeminded interest. In year 13 however, participants gave the 'common room' a go. Many mainstream high schools in NZ have traditionally enabled year 13 students to have access to a 'common room' where they could spend break time, use facilities like couches and microwaves, and socialise in seclusion from the rest of the student body. This privilege signifies increased trust and responsibility in the task of being able to manage oneself, with less need for 'policing' and a greater expectation that young people would exercise self-control to conduct themselves appropriately.

Some autistic participants reacted to these spaces positively, with the expectation that they might afford them the opportunity to socialise, or remain within a more ordered and manageable space, thus aiding social companionship and increasing the potential for additional interactions with their same-aged peers.

> *up until year 13 I was pretty much a loner and then quite often I hung out in the common room where I got to talk to people in there, but other than that, I*

> *didn't really feel all that welcome hanging out near other people's friendship groups* (Emily [ter], p. 4).
>
> *I just went into the common room because everybody was allowed to hang out there and people just usually talk to each other - whoever was in the common room. So, I got to have a bit of a chat with people without having to necessarily be part of a group* (Emily [ter], p. 12).

Whilst Chris [adol] gave the common room a go in year 13, he didn't find it particularly stimulating and returned to wandering around during his breaks, occasionally returning to the SSC to doodle or pass time.

> *I just wondered around until my last year when I could sit in the special place with the year 13's. I did sit in there, but it was still boring, so I just preferred to wander around* (Chris [adol], p. 9).

Chris [adol] would have preferred if high school also had a specific type of fitness equipment, perceiving little thought had gone into the 'carving up of the outdoor spaces' for teenagers in high school.

> *Well not exactly a playground; not one with slides and whatever but something like a gymnastic place. You know where you could swing around, do some climbing and that kind of stuff.* ***Now that,*** *that would be good for the teenagers you know, just to work out without going into the gym to kick some balls around… Because gymnastics can't just be a sporty thing, it could also be something that you do in break time, you know - get into the 'Fit zone'* (Chris [adol], p. 10).

Grace [ter] expressed typical concerns that other autistic high school students have regarding the desire for having more 'order' at recreational times and a desire to avoid unstructured spaces as well as events (Connor, 2000; Humphrey & Lewis, 2008a). Looking back, Grace and Emily [ter] believed that having 'common rooms' for each year level in high school would be helpful.

> *Things that could make it better maybe is like groups at lunchtime - may be a common room throughout all the years, like have a year nine, year 10, year 11, year 12 and 13 common room* (Emily [ter], p. 14).
>
> *They had an entire building, which was the common rooms and so each house had their own common room and by common room, I mean a space probably*

> *as big as the [library we were in]. They were huge rooms and there were maybe 60 to 80 students in them. [...] Having a place to go was really good because I think um, one of the things that I struggled with the most at school was unstructured times, so lunchtimes, morning tea times, assemblies - things where lots of people were all moving at the same time or where you didn't really have a place to go* (Grace [ter], p. 15).

6.5 Routine and structure

Knowing what to expect and when to expect it can be particularly important for autistic students, aiding one's sense of control over an otherwise seemingly unpredictable environment. This includes alterations to planned routines and teacher replacements (Murray, 2006). Advocates and autistic students shared a common understanding that when little provision was made for accommodating changes to routines, students' anxiety escalated, whilst a smoother transition ensured when advocates or teachers took the matter in hand themselves, managing the unpredictability of change.

> *I used to have to be very careful if there was a reliever in his class that I would take him up and introduce him to the reliever because he'd [high-functioning autistic senior student] be terrified if I hadn't done this and he arrived at the door and saw a stranger in the class. He would come scurrying back to me. So it was important that I take him up and introduce him to the teacher and then he was fine and felt comfortable with that teacher, which they were always very good with him* (Nellie [adv], p. 2).

> *They've got a substitute teacher there and it's a teacher that she doesn't particularly like and so with an honest and open - 'this is what I say because I'm thinking it' -walks up the corridor and it's not the teacher she is really looking forward to having and she goes " Oh gawd, I hate you"..."we haven't got you have we?" or, "I hate you". [...] And she's got a detention because you know, she said this (Paddy [adv]; Rachel [adv], p.28-29).*

Despite parents providing considerable information about their adolescents' likely reactions to unpredictable changes, normative governance was apprehended as an entrenched system that was well-nigh impossible to penetrate 'from the outside'; parents (and advocates) like Paddy and Rachel felt helpless, even when working within the school, particularly when the consequences led to detention "because she was extremely rude" (Paddy [adv], p.29). For

Chris [adol] and Brad [adol] it had the potential for being very distressing, especially if the unknown relieving teacher's characteristics were off-putting. Other participants made no mention of these problems.

6.6 School rules

Participants in this project were often frustrated by the inconsistencies in the application of school rules; the 'governance' of the school space. They did not so much resist school rules as they desired to understand them and see them implemented fairly. Catherine [adol] for example, experienced a persistent, low-level form of frustration, desiring to understand the logic of rules that were regularly enacted and enforced, but never explained, despite asking about them. In this sense, she wanted 'governance' rendered 'visible' and made understandable because fundamentally these 'encounters' of silence rendered her typical 'lived experiences' more exclusionary.

> *Catherine: that's where [in assembly] we are not allowed to wear our jackets. It's really annoying.*
>
> Sharon: Why is that?
>
> *Catherine: I don't know. We were never given an explanation. We were just told we have to take our jackets off*
>
> Sharon: so how does that effect you…
>
> *Catherine:* ***I like my jacket!*** *But they never explain why I have to take it off – just* ***"take your jacket off!" "But why do you have to take your jacket off?" "Just take your jacket off!"***
>
> Sharon: so, there's no reason as to why you've got to take it off?
>
> *Catherine:* ***noooo!*** *And we have to stand up in some parts of the assembly and there is at least one time in most assemblies we have to stand up and then after a few seconds you have to sit back down again.*
>
> Sharon: And you don't know why?
>
> *Catherine:* ***I don't know why!***
>
> Sharon: ok, ok
>
> *Catherine: it's really weird!* (Catherine [adol], pp. 13-14).

> *If the rule makes no sense at all, it's like 'ok' and the rules that don't make sense is stuff like there is this um 'caff' [cafeteria] line. There is often no*

> *indication of them at all […] like there are particular lines for years 12 and 13, but there is often no indication of that* (Catherine [adol], p. 12).

When assumptions about rules remained veiled off and no one was able to step in and make explicit that which Catherine [adv] failed to understand, it left her as though 'blind' to expectations, increasing the possibility that she would stand out like a 'sore thumb'. This was anxiety inducing.

6.7 'Embodied' battles as daily experiences

Kientz and Dunne (1997) suggest that the sensory profile of autistic people commonly reflects sensitivity to auditory input and hypersensitivity to touch. Some autistic participants in this study mentioned being hampered in some way by sound and tactile sensations, namely music and loud noise, pain from wearing the school uniform, and discomfort from being wet. Sensory disorders, however, can also include food intolerance and dietary restrictions and one participant mentioned being celiac and another, disliking the texture and taste of most vegetables and being more of a 'carnivore', impacting school lunches and suitable options from the canteen.

Catherine [adol] experienced tactile sensitivities and asked if we could change chairs during the interview. She had trouble with her school uniform and returned to this theme several times. Catherine noted that her uniform wasn't simply a 'sensitivity' that caused discomfort, but a problem that caused pain. Persistent pain and discomfort in children and adolescence requires effort to manage and cope with when experienced daily (Bursch, Walco, & Zeltzer, 1998). Whilst Catherine might not meet criteria for pain-associated syndromes, the 'problem' of her school uniform was embodied, significant, and persistent. She had no power to overcome this problem, though took what opportunity there was, with relatively unsatisfactory results.

Similarly, Catherine [adol] found participating in extracurricular activities like abseiling, frustrating because of her tactile sensitivity.

> *We went abseiling in the caves and the rope was very tight and it hurt* (Catherine [adol], p. 23).

Activities that afforded other students the thrill of enjoyment became a source of pain and frustration for Catherine. This overshadowed her otherwise positive experiences of trying new activities on camp during her senior years of high school. Catherine seemed to apprehend that other students did not experience these activities as 'painful' in the way that she did, setting her apart from her peers.

Whilst it may be meritorious for NZ schools to bring their student body into ‘uniformity’ as ‘disciplined citizens’ through the dress code (Museum of New Zealand Te Papa Tongarewa, n.d.), the question needs to be asked as to how ‘inclusive’ this ideology is for autistic students. Whilst ‘fitting in’ is an important aspect of high school on the one hand, enforcement of uniform codes and standards that lead sensory sensitive students ‘tolerating’ pain in the name of ‘belonging’ and ‘school pride’, can also become a problem of governance.

Given participants’ abilities to articulate their sensory sensitivities, it should be incumbent upon high schools to nominate someone to sit and discuss these issues and their potential solutions with their verbal autistic high school students. In this regard, disciplining the autistic body in the name of ‘governance’ was understood as ‘rigid’ and not negotiable, and embodied as painful and cruel. These experiences contrast with the intentions of the Ministries of Health and Education (2016, p. 76) to improve student wellbeing, by advocating for simple environmental changes, such as giving attention to “aversive reactions to environmental materials and clothing”.

Some students and advocates noted problems caused by sports clothing and the need to change quickly. Some participants highlighted how they, or others, were castigated in front of whole classes or given detentions for being less nimble and agile, reducing the speed at which they could get changed, or dried and changed. Other students wore multiple layers to school, putting sports uniforms on underneath their uniform to speed up the process and reduce implications of coming to the attention of disciplining staff. Chris [adol] and Grace [ter] struggled with showers and wet hair, whilst Catherine [adol] couldn’t dry herself sufficiently to avoid clingy clothing, forcing her to wash in the evening in order to avoid being late for school if she showered in the morning. These problems had implications for water-based activities at school, as well as hygiene.

It is also possible that participants’ dislike of, and infrequent use of, hygiene procedures, increased bodily odours and ‘spoiled’ their look, particularly through the build-up of oil in their skin and hair. Compared to their peers, these students failed to engage in the normative disciplinary practices of caring for the body at a time when adolescents notoriously increase their preening, monitoring themselves and others (Rysst, 2010). As such, disciplinary attitudes and the judgement of others, may function to further ‘ostracise’ autistic adolescents.

> *I’m trying to force myself to get it [taking a shower] over with because Mum read something out to me earlier this week and I’m a bit too scared to not take*

> *a shower anymore. Basically my skin will go very…I'll get prone to more certain problems… diseases or cancer and I don't want any of those so… plus I've got a bad case of acne along my back…[water] makes my hair all sticky and it gets hard to dry it all out […] I had a shower two days ago since mum told me that. When she told me that I thought 'screw it, I'm going in'. From now on I'm going to make sure I take a shower every third day!* (Chris [adol], pp. 17-18)

> *I have a lot of trouble with personal hygiene as well because I have trouble with being wet, so showering and that is still something that we just can't get the hang of, on a regular basis because I refuse* (Grace [ter], p. 33).

In addition to indoor showers, the outdoor variety, were also problematic for Grace [ter] and had an impact on the school day.

> *Rainy days were always the worst - I don't like the rain very much; I dislike being wet, um so a… This is dad's comment, 'as soon as you woke up, a miserable day, it was always going to be not a very good day'. Even now, rainy days are not something that I'm really that good at dealing with; I'm better, but not great ... So as soon as it was rainy that would be a bad day [in high school]* (Grace [ter], p.32).

Grace [ter] found going through puberty particularly distressing, and a problem in high school. Others have reported similar difficulties for girls on the autistic spectrum (Simone, 2010), recommending that time is needed to discern how best to manage menstruation (Ross & Lesko, 2018) and to become accustomed to the feel of sanitary products, bras, and the smell and sensation of deodorant (Wrobel, 2016). To date, there has been very little research specific to puberty and menstrual care relevant to young women with ASD, as opposed to those with an intellectual disability (Klett & Turan, 2012).

> *Because I think one thing that I struggled a lot with was, from a puberty point of view growing up, was things like having to start wearing a bra and wearing deodorant and shaving and all those kind of things, I found from a sensory point of view, really difficult* (Grace [ter], p. 20).

Several advocates and autistic participants noted that tactile sensitivities also caused curriculum-related problems for them, which were difficult to overcome. For example, 'standardised procedures' laid down by New Zealand Qualifications Authority (NZQA) for NCEA Art papers note specifications regarding the use of mediums, like 'wet' (paint) or ‘dry’ (charcoal, graphite, chalks or pastels). Because NZQA “has a formal quality assurance process to ensure that the assessment of each standard is fair across all students, regardless of the school they attend” (NZQA, n.d., a), quality assurance makes modifying some NCEA papers difficult.

> *With the first boy, being SO very good at art, he didn’t like that the art course was very prescriptive, and it doesn’t allow for their [autistic people’s] wonderful sense of imagination at all. And with some mediums – they don’t like paints for instance. But after much enquiring I did find that felt tips can be substituted because they’re a ‘wet’ medium* (Nellie [adv], p.6),

Despite art being Chris’s [adol] favourite subject, with much of his past-time spent drawing dinosaurs, Chris found paint to be an intolerable substance.

> *Chris: One thing I didn’t want to do was painting. I hate painting!*
> Sharon: why is that?
> *Chris: well I’m not the kind of person who likes to get his hands very dirty [..] I use pens that give off a lot of ink, typically black in colour, you know to do outlines or whatever* (Chris [adol], p. 2).

> *Dried paint is awful. Dried paint on the canvas feels weird but dried paint on like, in the pallet thing is fine, especially when it is like peeled up in the bottom, so it is smooth and that is nice, but not on canvas and bits of paper. It is bumpy and it kind of feels like flies feet* (Catherine [adol], p. 11).

Noise sensitivities are also a commonly reported phenomenon for autistic people and can be a source of emotional distress in high school (Church, et al., 2000; Hadjipavlou, Baer, Lau, & Howard, 2008; Humphrey & Lewis, 2008a; Saggers, et al., 2011; Scuitto et al., 2012). Excessive noise has long been recognised as inhibiting learning, prompting others to publish at length on the matter (e.g., Plevin, 2016; Dockrell & Shield, 2006). In this study, Chris [adol] in particular, was sorely troubled by noises, especially loud music:

> *I was with the teachers, I preferred* ***SILENCE!!*** (Chris [adol], p. 15).

The college Chris [adol] attended had an active music suite. In a bid to avoid ‘being deafened’, Chris avoided assemblies when he could and all social and celebratory occasions involving musical instruments and excessive noise. There were times though when he was neither forewarned, nor in a position to escape, but seemingly ‘trapped’ and forced to endure the ‘pain’ of sound.

> *Chris: I could go to the SSC [to escape]. Sometimes it was too late for me. I'd be just going in the hall and I'd just notice…I'd just gone into the hall, I can't just back out like that otherwise I'd get into trouble so "oh well" [plugging his ears with his index fingers whilst curling up into a ball, cringing] and just wish for it to be over.*
> Sharon: what would of happened if you'd just walked out?
> *Chris: I'd get stopped by the teachers*
> Sharon: would you have been able to say it was too loud?
> *Chris: I would have just said that I don't want to be around with the music and honestly, I really wouldn't because it was […] it is* ***LOOOUD.*** *You know, being in a tiny echo-ee hall. I just don't want to lose my hearing* (Chris [adol], p. 24).

The WHO (2001) has previously highlighted that habitual sound avoidance is not an effective solution for students because it can lead to ongoing difficulties in tolerating sound. However, it is possible in NZ at least, that some students are physically forced to exceed their threshold, if exposure becomes 'painful' and opting out is not an option. Individual solutions for managing such a threshold necessarily involve consultation with students; however, none were asked what they could tolerate.

In addition to music and loud noise in general, the tone, pitch, and articulation of some voices were a 'natural' source of 'exclusion' for Catherine [adol] in high school. Catherine described some voices as being 'blurry'. This affected her ability to hear what was said, impacting participation, engagement, and enjoyment of particular classes, especially when it was the teacher's voice that was 'blurry'.

> *Some people's voices are very clear like Dr Kyra's voice and my English teacher. Some people's voices are very, very blurry like the biology teacher and my cousin. I like my cousin, but I have to tell him to repeat himself. I just sometimes cannot understand what they are saying. It's just like noise […]sometimes it happens with people who I am focusing on and I want to listen to, like my cousin and it's really annoying especially when he's saying really interesting stuff and I have to keep telling him to repeat himself* (Catherine [adol], p. 22).

In her reflexivity, Catherine noted that there is an appropriate time when voices *should* be blurry, providing insight into the type of blurry she might experience:

> *I guess it's kind of like conversations that you are not in and they get upset at you when you can hear the conversation - when they are talking loudly right next to you, but apparently because you weren't in the conversation you aren't supposed to hear it. I can because I'm right next to it but apparently, they're supposed to blur or something because you're not supposed to be focusing on it* (Catherine [adol], p. 22).

Some noise sensitive autistic adults have described emotional reactions to sound, particularly in social contexts (Landon, Shepherd, & Lodhia, 2016). James [ter] had difficulty tolerating certain frequencies of sound, like Catherine [adol], rather than all sounds, and he lashed out when his tolerance for sounds was exceeded. James [ter] recalled how his dad accurately summed up some of his auditory anomalies during their interviews with Dr Kuro:

> *'Hey, James really hates a lot of loud noise and stuff. And so things like, there's a ticking clock, he'll just remove it and throw it across the room kind of thing, but the other day I came home and he was blasting loud music from the stereo, so obviously there are some frequencies he's more sensitive to than others'* (James [ter], p. 18) .

In summary, autistic students discussed several sensory sensitivities and painful experiences, some of which they had little or no control over in high school. The NZ ASD Guidelines (Ministries of Health & Education, 2008, p.111) notes these types of problems and suggests that "…young people who are challenged by these will need to have adaptations made to their environment and planning to optimise their successful participation." The MoE likewise suggests small environmental changes can lead to substantial assistance for autistic individuals. To know how to accommodate each student though, they must be consulted and it would seem that no one was 'doing the asking'. Most senior autists in this study did not qualify for an IPE and were not self-advocating for ecological adaptations to assist them; they were putting up with their 'lot' and trying to make personal adaptations, such as wearing two sets of clothes (school uniform and sports uniform) and bathing at night.

6.8 Carving up time

Governance of high schools involves the implementation and enacting of micro rules as the technologies of structured spaces. These include the school's timetables, routines, rules, and regulations. Previous studies have highlighted that autistic students experience difficulties in navigating the school grounds, following a timetable, and abiding by the school rules (e.g., Morewood, Humphrey & Symes, 2011). Autistic young people shared the problems that they encountered through the judgement and enacting of micro rules, which shape daily school life.

6.8.1 Navigating the timetable

Whilst few participants mentioned difficulty navigating the school, all students had difficulty mastering and managing their timetable. Most participants considered their timetable as being overly complex, for example being set to a six- or seven-day rotation. During the senior years of high school my neurotypical adolescent daughters frequently had no idea what classes they were to attend on any given day they were asked. However, they had strategies based on their peers' timetables: if one had History first, they had English; if another friend had Physics second, they had Geography etc. Most autistic students in this study, however, were comparatively self-reliant, committing their timetables to memory, trying to discern patterns, and implementing 'home-grown' strategies that worked for them.

> *Oh, I got given it [timetable] and transferred it from paper form so I just flicked it all into bot.net google calendar and that reminded me the exact classes and stuff and I'd have a map of the school in my phone as well… I remember checking, even week-after-week my classes. I think it was on a two-week rotation, so it took a long time to remember what classes were next* (James [ter], p. 36).

> *When you get out of math, you just move on to the next subject. […] With math and science and math to Māori it's alright. Yeah, so there's like transition from math, science two times and then math to Māori, once.*
> *[…] We've got like 6 days and there is day 1, day 2, and day 5 is the maths transitions, so there's like, I have math 2nd period and then science 3rd period, and then 3rd period on day 2, I've got math and then 4th period, which is the last period, I've got science and on day 5, it's math 1st period and Māori 2nd period* (Brad[adol], p. 17).

> *I generally had a timetable, but yeah generally I'm not actually good at remembering what I have next, like I always sort of know, like I know I always have specific subjects after each other, but I never remember, like specific…like days, which I have first* (Liam [adol], p. 27).

Participants noted that mastery of their timetable, or successful implementation of strategies, increased over the years. Lacking the means of mastering the timetable and understanding where one should be and when, was a significant source of anxiety for autistic young people, leaving them with a sense of being overwhelmed by their environment, and lacking a sense of control.

> *Chris: I was anxious about classes in my earlier years because it's not exactly easy. You just go… In my previous school you just stay in one class all year long and then in college, you go to different classes, about five different classes, or two classes at the same time sometimes, just everyday… on a five or six day timetable and that got really confusing […] yeah, I had to keep a timetable with me all of the time.*
>
> Sharon: and that worked?
>
> *Chris: well it took a long time -about half a year or so but I remembered; I got it memorised enough so that I didn't need the timetable, but of course next year comes along, everything changes, and I'll need to have the timetable again. Only as each year passed, I started to use the timetable less and less; it started to click better into my head that… I guess maybe it was because I had less classes or something or they were starting to get a bit easier so I could remember which class to go to (Chris* [adol], p. 6).

6.9 School Culture: The 3R's: Rugby, Rugby, Rugby (Revered, Recognised, and Rewarded)

It has generally been accepted that sport in schools encourages entrenched classed and gendered subjectivities (McDonald, 2016). As such, sport can lead to a sense of inclusion and exclusion. A few participants in this study enjoyed sport and cultural activities at school, such as croquet, cricket, choir membership, participating in school productions, and doing kapa haka. Paddy [adv] had been instrumental in coaching croquet and creating opportunities for students to take ceramics, noting that it was a hub for 'geeks united', especially drawing students together, like autists who disliked sport.

One adolescent belonged to the school rugby team and was so passionate about it, he said: "I want to just play rugby all my life" (Brad [adol], p. 14). In NZ however, rugby is known to be a dominant obsession whose deep roots sometimes penetrate our green school fields, more than any other sport! The mere mention of 'Auckland Grammar' and 'King's College' would not, for most NZ rubgy-loving citizens, conjure up images of schoolboys at study, but rather, young men at ‘war’ on the rugby field, fueled by the ‘weapons’ of historical school rugby rivalry.

As a male-dominated sport, a ‘culture’ of rugby also permeates NZ, including schools (Pringle, 2008). It has been argued that through the promulgation of rugby in high school, explicit consent is given to teens to enact ‘violence’ in masculinised ways, perpetuating the implicit subjugation and oppression of ‘others’ (Schacht, 1996), including women, as well as hemophiliacs and ‘gays’ (Pringle, 2008). This means rugby can also have the power to define ‘successful students’, dominate school interests, and thus, serve as an ‘inclusive’ function; students who resonate with a rugby culture will naturally feel quite at home.

Advocates in this study also suggested that the culture of rugby has the power to subjugate others, especially anyone who is ‘different’, including male students who value artistic, intellectual, cultural, or minority sports over rugby. Thus, the culture of rugby was perceived to function not only as an indoctrination process for ‘doing’ masculinity, through violence[22] and subjugating ‘femininity’ (person and activity), it was perceived as shaping students’ sense of ‘belonging’, and ‘being accepted’, through the ways that some get ‘R’evered, ‘R’ecognised, and ‘R’ewarded (the 3R’s of ‘rugby-mad’ schools), whilst others develop a sense of not being part of the ‘majority’.

> *I scored a try and then during the last few minutes it got… I was in the…trying to get the ball out of the ruck, I got ‘booted down’ and then I got lifted up and I got punched in the face by this big prop. He was a Pacific Islander* (Brad [adol], p. 15).

> *Paddy: so you are talking about integration, and you are talking about including these people with autism and Asperger’s and everything into the fold, where everybody, in the school does a sport but yet these kids don’t get to do ‘a sport’ ...*
> *Rachel: and to this point, they don’t get recognised.*
> *Paddy: I’ve sent an email letter today and you know they will not talk about any other sport - rugby, this, that, and the other - and these [autistic] kids did this well [won a croquet cup three seasons straight] and not once have they ever mentioned about the croquet or anything that these kids have done, you*

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[22] Attempts have been made in NZ to de-power the scrum, but by virtue of the contest “it remains a contest of power in which mental and physical domination is necessary” (Light & Kirk, 2000, p. 170).

> *know. They have not been called out in assembly, and 'wow, well done and dah-di-dah'*
> *Rachel: well is croquet a sport; what is it? [said with 'tongue in cheek']*
> *Paddy: and it's like - and this is where I am saying to you - like all teachers, or whatever….you know…it is all about the mainstream and everybody is […] going to do rugby* (Paddy [adv]; Rachel [adv], p. 10).

What is normative at a macrosystem level as 'our obsession', permeates schools through its endorsements at the exosystem level, whilst the 'culture' of violence and the extraordinary revering of star players is also part of the team comradery and male bonding (Light & Kirk, 2010; Schacht, 1996), enacted and embodied at the microsystem level. Thus, recognition for autistic peoples' achievements in mainstream NZ schools can be minimised or sidelined through the ordinary means of adopting dominant values, attitudes, and the culture of broader society. Achievements that could have afforded autistic students' opportunities to stand out, 'be noticed' and seen in a positive light, were apprehended as missed opportunities. This was deemed oppressive, because it occurs in a culture that already typically 'others' autists. Thus, there were few opportunities in existence within schools that could enable autists to be noticed. In this way, participants were alluding to the fact that rugby does not function as simply another sport in NZ mainstream high schools, but as a cog in the technological machinery that shapes the experiences of the entire student body, including autistic students.

> *We had two options to fly [to Hawaii for school choir contest]…if we left a day early and came back a day later we could have flown direct from Auckland to Hawaii, which would have cut the trip [travel time] in half. But it was over the school holidays and means we would have missed two days and the school said 'no'. They weren't willing to let us have two days off despite the fact they let their rugby team go off on all sorts of adventures* (Grace [ter], p. 22).

> *The choir was not quite as well regarded; The school was very much a sporting school that had a cultural side that 'yes, we're very proud of them but …[gestures as though shooing them away*] (Grace [ter], pp. 22-23).

Despite not asking a single question about rugby, the pervasive influence of rugby and the 'All Blacks' dominated transcripts, as though reference points for what constitutes a normative understanding of kiwi culture as well as a pervasive form of culture within NZ schools, around which other activities are experienced and understood as subordinated. Rugby encroached into every aspect of some participants' school and home life. For example, Emily [ter] reflected on her high school ball experience where she was able to hang out with a friend, however "they wanted to watch rugby" (p.15); whilst Catherine [adol] opined that 'quiet time' at home was drowned out by 'rugby parties' of which she had no interest.

6.10 Chapter summary and transformative potential

In summary autistic young people and advocates in this study apprehended high school as 'outer-world spaces' structured and governed to privilege 'normal' students who share similar sensorial experiences and sociocultural beliefs, understandings, and assumptions. This 'outer world' was experienced interiorly, or embodied, as forms of intrusion (heightened sensory stimulation) and confusion (where to be and what was required of them). This incompatibility between the 'outer world' of school and the 'inner world' of the student, was oftentimes an embodied experience of exclusion. A variety of problems, tensions, and difficulties were therefore illumined and explored at their intersecting reference points, in the context of the body, space, time, and culture.

These tensions were experienced bodily as sensory overload, emotional arousal, frustration, exasperation, and anger, making controlling and managing self, difficult, if not near impossible at times, particularly when 'baited' in the heat of arousal and prevented from seeking solutions, quickly, and silently. In this regard teachers, support workers, and the schools in general failed to offer a milieu that brought out the best in these students. Instead, they offered limited support for ecological problems and the problems of governance.

Given that autism is life-long, it raises questions about the suitability of high school as an appropriate milieu for some high-functioning autistic students, if the site is governed according to normative development, having few resources to help autistic students manage, coupled with limited knowledge about the needs of each student. McCray, Trevvett, and Frost (2013) have postulated a phenotype ontology, scaling phenotypical patterns across modalities of functioning, including emotional regulation, ranging from emotional control to emotional outbursts. Whilst these observations capture the gamut of human reactions to intense frustration and exasperation (and therefore support the stories told here), they miss telling the story of the impact of one's environment on one's ability to de-escalate arousal caused when one's outer world imposes itself; 'control' and 'regulation' can end up becoming particularly onerous for autists and potentially, traumatic. The lived experience of ‘being autistic’ and ‘being in a mainstream school’ involves sensorial arousal and emotional arousal in real-time; solutions are therefore needed immediately. If the implementation of strategies can easily be thwarted in the ‘heat of the moment’, increasing frustration and emotions like anger, with whom does responsibility rest? Failing to take responsibility and accommodate those who need assistance to self-regulate arousal, places the blame for arousal squarely on students’ shoulders.

In this chapter, participants drew on their lived experiences to highlight potentially effective strategies that could make high schools more inclusive. Whilst they were not all able to articulate the depth of their struggles, or the effectiveness of solutions, together they painted a picture of how being marginalised occurs through the oppression of normative dominance in relation to how space and time get carved up and governance gets enacted. Thus, if schools fail to take stock and introspect on how dominant attitudes, beliefs, and values might impinge upon autists, then schools are natural sites for contributing to the marginalisation of the oppressed through the production of normativity. To be transformative, schools must also understand the differences and similarities between the ontology of autists and typically developing adolescents and then find ways to take seriously the task of bringing into the light what remains hidden and veiled off for autistic students, including reasons for rules, and the taken-for-granted assumptions pertaining to governance, the ecological environment and the expectations for managing oneself. Autistic adolescents and advocates with extensive autistic experience can open discussions and steer introspection on the concept of ‘inclusion’; for example, consider another question posed in this Chapter: “Well, is croquet a sport? What is it?” How would a school steeped in a ‘rugby culture’ answer this and what are the implications for autists who experience repeated ‘success’ in croquet?

Chapter Seven
NCEA: (Not)Achieved

"…CREDITS?... *The credits don't matter much to me…I just want to get this done!"*

(Chris [adol], p. 22).

7.1 Introduction

Chapter One alluded to how the Salamanca Statement (ratified by members representing more than 90 governments) recognised that children have a fundamental right to an education that is person-centered and aimed at meeting their needs through implementation of inclusive educational practices and policies (Glynne-Owen, 2010). The preference for 'mainstreaming' students with ASD therefore has its origins within the global political context of 'normalisation' (Glynne-Owen, 2010). Whilst inclusion may not result in equal outcomes for each child, the challenge is for educational departments to develop inclusive educational philosophies that can guide policy and practices. There have been very few studies investigating either the barriers to inclusion, or factors that facilitate it, for ASD students (Roberts & Simpson, 2016).

Aronowitz and Giroux (1991, p.115), have argued that educative institutions in the West have predominately failed at inclusion by marginalising students who fail to fit the mainstream mould, consigning them "to the margins". As such, in a neoliberal climate, like NZ, the 'learning environment' is both structured and governed to 'shape' a specific type of 'learning citizen'; something that becomes the 'natural attitude' of one's learning environment. NZ high schools use the NCEA curriculum to stimulate critical thinking rather than transmit specific knowledges; thus, both teachers and curriculum function as technologies in the transformation of the 'student body' to school leavers considered to be 'life-long learners.' In this sense, education has become the normal means for (re)producing viable citizens for neoliberal society (Schacht, 1996). It is through our ideologies and philosophies that policies enforce standards of conduct for staff as well as students; these are the normal operations that function to discipline the body (Rose, 1998) within the process of 'educating' the student.

Being present *and* engaged in high school has become a fundamental concern of inclusive educational research. Engagement is sometimes conceptualised as a political concept because increased student engagement results in lower student dropout and thus reduced burden to society (Vallee, 2017). In order to increase student engagement a ‘normal’ hegemony may be promulgated, with all facets of governance (curriculum, structural, ecological, and agentic) functioning to steer outcomes towards higher achievement and employment (Vallee, 2017, p.10).

An ‘education’ that neglects meaningfulness to those ‘being educated’, in the production of a certain type of people ‘fit’ for market place, is an education steeped in the reproduction of sameness, secularism, materialism, and neoliberalism; and, by implication, is potentially anti-Christian if one’s sense of well-being and human flourishing is teleologically diminished or compromised within institutional educational systems. One’s ‘education’ could become a personal experience of exclusion, through the realisation that one is not ‘fit for market’, nor motivated by material wealth or prestige (Esposito & Perez, 2014). This has implications for inclusion as well as identity formation.

The commodification of knowledge is valued in NZ, where one’s knowledge and critical thinking skills can be developed, then traded, within the spheres of commerce, enterprise, and research development. For example, the NZ government “sees investment in research, science and technology as fundamental to New Zealand's development as a knowledge society,” so posits that “individuals who are well-educated, self-motivated, and linking into information networks, are the most likely to live prosperous and fulfilling lives” (Roberts, 2004, p. 352). This not only drives the development of curriculum, but pharmacological supplies as a legitimate and benevolent approach to ‘helping’ (Esposito & Perez, 2014). However, it raises the question as to how ‘inclusive’ education is for students whose values and attitudes do not align with ‘normative’ hegemonies; that is, globalisation and living in the era of the ‘knowledge economy’ (Roberts, 2004). As economist Milton Friedman highlights, we are oftentimes prone to considering the *intentions* of policy whilst forgetting about its end results and implications (Duronio, 2012)!

To that end, Heidegger’s hermeneutical perspective enables the analysis presented here to illumine *Dasein’s* understandings and meaning-making, as being grounded in historicity, whilst also moving toward a *potentiality-of-being*. One’s understanding and meaning of being educated as an autistic student in a mainstream school is thus constituted through the ordinary encounters of preparing for Levels 1-3 of NCEA and is similarly constituted through the potential (or actual) throwing of oneself into something beyond NCEA. From this standpoint, *Dasein,* is *thrown* into its possibility (Heidegger, 1953/2010, p.321). Through these lived experiences, out of which meaning emerges, one’s *Wissen* or ‘knowing’ of “what is going on with itself” is revealed through its existential possibilities

(Heidegger, 1953/2010, p. 321). NCEA was temporally positioned by participants in this research, within the broader context of being educated for a position (or lack thereof) beyond high school and this highlights that participants were aware that education has a function linked to identity formation, freedom, and normativity.

This section of the chapter begins with a brief analysis around being present in high school. It then introduces five subthemes pertaining to the major theme of 'being educated'. These pertain to being motivated; encountering incongruence between one's ontological sense of 'being autistic' and a normative curriculum; effort needed for achievement; 'being tested'; and homework.

When asked, not all participants recalled all of the subjects they were currently taking, however, those mentioned included geography, chemistry, design and visual communication, recreation studies, woodwork, drama, craft, art, English, primary industries, Māori performing arts, Te Reo Māori (language), gateway (transition to workplace option), physical education, classical studies, history, calculus, math, biology, tourism, and 'SSC' (un-official period of structured and unstructured study and activity in the SSC).

7.2 Being Present (or absent),

Over the last two decades, it is claimed that the NCEA curriculum has evolved to provide not only a more positive educational experience for all students, but to enable those who had previously struggled to obtain a qualification, to now have the opportunity to do so (Hipkins, Johnston, & Sheehan, 2016). At present, approximately 90% of school leavers aged 16 and over, leave with NCEA Level 1 (Education Counts, 2020c); in contrast, in 1991, 16% left school without any formal qualification (Statistics New Zealand, n.d.). James [ter] was the only student in this study to 'drop' out for a period. He recalled the 'behavioural challenges' he presented in class before he dropped out, namely violent acts, such as throwing chairs, and his experience of anxiety and depression, thought to be more prevalent in ASD, particularly teens (Attwood, 2007). James therefore spent a significant period, spanning part of year nine and all of year ten away from school, predominately in his bedroom, returning to (a new) school in Year 11 before being expelled in the third term for breaking his teacher's arm.

Several advocates drew on their collective knowledge of autistic students to highlight that many are dropping out of school, some well before entering NCEA Level 1, making the current statistics problematic. In addition to advocates' collective experiences of student exclusion, there has been persistent media coverage within NZ and Australia of parents being ‘forced’ to home school, when their children have been ‘excluded’ on the grounds of presenting with ‘behavioural challenges’ (e.g., Breitnauer, 2018; Redmond, 2016; The New Zealand Herald, 2014b). However, as noted in the previous chapter, what appears as autistic ‘behavioural challenges’ is sometimes poorly understood.

> *I think we would be quite shocked if we did some data gathering and found out how many kids actually homeschooled or are on correspondence, or not doing anything because they have autism; they’re not coping with the sensory overload and anxiety; mental health stuff that stems from anxiety to do with autism. I know several kids like that* (Karen [adv], p. 7).

> *I mean our data tells us that that’s where we get this big drop-off [year 9] and I think for kids with Asperger’s it would probably be more pronounced; then there would be a subgroup [of those with Asperger’s] dropping off [later on], with attendance dropping, you know, more illness, more absenteeism from illness* (Karen [adv], p.19).

> *I think there’s a growing trend of people pulling their children out of school, particularly kids on the spectrum […]and homeschooling or enrolling them in correspondence* (Grace [ter], p. 11).

> *And he would just want to stay home and do his, play games on his computer. Not ‘play games’ on his computer. It was his own games –he’d made up stories* (Pamela [adv], p. 21).

Grace [ter] recalled how her significant absenteeism in Year 13, equating to approximately 25% of the year, signalled substantial and noteworthy distress. Unable to communicate the depth of her misery at school, she began to manipulate regulation of her Type 1 diabetes, jeopardising her physical health to justify significant absenteeism. By Year 13 Grace had endured being bullied for many years and experienced significant social exclusion; sensory overload was difficult to manage; and a sense of academic failure led to a reduction in motivation and then a questioning of education as having personal meaning.

> *I was refusing to go to school because I couldn’t see a reason; I couldn’t see a point. When she [private psychologist] met with mum and dad she said “well, at this point she can’t see any positives there and to be frank there probably are none for her to go to school. Why would she want to go to a place that*

> *makes her miserable; makes her unhappy?" She can't see a way out of…. And she can't see ahead* (Grace [ter], p. 30).

By manipulating regulation of blood sugars to satiate her need for time off, Grace [ter] highlights her understanding that diabetes is perceived by others as a legitimate impairment, whilst anxiety, exclusion experiences, and general dissatisfaction with education are not. Grace acts on the dominant assumption that exhaustion is expected following salient blood glucose dips and spikes, whilst 'dips' into depression and 'spikes' in anxiety due to her lived experience of the daily stressors of high school, cannot similarly quantify exhaustion (if it could be articulated), and justify significant absenteeism.

The implicit assumption Grace [ter] makes is that (positivist) measures of biomedical data yield results because they are 'legitimised'; it is this data, not the internal experience one has of 'lived' distress, which elicits empathy from others. Grace highlights her sense of alone-ness in suffering. She may have lacked the intersubjective skills needed to elicit empathy for her actual problems, but she understands something of how to elicit help within the context of her milieu. That is, like Paddy and Rachel [adv's], she perceives school personnel as having a limited understanding of autism and mental health in general. At times, she also feels like her parents also fail to comprehend how difficult it is for her to manage the degree of distress invoked through daily school life. In being able to talk about this now, Grace not only highlights significant maturation in being able to articulate her lived experiences, but that she is looking through the lens of the 'paradigm shift' she experienced upon entering tertiary study and coming to understand that the medical model is only one-way to understand 'disability'; however, it is this model, she experienced as the dominant narrative pervading the high school milieu.

> *I would overdose on my insulin at night time, so I would go low in the night, so my blood sugars would drop and then I would get up and I would wake mum or dad…mum, and she would come and we would treat it […]. Whereas a physical reason "she can't come to school today because she has been 'low'" so that was something that people understood and it was something that was considered an* ***acceptable*** *reason to not be at school* ***for a physical reason*** *whereas what we call 'mental health days' now, weren't […] even mum and dad sometimes at that point, there wasn't always a lot of acceptance of 'I'm having a really bad day today, I can't deal with this' but particularly from a school perspective, it's like well 'so what!' Whereas a physical reason she can't come to school today because she has been 'low' so that was*

> *something that people understood and it was something that was considered an acceptable reason to not be at school for a physical reason, whereas what we call 'mental health days' now, weren't…*
>
> Sharon: so, what was a bad day like for you?
>
> *Grace: Bullying. I was quite badly bullied most of the time at school* (Grace [ter], p. 32).

On one level, Grace's [ter] strategy highlights how mental health difficulties can remain obscure and unexplored (Timmini & Maitra, 2005). She seemingly understands the dominant assumption of personal responsibility where one's well-being or mental health is the result of personal deficits, as opposed to stemming from the milieu one is embedded within. Disturbingly, Grace points to how absenteeism is a 'sign' of significant distress, caused by ordinary experiences. This was something that Paddy and Rachel [adv's] found frustrating too, given that Paddy repeatedly tried to provide information about his daughter that would increase understanding, yet it fell on 'deaf ears'. Being absent from class was not (for these participants), always just about missing course work; it was about distress, depression, and anxiety, and it comes 'packaged' with a suicide warning.

In the previous chapter, the need participants had for retreating to 'safe spaces' meant that they might not always be present for the entirety of their classes. Whilst there is also a paucity of research investigating the presence of students with disabilities in high school classrooms, Feldman, Carter, Asmus, and Brock (2016) note that individuals with severe disabilities are more likely to experience a reduction in being present for the entirety of their classes, resulting in reduced opportunities for peer engagement and learning experiences. In this study, participants highlighted several reasons for not being present for an entire class, namely being slow to prepare for sport, sensory overload, general anxiety, and emotional escalation as a result of academic difficulties, including failing to achieve NCEA credits. Brad [adol] for example experienced significant emotional reactions to what was transpiring in class, including his interactions with teachers and NCEA results, both of which sometimes exceeded his capacity to cope and remain in class.

> *I'm just going to have downtime, or the teacher has upset me and all that and I'm just going to go away and have time alone […] I just go somewhere and just sit down and just relax, that's what I do* (Brad [adol], p. 21).

> *And some other activities like sports, I did not like but they still want me to participate in them and I was all "I don't want to do this, I'm not into sports!"*

> *[…] well, I ran away from school one time because of sport* (Chris [adol], p. 14).
>
> *She is told to go and change in the changing rooms and then… with the other girls and everything. So, she is body conscious, she hangs back until most of the girls are out of the change rooms, goes in quickly to get changed and then the teacher gives her a blue slip (a detention slip) straight away for being late to the lesson* (Paddy [adv & par], p. 27).

Paddy [adv] reflected how ‘seemingly’ trifling incidents, for example finding out the usual teacher will be absent, and a substitute present, were part and parcel of distress for autists and the cause for absences. He believed that an accumulation of stressors resulted in many missed learning opportunities, not only compromising autistic students’ well-being, but increasing the likelihood of potentially devastating trajectories, including suicide ideation.

> *Paddy: I’ve been on to all teachers [about these issues] and I’ve said, potentially down the line, she falls into this category of either someone who could self-harm or commit suicide*
>
> *Rachel: she has been to CAFS. She’s been referred to CAFS three or four times since we’ve been here, for different things. And there is that potential and we live with that all day long and I want other people to understand that so that they don’t push her to this place; they work with her recognising that there is something they might do that might make that happen* (Paddy [adv] and Rachel [adv], pp. 12-13).

Paddy [adv] and his wife, Rachel [adv] lived in fear that everyday experiences and incidents of distress at school, could ‘push their daughter over the edge’. New Zealand has one of the highest suicide rates, including youth suicide in the OECD (Ministry of Health, 2019a), with the Christchurch Health and Development Study highlighting that academic success and peer affiliations are two protective factors (Flemming, Merry, Robinson, Denny, & Watson, 2007). So far (from the small body of research investigating autistic peoples’ suicide ideation, planning, attempts, and successes), it can be gleaned that “people with AS match a high-risk profile for suicide” (Richa, Fahed, Khoury, & Mishara, 2014). Paddy and Rachel suggest teachers and schools in general should consider regular absenteeism among their autistic students as serious indicators that their well-being may be compromised. The stories autists told converge, highlighting that their absenteeism is about ‘managing self’ in acute distress.

7.3 Being (un)motivated

In their review of NCEA, commissioned by the MoE, Meyer et al. (2009) noted several factors that influenced students' motivation, including an understanding of the four-tier endorsement system and students' relationships with teachers (explored further in Chapter Nine). In this study, some students demonstrated a good understanding of the NCEA system and were motivated to gain enough credits for university entrance. Others, like Taylor, Chris and Liam [adol's], did not know how many credits they had accumulated, and it was of little concern to them. Taylor [adol] knew how to log on to the NZQA website, keeping a card with her log in details handy; however, Chris and Liam [adol's], despite being in years 13/14, were still unsure how to access the appropriate website to check their academic record and they had little motivation for doing so.

> ***…CREDITS?...*** *The credits don't matter much to me…I just want to get this [schooling] done!* (Chris [adol], p. 22).

> *Kym: so, he's gone through his whole school career undiagnosed and he's in year 14 this year because he's got no credits.*
> Sharon: none at all?
> *Kym: at all! He's now got Level 1, hey? 2? I don't even know what he's got; nobody knows what he has got because they are just trying to shove points at him now that he is diagnosed, and they can get him help. Whereas prior to his diagnosis, he had no credits whatsoever. None at all.*
> *Liam: well a little bit, but not much* (Liam [adol], p. 2).

Catherine [adol] and Brad [adol] were trying to achieve NCEA Level 1 at the time I interviewed them and were doing their best to accumulate Merit and Excellence credits. Both knew how to check their academic transcript; however, Catherine found the system confusing at times, especially regarding the lag in loading credits and in recognising them by their allocated label.

> *Catherine: I think I've got numeracy credits that aren't math, but I don't know if I ever got them.*
> Sharon: Do you ever go online to have a look on the NZQA website?
> *Catherine: sometimes. It's confusing because the things there are different names to what they were called in school, so we don't know and sometimes they are not put up even though they've been marked and we have had the*

> *mark handed back and they are not put up on the thing so I don't know what happened.*
>
> Sharon: do you find them up there later though?
>
> *Catherine: sometimes, but it's often weeks later. Like in the first week of study leave we did a chemistry test and it is still not up on the site even though it was for credits. It's still not up, at least I don't think it's up. I don't know if it's up or if it was something else that was up.*
>
> Sharon: ok, just because they're not using the same name for everything?
>
> *Catherine: yeah. I just know it as 'the titration one' because that was all we did* (Catherine [adol], pp. 14-15).

Grace [ter] and Emily [ter] reflected on being externally motivated by the accumulation of credits as a means for attaining their goal, university entrance. However, despite being motivated to 'work for credits' at various times, as is evident throughout this thesis, students suffered from a lack of internal motivation as a result of so many daily obstacles including bullying, disappointments over results, ongoing misunderstandings regarding the 'silent' social and academic 'curriculums', and substantial 'gaps' in available support, academic and relational. For example, Grace went through a period in year 13 whereby she lost motivation and no longer felt any purpose to her education. She reflected on how accurately her private psychologist recognised the effect of her despair, being the annihilation of internal motivation and the need she had for external forms of motivation to pull her out of despair, before despair gave way to disengagement and high school dropout. Grace recalled the private psychologist saying to her mum and dad:

> *"You need to think short-term and what is something that she really wants?" And mum and dad both said a laptop, because at that point I had to share a computer with my brother, and it was the single biggest cause of arguments and as soon as I got my own laptop all of them pretty much ceased between my brother and I - our relationship improved* **miles***. And mum was like "but I can't, we can't, that's like bribing her to go to school and that's just wrong". It's just something you have to do* - was sort of like *"well, yes but at this point you've got no choice, the cons significantly outweigh the pros for her; there's no reason for her to go, so you need to make a reason and unfortunately… Or fortunately, whatever you want to call it, it will have to be short-term; it has to be something she can see and that is active now. That long term – 'so you can get a job some day in the future' is never going to work because she is not at a*

> *point where she can see that". So, they set up an account and $10 would go into it every day that I went to school [...] Once I finished school, my parents probably would have bought me a laptop anyway! [...] It got me there daily!* (Grace [ter], pp. 30-31).

Student motivation and achievement can also be subject specific. Some autists evidenced pride and motivation in favoured subjects, where they were able to gain a larger number of credits and experience success. For example, Grace [ter] reflected that she had accumulated more credits in the subject of graphics "like most of my grades in Years 12 and 13 – half of my credits – were from graphics" (p. 13). She noted that these were all internally derived credits. This enabled her to achieve particularly well given that she "didn't do very well in exams" (p.13). Brad [adol] also had a similar experience of success, which was motivating and gave him a sense of pride in his achievements:

> *Brad: So I've passed Kapa Haka and I've got 10 Level 3 credits for doing a Kapa Haka performance in town*
>
> Sharon: Level 3!?
>
> *Brad: yes, Level 3 I know!*
>
> Sharon: but you are only Level 1!
>
> *Brad: Yes, I am, I know! Yes, I'm only Level 1, but I got told by one of the teachers that you can use those Level 3 credits as your Level 1 credits so you will be on track – that's what you do! (Brad [adol], p. 6).*

Conversely, subjects that were difficult or disliked, provided little motivation. For example, Catherine [adol] took math because she thought she had to in Year 12:

> *Catherine: I don't like math, so I only took math because I thought it was compulsory [...] it's not compulsory but I only learned that after it was too late to drop subjects (laughs).*
>
> Sharon: Oh no! How come you didn't know that beforehand?
>
> *Catherine: I don't know. I was just thinking that math is compulsory, so I have to take math; I have to take a 'math subject' so I took a 'math subject' and it turns out that it's not compulsory and I didn't need to –* ***oops!***
>
> (Catherine [adol], p. 18).

Advocates also highlighted specific problems with NCEA criteria that can be particularly problematic for autistic students, stemming motivation by reducing learning opportunities and the chance to generate credits, impacting overall success. For example, autistic individuals are often ‘specialists’ in specific areas of learning, although they are often portrayed in the autism literature in more derogatory ‘clinical’ terms, as having ‘narrow interests’ (Matson & Wilkins, 2008; Tsai & Ghaziuddin, 2014). Educating and enabling ‘specialists’ therefore requires not only fostering a person-centred, strengths-based approach but necessitates having a degree of flexibility within the curriculum to enhance meaningful learning and productivity.

> *This boy has been really into Holden’s. It’s his life! So, it’s quite challenging because he’s also very bright and good with words. We actually had him pass all his English assignment assessments for NCEA around Holden’s. Might have been a speech about Holden’s or a persuasive writing about the Holden’s. He nailed it every time; he was in his passion! It’s been very difficult with the students who are so able. With the first boy, being SO very good at art. He didn’t like that the art course was very prescriptive. And it doesn’t allow for their [autistic peoples'] wonderful sense of imagination at all. And with some medium – they don’t like paints for instance […] Our curriculum doesn’t cater for them […] But, particularly for our boy who is left. He was so into climate and conservation. He wasn’t eligible for any form of correspondence work because the course was already offered, so he was not eligible […] I’d looked down all avenues and different courses but because it was offered here, he couldn’t just pick out one [internal] and do it* (Nellie [adv], pp. 5-6).

> *It’s kind of like to get through school, you have to be a generalist not a specialist and what we know about autistic people is that they’re much more likely to be a specialist than a generalist. And I sometimes say to people who are in Year 13, or not even at Year 13, maybe a little bit earlier, with some of the clever kids that I’ve worked with, I’ve said “when you get to university, you can just study math” you know […] and that can sometimes just kind of help them hang on a wee bit and keep going, but yeah, it does worry me that schools want to have generalists and this is a population that’s much more a specialist population* (Michelle [adv], p. 25).

Unlike other countries, for example Australia and the UK where the curriculum seems less structured (Slee, 2001), in NZ it is more difficult to make ‘idiosyncratic’ adaptations. As a result, greater adaptation and flexibility is demanded of autistic students, which can also be demoralising and unmotivating, for example Catherine [adol] worked for one year to 'write an essay' for the exam. If 'well-being' is central to 'education', which is essentially 'the unfolding of the person' (or flourishing), then it is important to tap into that 'kernal' holding as it were, the key to unlocking the person's fullest human potential (Brenner, 2015). This is not to say that focusing all of one's education around *holdens* (or other significant focus) would lead to revealing an autists' 'fullest human potential', however it is *the* key that unlocks motivation for learning.

Advocates in this study likewise indicated the necessity of ensuring autistic students take subjects that work to their strengths, for optimal motivation, engagement, and therefore results:

> *Without using a strengths-based approach we don't get anything out of a student with autism generally. Their compliance for boring tasks is pretty low. I mean [...] think about how hard it is to engage in a boring task when you've got normal executive functioning skills* (Karen, [adv], p. 3).

Catherine's [adol] error in judgement about the 'requirements' at each level of the curriculum led to a general dampening of enthusiasm, enjoyment, and a lack of motivation in the ordinary course of a school day, simply because she disliked math. Other subjects, like computing were not sufficiently individualised to motivate her and keep her engaged, thus dissatisfaction during the school day, accumulated.

> *Catherine: I took computing because I thought it would be interesting stuff, but then it was a mixture of really boring and obvious stuff and it was also quite confusing. But it was mostly really boring and obvious stuff like how to use Word.*
>
> Sharon: and you don't like to do boring stuff like that?
>
> *Catherine: **No!** I already know how to use Word. I use it all the time. That's what I use to put down all my notes. With computing, or if the whole subject is boring, I dropped it. If other subjects are only a little bit less boring only because I already know it, so I try and pay attention to the stuff that's not the stuff I really, really know [...] yeah, but then there's maths and maths is always hard* (Catherine [adol], pp. 5-6).

Gaining credits in NCEA is constrained by a curriculum split into two pathways: academic and vocational, with the academic pathway enabling students to amass endorsed credits (Not-Achieved to Achieved with Excellence) and gain (or not gain) 'University

Entrance’. Vocational Pathways subjects enable students to accumulate either ‘Achieved’ or ‘Not-Achieved’ credits (NZAQ, n.d.). A vocational pathway prepares students for direct entry into the workforce; however, it can also function to exclude some high achieving, ‘academically minded’ students from the chance to take certain subjects for interest and enjoyment, based on the accumulation of un-welcomed ‘Achieved’ only credits (Meyer, et al., 2009). With publication of NCEA results, and subsequent school ratings (Education Central, 2019), schools may steer high-functioning ‘able’ autistic students into subjects that result in endorsed credits and potentially away from a subject of interest. This has ramifications for learning, ‘being productive’, and thus remaining motivated in school.

> *I think about my (autistic) son in this. He’s a clever person, so was expected by the school to be in the top stream and he mostly was, barely scraped through […]. He’s now 24 and almost finished his qualifications to be an arborist. A love of nature, a love of trees, a love of climbing, has been there since he was tiny [...] There was a point in his education where he thought it would be nice to do horticulture at school but he was told very clearly by the school, that because he was bright he was expected to do physics and chemistry and maths and English and that kind of stuff and horticulture was for the ‘not bright students’. […] He is planning to go to university next year and do a one year of the BSc which will convert his Arboriculture into a BSc and he’s starting to think about what research he might go on to do. […] He’s starting to become ‘academic’ in a field that the school said he shouldn’t study because it’s not academic!* (Michelle [adv], p.25).

The separation of academic from vocational offerings is also underpinned by a neoliberal ideology that reproduces ‘manual labourer’s and associates certain ‘industries’ with the non-academic. However, an industry interest like dairy farming, can also lead to advanced tertiary study, where a Doctoral level qualification could be obtained, for example, by mapping the genetic markers of cows on once-a-day-milking (e.g., Lembeye Illanes, 2016). Thus, an inflexible curriculum can also be a ‘disabling’ curriculum, not only for autistic students, but all students (Slee, 2001).

Motivation to participate in a subject was not always considered in terms of credits to be earned. Certain subjects afforded autistic students the joy of learning or ecological opportunities that other subjects did not provide.

> *Liam: I enjoy classics, and history and stuff. I’m more interested in Ancient History and […] Ancient Greece*

> Sharon: is that a subject you did quite well at?
> *Kym [par]: once again, he never wrote, so we don't know* (Liam [adol], p. 4).

> *I liked Primary Industries for going on the walks. Although I did help in the garden on a few occasions [...] The other kids did written work for primary industries. They wrote a lot. I thought it was more of the physical stuff and less of the writing stuff* (Chris [adol], pp. 11; 22).

Chris [adol] admits that Primary Industries requires a written component, which other students were engaging with. However, he described himself as being more open to the physical opportunities that the subject provided him, namely going for walks. Walking possibly provided Chris with an opportunity to experience refreshment in an environment he perceived as being fraught with excessive noise and the constant threat of bullies. He found a creative solution to cater for his need for solitude and peace throughout the day, which no doubt motivated him to keep up his attendance and make the most of the additional outdoor opportunity the subject presented him with.

Similarly, James [ter] reflected on the time he became very motivated. Around age 12, James hit 'rock bottom' and "didn't really have any motivation" (p. 5), so being able to work one-on-one with an IT specialist, in a 'Health school', enabled him to complete some NCEA Level 2 credits in computing-related papers. Whilst this was well beyond expectations for his chronological age, and the credits had no meaning, James believed it was one of the most highly motivating experiences in his schooling career. Someone noticed him and someone worked with him in an area of interest and this left a lasting impression.

Keogel and Keogel (2006) suggest that an underlying element of motivating students is task variation, particularly in providing the movement between something easy and something challenging. According to Vygotsky's theory, movement between that which is challenging and that which is easy, would be "impossible as an independent activity that is withdrawn from consistent human interaction" (Lake, 2012, p. 38). Some of the autistic participants in this study wanted that balance and noted the detrimental impact it had on learning when they were forced to work outside the optimal zone, or 'zone of proximal development':

> *I also dislike getting bored and not being challenged as well. So, there is this very fine little ground for me that, that if things are a little too hard I'm not interested, but if they're too easy I also get bored* (Grace [ter], p. 23).

> *I went to a regular mainstream high school [after private immediate] and suddenly in Year 9, I was doing things that I had done two years ago, so I became a very lazy student. I didn't have to do anything, I didn't have to work, and I lost a lot of the ability [natural desire] I had, to learn, because I wasn't pushed* (Grace [ter], p. 21).

Some students experienced a quantum leap of sorts between the curriculum and expectations in the 'junior' years, Years 9 and 10, compared with the commencement of the 'senior' years, in Year 11, corresponding to the beginning of Level 1 NCEA. This 'leap' not only curbed their motivation to learn but left them having to adjust their perception of their academic ability and cognitive functioning. Some students looked back, making positive appraisals of their achievements prior to NCEA Level 1, then acknowledged the strong emotional effect their seemingly comparative lack of success began having upon them and the subsequent amount of effort they had to exert if they were going to achieve.

Emily [ter] described being 'overwhelmed' to convey how Not-Achieving' felt: as though a weight bearing down upon her, threatening, as it were, to engulf her. Brad [adol] foresaw that with the progression of NCEA, he would need to 'step it up'. In fact, trying to stay motivated, in the face of repeatedly realising he needed to 'step it up', became the challenge for Brad.

> *Emily: I used to be reasonably good at it [math] in Year 9 and 10 but in Year 11, I did the easier maths program because I got overwhelmed because the maths I tried to do in Year 11, I found it overwhelming.*
>
> Sharon: how was it overwhelming for you?
>
> *Emily: it was like heaps, there was like heaps. . .you had to do a maths problem like a maths essay but with numbers and it was about this [six inches] long and I couldn't do it* (Emily [ter], p. 8).

> *In Year 9 and 10, I was doing quite - reasonably - good but in Year 11, I started to really fail due to NCEA, but I ended up learning how to do it and doing alright in Year 13* (Emily [ter], p. 4).

> *At the start of the year, I started struggling. I mean last year (Year 10) I did Te Reo Māori and I was fine, but now this year (Year 11) I am coming up to upcoming challenges which is going to test me and I really want to pass and get my final credits, so just got to…*(Brad [adol], p. 3).

> *From Year 10 to 11, I got to know more about the subjects that I was doing, so I got to know more about maths work, and it was really slowly, yeah. So once I did my first assessment I realised Oh, I needed to step up from that because I was starting to fail and during my first Recreational Studies assessment I almost failed like I got an Achieved and I was like 'oh man' 'I just need to step up'* (Brad [adol], p. 8).

> *And you've got to find out how you can step up from what you did in the past to what you are going to do in the future* (Brad [adol], p. 10).

> *It was annoying - I cried. It was just really annoying and then the teacher was like 'this question will be in your exam so you don't want to miss this question because you sort of know this one and so we practiced the entire year so I could answer that one question in the exam [...] it is frustrating (Catherine [adol], p. 16).*

Grace [ter], like several students in this study, spoke of how she loved learning; however, what she learnt was not always consolidated and this subsequently meant she would have to relearn material months later for exams. This also resulted in a loss of motivation because it required considerable effort to remaster material on her own. Whilst James [ter] suggested that schools should progress able students quickly through the curriculum (or parts thereof), students like Grace, would need greater assistance to ensure learning was consolidated.

> *I pick things up incredibly quickly; it doesn't take much to explain something to me and I understand it immediately, and so like take calculus for example in maths - they would explain the thing on the board and the teacher is only halfway through writing the explanation on the board and I've already got enough done there and have already got the answer done in my book and I'm finishing them as everyone else is starting. So [having completed her homework as well] it was like 'okay, I've had enough now, I've learned this and I don't want to keep'... And, for long-term memory you need to repeat things, but for me I'd got it. I wasn't interested in keeping on repeating because I got it already. But then by the time exams came around at the end of the year and I was supposed to know all this stuff, it had kind of fallen out*

> *the side of my head and then I had to go and relearn it and it became boring to relearn it. But then it was frustrating to not be able to answer the questions because I didn't know it as well as I should have. I couldn't win at that!* (Grace [ter], pp. 23-24).

Group work, which has its roots in Vygotskian psychology (Vygotsky, 1978) has sometimes been considered a more effective means for increasing learning and aiding motivation. When Dillon, et al. (2014) explored autistic students' schooling experiences, they found that some students favoured group work, especially when peers were better at explaining something and the group wasn't too noisy. In this study however, participants who reflected on group work suggested that it was their least favoured method of learning, especially as grades became increasingly important through NCEA and university. Grace [ter] in particular, highlighted that it wasn't simply the difficulty she had in relating to others, which has previously been considered an obstacle for autistic participants (Asberg, Zander, Zander, & Sandberg, 2012) but rather, it was also her tendency to try and control her peers, along with her repugnance at potentially being forced to receive a grade lower than she was capable of obtaining, as a result of being grouped with less capable students. In this sense, again Grace suggests that grades (or in her case, 'credits') mattered and she was motivated by obtaining them for what they ultimately afforded her, which was entrance into university.

> *Group work was not my forte! So, I did not work like that* (Grace [ter], p. 21).

> ***I never liked group work*** *and I still don't like it to this day. It's always caused problems for me; it irks me that my outcomes can be based on someone else's participation and that bothers me and I mean…it's funny because it's evolved from when I was younger, more just having to work with other people, and then as I got older it was more "what if your work isn't at the same standard as mine?" I know it sounds really snobby but, but particularly at University-level it is like 'well, that's great, I am an A-grade student and you are a C-grade student and I really want my 'A' actually…'* (Grace [ter], p. 33).

> *James: I didn't like interacting with the teachers or interacting with the students – it didn't go well, or most of the time.*

> Sharon: what did you do if you had to do group type of work?
>
> *James: there were only ever two options. I would take over and do it all, or I would do nothing. I couldn't work in a group* (James [ter], p. 34).

To meet the goals of the marketplace, it has been noted that the curriculum may become far removed from one's ability, interests, needs, available support, or personal end goals (Seltzer-Kelly 2012), all of which impact motivation and at various times, to various degrees were experienced by autistic students in this study. Some, however, were highly motivated to learn, but this did not equate to engaging in the same subject at the 'right' time, or in the way envisaged by the curriculum. As such, their knowledge remained unassessed or in James's case irrelevant when taking a Level 2 paper approximately four years earlier than expected. Individualised programs of learning that capitalised on their interests and abilities were most motivating for autistic students, supporting advocates' assertion that strengths-based learning is essential for successful academic outcomes and one's sense of a purposeful, and inclusive, education. Neoliberal assumptions of individual responsibility for learning that would ultimately "enable the learner to work harder, faster and smarter and thus enable[s] their employer to better compete in the global economy" (Boshier, 2001, p. 368), is at odds with the desire autistic students have to find personal meaning in 'being educated'.

7.4 Pedagogical 'sameness' for an ontological 'difference'

Overall, parents, advocates, and autistic young people lamented that the NZ curriculum was not well suited to autistic people. It was neither constructed with the particular workings of the autistic mind 'in mind', nor was it being adapted and taught in ways that made sense to the students in this study, with assessments and measures of learning, being perceived at times, as grossly missing the mark. Pedagogy was understood as being 'normative' and education understood as fundamentally being about educating the 'normal person'. This added to the growing sense that autists had of apprehending themselves as ontologically different. 'Education' was experienced, at times, as though another 'technology' that functioned to exclude them from the dominant body of pupils, who were at school to 'be educated' and for whom the curriculum was designed and taught.

Whilst much has been written about the academic characteristics of students with HFA (e.g., Hagiwara, 2001-2002), the emphasis in this Chapter is on autists' understandings and experiences of themselves in relation to the school generally, and the academic curriculum, more specifically. Chris [adol] perceived problems of a normative curriculum and pedagogy, not as problems that will necessarily remain unresolved, but as having not yet been resolved because so little is known about the lived experiences of autistic people. Teachers, school staff, and curriculum writers, still have much to learn. This suggests that he, like other participants, including advocates, interpreted their current experiences of academic ‘exclusion’ as a problem of their sociohistorical era: in time others will learn more about autism and this will lead to the necessary changes so that autists can also learn and achieve academically. For now:

> *Well I couldn’t understand a lot of things and yeah, I am on the high levels of autism. Well, despite this my only set back would be, I wouldn’t ‘get it’. I would just be all… I wouldn’t understand the concept or how to work it out and even if I do figure it out, it will be the wrong answer because… We took a test a couple of years ago and apparently, I failed, but I swear on my life, that it looked like I had answered every question good. But apparently, I got them wrong. Whatever I was missing… it just looks so different to me* (Chris [adol], p. 12).
>
> *[On further reflection, returning to the same issue] How can I fail? I did it right, it looked like I did it right,* ***I did it right****, I feel like I did it right, how could I fail? It was just really confusing. It has left me confused to this very day – because how the heck do I even work?* (Chris [adol], p. 22).
>
> *Even if I did ask for it [help] at my first school… I would have… I still wouldn’t have got it because they would have had a hard time trying to explain to me since they didn’t know how to handle autistic kids. And I highly doubt that the school would allow them to help* (Chris [adol], p. 12).

The mismatch between Chris’s [adol] perceived ontology and pedagogical experience meant that Chris consequently felt like he ‘hit a barrier’ in trying to work out what ‘right’ even is! In this way, normative education was showing Chris his abnormality and differences, confirming *his* notion of being ontologically different; it left him confused and as though he was a ‘mystery’ even to himself. He perhaps thought ‘I don’t get it, and I never will’, but more worryingly he wasn’t worth the effort.

> *Since one of the reasons I couldn’t learn very easily was, you know, the tests are for normal people but due to my autism, you know, the different wiring of*

> *my brain, my understanding of how it works and what to do was… I just kept hitting a barrier. It was like… I don't get it;* ***I just couldn't get it*** (Chris [adol], p. 11).

As has been highlighted, Emily [ter] and Grace [ter] have reflected, since leaving high school, that their differences were made considerably more evident in high school, than in university. In university, a specialist course or study is usually taken. However, it was not simply the content, but the assessment method, that contributed to their sense of deficiency; some methods of assessment being more compatible with their ontological differences. For example, Emily liked quizzes in university and reflected that had this mode of assessment been offered for a subject like History in high school, she would have achieved "10 out of 10 sometimes" (p. 13). As such, Emily and Grace bemoaned the ways in which high school enacted narrow pedagogical technologies of assessment. They experienced the day-to-day transactions of the normative curriculum as functioning to obscure their intellectual ability, thus punishing them for being ontologically different. As Emily and Grace reflected, this inhibited the realisation of *Deisin* in high school.

> *I'm a Master's student now and my grades are A/A+ level, consistently, and at school I got through on merits and barely on merits for most of the time. So, I was nowhere near my academic potential at all* (Grace [ter], p. 13).
>
> *Emily: [In university] I'm getting B's*
> Sharon: oh, that's good; that's really good!
> *Emily: yeah, and at high school it's usually just getting 'Achieved' […] it kind of made me feel a bit stink that some people were managing to get better grades than me* (Emily [ter], p. 13).

These outcomes are commensurate with current literature that suggests children with ASD "show discrepancies between actual achievement levels and levels predicted by their intellectual ability" (Estes, et al., 2011, p. 1044). However, to further illustrate the problem of assessments (and being unable to work to one's strengths, generally), Grace [ter] emailed a cartoon (often incorrectly attributed to Albert Einstein [Pruitt, 2018]) that she thought aptly illustrated the plight of autists (see Figure 3),

> *Because, in the schooling system, they very much want you to fit in all the little boxes and there's that very famous comic of all these animals lined up and there's a tree behind them and there's a monkey at the desk and the monkey says "right, we are going to be really fair and make sure you are all assessed*

> *the same so all of you need to learn how to climb that tree." And there's an elephant's, there's a fish, and there's a monkey and the monkey is going "yes" and the others are going "what?". Whereas here [in university], it is very much…well you focus on what you* *are good at* (Grace [ter], pp. 8-9).

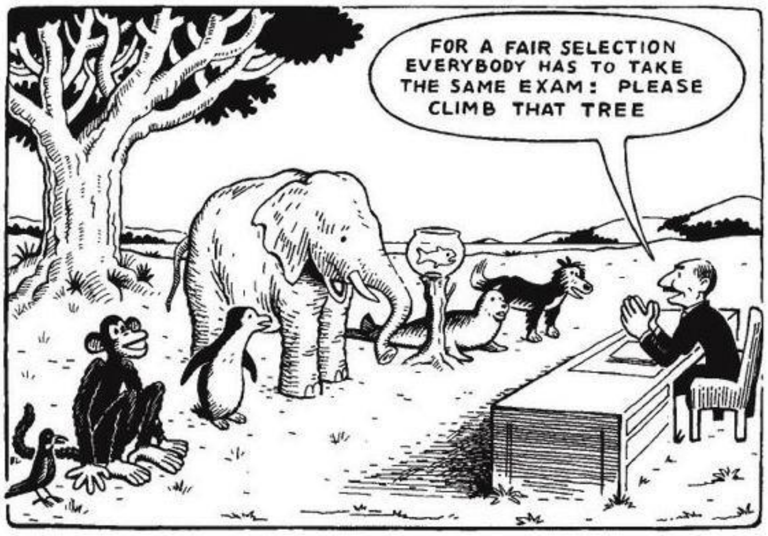


Figure 3. *A 'fair' selection*

Another way in which students and advocates in this study framed their lived experience of being made to look 'stupid' as a result of their ontological differences, was through the utilisation of the metaphor 'ticking the box', whereby the one who 'ticks the boxes', "satisfy[ies] all the apparent requirements for success" (Collins, n.d.), be that student, teacher, worker, or institution. Interpreting autists' perceptions of the 'problems' of 'being educated' this way, autists were problematising the 'institution of education' much like the 'institution of health: it does the work of 'othering', labelling and disabling; it 'sifts and shifts' students.

7.5 Ticking the boxes

Welch (1998, p.158) suggests that "the rising tide of 'efficiency' in contemporary education often masks not only a reduction in both the quality of education provided, but also attempts to increase productivity levels in education, particularly in the public sector." The metaphor, 'ticking the boxes' is fundamentally associated with industrialism and a neoliberal governmentality of efficiency. In schools, as in economics generally, this approach can be passed off as an objective form of 'measuring' performativity regarding teachers *and* students. Teaching performance and learning outcomes, when reduced to checklists, however, may have little to do with the needs of students (Leaton Gray, 2006) and subsequently constrains the educational ‘experience’; teachers are not always at liberty to bring their own teaching philosophies to bear on the teaching/learning experience.

Some autistic young people and advocates attributed some of their (or their students’) difficult academic experiences to this pervasive style of ‘tick-the-box’ governmentality. Teachers were often perceived of as having an obligation to the ‘duty’ required of them ‘to perform’, bringing into focus a range of tensions, suggesting that autists and advocates were attuned to the problems of ‘doing’ education - whereby the pendulum, of necessity, swings between taking a strengths-based or other ‘personally meaningful and good approach’ to a more feasible and necessary path conducive to performing to a ‘teaching schedule’ resulting in ‘good’ performance.

> *And I know we talk about it [strengths-based and person-centered approaches] in our inclusive documentation - I know it's talked about - but then we still have this other side where you must pass and you must achieve and you must tick all the boxes, all that sort of stuff* (Karen [adv], p. 5).

As tertiary students looked back, they believed that this tick-the-box mentality of performativity devalued *their* ‘education’ and impacted on their developing identity as intelligent and capable learners; thus, it functioned to amplify their failings and differences, ‘shaping’ subjectivities. Grace [ter] and James [ter] in particular, noted that mainstream high school is governed and dominated by outcomes, where getting the maximum number of students ‘over the [pass or ‘Achieved’] line’, ticked the ‘right’ boxes. This contrasts with offering person-centered learning experiences that would result in maximum ‘achievement’ per person; something advocates repeatedly highlighted as being the ideal. This interpretation is commensurate with that promulgated by Catholic Personalists and philosophers who were also educationalists, like Edith Stein. She advocated for a return to an education that is personally meaningful, capitalising on one’s strengths and talents, to facilitate flourishing and maturation of the ‘person’, leading to the unfurling of God’s plan for each person to become as He destined (Burgos, 2018; Lebech. 2015, p. 99).

Whilst some autistic students did experience specific incidents where teachers made adaptations to enable them to complete more advanced work, overall, they didn't experience ‘education’ in high school as being made personally relevant a lot of the time because of the extraneous factors they perceived as limiting what could even be offered to them. In this way, autists were seemingly apprehending the neoliberal consequences of a governmentality where education is about the ‘production’ of citizens, whilst they themselves were in the ‘business’ of seeking a (personally meaningful, and relevant) ‘education’.

> *That's one issue I have with the New Zealand education system, is 'hey we need to get all the failing kids up to a pass line but once you pass the pass line no one cares!'* (James [ter], p. 6).

> *I said [to mum] 'well, so why didn't they do the same thing they had done in primary school then and enrolled me in Correspondence or something?'. And she said, "well possibly they could have, but at that point they didn't" and so, unfortunately it meant that lots of the great skills in academics I learnt from [private school and via correspondence] I lost [in mainstream high school] […] I wasn't interested in* ***having to work*** *hard anymore, so it was, in many ways, quite detrimental academically* (Grace [ter], p.21).

From a neoliberal perspective, some high-functioning autistic students, at times, felt like they were invested in their learning opportunities, and wanted teachers to *offer some bang for their buck.* Whilst it could be argued that interest in the topic was the students' sole source of motivation, the following extract, drawn from James's [ter] story acknowledges two pre-constructed narratives that are assumed priori (Labov, 2006) to highlight that 'teaching' is 'performed' with the end goal to see the maximum number of students achieve a 'pass'. The students' personal learning experiences, like the financial reward for teaching, are deemed seemingly insubordinate to the 'performance' of teaching, which is the disciplining of the student body in order to restrict attention to what leads to 'a pass', and thus a 'good [teaching] performance'.

> *James: And they [the teacher], yeah, they got irritated with me, saying things like 'that there's a better way of doing it.' So, he's like "**why don't you teach the class?"** "Oh, I will!" He's like "**I'll even pay you for it!**"*
> *So I taught classes for $20 a lesson.*
> Sharon: is that right?
> *James: yeah! So that was before I was on a disability benefit… that was my income.*
> Sharon: was the teacher happy with what you taught?
> *James: Yep.*
> Sharon: what about the students?
> *James: I don't know. They're just there to pass!*
> (James [adv], p.16).

It wasn't until entering university that Grace [ter] and Emily [ter] began to reconstruct their intellectual identity in congruence with the earlier notion they had of themselves, prior to NCEA, as being intelligent. In high school, autistic students were trying to manage their ‘differences’, masking their deficiencies and reducing risk of being categorised as having failed to tick the appropriate box and be categorised as ‘learning disordered’. The meaningfulness of education was experienced as ‘lacking’, contributing to a loss of motivation at different times. By contrast, conformity and sameness amassed far less credibility in university where one's ‘differences’ could be apprehended as having value; intellectual ‘break throughs’ typically occur when thinking moves ‘outside the box’.

> *I sometimes think about things in a different way which might be helpful [...] sometimes I am quite good at suggesting ideas in the class and being autistic, sometimes people who are not autistic, they feel too much pressure to conform but I don’t and that’s sometimes why I’m happy to say ideas in the classroom and things like that [...] In high school I still felt sometimes, pressure to conform* (Emily [ter], pp. 22-23).
>
> *I think particularly at University level, it is very valued even to have someone who thinks outside of the box a little bit, which I think in the schooling system, very much isn’t the case. Because, in the schooling system, they very much want you to fit in all the little boxes* (Grace [ter], p.8).

In this sense, the opportunities that neoliberalism presents, worked *for* tertiary students. Courses could be selected oriented to one’s strengths, resulting in greater confidence and propensity to contribute. Students felt accepted for their thoughts and valued for their ‘differences’, no longer feeling the need to conceal that authentic (autistic) aspect of themselves: *Daisen*. Having variety in assessments increased their experience of ‘success’, contributing to their re-interpretation of their previous ‘spoiled identity’ (Goffman, 1963). Thus, ‘being different’ can also be interpreted as being a valuable commodity, which also promotes a sense of ‘success’ through achievement and a sense of belonging (Picton, Kahu, & Nelson, 2018), highlighting how, through neoliberal governmentality, resources, both material and discursive come to be distributed in certain ways (Nairn & Higgins, 2007), constraining how one can make sense of themselves over time, or within the context of Bronfenbrenner’s chronosystem.

Neoliberalism can (unfairly) constrain certain individuals who either refuse to, or cannot, conform to market ‘ideals’. In placing more value on contributions ‘outside the box’, the university is capitalising on the ‘points of difference’ or the potential entrepreneurial ‘breakthroughs’ that academic careers are carved out of, funded for, and tertiary sector ‘success’ is built on. There is still the matter of being able to get along socially in order to ‘climb the ladder’ and ‘play the game’. At a minimum however, what can be gleaned from participants’ experiences is that in/ex-clusion for them, is not about isolated experiences so much pe se, as it is about the production of oppression[s] and opportunit(y/ies) to become all they can become through ‘education’: whereby subjectivities are formulated through the substance and technologies in use within the setting, enabling and constraining how one can ‘be’ and ‘be known’.

> *University values you a lot more for thinking differently and I think even at a teaching level and everything, unfortunately high school is about ticking boxes. Ticking, NCEA off; ticking the boxes and making sure all of your little students are in little cardboard boxes and slot very nicely into society* (Grace [ter], p. 47).

Autistic participants in this study also experienced their differences and divergences from assumed ‘normal’ academic trajectories through their experiences of ‘ticking the [right] box’, wrongly. For example, Catherine [adol] recalled in primary school how she was constantly corrected for her handedness (being ambidextrous and desiring to write with either hand and being equally fast and efficient with both); and in her reading method (being equally fast and accurate wrong side up as right side up). Catherine noted that this extended into high school and was particularly notable for her in NCEA, where it was expected that students would build on prior learning by complying with predetermined learning sequences. Catherine was therefore bemused at being told by teachers that certain learning experiences were ‘pre-requisites’ to more difficult topics, only to discover that the pre-requisites were particularly difficult, whilst the assumed ‘difficult’ learning experience that followed, was relatively simple, implicating motivation and effecting accumulation of credits if earlier learning needed to be ‘demonstrated’:

> *Weirdly enough, I found calculus to be easier than the stuff that is supposed to be a pre-requisite for calculus. So differentiating and anti-differentiating is really, really easy, but then anything involving finding roots or like ‘quadraticising’ – I can’t remember the words – I’m just going to say ‘quadraticising’ - it is really hard and I just don’t get it* (Catherine [adol], p. 6).

> *She was also very good at maths and she was in strife a little bit, because they said you're not explaining how you got the answer. She said "well I don't know I just see it all there. I can see this, and I can see the answer, and there it is"* (Pamela [adv], p. 26).

These everyday experiences of failing to 'tick the right box the right way', added to autistic participants' sense of being othered by normative assumptions pertaining to the 'right way' to do things, or the 'right ordering' of things. They perceived NCEA as being 'rigid' in nature when it requires students, for example, to demonstrate their 'workings' or requires demonstrating mastery of pre-requisites. This was experienced as privileging the 'normal' student, whereas autistic students seen themselves as having skills and extra-ordinary minds that shouldn't be 'forced to fit' like round pegs into square holes (Harrington, 2014), but should be developed to capitalise on their abilities and interests.

7.6 Literacy and numeracy

Aharoni (2015) suggests "…poets, like mathematicians, are hunters of hidden patterns" (p. 28). Both seek the beauty of truth fundamentally present in their respective patterns; however, poet and mathematician would seem to differ substantially, not so much in their striving for truth and beauty, but in their means for arriving at truth and representing beauty for others to see. Thus, complexity exists in the insights gleaned and not simply the algorithms mastered (De Lange, 2003). Both have their roots fundamentally embedded within macrosystem level culture, where the forms and functions of society are transmitted through formal and informal 'schooling', and scholastically measured in the spirit of positivistic reductionism to determine the literate from 'idiot'; the 'normative citizen', or the same from the 'different'. As such the 'quantification of progress' (Glynne-Owen, 2010) is enacted through the ordinary means of education, to signify who the literate is. Thus, a 'normal' citizen is determined by virtue of their ability to communicate in culturally acceptable forms of the 3R's (and this time, I'm not referring to rugby, rugby, rugby!).

It has previously been highlighted that autistic students have the greatest difficulty with math, English and science (Baric, et al., 2015; Harrington, 2014 , p. 174; Humphrey, 2008; Humphrey & Lewis, 2008b), with approximately 37% of students with ASD experiencing reading and comprehension difficulties and 23% experiencing a mathematics-related 'learning disability' (Whitby, Travers & Harnick, 2009). Despite these findings, there has been limited research regarding the effectiveness of teaching techniques for ASD students (Carrington et al., 2016; Roberts, 2015), and resultingly, few solid recommendations available for teachers to adapt classroom practice. The difficulty is that effective adaptations must align with personal needs, philosophical teaching practices, school policy, and curriculum flexibility.

Unless lived experience of the educational phenomenon is expounded upon, meaningful policy, pedagogical, or philosophical changes will remain well-nigh ‘hit and miss’! Participants in this study homed in on ‘literacy’ and ‘numeracy’ in their storying of school experiences because these played a salient role in their understanding of success and failure of NCEA. In NZ, ‘literacy and numeracy’ are privileged in ways that they might not be in other curriculums and therefore students’ understandings and interpretations of lived experience are an important site for analysis. For Brad [adol], ‘literacy’ was the ‘key’ to success; he perceived and experienced literacy skills as being pivotal in determining who succeeds and who fails in high school, period!

> *I realised literacy is the key to everything* (Brad [adol], p. 7).
>
> *…and literacy is the key to everything!* (Brad [adol], p. 33).

‘Literacy’ is not easily defined; however, it most often refers to reading and writing, can pertain to textual and numerical text, and may mean being able to read, but not necessarily being able to write (Fischer, 2005). This definition of ‘meaning making’ is tied to ‘written language’, whereas broader-based conceptions might also include art, music, and drama (Albers, 1997). According to the NZQA (NZQA, n.d., b), ‘Literacy’

> *is the written and spoken/signed language people use in their everyday life, learning and work. It includes reading, writing, speaking/signing, and listening/attending. Skills in this area are essential for good communication, active participation, critical thinking and problem solving*

whilst ‘Numeracy’ is

> *being competent, confident and able to judge in everyday contexts whether to use mathematics in a particular situation, and if so, what mathematics to use, how to use it, what degree of accuracy is appropriate, and what the answer means in relation to context. Numeracy knowledge and skills are essential for mathematics in everyday family and financial matters, learning, work and community tasks, and social and leisure activities.*

In NZ, the concepts ‘literacy’ and ‘numeracy’ are present throughout curriculum documents. In addition to being heavily connected to English and math, the concepts are also used to indicate whether various subjects beyond English and math contain enough ‘literacy’ or ‘numeracy’ content within them, to meet criteria for obtaining additional credits towards ‘Literacy’ or ‘Numeracy’. Thus, exposing students, advocates, and parents repeatedly to these concepts, from primary school through to completion of NCEA. For example, NCEA subjects containing ‘literacy’ credits beyond English, range from Te Reo Māori to dance, religious studies, business studies, Latin, and visual arts; numeracy credits can be obtained in subjects from a broad spectrum of curriculum options, spanning agricultural and horticultural studies to chemistry, physics, geography, earth and space science, as well as economics (NZQA, n.d., c). At the time of this study, NCEA required students to achieve a minimum of ten literacy and ten numeracy credits at Level 1, with these 20 credits contributing to the minimum requirements for gaining University Entrance at the successful completion of Level 3. Whilst most students achieve or exceed this number of literacy and numeracy credits in their first year of NCEA (Level 1), students can continue working toward these credits throughout their senior years if unsuccessful initially.

Reference to literacy and numeracy credits were not limited to students, but all participants in this study, highlighting how pivotal mastery in both is perceived to be for success in high school.

> *The two subjects that you’ve got to get so that any other subject bl##dy counts is numeracy and literacy. The two things that no-one…I mean she [daughter] has got dyscalculia which means that she struggles with numbers like, anybody would struggle with dyslexia and yet she can be great in other things* (Paddy [adv], p. 13).
>
> *He’ll never get his literacy. He’ll never get Level 1* (Nellie [adv], p.11).
>
> *I think my first challenge [as autism 'expert' in education] came from a boy who has left now. He had no interest at all in maths and he just saw maths as a bombardment of things coming at him, you know […] I don’t believe he actually finished with his numeracy. His skills were in the languages* (Nellie [adv], pp. 1-2).
>
> *Math - he couldn’t understand so he didn’t want to know* (Victoria [par], p. 19).

> *He did NCEA the first year and he failed everything, but English he passed* (Victoria [par], p. 27).

Chris and Liam [adol's] struggled with writing throughout high school. Chris said he "didn't do the sit down and writing thing. I avoided that" (p. 8), though he did enough 'internals' to achieve his NCEA Level 1, including literacy credits prior to the end of Year 13. Liam, however, didn't write at all. Neither student had a 'reader/writer' or access to a laptop to aid them, unlike Catherine [adol] who was assigned a laptop. In fact, Liam said he wouldn't have wanted one (even if offered) because he still wouldn't be able to 'pad' things out and find much to write about.

Liam's [adol] situation differed substantially to the experiences of other participants in that he remained indifferent to NCEA, aloof from the educational 'system'. Because he was undiagnosed for a large portion of his high school experience, Liam did not see himself so much as 'deficient' as just 'different'. Whilst he would engage verbally at times in literacy-based subjects, by not engaging in any written work, there were no formal options for assessing his literacy skills and thus marginalising him for 'failing'. However, this positioned him binarily as *disengaged*, a concept located on the same side of the ledger as 'abnormality' despite it also evidencing a paucity in the teacher/student relationship (Vallee, 2017). From a neoliberal perspective, 'choosing' not to write means Liam must take personal responsibility for these actions; the consequences of *his* 'choice' will be a raft of severe limitations imposed on him beyond school. Nonetheless, whilst Liam failed NCEA by virtue of all 'he failed to do', his sense of identity, as intelligent, did not seem eroded or perturbed. Perhaps it would have been more so, had he failed NCEA by 'being [hopelessly] engaged', as other advocates noted, including Grant [adv], whose autistic son 'dropped out', being unable to succeed in literacy-based subjects.

By resisting writing, Liam [adol] was a non-disciplined body that couldn't be 'kept' and so easily classified. He enjoyed learning, especially 'the classics'; however, his 'profile' as a high-functioning autistic student is also typical of those from whom much might be expected, but little is 'achieved' (Estes, et al., 2011). Liam's refusal to write and resulting academic transcript, therefore, could be evidence of a 'learning disability'. However, this would be highly inconsistent with his, and his mother's interpretation of his 'ability' to learn and it would also confuse 'learning' with 'results', being the typical 'evidence' of academic achievement in a neoliberal economy. This interpretation supports participants' experience that tick-box checklists functioned to recognise those who can 'prove' themselves successful in *particular* ways, regardless of the actual learning experience.

> *Kym: they are over-achievers his friends. Lance is an absolute… He's a Midas Touch… He just, it doesn't even study, he's just got it and is doing all five sciences*
> *Liam: and is going to write a book (laughs)*
> *Kym: they're all just super intelligent kids. Liam is too. He just doesn't put pen to paper, to prove it. Liam is very…. he's far more intelligent than [sister who is a straight A student]* (Kym [par]; Liam [adol], p. 30).

For those who try and engage in literacy, English has previously been perceived as the *most difficult* subject for students with ASD (Church, et al., 2000), with the greatest difficulty being creative and analytical writing, organisation of thoughts, and the structural elements of essay writing. This is consistent with previous autism studies highlighting the a-symmetrical nature of having 'unimpaired reading accuracy' and 'impaired reading comprehension' (Brock & Caruana, 2014). Grace [ter] reflected how she loved English in primary school because it consisted of reading and spelling and in these she was "miles above [her] peers". Somewhat perhaps, oxymoronically, she hated math, precisely because "it was basic facts and it was rote learning" (p. 24). As Grace progressed to high school, and especially in her senior years, her loves reversed:

> *Math became algebra and calculus and trigonometry, and all those really interesting things and I loved it and English became* ***"the curtains are blue" – what does that mean?*** *I had no time, no time for that whatsoever and English essays just became, taking what I loved, and I loved reading and…* (Grace [ter], p. 24).

Catherine [adol] also loved reading and highlighted that she had completed speed reading tests and could "read about three times faster than normal" (p. 24), being able to also read "upside down easily" and "faster than the other kids" could read normally (p. 3). English, however, also became a form of torture, if not scholastic abuse for Catherine, taking her great love for reading and focusing her attention entirely on mastery of essay writing. In Catherine's first year of NCEA, she was given the task of working on how to write an essay, spending the entire year working on one *particular* essay, in preparation for the exam. This illumines how 'sameness' is rewarded through the technologies of education, not only separating her from her peers, given that she was taken aside to 'practice', but that she was deprived of the joy of learning, being expected instead to take up the responsibility of garnering credits, spending an inordinate amount of time pursuing a small number to gain

‘Literacy’. Like other autists, Catherine wanted to learn how to write an essay, but within a context that better catered for personal well-being and a meaningful education:

> *…and then we did like pretty much the entire rest of the year, we didn’t do the unfamiliar text I just did essay preparation and I just barely managed to get an ‘Achieved’. After having written the same essay at home and the teacher telling me how to do this one particular essay and it was on the Truman show* (Catherine [adol], p. 16).

Some autistic participants described how they were also particularly attracted to one aspect of literary ‘works’, namely descriptive settings. Chris [adol] for example suggested that works chosen for NCEA English papers almost exclusively focused on plot analyses, with comparatively less focus on the settings, which are no less essential to development of good literary works, being as they are, the anchor points of time and space by which plots become embedded and the moral of the ‘story’ reckoned.

> *It was like ‘here’s the setting’ and it’s* ***“oooh****….” I’m the kind of person who, you know you have this setting and they just go through a story but never explain the setting… I’m more along the lines of I want to hear how this world works; how the situation works but they don’t explain it, they just go along with the story, but even the story itself in one of the books just went ‘here’s a story, and this is how we’re gonna end it, and I hope you don’t get grumpy at this’ and even the teacher said “yeah, it was a disappointing ending”. I can’t remember the title of the book, but I remember the situation* (Chris [adol], p. 9).
>
> *I’ve often done plot summaries when I went to write essays and they were like…. I remember the first few times I went to write an essay and early on we were given this guide which sort of started the sentence for us and that sort of came out ok for us. That one was in Year 9 I think and then in later years I just couldn’t do the essays* (Catherine [adol], p. 16).
>
> *I want to do English but actually I want to get an English thing that doesn’t have so many essays because I can’t do essays* (Catherine [adol], p. 15).

As literary techniques began to change, especially when writers like Ernest Hemingway began to move away from thick description, descriptive writing became more of a ‘dying art’ than an ‘art’. As such it has now become “almost a foreign language and they [writers] have little idea how to speak it" (Punales, 2018). This suggests that the neurotypical, social, and neoliberal perspective of the literary task, which emphasises social relations and therefore 'partnerships' commensurate with the economic goals of 'contribution' are assumed 'normative'; it has been privileged and is perhaps unwittingly being offered as a dominant focus for all students, with little recognition given to the spirit of 'inclusion', an autistic subjectivity, and diversity in the love of the 'literary arts'.

There has been insufficient research regarding the need and impact of developing different pedagogical strategies, multiple curriculum objectives, or multiple curriculums for individuals with learning differences (Imray & Hinchcliffe, 2012; Norwich & Lewis, 2005). However, if literacy were also tailored to autistic people, and descriptive (not metaphorical) writing were promulgated as the epitome of the art form, like it once was, then perhaps many more autistic students might be more encouraged to pursue literacy; learning how to 'speak the foreign language' of this dying art form.

Participants in this study also perceived and experienced the literacy component of assessments and criteria of other NCEA subjects as a barrier to success, as well as enjoyment. This was experienced as an injustice in subjects like history and algebra, which required perspective taking, abstraction, and use of conceptualisation using literacy skills. Participants wanted to be assessed in ways that would capture their factual knowledge base of subjects and enable them to also earn credits for what they had learned, but could not express in limited or narrow ways, for example, a single essay:

> *History for example, was a total disaster because although he [son] understood everything and he memorised the whole thing, he couldn't put it into an essay* (Grant, [adv & par], p. 10).
>
> *Then I found it really hard in history, which was a social science because of all the essays* (Emily [ter], p. 5).
>
> *When it came to the [algebra test] what we had to do, we had to explain things carefully. Just put enough literacy in to get achieved […] most subjects in school include literacy so recreational studies includes literacy, kapa haka and Māori – they include literacy* (Brad [adol], p. 6).

> *I'm fine with doing work in class in maths, it's just when I come up to the assessment, it's just…I think of all the literacy I've put in and my teacher says, "it's not enough!"* (Brad [adol], p. 18).

Rather than being so heavily 'essay' focused, Emily [ter] thought schools should supplement these with some quizzes to enable students to demonstrate mastery of content, without detracting from the importance of learning how to write an essay. This solution would be most applicable for literacy-based subjects like history:

> *And maybe as well is having essays, they could have essays but have some other methods as well, like quizzes, like they do at university* (Emily [ter], p. 5).

Unlike some participants' pervasive lamentations regarding literacy, several participants enjoyed numeracy and shared their successes, like James [ter] who completed a Level 2 math exam, without any tuition, and obtained 'Merit' for it; and Grace [ter] who grew in her love of algebra, calculus, and trigonometry. Other participants, however, found the numeracy requirements difficult. Chris [adol] for example said "I never got maths. It was again, like a barrier going past. It was all **what is this?** This is really complicated" (p. 12). Other autistic students associated being unable to understand math with strong emotional reactions, with little-to-no support for managing these reactions, except to grin and bear it, or take time out, detracting from the teaching/learning time.

> *You had to do a maths problem like a maths essay but with numbers and it was about this long [six inches] and I couldn't do it.* ***I couldn't do it*** *[...] I think I just got overwhelmed by it* (Emily [ter], p. 8).

> *I was feeling angry and upset. That's what I was [...] It's when I don't understand it* (Brad [adol], p.31).

Lacking in participant's transcripts were references to negative experiences regarding science-based subjects, where conceptual and abstract thinking or extrapolating are often required, in addition to literacy skills. However, there are no compulsory subjects beyond Year 11 or Level 1, NCEA. Only one participant recalled taking biology (however this was her 'specialty'), whilst another took chemistry and recalled enjoying it.

7.7 Being 'tested'

Exams are commonly considered a major source of anxiety for adolescents in high school (Kouzma & Kennedy, 2004; Smyth, 1995), compromising test performance (Clark, Fox, & Scheider, 1998). Exam stress is thought to be multidimensional in character, including worry, strong emotions, and thoughts and concerns about failing (Stöber, 2004). In India, heightened anxiety has been linked with parental pressure (e.g.., Deb, Strodl, & Sun, 2015), whilst in Turkey, it has been linked to limited tertiary places, determined by examination results (Aysan, Thompson, & Hamarat, 2001). Adolescent coping mechanisms range from withdrawing and avoiding, to suicide (Frydenberg & Lewis, 1991). There has been little research undertaken to specifically understand the lived experience of test anxiety in learning-diverse populations. In this study, some autistic participants reflected on the extent of their anxiety by highlighting both short and long-term implications; as being a direct result of their assessment experiences. Brad [adol] for example, recalled the need for not only short-term, immediate solutions like ‘downtime’, but longer-term ones too, like stepping away from the subject, which would be more indicative perhaps of trauma, than simply emotional arousal.

> *So, I remember struggling in my Māori exam and that made me have down-time. It stopped me from studying Māori for a while* (Brad [adol], p. 21).

By drawing on the collective stories of mainstream schooling experiences of her adolescent autistic clients, Michelle [adv] highlighted a particularly disturbing pattern of interactions, each of which have been depicted in the suicide literature as the ripest conditions for suicide ideation and suicide attempts, namely erosion of self-esteem and the development of depression; “seeing the self as worthless and the future as hopeless” (Overholser, Adams, Lehnert & Brinkman, 1995, p. 920), not too dissimilar to the stories of themselves that James [ter], Taylor [adol], Chris [adol], Brad [adol], and Grace [ter] told.

> *There’s a guy that I am working with currently and he left formal education at about the age of 16 with nothing […] he is now 19 and he’s thinking about going to a polytechnic institute, in fact he just enrolled and he is ‘test terrified’. He is terrified because his experience of the school system was so negative; nobody understood him, he was clearly in major distress and all that happened was he got labelled as bad, different, wrong, mentally ill, all that kind of stuff and so for the last few years he, been in a holding pattern at home, incredibly reclusive* (Michelle [adv], p. 16).

Other autistic students and advocates also noted that tests and assessments in general, had had a profound impact on self-esteem, beginning in primary school. Chris [adol] looked back to consider how a teacher aide might have been useful:

> *to keep me on track for one thing and to help me understand, since one of the reasons I couldn't learn very easily was, you know, the tests are for* **normal** *people but due to my autism, you know, the different wiring of my brain, my understanding of how it works and what to do was… I just kept hitting a barrier* (Chris [adol], p. 11).

James [ter] recalled a style of test that exposed his weakness in executive processing skills, beginning early on in his school career, impacting his perception of self, as 'highly intelligent', noted by his reference to being in the 'top five percent'.

> *Tests were always an issue for me. I remember, like every few weeks in primary school, we'd have a math test where we would get a list of like 100 simple arithmetic questions and you had to do as much as you can in five minutes. And that didn't work for me at all. Like, when you know that you are in the top five percent of your class and you are not doing as much as them in that time, that just…it just really kind of …yeah, it wasn't great for your self-esteem […]. It's terrible. I guess the whole thing with [timed] quizzes and stuff never worked as well. Having slower processing means that you can't do a lot* (James, [ter], p. 32).

In Year 11 however, James fathomed a solution for overcoming his slow processing speed by cajoling a student who took an interest in him to "do all the real simple things" whilst he directed the "overarching [algebraic] equations". This enabled the duo to complete a "45-minute class…in like 10 minutes" (p. 6) and significantly impacted his self-esteem.

Whilst Emily [ter] did not pass all her exams, she was the only autistic student to reflect on how she had increasingly come to understand what was required of her by Year 13. The exam accommodations she had experienced, together with her growing understanding of expectations, led to a sense of accomplishment by the end of her high school career.

> *Emily: I had separate accommodation for exams. The reason was that I didn't really find exams harder.*
>
> Sharon: so exams were easier or became 'okay' for you?
>
> *Emily: yeah, they were okay for me. I sometimes failed them.*
>
> S: why do you think that was?

> *Emily: because I found them hard and I didn't always know the right material and by the end of year 13, I seemed to pick it up over years of practice* (Emily [ter], p. 14).

Grace [ter] was the only student to reflect on the fact that she liked NCEA because it contains a good balance of internal, versus external assessments. She believed this helped her to achieve better than if overall achievement for the year was weighted more heavily on examination results. She relied heavily on a limited number of credits with assessments that suited, in order to amass a larger number of credits. NCEA criteria has however been changing since she completed it, and plans are afoot to restrict the number of credits students will be able to earn from a limited array of subjects (Ministry of Education, 2019). This could have repercussions for autists who specialise in one or a few subjects and want to gain University Entrance.

> *I quite liked NCEA as a 'thing' because I did significantly better in internals than I did in the externals. However, there are only so many achievement standards that are internals. Most internals are unit standards and if you want to be a high achieving student, it is very difficult to be a high achieving students and do the internal work because if it's a unit standard you can only do maximum of achieved; the pass/fail system. It is possibly all changed by now; it seems to change every year. Because I mean, like most of my grades in Years 12 and 13, half of my credits that I got were 'Merit' or 'Excellence' were in graphics, which was a totally internally based… because I didn't do very well in exams. Mum said that when I used to study for exams… if I didn't understand something straight away; that I've got no interest in, I would refuse to work on things and if I didn't understand it, or if I got something wrong, I would push it all away and say "no" and mum was like "you are three weeks out from an exam and you refuse to look at the work?" There were many times that mum and dad were quite…very thankful that I managed to finish all my NCEAs. And I only failed one thing in the entire time which was a Year 13 English essay. I hated nglish so…* (Grace [ter], p. 13).

Brad [adol], Emily [ter], and Grace [ter], all felt that separate accommodations for undertaking their exams was essential for focusing. They all believed their anxiety was heightened substantially by sharing space with others who collectively moved their chairs and created distractions, whilst the spatial arrangement of the exam room, filled with students, gave some autistic participants a sense of being 'crammed in' and thus overwhelmed. Once again, participants highlighted that in order to obtain accommodations, one must be diagnosed with an ‘abnormality’ first; and in Grace's [ter] experience, obtaining accommodations was a difficult and stressful procedure in high school, but comparatively straightforward in university.

7.8 Homework: and learning boundaries

What might begin as learning ‘in the learning space’, is, by necessity at times, taken beyond the school gates, to be completed at home as ‘home-work’. Liam [adol] and Kym [par] recalled very different expectations regarding homework between primary and secondary school, noting that “in high school they get away with not doing any homework, but in primary school they never” [get away with not completing it] (p. 8). Whilst parents of autistic primary school children have expressed feeling anxious about the prospect of their child completing homework in high school (Tobin et al., 2012), Kym reflected on how she found homework in primary school particularly stressful as a parent and time consuming.

> *Homework: three sums, okay, 10 sums, let’s be realistic - three hours no problem. Just to get that 10 sums written* (Kym [par], p. 5).

As time went on, Kym's [par] relationships with Liam's high school teachers deteriorated significantly. Teachers increasingly positioned Liam's sibling as excelling and Liam as ‘failing’, extolling the virtues of one child and expounding the vices of the other, creating a wedge between Kym and the school, impoverishing her mesosystem level connection and therefore opportunities for conversing regarding Liam’s progress.. This left Kym angry, frustrated, and retreating, thereafter supporting Liam’s perception that the home-school boundary really should not be so permeable. Thus, whilst disciplining of the body can transcend place boundaries (Dillon & Underwood, 2012), Liam, supported by his mother, limited this, refusing to participate in homework during high school.

> *I felt angry and frustrated and for what? He was never going to write! I look back from today and see that he has never written anything, and they call me in, I was going to say ‘he’s not going to - make another plan!’ But I didn’t. So, I tried everything else… And spent hours doing homework and arrrggg… That was a waste of time too!* (Kym [par], p. 6).
>
> *Liam: I've just put up with six hours of your crap, why do I need to take it home?*

> *Kym: I think when you're at school, you're at school and when you're at home you're at home* (Liam [adol]; Kym [par], p. 27).

Karen [adv] suggested that some autistic students found homework particularly difficult in the senior years of high school, lacking strategies for managing and monitoring what gets done, when. As a result, Karen suggested that many autistic students become overwhelmed and subsequently avoid homework, only to then try and avoid the consequences of not completing it.

> *I see that in that high school. They just avoid. There've forgotten a book or there've lost their bag and to the point where they'll do some extreme things, like throw away their bag, you know, new school bags – thrown away because then they don't have to say they didn't do their homework. It doesn't sound 'normal' but it's not really, it's not typical, but it's quite a good way of solving the problem because then how can the teachers say, "well you haven't done your homework". If they say, "yes I did, but my bag got lost", then … this is the sort of stuff that happens all the time, you know. It's constant!* (Karen [adv], p. 8).

James [ter] and Grace [ter] recalled times when they completed their NCEA homework within their usual class. At other times, however, they, like other autistic students, struggled primarily as a result of executive processing difficulties and/or emotional overload. James [ter] and Brad [adol] for example described executive functioning problems, including auditory processing skills, as inhibitors for being able to process instructions and later recall what was required regarding homework, even when the work seemed relatively easy in class. As a result, they experienced significant levels of frustration, anger, and distress. They recommended that when homework was issued, written instructions should also be provided. For example, Brad [adol] felt that he understood math in class, but when required to complete class work for homework, he couldn't remember what was required and became angry. He lamented the way in which instructions were issued by his math teacher, in an authoritative tone, recollecting how this decreased his ability to remain calm and focused and thus be able to process what it was he needed to do, in class and later, at home.

> *sometimes I'm really upset and go grrrr and go to my room really angry. Sometimes… I just like ….sometimes my maths teacher tells me to finish this overnight and "**if you don't finish this, you'll have to stay in at the***

> ***next class**" and I'm like, oh gawwwd, she's needs to stop doing that – it's hurting most of us and most of her students* (Brad [adol], p. 21).
>
> *When I don't understand it properly - that's what it is…it's like in my own time when I'm trying to finish up here and it's like* ***"I'm not getting this; how am I going to get this?"*** *When at school it is just easy* (Brad [adol], p. 31).
>
> *So, 'hey you have to do this over the weekend or whatever, [teachers] make sure they [your students], know exactly what to do' because there were so many cases of me where 'hey I could do a thing about this', which, is like I just get tunnel vision I guess and then I spew out this massive amount of stuff and it's nowhere near what the teacher was looking for* (James [ter], pp. 13-14).

It has been well-documented that autistic adolescents experience more intense emotional arousal than non-autistic adolescents (Pisula et al., 2016). Whilst research remains mixed regarding sex differences, it is thought that emotional arousal is predominately caused by social problems for girls, and social problems as well as attention problems for boys (Pisula et al., 2016). In this study, Brad [adol] and other participants reflected that emotional arousal was related to social as well as academic problems: being bullied, having problems with teachers, and failing subjects. Brad therefore *needed* 'down time' to alleviate arousal, which he felt impeded his ability to complete homework 'on demand':

> *Brad: It was at school and the last period was science and we were all just watching a movie and I just decided to have some down-time, just playing games on my laptop, though I had homework, I still had to have down-time… because having "Not Achieves" that's what made me have down-time […]*
> Sharon: when you have down-time, do you need it for a long time?
> *Brad: sometimes 'yes' and sometimes 'no'. If I have homework…so if I've just found out 'oh, I failed at my favourite subject,* ***ohhhh****' or this friend has upset me, I'm just going to have downtime, or the teacher has upset me and all that and I'm just going to go away and have time alone* (Brad [adol], pp. 20-21).

Grace [ter] also reflected that in the senior years of high school (and to a lesser extent, in university) she would become highly aroused, but would strive to keep her emotions in check during the day in a bid to appear ‘normal’. She saved ‘meltdowns’ for home, where possible. They were tiring events for Grace (and her parents, as she now recognises) and recovery was often slow, spanning the evening and into the following day, inhibiting homework and study in general.

> *Particularly at school, even when I got through the days without a meltdown, unfortunately my poor parents – I would get home and they would deal with the aftermath of managing the day* (Grace [ter], p. 30).
>
> *And maybe a day that looked like it went quite well, from one person’s perspective, actually from my perspective was exhausting and there was so much going on and they changed my routine and I just managed to hold on from not having a giant meltdown in the middle of school, but I had it when I got home and the next day: It was a loss!* (Grace [ter], p. 48).
>
> *When they have been at school all day and they are living at that high pitch of anxiety, they are exhausted and they will often not want to do any more work* (Karen [adv], p. 24).

In summary, some autistic high school students and advocates felt that firmer boundaries around home time are needed in order to process the events of the day. This is a similar finding to other studies (e.g., Clark & Griffin, 2014), which also depict the overwhelming nature of high school for autistic students. Students in this study however, also highlighted solutions for making completion of homework easier for them, namely ensuring they don't leave class without clear written instructions, regardless of how well they might appear to master the content and understand the requirements in class. Failing to provide these supports, resulted in high levels of emotional arousal for participants, which they experienced as a barrier to learning, achieving, and staying motivated.

7.9 Chapter summary and transformative potential

The themes of this chapter predominately focused around ways in which governance and pedagogical assumptions embedded within the curriculum, illumined students’ differences and thus, set them apart from their peers in ways that made them feel as though ‘ontologically different’ and fundamentally excluded from ‘education’ and the opportunity to be educated. Students had diverse experiences of success and failure, within the context of difficulties associated with a sometimes meaningless, or excessively frustrating education, particularly when topic knowledge was high, but ability to express it, low.

Autistic students predominately perceived the curriculum as being overly ‘normative’ and prescriptive, privileging non-autistic or ‘normal’ students and thus limiting their opportunities to ‘be educated’. They believed that NCEA is too rigid and inflexible to accommodate them, making it ‘naturally’ ill-suited for autistics in general, being impregnated with inherent normative pedagogical assumptions about learning processes, and what constitutes as ‘proof of mastery’ of content.

The ‘normative’ nature of the education system, and the most problematic for autistic participants, was regarding literacy and numeracy, with mastery in both having long been considered ‘apt’ markers of the ‘educated’. Some autistic students perceived and experienced the NCEA literacy curriculum as favoring and rewarding assumed dominant (or ‘normative’) skills, such as perspective-taking and plot analysis over descriptive, contextual, and factual considerations. Likewise, the numeracy curriculum was contested regarding the assumption that ‘normative’ limitations imposed by our cognitive apparatus, necessitates a sequential style of learning predicated upon prior knowledge and acquisition of specific types of skills. Thus, pedagogical practices were experienced by autistic students as being ‘off beat’. This led tertiary autistic students to perceive their non-autistic peers as comparatively methodical and sequential learners, who were ill-suited to the task of ‘thinking outside the box’, more highly prized in university but shunned in high school.

Other autistic high school students who had not been exposed to alternative narratives about ‘disability’ and were failing academically, became increasingly confused about how they ‘worked’. This impacted self-esteem and self-understanding, being the lived experience of the double-strand of the ‘special education’ or ‘inclusive education’ narrative, which is education and inclusion of the ‘gifted/disabled’ (Rose 1996).

From Bronfenbrenner's perspective, it is possible to situate ‘the problems of participants’ experiences’ as spanning the macrosystem-to-microsystem levels, commensurate with neoliberal and normative ideologies that not only permeate economic conditions at the broadest social level, but are inflicted at the personal level, through a rigid education system organised around the production and ‘shaping’ of a specific class of citizen, who ‘ticks’ many normative and ordinary ‘boxes’. Governmentality suggests that (inclusive) students are all somehow ‘teachable’ (Douglas, 2010). However, NCEA, as a technological tool, was experienced as more or less having power to repeatedly shunt students from one side of the ‘gifted-disabled’ binary to the other, commensurate with their successes and failures stemming from a-synchronous cognitive abilities, particularly in the areas of numeracy and literacy and then specialist subjects. The current curriculum, having been constructed on the assumption of ontological ‘sameness’ has resulted in widespread experiences of failure and ‘exclusion’. Transformative potential therefore exists by (re)considering high-functioning autism as an ‘ontological difference’ as opposed to a ‘disability’. Accommodating the person who is ontologically different would necessitate re-examining assumptions about the person, education, and the need for support, an analysis of which will be considered in Chapter Nine.

Beyond 2020 it is expected that a range of key changes to NCEA will begin to be implemented over the course of five years (Ministry of Education, 2019). This will impact all students. However, of interest here are the proposed changes relating to the doubling of literacy and numeracy credits from ten each in literacy and numeracy, to 20 in each. It is proposed that these credits will now be a co-requisite sitting alongside the NCEA program, which is proposed to soon comprise three, 60 credit levels. It is expected that the widespread practice of resubmitting work will be eliminated, except for those occasions whereby students might make minor changes enabling them to submit their previously ‘Not-Achieved’ outcome, in the hope of obtaining ‘Achieved’ credits (Ministry of Education, 2019). This will impact students who previously relied upon feedback in the hope of obtaining a higher endorsement through resubmissions. This has implications for autists, for example, if autism is considered to be an ontological difference, it could be expected that ‘interpretation’ of key aspects of the task, are misunderstood first time around (or for that matter, second and subsequent times). James [ter] for example makes the point that he often misinterprets questions on the first go, however, his current tertiary course enables ‘corrections’.

> *So, if you make a silly mistake, which happens basically every time with me, because I didn’t read the question or I didn’t understand the question, it will tell you you’re wrong and it it’s like “Oh! I’m wrong because I know exactly what I’ve done”* (James [ter], p. 32).

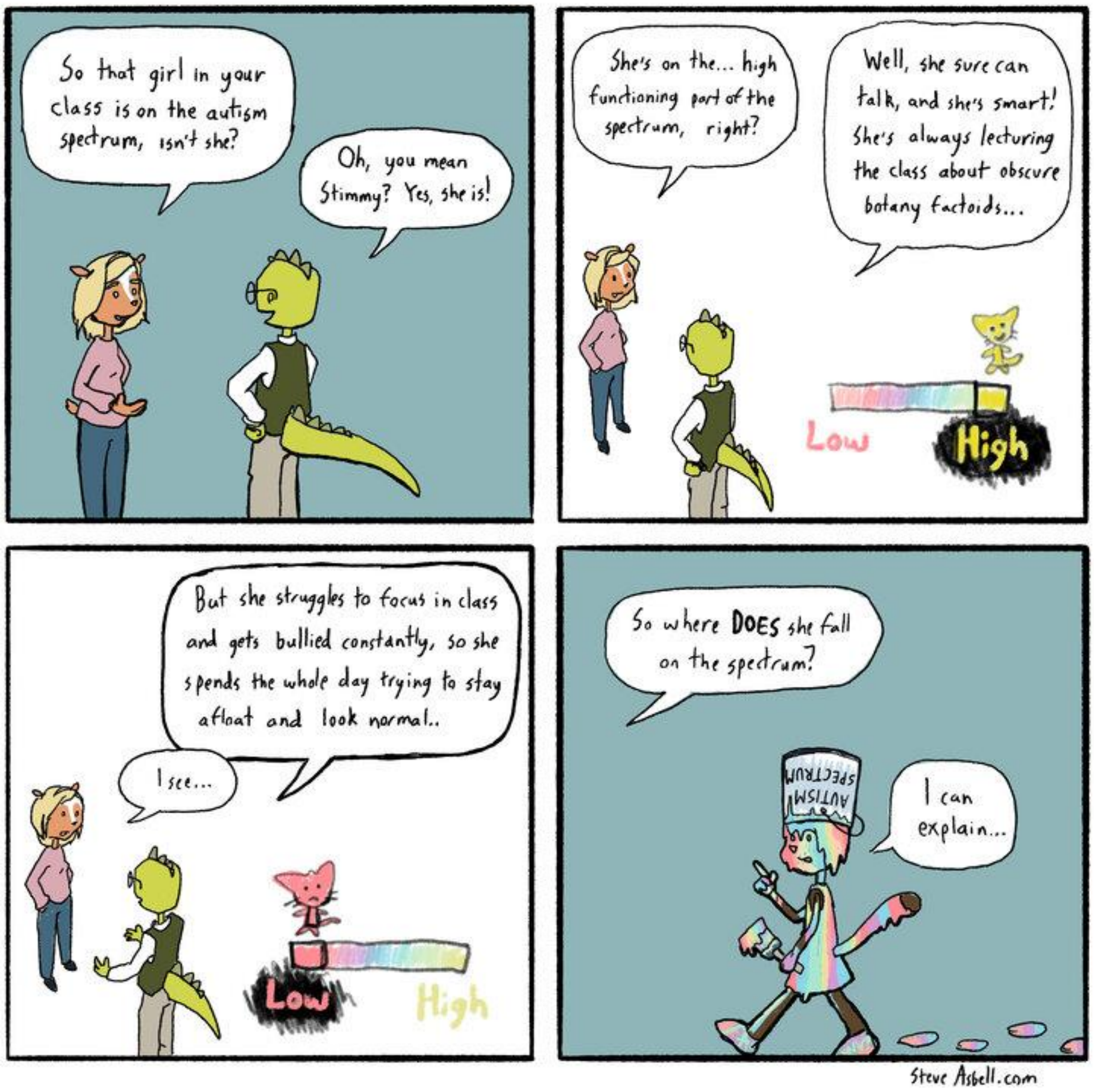
Additionally, it is proposed that each subject will only offer 20 credits, ten being internally assessed and ten externally assessed, effectively capping credit offerings and streamlining both modes of assessment (Ministry of Education, 2019). Whilst the proposed changes will not impact the current cohort of participants in this study, changes are the result of widespread consultation with current NCEA students and stakeholders (Ministry of Education, 2019). It is unknown how many (if any) of these participants identified as ‘high-functioning autistic’. Nonetheless participants like Grace [ter] may have failed to achieve

University Entrance had credits been ‘capped’ during her high school career, jeopardising her chances of reaching Doctoral level study, this being her current goal.

In conclusion, this analysis suggests that the education system must quickly consider the perceptions, understandings, and experiences of autistic adolescent high school students before envisaged changes take effect and function to further exclude those who experience themselves as fundamentally different and not necessarily deficient. By taking a strengths-based approach and increasing flexible elements like assessment within the curriculum, a transformative paradigm would also trouble pedagogical assumptions in relation to the meaning of our human-being-ness, in all its diversity. A good starting place would be to consider one’s ‘right’ to ‘being educated’ and the proclivity that ‘education’ must produce ‘subjectivities’.

Chapter Eight
Getting support: “He gets us…he’s positive and he can get us ‘passed’”

I believe that all of these people can succeed if you find what it is that they can succeed at (Paddy [adv], p. 13).



“Stimmy Kitty” cartoon series by Steve Asbell (steveasbell.com) (used with permission).

8.1 Introduction

In order to facilitate inclusion (defined in this thesis as pertaining to belonging, being accepted, achieving, and participating), teachers, support workers, and educational policy developers will want to know what needs autists have for ‘support’, along with their current perceptions and experiences of ‘being supported’ At present there is a ‘gap in research’ regarding autistic peoples’ needs, especially in the context of high school (Baric et al., 2015; Humphrey & Lewis, 2008a). This reflects that whilst the contribution of autistic people might now be a policy requirement in disability legislature, autistic voices have so far only been present in a ‘tokenistic’ kind of way (Milton & Bracher, 2013, p. 63). Schools in NZ do not typically employ school psychologists who may have access to evidence-based interventions; notwithstanding that few such interventions even exist for autists over the age of 12, and that there are barriers to implementation (Bond et al., 2016). Tippett (2004) noted that in her experiences as an RTLB in NZ, there has been a lack of funding available for AS pupils. Whilst they typically need one-to-one support, they do not meet criteria to access funding set aside only for those with ‘severe needs’. McLaren (2013, p. 28) describes his high-functioning 15yo autistic son as having “highly complex and challenging behaviour”, along with “social and education needs associated with an intellectual impairment (of classical autism)”, making him “one of the highest-funded students in mainstream education”. However, despite access to *Intensive Wraparound Services*, providing significant support, the challenges he presented were not overcome; his son failed to thrive, and eventually had to be removed from mainstream schooling (McLaren, 2013).

Participants in this study focused on their need for, and their experiences of, support within a variety of contexts, with many focused on the difficulty of obtaining personally relevant forms of support. Commensurate with the tenets of Bronfenbrenner’s microsystem level of influence, participants contextualised their stories of ‘being supported’ (or not) in relation to their roles, activities, and settings, and illumined therefore, priorities of need within their ecological context. For high-functioning autists, ‘being (un)supported’ enabled and constrained not only academic success but pertained to well-being.

Teachers and supporting school staff (sometimes referred to as paraprofessionals elsewhere), as well as parents, typically provide salient microsystem and mesosystem levels of support for their children (Kreppner & Lerner, 1989). This extends into adolescence, whereby the parent-child microsystem remains a strong source of influence, “followed closely by a group of friends and peers in school, clubs, sport teams, and church” (Muus, 1996, p. 323). However, individualised forms of support are also constrained and enabled by broader levels of influence at the exosystem level. These include support for teachers from the school principal and local BOT, availability of funding, access to supporting organisations, professional development opportunities, and development of teaching programmes, which impact teacher knowledge and provisions for facilitating support. From these perspectives, ‘being (un)supported’ is thus embedded within the context of the personal and political, with all levels contributing to one’s sense of in/ex-clusion. Support cannot be understood outside of its contextual embeddedness; thus, it is complex and multifaceted.

The various participant groups spoke of numerous personal and political issues of concern, under the dominant theme of ‘support’. Whilst there are various ways in which these ‘issues of concern’ might be read and interpreted, the analysis presented here recognises that underlying the personal and political stories, support is something desired, needed, accessed and experienced (or not). Thus being (un)supported is a personal and interpersonal experience, regardless of its application to cognitive, social, or emotional functioning, being enabled and constrained by other people through the governmentality pertaining to the ‘structures’ one is embedded within. If the focus of previous chapters has been predominately related to the body, or corporeality (for example, sensory challenges, cognitive ability, and executive functioning difficulties), then this chapter, and the next, focuses predominately on that other aspect of the ‘person’, the ‘heart and soul’.

This Chapter begins by following on from the lived experience of NCEA, with an exploration of being supported academically and relationally within class and the broader context of ‘being educated’. The following chapter extends to peer support and social relational experiences within school and beyond, considering the intersecting and structural forces, constraining and enabling being (un)supported within the broader context of an ‘autistic’ family.

8.2 Being academically supported: It's more *and* less about achieving NCEA

It is thought that because some autists have a high level of cognitive functioning, they have less need for academic support (Bowen, 2014; Moore, 2007). Very few autism studies have focused on autists’ lived experiences or perceptions of ‘being supported’; most ‘support-related’ studies have focused on parents’ perception of their children's education, with support being one aspect of this (Baric et al., 2015). The analysis thus far, however, suggests that for some participants at least, this would be more about ‘box-ticking’ and less about one’s personal education, learning, and academic satisfaction, therefore perception about whether they *felt* sufficiently supported.

There were two broad themes drawn on by autists and advocates in relation to needed support: *how* teachers, educators, and assistants modify and adapt materials and opportunities in personally relevant ways (or not); and, *how* support is constrained and enabled within the broader ecological context. Prior to the integration of (almost all) special needs students into mainstream schools, there was no need to consider the impact of school environment, a normative curriculum, or assessment styles on students, much less support options. It was assumed that students were social, able-bodied, and ontologically similar, enabling the vast majority to feel secure within their environment and fall beneath the ‘bell curve’, academically. However, since attempting to become ‘inclusive’, the educational institution has invariably been exposed as harbouring barriers to inclusion (Moore et al., 1999). From the analysis thus far, these ‘barriers’ could be postulated as including rigid ecological structures governing day-to-day running of a school, inflexible curriculum, inflexible assessments, inflexible pedagogical practices, and a lack of communicative ‘bridges’ linking autists to others. These were the barriers *felt* the greatest, regardless of overall academic achievement. The analysis presented here therefore continues to explore and elucidate on participants’ salient perceptions and lived experiences of being (un)supported in school, by giving prominence to their voice.

8.3 Does (s)he [the teacher] even like me?

There is little evidence in the earlier educational literature that teacher-student relationships were considered relevant, or even influential to a student’s social or academic success (Pianta, 1999). However, philosophers like Bronfenbrenner, have expounded the relational (and therefore, emotional) aspect as significant to learning (Steinberg, 2005). Not quite two-and-a-half thousand years ago, Plato touted that ‘all learning has an emotional base’. More recent research suggests that the social and emotional aspects of relationships, including the quality of the teacher-student relationship, influences not only learning, but adjustment to school, and the quality of peer-to-peer relationships; it contributes to one’s overall well-being (Harvey, et al., 2012). Positive teacher-student microsystem relationships are assumed to be predicated upon bi-directional dyadic engagement, which is permeated by warmth, caring, and understanding.

There has been scant focus on the importance of student-teacher relationships for students with autism (Roberston, et al., 2003), where reciprocal intersubjective engagement is more difficult or wanting; however, NZ parents have previously “stressed the importance of positive relationships between their (ASD) child and teacher” (Bevan-Brown, 2010, p. 16). This is supported by Falkmer et al.’s (2015) study suggesting that parents hold deep-seated concerns about the impact of teacher attitudes and relationships, given that they can both enable and constrain motivation and outcomes.

To be inclusive (and to aid the development of the key competencies, particularly belonging and being accepted), teachers need to take responsibility for engaging with autistic students, whose diverse learning needs and social difficulties, make reciprocation of warmth sometimes more challenging (Roberston, et al., 2003). Whilst it is beyond the scope of this project to consider the complexities of the autistic student-teacher dyadic relationship, the following analysis provides an insight into what autistic students and advocates considered most important relationally, particularly in terms of feeling supported.

This analysis, though not demarcated, is loosely grouped under the themes of connectedness, availability, and communication, similar to that previously postulated by Leitão and Waugh (2007), as relevant to understanding relationships between staff and pupils. Participants in this study emphasised the positive aspects of connecting with teachers who demonstrated an interest in them, however, they focused predominately on the many experiences that came to mind, about teachers who failed to ‘get them’.

The experience of enjoying teacher support therefore spanned not only the learning context, but the entire school milieu as a social environment, bringing with it, a sense of belonging and being accepted. Some examples of being connected to caring teachers were long-lasting experiences, and others were fleeting. Regardless, these encounters were highly valued, emphasised, and cherished, being recounted as signs that *someone* possibly liked them. Participants who experienced caring teachers, emphasised their understanding that the quality of their relationships with teachers impacted their ability to learn and achieve academically.

> *I understand the teacher – what he wants us to do. He gets us…he’s positive and he can get us passed if we are controlled and stuff* (Brad [adol], p. 3).

A teacher’s warmth and interest in students made classes enjoyable, whilst poor student-teacher relationships were characterised by authoritarianism and possible verbal abuse, which had an emotional, behavioural, and academic impact. The student-teacher relationship was therefore experienced as having a direct impact on well-being and one’s sense of inclusion.

The teacher who Taylor [adol] once disclosed intimate abuse to (discussed in the following Chapter), had previously made herself available to Taylor in ways that fostered trust and a lived experience of being accepted and cared for. Taylor recalled being driven home (especially if raining) and being given lunch, if she’d forgotten hers. Taylor, who lived alone with her dad, was also encouraged by this teacher to buy groceries that would enable her to cook what she had mastered in home-economics, for her dad. In this way, Taylor's life was enriched at home through this home-school link. It gave Taylor a genuine lived experience of being cared for. This positive relationship also however, cast a shadow on the future; Taylor repeatedly commented that there was nothing for her outside of school, emphasising how this teacher and the learning support centre had made her feel as though she 'belonged' *at* school.

> *oh, she does everything for me. She drives me and she drops me off home and everything* (Taylor [adol], p. 23).

My interpretation is not that Taylor [adol] was not so dependent on her teacher that the relationship encroached on her autonomy (she held a job, cooked for her dad, and tried to make friends with peers in the SSC), but rather, 'doing everything' was a signifier that the teacher was there for Taylor in whatever capacity she was needed, including the mundane, like driving her home on a wet day or organising lunch when she forgot hers.

This positive relationship between Taylor [adol] and her teacher was salient given that Taylor's ecological niche was impoverished in familial and peer relationships. This contributed to Taylor's sense that school is much more than an academic milieu; rather, it is more like the proverbial 'village' that raises its 'children'. In this instance, the teacher, like a surrogate mother, fulfilled that which we naturally crave by virtue of our social nature: to be loved, accepted, and made to feel as though we belong, characteristics Taylor noted as having been lacking at home.

Whilst this could be read to suggest that it is not the 'educational system' per se that has provided an experience of 'inclusion' for Taylor [adol] but one *particular* person within it, it should also be noted that this person operated within the smaller learning unit where Taylor spent a larger part of her time. Whilst other autistic people position the special learning unit as a space for exclusion, Taylor (and Chris [adol]) experienced this 'space' as having a 'normal' feel to it; Taylor's 'friends' were there too. In this respect, the smaller unit and the intimacy Taylor enjoyed with this teacher is very much an inclusive experience; she envisages no other place beyond school where she could 'belong' like this and this causes her considerable anxiety, as she approached the end of Year 12. Whilst it is difficult to tease out the ratio of positive influences the 'space' and the 'teacher' had on Taylor, it would be fair to say that the together they provided a positive sense of support that lent itself to an experience of school as inclusive. Taylor's lived experiences also suggest that the lived experience 'of school' leaves its mark on 'the heart' too; thus, what is lived and experienced is neurobiologically 'transcripted' (Crooks & Kirkland, 2011; Thompson, 2000).

Having already noted in Chapter Five that some advocates went the extra mile to support parents in the diagnostic journey, advocates like Nellie, and Karen, also went the extra mile for autistic students/clients, similar to that which Taylor [adol] describes. These 'extra miles' were unconventional, and as such demonstrated personal care, availability, and commitment to the student's well-being. Nellie for example had been working with a Year 14 student returning to school on an ad hoc basis to work on a specific project. She noted that he had a sensitivity to shoes with tongues and found shoes in general difficult.

> *Nellie: So, he'll come in; he'll walk in from [3km's away] […] He came in on Monday last week in bare feet.*
> Sharon: walked in bare feet?
> *Nellie: walked in, walked in bare feet because he didn't have any shoes. His one pair of shoes he'd grown out of. And he said: "could you take me home Miss" and I said "sure" […] So I took him home and today he arrived in his new shoes* (Nellie [adv], pp. 2-3).
>
> *Karen: He was really worried. He rang me that night because he was really worried […]*
> Sharon: is it normal for you to give students your after-hours number or allow them to contact you?
> *Karen: this is a long-term relationship and I've worked with the family* (Karen [adv], p. 22).

James [ter] and Grace [ter] also emphasised times when they experienced teachers taking a specific interest in them academically, appreciating the extra effort they went to because it fostered a sense of being a person worthy of attention, of being understood and connected, even if momentarily, in James's case.

> *I remember I was in one of the Chemistry labs and it was one of the special needs teachers who helped a kid who was deaf. And yeah, I remember playing around with optics and light and stuff and prisms and she came up to me and really noticed that I had quite an interest in it. It was the first time I noticed the teacher come and notice interests or whatever and just noticing - that is something quite different and that was good* (James [ter], p. 22).

Grace experienced her science teacher's availability to get her started on the Year 12 work, as giving her sense of belonging and being accepted by him. This increased her learning enjoyment, sense of belonging in school, and no doubt improved her academic level of achievement:

> *So I had a science teacher in Year 10 or Year 11… Year 10 it must've been […] he had a Year 12 class, the class before mine, so I would finish my work way earlier and he would give me their work and then I would work through their worksheets and I loved it* (Grace [adv], p. 41).

In addition to teachers who went the extra mile, the most important underlying characteristic of good student-teacher relationships, from participants' experiences, was a teacher's style of communication. For example, Catherine [adol] liked her English teacher because she was a good listener, taking the time to allow Catherine to relay her dreams and tell the plots of her fan-fiction stories. Paddy and Rachel [adv's], parents to a high-functioning autistic adolescent in NCEA, similarly noted how their daughter responded positively when teachers took their time to communicate to her, sometimes leaving her bursting with excitement when she felt listened to, interpreting this as 'being liked'. In their compassion for autists who desire and strive to communicate with teachers, Paddy and Rachel ruminated on how demoralising it can become for autists, who experience daily being fobbed off by teachers with insufficient time and/or inclination to listen with interest. Whilst they note that it can require more patience and perhaps, even skill, to listen to autists, they also highlighted the need for being more compassionate and caring. They were advocating for teachers on behalf of autists, to put in more time and effort to develop interpersonal relationships with them.

> *Just by giving them 10 seconds of your time…it can make… you have no idea how much she'll [daughter] be floating on Cloud 9. She's gone to your class hasn't she [says Paddy to Rachel] many-a-time, "you will never guess what?" and she's just exploding "Mrs De-de-de has just said this to me…***oh my God she likes me!***" and it's just turned her whole world around […] Well for a lot of the kids…it's the 'pain in the #ss thing' you know, because many children who have got autism will go over and over the same things. They might be talking about something and it's not going to be something that we are interested in or anybody else is going to be interested in you know, and so they are coming into class and that's the biggest thing in their world and 'this has just happened, and I'm desperate to tell you about this, because it is such a*

> *major in my life,' but it's actually…It's got a be the 'I'm the lowest of the scale for everybody else' and it's "Shut up Amanda, nobody wants to hear that" you know, and when it's every lesson…I guess these teachers want to get on [with it], but it's about getting on for the majority … and then they're getting into the lesson and this person is still like 'I'm..' and they're then thinking…and they're not even listening to what the teacher is saying because they're like '…why doesn't she like me; why won't she let me tell her about this and that?' and that's what's going on their head and they're missing all the instructions; all what the work is all about. And then, the teacher says 'right, off you go' and this kid is like 'off you go, off you go what?'*
> *Rachel: 'you said you'd listen to me'*
> *Paddy: 'off you go?' What have I got to do?' "Sorry miss, what do I have to do Miss?" or whatever, and the teacher's standing there thinking 'I've just spent ten minutes here telling you all that you've got to do, and you're asking me what you've got to do' you know. And, that frustration comes out, because they're not thinking of that person and the way that they think, you know, and the way that they process things* (Paddy [adv]; Rachel [adv], pp. 32-33).

The tone used by teachers to communicate was also a salient point of contention for students. Whilst Catherine [adol] repeatedly acknowledged that some teachers had acoustically pleasant voices, making them easy to listen to, most students noted how they enjoyed particular teachers for their story-telling, especially about their own private life and topics of interest, being personable in nature and far removed from the 'learning' topic. They deemed these teachers interesting people and enjoyed not only the diversions and being part of a class that was permeated by the teacher's warmth, but the resulting inter-relational connection between the teacher and student body. This had a positive effect on their own mood and enjoyment of school.

Conversely, Catherine [adol], James [ter] and Brad [adol], similar to other students (e.g., Humphrey & Lewis, 2008a; Saggers, 2015), became anxious or frustrated when teachers were authoritarian in their tone, failing to explain why something was being asked of them, or when they raised their voice and yelled. This not only hampered development of student-teacher relationships, it had a perceived detrimental impact on their ability to understand content and enjoyment of academic materials, as well as inhibiting their focus and impacting their achievement. James for example, became anxious at being yelled at, whilst Brad became increasingly frustrated by his math teacher's tone. Brad believed her mannerisms were having a detrimental impact on his grades, over which he had no control. When he expressed his views on Facebook, he was stood down, perpetuating a frustrating cycle of academic 'abuse', in the sense that Brad perceived himself as being deprived of further learning opportunities whilst suspended. In addition, he experienced a lack of support and understanding from the school regarding how the teacher's behaviours impacted him and his grades. Whilst he was punished, he perceived the teacher as being able to continue to teach in ways that severely restricted a student's opportunity for learning.

> *I remember just being yelled at "if you say: 'I don't know' one more time, I will really show you something". And it was just like I don't know what I've done, I just don't know. Apparently, the class thought it was hilarious, but being a scared little child, I didn't think so* (James [ter], p. 3)
>
> *It would be good if teachers could just understand certain things like 'hey this kid doesn't understand audio instructions very well, so don't yell at him if he can't remember what's going on'* (James [ter], p. 13).
>
> *When she [math's teacher] teaches the work, she's just like '***Ok, what is** ***this…YOU DO BLAH, BLAH, BLAH"*** *whatever she says and then suddenly and then one of the students interrupts she gets emotional like* ***"YOU TALK AGAIN, I'M GOING TO MOVE YOU".*** *She should like stay positive* (Brad [adol], p. 6).
>
> *I remember my math's teacher, I was playing with some cards whilst she was teaching, and she was like* ***"you put those away or I will just confiscate them!"*** *I would rather she said: "Brad I don't want these cards out, for like…" and she would say a particular reason. That would have been better […]* ***"You just*** **do this, blah blah blah, blah whatever** ***they say…."*** *It doesn't help us. What helps us is people who can relax and stay positive and make the class pass easily* (Brad [adol], p. 11).

Like the dynamic changes in Beethoven's 'Symphony No. 1, 3rd Movement, Menuetto', the transcripts, being at times **bold** and enlarged, assumes that the typography also conveys something of the rise and fall of prose-aic stress. In the context of these interviews, the prose-aic stress was indicative of the hermeneutical capturing of ‘being yelled at’. Brad's [adol] interpretation of teachers who ‘tell him what to do’ instead of explaining ‘what he should do’, hints at authoritarianism; however, his interpretation of how *she sounded to him* at least, can also be interpreted as his experience of being verbally abused. Whilst verbal abuse in the context of teacher-student relationships can include ridiculing, teasing, and name-calling, it also includes yelling (Brendgen, Wanner, Vitaro, Bukowski, & Tremblay, 2007, p.26).

It is thought that as a result of being the victim of teacher verbal abuse, younger students respond with emotional and behavioural problems, which eventually lead to academic failure (Brendgen, et al., 2007). This is similar to the cyclical response pattern Brad [adol] identifies, in that it became too hard to focus because he too became emotionally aroused. Thus, the perceived affective state of teachers can be mirrored in students’ negative emotional responses; commonly referred to as emotional contagion (Happé, Cook, & Bird, 2017), and deemed a significant influence within the regular classroom environment (Harvey et al., 2012; Harvey et al., 2016), similar to the joy noted earlier, at being in the presence of interesting teachers.

In addition to being stood down for what he perceived as his math teacher’s lack of emotional regulation, there were other potential academic repercussions for Brad [adol] too, in that when he considered his papers for the subsequent academic year, he did so based on who was teaching them, potentially limiting his subject choices and agency to determine the most desirable academic pathway:

> *Brad: Every time she teaches one of her classes… because she teaches social science as well, like geography or tourism and I’m doing tourism next year and I want last year’s social science teacher to teach me tourism.*
>
> Sharon: are you likely to have her [maths teacher] next year?
>
> *Brad: I don’t know if I’m going to have her next year. I just want to avoid her* (Brad [adol], p. 5).

Advocates emphasised that for autists to flourish academically, ‘education’ needs to be about more than transmission of curriculum knowledge. It is about relationships. Unless teachers come to know their students, strengths-based approaches directed towards personalised interests will be more difficult to ascertain, as will making adaptations for ontological differences. Strengths-based approaches are not necessarily a corollary of deficit-based approaches; however, they open dialogue for moving away from deficit ways of understanding. Deficit discourses have been related to self-fulfilling prophecies in indigenous studies (e.g. Comer, 2008), whilst strengths-based approaches have been taken up in order to improve outcomes in indigenous populations (Fogarty, Lovell, Langenberg & Heron, 2018) and have been recommended in autism studies (Humphrey & Lewis, 2008a). Advocates extended this to best practice for educational outcomes; for those times when manipulating flexible elements within curriculums leads to greater success.

> *I think that having worked in disability for years and years before specialising even further into autism, it really taught me to listen to people, to listen to the voices of the clients and to value people of all strengths and, yeah, everything about them. I suppose I take a really 'valuing' view to my clients and I really like to look for strengths. I am really mindful of the language that I use when I'm with my autistic friends and clients* (Michelle [adv], p. 19).

If the heart of the teacher is cold (authoritarian), and teaching 'institutional' (purely based on academic achievement of NCEA), then box-ticking (meeting criteria) functions to stranger the autist, leaving them proverbially, as though 'out in the cold'. Like the findings presented by Baric et al. (2015), students and advocates asserted that good relationships are fundamental to academic achievement. It may be that for autistic students who experience peer exclusion, relationships with teachers take on even greater significance.

> *It's about having an attitude that's a 'working with' rather than a 'teaching to' kind of attitude; people who are more interested in, or who are collaborative rather than (pause) authoritarian; it's a 'people first kind of approach'* (Michelle [adv], p. 11).
>
> *They [the autists] want to be accepted and liked and included and they just want to be understood really – that's my experience – I really mean that – they just need to be understood* (Karen [adv], p. 40).
>
> *I think we do have to acknowledge that everybody has strengths and sometimes those strengths don't fit school, but we need to make them fit. We need to acknowledge that what they are bringing to the table has value* (Karen [adv], p. 15).

Participants in this project, noted the tension between reason and emotion in education. For example, the influence of neoliberalism posits educational policy be constructed to ensure the maximum number of students pass and are prepared for contributing to the economic marketplace. This is a reasoned approach to education, whilst ‘inclusiveness’ is about ‘belonging’ and ‘being accepted’, which is an appeal on ‘compassionate’ or emotional grounds to strive towards providing the adaptations necessary. For autists to flourish, there is a perceived need for not only a quantitatively different type of education and pedagogy, but a revolution in understanding autism and autistic people; token intellectual curiosity and relational indifferentism (Nussbaum, 1996) must give way to a better understanding of lived experience in order to illicit the type of compassion, care, and understanding that would bring about significant change.

> *I think it’s a really powerful message, that so many people are missing; that it’s… [long pause]…that you’ve got to start with the autistic person and love and value what they’ve got and fit in with them and help them fit in with everybody else and get over,* ***just get over it*** *– they’re different,* ***get over it!*** *Stop banging your head against the wall or whatever […] and instead go ‘this is the person that I’ve got, that I love, and I’m not going to try and change them, I’m just going to help guide them through life like I would any other one of my students, any other one of my own children and yeah, that’s what’s…. That’s what’s missing* (Michelle [adv], pp. 28-29).
>
> *"If they need help, you help them!" I mean autistic people, people with my disability are just…usually don’t get a lot of help from other people. I mean the other people don’t care do they* (Chris [adol], p. 22)?
>
> *Kym [Par]: they were happy to ignore him, because it is high school, and they don’t* really care.
> Sharon to Liam[adol]: did you feel ignored?
> *Liam: no, I didn’t. For the most part I actually enjoyed it* (Liam [adol], p. 28).

Nussbaum (1996, p. 38) argues that it is very difficult to have compassion for the stranger: “We all learn in books that human beings are mortal and subject to various diseases. I think it is fair to say, however, that being able to parrot these sentences does not suffice for really having the judgment: to have the judgment, one must understand what those facts really mean”. As such, it can only be through close contact with the autist that one could judge the need for a compassion-driven education too. That autistic participants appeal to compassion, as the ‘driving force’ behind ‘belonging’ and being ‘accepted’ over cold cognition, suggests that from lived experience, they understand the route to increased academic success; inclusion is interpersonal; it has its roots in good student-teacher relationships. If teachers know the autist, accept, and love them, they will want to offer accommodations, discerning how by capitalising on their strengths, wherever possible. This converges with autistic students' perceptions that a teacher's proclivity toward warm interpersonal engagement, contributes substantially to personal joy, enjoyment in class generally, and the environment most compatible for learning.

8.4 Autism knowledge: (Not)Achieved

To date, autism studies relevant to mainstream high schools, have indicated that teachers have received very little training (Robertson, et al., 2003) and yet it is assumed teachers must have "a good understanding of ASD and be prepared to respond to the characteristic behavioural manifestations of the disorder" in order to be inclusive (Griffith et al., 2012; Lindsay, et al., 2014, p. 102; Tobias, 2009). As a result of a lack of research and limited teacher understanding, very little is known about how learning and participating is best facilitated for autistic students (Humphrey & Lewis, 2008b; Norwich & Lewis, 2005). Most participants in this study noted that unless teachers have a good understanding of autistic heterogeneity, they will not be successful in raising autistic students' academic achievement and sense of 'having learned something'. Some studies have also highlighted instances whereby teachers felt prejudice towards those with learning disabilities and differences (e.g., Kearney, 2009), presumably because they lacked the skills and knowledge to provide any support or were overwhelmed in their current role.

The topic of teachers' autism knowledge was of extreme importance to students like Chris [adol], Grace [ter], James [ter] and Emily [ter], being their primary reason for participating in the interviews. They wanted to inspire teachers to learn from their lived experiences. James and Catherine [adol] went to some length to elucidate what autism is like for them, be it a whole different language, or more like an ice-cream sundae (see Chapter Five), which was interpreted for its complexity in regard to the interplay between biology and ecological contexts and its prodigious implications for autists, as well as those whose lives are touched by autistic people. They wanted teachers to learn about autism in their bid to help prevent other autists from being as misunderstood, excluded, and unfairly treated ('as though they were like other students' [Chris {adol}, p. 16]), which had had a detrimental impact on their own lived experiences of being an autist in high school.

> *I guess the more autism and other disabilities like Down Syndrome…a bit of a 'well this is what they are, we're going to have to deal with it, let's see if we*

> *can learn about how this works as much as we can so we can help them'. So basically, it's more or less about them trying to teach kids with disabilities about how to learn without any problems [...] and teachers will find that difficult as they don't really understand autism* (Chris [adol], p. 23).

Advocates reported that some teachers wanted to learn about autism, consistent with previous research highlighting teacher willingness to learn (Tippett, 2004) and engage in professional development opportunities (Florian & Black-Hawkins, 2011). However, advocates also believed that teachers' autism knowledge was very rudimentary, suggesting teacher training, relating to diverse or 'special needs', continues to be very limited in content and scope, or is being overshadowed by normative developmental expectations.

> *Michelle: We did about six sessions with one of our local high schools and it was on teenagers with autism in the schools and how to support them and that kind of stuff. So, we had to start right at the very basics with 'what is autism?' Because most of the teachers had struggled with that really.*
> Sharon: how far back are we talking?
> *Michelle: We're talking maybe four years ago, so it's not that long ago. It was interesting because this was organised by the special unit of the high school and it was an optional thing for teachers to come to and it was a very big school and we got quite big numbers. About 30 teachers came along, but there were over 100 teachers at the school [...] we got more people coming the second time than on the first time, so word had got around. It seemed to be very clearly recognised area of professional development for the teachers. They were lacking in knowledge on autism; they had lots of stereotypical views* (Michelle [adv], p. 12).

> *Well as far as I understand, in most high school training courses they probably wouldn't even know about it at all. The one-year training on top of your degree - I don't know many who had ever heard anything about it. From what I understand and I could be wrong now, but I think most teacher colleges and training places are referring to a very small component of special needs stuff, maybe not even about autism; special needs, 'inclusion' I suppose, but unless you're interested, some teachers could come out with no knowledge whatsoever and yet they are more likely than not, to hit someone with autism*

> *in their first year out teaching and I don't think it's fair, on the teachers or the kids* (Karen [adv], p. 7).
>
> *The teachers that I come across that are new teachers have very, very little knowledge, so I'm assuming it is still not there in their training.* (Karen [adv], p. 35).
>
> *…some teachers could come out [of university/training school] with* ***no knowledge whatsoever*** (Karen [adv], p.7).

Nonetheless, training programmes do exist that would enable teachers to enter more specialist autism roles in NZ high schools. Currently, the number of individuals in these roles are few, meaning that these 'specialists' are not yet regularly accessible to all autistic students in NZ:

> *I think all teachers need to have that expertise as well as there being specialists and I think we acknowledge that in NZ and that's why we have Postgrad Diploma in Autism* (Karen [adv], pp. 30-31).

Kym [par] highlighted how all the teachers in her son's high school participated in a one-day professional development autism programme, only after Liam [adol] was diagnosed in his final year of high school. Although Kym was appreciative of any training undertaken to help teachers and school staff understand autism, she emphasised how she endured many years of suffering through their misunderstandings of Liam and assertions that she was to blame for his being disengaged from the curriculum, before *some* 'training' was offered: that is, a single day's training as though a 'single day' was 'sufficient' to bridge the autism knowledge 'gap', and right the wrongs of years of misunderstandings! Again, this could be taken as a tokenistic gesture, with the notion that 'real' autism training is still some way off yet. Despite the ideology of inclusiveness being firmly embedded as policy now, parents and advocates were therefore alert to what they perceived to be tokenistic attempts by government to accommodate autists and implement those structures that would result in inclusive practices:

> *If the government want inclusion, as more than an ideal, they have to start funding for it. They have to start accommodating those kids who are difficult to include and training those teachers who find the concept difficult* (Karen [adv], p.27).

As a result of constantly feeling misunderstood, James [ter] took up the labels he'd been called in school, referring to himself as 'naughty' and 'violent' for acting out and throwing chairs. Whilst James lacked a diagnosis at this time, advocates also noted that even with a diagnosis, teacher understanding can still be lacking, leading to the exact same labels:

> *they kept on saying "they're just naughty kids and they were not going to get away with [being naughty]"* (Pamela [adv], p. 6).
>
> *The teachers just aren't equipped [...] and so they get labelled immediately as troublemakers or the class clown* (Paddy [adv], p. 12).

Thus, students' sense of dignity and understanding as being a person of worth and value was eroded in multiple ways in high school. In addition to being excluded by peers (see Chapter Nine), often having poor teacher-student relationships, and experiencing 'failure' due to a lack of pedagogical adaptations to suit their ontological differences, ordinary innocuous incidents also eroded dignity, particularly when incidents resulted in disciplinary procedures for autistic participants. Whilst this thesis has already illuminated several examples, Karen [adv] offered a particularly poignant re-telling of an experience involving a high school biology teacher and a high-functioning autist. The biology teacher had brought out a real human skeleton during his science lesson and whilst the student was touching it, with no intention of harm, the teacher jokingly said, that 'she' came from, 'the Ganges'.

> *…and of course the student didn't realise he was making a joke and believed that he had actually bought this body over, the skeleton over himself, in the 60s and so demanded to know what the person's name might have been; what the origin of it was and whether or not she gave permission to have her body used and he [the student] couldn't be averted from it, you know, he just couldn't get off it [because it was an ethical dilemma]. He did tell me when he was telling me the story later, that he did stop eventually but not before the teacher had got to the point of feeling very, very threatened by the possible repercussions and actually lost his temper and actually swore about the way that this boy was suggesting that he might put it on social media to see what sort of response there would be to knowing that a school had a real human skeleton* (Karen [adv], p. 13).

Like other stories recounted in this thesis, the conclusion was invariably the same: disciplinary action was taken by the school, *upon* the student. As in other scenarios, the science teacher had no knowledge of autism and thus lacked strategies for responding to the student who perceived an ethical dilemma. Whilst Karen [adv] was able to mediate, educate, and reconcile differences through her own understandings of the 'language of autism', and thus provided real-time ‘training’, it only came after considerable suffering and several hours of dialogue on Karen's part, advocating for the student and facilitating the process of reconciliation.

Michelle [adv], (like autists), was at pains to highlight that there is more to teaching autists than equipping teachers with knowledge of ASD. She suggested that it begins with having teachers whose profiles or disposition, are oriented toward warmth and intersubjective engagement. If the ‘nature’ of the teacher is ‘right’ and the school milieu is ‘supportive’, then autism knowledge (general and individualised) can lead to effective use of pedagogical strategies, resulting in meaningful learning experiences for autistic students ‘open’ to that. However, as Karen [adv] noted regarding the biology teacher, whose ‘joke’ might evidence some ‘warmth’, ASD knowledge might have diffused the situation but it does not negate the fact that additional student support may be no less needed.

8.5 Needing support and being (un)supported

It appears that there is a widespread lack of services available catering for a ‘specific’ autistic person’s needs (Humphrey & Symes, 2008; Sedgewick, et al., 2018). Karen [adv] postulated, that the ASD label provides few clues regarding what support may be needed because it fails to highlight *how* sensory and communication differences, as well as executive functioning skills like planning, organising, and understanding task requirements, impact each student. Thus, advocates generally believed the need for support should be considered as essential, regardless of academic grades or IQ.

> *You can say they have autism but that doesn’t really tell you very much at all except that they’ve got some sort of difficulty; they have got difficulties in diagnostic areas* (Karen [adv], p. 2).
>
> *It’s like another curriculum really: it’s the curriculum of executive functioning* (Karen [adv], p. 16).
>
> *I think the kids who are recognised as being very bright – they may be avid readers or just very able, should be given assistance to succeed, you know, they should (Karen [adv], p. 8).*
>
> *If you’ve got a bright student, who can't organise, or plan, you may need to give them special training in ‘how do you plan the story’, ‘how do you work*

> *it out', or whatever you want to call it. 'How do you actually put that story together, where do you start? Where do you go next?' […] They may be very bright, but they just can't get started unless there've got some type of help structure and that's not their fault, that's not stupidity or anything like that, it's actually an inability to plan and organise and that's often a deficit with kids with Asperger's* (Karen [adv], p. 9)

> *I know a lot of people with Asperger's do really well at university once they get there, if they get the right support and it's usually in the area of organisation, planning and managing themselves rather than their ability* (Karen [adv], p. 16).

Karen [adv] noted that it is usually not one type of deficit or difference that high-functioning autists need help with, but an array of difficulties, pertaining to executive functioning deficits. A lack of support in this area, typically results in compounded problems. For example, Karen noted that it might begin with an incomplete set of notes, or misunderstood instructions, and results in an accumulation of unfinished work, all of which continuously increases the autists' chances of being unable to achieve, regardless of IQ.

> *You know it is* ***really, really difficult*** *to have Asperger's Syndrome […]* ***it's very, very difficult*** *without extra structures, or extra supports* (Karen [adv], p. 23).

The type of support advocates postulated as being needed, was simple, often practical and structural, like breaking down homework projects into manageable chunks and keeping a diary, rather than specifically related to academic tutoring. This converged with autists' perceptions and experiences detailed throughout this thesis:

> *making sure they are using their diary for instance [with] special notes in the diary for the parent […] they may [need to] put in that '[Jim] needs to do such and such tonight' […] even at quite senior level so that those kids are getting the ongoing link between home and school […] and lets plan homework differently […] planning and orgnising, so it needs to be broken down. 'You know, maybe by tomorrow, I want you to have done this'* (Karen [adv], pp. 23-24).

Whilst Grace [ter] acknowledged her ongoing need for support in some areas, she noted that there were many teachers in the schools she attended who had tried to work with her, include her, and enabled her to 'make mistakes' without severe disciplinary procedures.

One example that Grace gave of ‘being supported’, was being able to serve in the tuckshop during interval and at sporting events. As such, she referred to herself as one of the ‘luckier ones’ to get through high school with these little accommodations along the way, making ‘the journey’ easier. However, this did not alleviate the frustration she and others, like Brad [adol] and James [ter] experienced at having been unable to reach their academic potential in high school, particularly to obtain grades that they thought reflected their capabilities. Thus, they wanted support, particularly for those things ‘hidden’ and taken for granted; for ‘interpreting’ what was being asked of them. However, because they were deemed to be ‘achieving’ by normative NCEA standards, their grades functioned to ‘silence’ their ‘real’ need, which was to reach their academic potential and have an equally fair chance of success, like their neurotypical peers.

> *Hey, I was an intelligent white kid – ‘nothing wrong with you!’ ‘You’re not failing; there’s nothing wrong; you’re doing fine, just keep going!’* (James [ter], p. 16).

> *In some ways it’s kind of like because I did in some ways quite well, because I am quite well spoken and quite intelligent; I do well in terms of grades and all of that and I did well in my classes and I picked up on things really quickly, people were sometimes a little less accepting that there were sometimes some big deficits in other areas and I hesitate to use the word ‘deficits’, but yeah* (Grace [ter], pp. 47-48).

Due to communication difficulties, some autistic students have not been able to communicate their need for academic assistance. Chris [adol] for example, initially intimated that he was ‘too modest’ to ask for help and “didn’t want to waste the teachers time by ‘going what does this mean, I don’t get it?’” (p. 12). At the microsystem level, we might conclude that it is *just* his ‘disability’ that prevented him from asking. However, he also believed, that although he needed help, there wasn't much that teachers *could* offer him, given their lack of training about autism, understanding of him specifically, and as a result of the broader tensions that he perceived as inhibiting support generally.

> *School is a long way from helping autistic people; they don't understand them – if you treat autistic people as though they were like everyone else, then nothing will change* (Chris [adol], p. 22).

> *The teachers - they're not bad teachers - not all of them - it's just that the system there doesn't work very good* (Chris [adol], p. 5).

> *They would have had a hard time trying to explain to me since they didn't know how to handle autistic kids. And I highly doubt that the school would allow them to help them* (Chris [adol], p. 12).

The 'tensions' Chris [adol] is referring to are not simply rooted in microsystem influences. It is not just teachers' ethics of care and compassion, or their lack of autism training and insights into Chris that are problematised. Rather, Chris is also aware of forces in the broader edifices of society, which he deems the causes of these local injustices that he experienced as part of his daily life in a mainstream school. It is these outer levels of influence, like neoliberalism, perhaps as macrosystem patterns and values that (re)produce (ab)normality, and its exosystem manifestations, endorsing conditions within the setting or environment that constrain and enable what teachers can do, which Chris is eluding to. Thus, he perceives a far greater array of tensions functioning to (dis)'allow them [the teachers] *to* help'.

8.5.1 Professional 'support'[?]

'Wanting support' and then 'obtaining support' is also not straight forward in NZ. Obtaining support is tied to specific diagnostic and assessment outcomes. In NZ, when a student is deemed 'eligible' for additional academic and behavioural support, a TA is typically obtained through funding allocations assigned to *that* student (Tutty & Hocking, 2004). There is no mandate or policy requiring TAs to have a tertiary qualification, or *any* qualification, despite being assigned to students recognised as having the highest levels of 'need'. As a result of funding, TAs tend to remain near 'their' student (Tutty & Hocking, 2004). It is commonly understood in NZ that TAs 'mark' their students as 'being deficient' (Tutty & Hocking, 2004), therefore, some participants in this study recognised their 'need' for additional support, but also considered its implications, even if it could be accessed, in terms of how it encroaches into notions of self and an autistic identity, as well as relational 'fit'.

> *I think, more of a TA role would have worked better, but then there is also the perception of 'it's a retarded kid with a TA' kind of thing* (James [ter], p. 31).

> *I tended to find that at my school, it was very separate - the unit - from the rest of the school and they have different attitudes there and I found it quite separated, which meant that the people from there didn't often hang out with the mainstream students* (Emily [ter], p. 10).

Students perceived that their academic activities had social repercussions; the twin aspects of schooling are entwined. Students perceived teachers as lacking recognition of the repercussions of academic support on their social lives that gave rise to their reluctance for 'being supported', even if they recognised their need for it.

> *Emily: and that's what also made it hard for me to make friends because I was, like they were like really separate and the people in the unit used to hang out with just the people in the unit but like I fit in more with the mainstream students [...].*
>
> Sharon: So, if you went to the unit for students with disabilities, you felt more excluded from the mainstream?
>
> *Emily: yeah, because it made me feel insecure because when I was that age, I had lots of insecurities and I felt like people would see me different and see me as more disabled if I hung out there* (Emily [ter], p. 11).

> *He [high-functioning autist] sat in the test and actually wrote his name on the paper and just sat there for 30 minutes doing nothing because he couldn't, but he was happy to do that because he was with his friends* (Nellie [adv], p. 10).

Catherine [adol] willingly accepted having a TA, whilst Grant [adv] noted, it is not just 'any' TA, or assistant reader/writer that an autist may have need of, but rather one they can build a rapport with; the relationship being key to success. Grant's high-functioning autistic son couldn't achieve in subjects like history despite knowing the content 'inside and out'; he wasn't able to express it in essay form. He didn't like the reader/writer assigned to him and felt misunderstood by her. The inability to work together caused additional frustration, leading to his decision to drop out of school altogether.

> *Well that was the problem, because the reader/writer he couldn't stand. So, it just wasn't going to work. She was doing everything wrong, in his mind. She wasn't supposed to ask the questions like this, and she wasn't supposed to write something for him and [...] it just wasn't going to work* (Grant [adv], p. 10).

> *He was very reluctant to talk to her [reader-writer] about anything. He would rather go talk to the counsellor who he had the rapport with and knew exactly how to talk to [autistic] people* (Grant [adv], pp. 8-9).

From an ecological perspective, support is embedded within the broader ethos and supporting structures of the school, which influence what teachers might be able to achieve regarding inclusion and tailoring support to a student's needs. Pamela ([adv], pp. 9-10) noted that in her capacity as a social worker she had worked with some "very good schools who have been very good from the Principal down" and this impacted teacher motivation to investigate and implement various forms of support through tailored initiatives.

> *If the principal can be involved that's quite good. If they show an interest […] If they don't seem involved, then it's up to the teacher and some teachers really try* (Pamela [adv], pp. 9-10).

Other participants including students, advocates and parents, noted that in their experience, 'top down' support within a school was not evident, hampering efforts to access support for students and professional development for teachers.

> *I write emails that are like books to the principal and I'm always going on about this; harping on it about 'what are we going do about these students', you know. It's so unfair* (Paddy [adv], pp 11-12).

> *Victoria: I had to fight for everything for him […] they just gave up teaching him. He was just…there was a couple of teachers who really wanted him to learn but they didn't know how to go about it and instead of engaging these teachers who showed interest, there was… "no don't worry", they'd just let him play on the computer; they let him go on the computer and just do his own thing. So, he stopped learning in the last year. […] Some of them tried to do as much as they could.*
>
> Sharon: what do you think was stopping them…
>
> *Victoria: well the Principal and the Board [of Trustees]* (Victoria [par] pp. 18-19).

It has already been noted that Chris [adol] doubted that "the school would allow them [teachers] to help" (p. 12). Special Educational Needs Coordinators (SENCOs) however, were perceived by advocates to be a potential form of support for students with autism. However, their lack of presence in the lives of mainstream autists in this study only functions to further notions of salient gaps in support options for those outside the SSC. Nonetheless, the SENCOs role is perceived as a pivotal one for ensuring inclusion, particularly in terms of being able to meet the actual needs of students (Education Review Office, 2016c). Most SENCOs in NZ schools have been teaching longer than 20 years (Education Review Office, 2012b), therefore may have received professional development in ASD, but lacked initial specific training opportunities.

> *The SENCOs I work with are fantastic people but they are overworked [...] if I've got a good connection [with a SENCO] that has an empathy with special needs, my job is half as difficult* (Karen [adv], p. 19).

The development of Individual Education Plans (IEPs) is also deemed important for supporting students 'with needs' in schools. NZ lacks legislation or policy guiding development and implementation of IEPs and research suggests there is a lack of professional development opportunities for NZ primary school teachers (McKay, 2016). Conversely, Karen [adv] reported observing good professional development opportunities for high school teachers regarding ASD students. However, she also noted that teachers commonly short-circuited the process of developing them sufficiently. She attributed this to difficulties associated with liaising with many teachers; IEPs were administratively difficult to manage, monitor, and implement in high school. Consequently, short-circuiting 'silenced' the voice of autistic students:

> *You can have really good IEPs but you've got to have someone really good coordinating it [...] be prepared to set the goal in their subject and not just say "he's doing alright" brushing over, you know [...] yet, we still get things like: [Teacher]: 'oh yes! I had all my IEPs last week.' [Karen]: 'oh, who attended, did parents come?' [Teacher]: 'Oh no! I just did them myself; I just set the goals myself'. [...] You know we've still got a long way to go in writing good IEPs [...]* (Karen [adv], p. 10).

Emily [ter] believed her IEP was (ir)relevant to her goals and desires. Emily's teacher wanted Emily to improve her essay writing skills and whilst this was not unimportant to Emily, it was not the goal *she* prioritised. Emily wanted to improve her socialisation skills; this was *her* priority. The lack of collaborative input frustrated Emily and functioned to reinforce her sense of exclusion through deprivation of opportunities and strategies aimed at bridging the 'gaps' pertaining to the hidden social curriculum. This highlighted for her too that school was more interested in her academic achievement, whilst she viewed school as being all about her abilities; she expected school to take a whole-person approach, including learning and social well-being.

> Sharon: Did the IEP reflect your goals – things that you really wanted to achieve or were they the teacher's goals for you?
>
> *Emily: sometimes they were like… they might have been the teacher's goals, but I tried to get them to use my goals and socialisation was the main one but they never seemed to pick up on that and they never knew what to do about it* (Emily [ter], p. 24).

A lack of access to support within the school was also coupled with difficulties accessing various forms of support beyond the school. Nellie [adv] noted she had difficulty locating essential and needed services for her autistic students:

> *It's frustrating! Because conditions change, people change…and they change the name of their organisation…I have found it frustrating because you know that there are all these little pockets of support out there…it's accessing them* (Nellie [adv], p. 21).

Some advocates also noted that it can be particularly difficult to access services that enable Specialist Assessment Conditions (SAC) within schools, including reader/writers.

> *If you are wealthy family and can pay someone to do it, you get that access for SAC. If you are not, you just don't get assessed. It really frustrates me…You've got to be an Educational Psychologist to have your assessment results accepted for receiving services. It doesn't seem quite right to me. In this province I don't know anybody who is doing it* (Michelle [adv], p. 37)

Other advocates suggested that the lack of assessment service providers force parents to not only travel long distances, but fund private appointments, similar to local anecdotal media reports touting that parents are increasingly required to fund tailored support options *in* schools (The New Zealand Herald, 2015; 2018).

8.5.2 Private [professional] support

Autists also referred to accessing private support to not only raise their academic achievement but improve their overall well-being. Brad [adol] received private tuition for literacy, whilst Grace [ter], like James [ter], obtained support from a private psychologist who specialised in autism. Whilst James accessed a private psychologist in preparation for tertiary study, Grace focused on building resilience and tolerance for staying in class during her final year of high school, especially for those times when she felt anxious and wanted to escape.

Grace [ter] was the only student who received assistance to develop strategies to persevere in class. Her private psychologist enabled her to develop and work on strategies to remain present in class, resisting her inclination to leave when overwhelmed or unhappy. She recalls her psychologist saying "you are nearly an adult and unfortunately you can't just leave the room when things get hard. That's worked great up until now, but now we're going to have to do start to work on techniques, on how to stay in the room and manage what's going on, staying there" (p. 22). Grace referred to the significance of working at staying 'present' as a "paradigm shift from running away." In doing so, she highlights how 'running away' had become the 'norm' for managing; as part of developing needed skills for beyond school, she was prepared to work on the difficult task of remaining 'present', something she might succeed at with effort, individualised strategies and personalised forms of support. The 'pass-out' card wasn't going to help beyond high school. Grace felt it "was quite an important thing to start to learn before I left school" (p. 22). In this and other ways, Grace perceived high school as a 'training ground' for what lay beyond and was privileged in having the resources available to her, through private arrangements, which were personalised forms of support, tailored to her needs.

> *And so it was very much a paradigm shift from running away, which at that point was really the only option I had, and it was the best option at that point in time, to having to learn to be an adult, or to learn how to start to deal with things, as they happened, in place […] actually it was by the end of that year that I started pushing that boundary into 'okay well, now we need to start to learn'. Because obviously in year 13, I missed a lot of school* (Grace [ter], p. 22).

James [ter] noted that it wasn't until after he left high school and began considering tertiary education, that he engaged a psychologist on his terms, based on his perceived need for support. His needs were regarding all three parsimonious hidden 'curriculums': ecological, social, and academic. He wanted to be shown around the environment ahead of time. He wanted to know where he should have lunch, and he wanted to know what to do if he knew more than the tutor. In sum, he wanted somebody to step into the 'gap' to illumine all that was 'naturally hidden' from him. Grace [ter] and James [ter] both believed their psychologist was one of few people who ever 'got them', understanding that their internal experiences differed from most people's. Thus, their aspect-perception (Dinishak, 2019) was easily fathomed by the psychologist but missed, or misunderstood, by others. They felt 'responded to' commensurate with those types of judgements that arise out of compassion, which recognises *this* individual's position in relation to the position others hold within the same milieu (Nussbaum, 1996). It is this level of understanding that autistic students wanted as the ‘norm’ within high school and Grant [adv] lamented as lacking for his son, who dropped out of school. To bridge this ‘gap’, James’s psychologist believed that the best person for this role would be a mentor.

8.5.3 Mentors and mentees

All the advocates in this study, along with Grace [ter], considered the possibility of mentors as forms of support for autistic students in high school, whilst James [ter] spoke positively of the difference a similar-age mentor made to his life.

> *I think they need mentors. They [high-functioning autists] need someone to look after them, because they can’t do it really* (Pamela [adv], p. 27).

At present there is a paucity of research regarding support generally, and peer-mentoring particularly, for teens within high schools. However in a small study recently, Bradley (2016) implemented a peer mentoring program for teens with autism in mainstream schools in England and suggested (through a mixed-method analysis), that there was “a positive impact on levels of self-esteem, decreased levels of bullying and increased social satisfaction for the students with autism” (p. 283). In addition, Bradley suggested this new peer mentoring program provided a positive sense of inclusion and an increased sense that peers can be a source of support.

In comparison, Karen and Michelle [adv’s] noted that mentors need training and support if neurotypical peers are paired with autists, raising concerns about appropriateness within NZ high schools:

> *I know some people kind of think a mentor should be within the same group [as TAs]. They’ll say, ‘let’s look within the school to see if somebody can be a mentor'. I worry about that because young people’s moods and beliefs and behaviour can change very quickly so somebody who looks like they could be a good mentor and actually could be a good mentor for a while - everything might be going along swimmingly - but then somebody else who they think is important makes some derogatory comment about the person they are mentoring and suddenly the mentor starts going ‘actually no, I don’t really like him anyway* (Michelle [adv], p. 18).

> *I think, mentors are fantastic but it’s finding them and it’s training them because the best kind of mentor is one who is roughly the same age, which means that if you are working with 15 year-olds, you probably don’t want*

> *them to be more than about 17 or 18 and you are expecting that person to have the sophistication of knowledge and views that most people their age wouldn't have, so somehow there've got to get some training in (Michelle [adv], p. 17).*

Nonetheless, Michelle [adv] believed that mentors may be better positioned to support high school students transitioning out of high school and into flatting and tertiary studies, particularly if the arrangement worked 'relationally' and if the dyad were embedded within a context of support, similar to what she offered mentor/mentee partnerships:

> *In this particular case, the university student [aged 22] who is working with the young person [aged] 19, so similar [ages] and it's really fortunate that this person is also a student going through a psychology degree, so he's got some theory, but even then needs to have some sessions with me to help him un-pick some of the stuff that's happening. So, he's in a better position than a mentor of the 15-year-old who is probably going to be 17 or 18 […]* (Michelle [adv], p. 16).

Whilst Grace [ter] had not been the recipient of mentoring herself, she derived satisfaction from the mentoring she offered her autistic friend, Madison. She reported supporting her mentee to navigate paths she'd already trodden, providing the benefit of her experience and insights (or 'expertise') garnered along the way.

It appears that high-functioning autists have varying needs for support, with some students perceiving they received insufficient support to achieve their goals in high school. The importance of support within the context of good personal relationships cannot be overstated, supporting Baric et al.'s (2015) finding that psychosocial support was crucial for academic success and personal well-being. In addition to official forms of support, peers and parents also play a significant role in supporting (or not) autistic teens. The following chapter explores unofficial forms of support and the implications these have for autistic students and their perceptions of 'being supported'.

8.6 Chapter summary and transformative potential

Whilst all students recognised their need for academic support, only a few felt supported, primarily the result of private and appropriate personalised support opportunities. This increased their perception and experiences of being understood and as having some autonomy and control over their environment. Some autists considered the types of personal support they had seen others having (such as TA support) as needed and desirable but also as something to be wary of due to stigma. They believed that one-on-one support within mainstream classes had potential to diminish their social standing (further), like entering a support 'facility' (like 'the block').

Most believed that tailored, appropriate support was impossible to obtain within the learning context due to teacher's lack of autism knowledge and general availability of support. Read this way, being consigned to a 'learning facility' or TA is 'political'. One participant believed that whilst some teachers might be well intentioned towards learning about autism and specific autistic kids, they are embedded within an environment that fails to support autists simply because they are ontologically 'different'. Others believed teachers perceived them as cognitively capable (in some areas), so on the whole, unworthy of assistance. Transformative potential exists in not only providing more in-depth training for teachers, but support staff, management and school BOTs, as well as curriculum and policy writers. Autists need to be recongised for their 'expertise' in autism and for their ability to discern their own need for support. They have a right to 'being educated' and thus support, which is not tethered to autistic nomenclature (*high-functioning*), but actual need.

Just as academic support was not something students considered aside from its social repercussions, students also considered teacher characteristics as impacting them emotionally and subsequently, academically. Students enjoyed warm teachers and thrived on recognition given to them by teachers. This made them feel as though they were liked and belonged in school and although these experienced realities were sometimes fleeting, they were treasured. On the other hand, authoritarian and/or verbally abusive teachers were experienced and endured with great difficulty. This increased students' anxiety and one participant felt as though the teacher's behavior jeopardised their ability to learn and achieve in NCEA. Just as it is possible to use multidimensional scaling techniques to garner ideographic profiles of autists' characteristics and abilities, it is also possible to garner similar profiles of teachers' emotional response profiles (Harvey et al., 2012). Given the severity of impact of emotional contagion on autists' lived experiences within classrooms, this might be a valued method for not only considering teachers' emotional competency in general, but direction of professional development.

Much has already been written on the transformative academic potential for students nurtured along by warm teachers (e.g., Crooks & Kirkland, 2010; Harvey, 2004; Harvey, Evans, Hill, Henricksen, & Bimler, 2016). From this analysis, transformative potential exists in furthering research into teachers' understanding of their own emotional regulatory capabilities and the experience of emotional contagion on autistic high school students. This research supports previous claims that a teacher’s emotions are a significant factor in emotional experiences of students (Harvey et al., 2012).

Chapter Nine
Being (un)supported: "Would you like to see my scars?"

Look, the tears of the oppressed – with no one to comfort them! (Ecclesiastes 4:1)

9.1 Being 'friends' and being socially (un)supported

Autistic students typically spend less time with peers and more time alone (Attwood, 1998; Wainscot, Naylor Sutcliffe, Tantam & Williams, 2008). However, quality of life is improved by friendships (Dillon, et al., 2014); we are social beings, called to have relationships with others (Matthew 22:37-39). Thus, there is a sense of fulfilment in friendships and connections with others and in adolescence, self-esteem typically increases with peer approval (Williamson, Craig, & Slinger, 2008). The earlier body of ASD literature generally supported the notion that high-functioning autistic children and teens have a preference for social isolation because they lack social skills (e.g., Whitehouse, Durkin, Jaquet, & Ziatas, 2009), lack ToM skills (Kaland, et al., 2002; Szatmari, Bremner, & Nagy, 1989), and cannot engage intersubjectively (Hobson & Lee, 1998) to 'make friends'. However, autistic children and teens often attempt to converse and try to make friends, highlighting that social abilities may not match their internal desires (Bauminger & Kasari, 2001). This can create a sense of loneliness (Bauminger & Kasari, 2000; Bauminger, Shulman & Agam, 2003) and increased rates of depression (Bennett, 2016; Ghaziudden, 2005). Friendships can therefore serve as an important protective factor for autistic youth. It may be that many autistic people desire friendships, but lack emotive skills, which, according to Whitehouse et al. (2009), function like the 'glue' bonding friendships.

Very few qualitative studies of friendships have been carried out among young people with ASD (O'Hagan & Hebron, 2017; Tomlinson, et al., 2020), yet, it is thought that adolescents spend about one third of all school time outside formal classes (Wainscot, et al., 2008) in the vicinity of peers. Peer friendships offer opportunities for social interactions that adults cannot offer (Roeyers, 1996), however, pushing social interactions upon young people can also function to highlight social clumsiness and accentuate one's deficits. In this study advocates believed that socialisation opportunities for autists are essential for well-being. Nellie ([adv], p. 14), for example, noted that "for [one] particular boy, I said socialisation is the most important thing for him […] becoming socialised in the school. I have put his happiness before NCEA. To me, his education comes second to his mental state […] It has to! He has to be happy!" Many autistic people have suffered social rejection in mainstream schools, despite schools being deemed a milieu where they might learn social skills and their neurotypical peers might learn tolerance for difference (Humprhey & Symes, 2013); one impetus behind 'inclusion'.

Attwood (2010) has supported the importance of friendship and companionship for healthy functioning and well-being of autistic adolescents, noting that 'ideal' friendships are often those based on like-mindedness, whereby shared interests rather than emotive skills would be the 'glue' that holds autistic friends together. The literature relative to defining 'friends' is more troubled by its inability to arrive at a succinct definition than its participants are, and who often do so in a single sentence. This is because the underlying dimensions drawn on in the process of constructing what a friend is, varies widely between individuals. This includes the elderly (Adams, Blieszner, & deVries, 2000), homosexual (de Vries & Megathlin, 2009), and autistic (Bertilsdotter Rosqvist, Brownlow, & O'Dell, 2015) with cognitive and behavioural processes featuring in all, making 'shared interests' a common dimension to draw on, not limited to an 'autistic' population.

It is appropriate therefore that critical autism studies have begun contesting dominant conceptualisations of social scripts and definitions, such as 'friendship', by privileging autists' conceptualisations and lived experiences of 'being friends' (e.g., Baggatell, 2007; Brownlow, Bertilsdotter, & O'Dell, 2015; Orsini & Davidson, 2013). Commensurate with this, the autists' voices are privileged in this analysis of peer support. Definitions of friendships are neither assumed, contested, nor redefined, but hermeneutically treated with epistemological humility, by accepting the autist's use of the term. This next section of the Chapter therefore explores what was meaningful about 'friendship' for autistic high school students in this project; the ways they understood and experienced their peers as 'being friends' or not.

9.1.1 Being 'in proximity', on the 'outer', and (non)friends

In Chapter Five, Grace highlighted the antithesis of 'being friends' based on assumptions about intersubjective experience underlying friendships. Grace [ter] noted that when she began spending all her break times with a pupil in primary school, 'proximity' was misinterpreted by others as constituting a 'friendship'. Whilst she shared a fairy-tale world with her friend, and taught her how to tell the time, she reflected that they were more of a partnership in a parallel world driven together by their oddities, giving only the illusion of being a true ‘friendship’. Grace believed that ‘proximity’ to another, obscured other people’s ability, including her primary school teachers, to recognise her as autistic. Looking back to this period, it is as though, she sensed a comparative self-imprisonment, locked in ‘her world’, which only later gave way to the experience of increasingly connecting with others, particularly adults who understood autism as opposed to ‘friends’.

> *But what people didn’t realise is that as we were ‘playing’ imaginary games over in the playground, we played in the same ‘world’ for three years […] but no one really noticed either because you had two girls sitting playing* (Grace [ter], p. 5).

Opportunities to make friends in high schools were limited for most participants, despite their interest in making friends. For example, Grace [ter] was very interested in the social world, avidly reading Jodi Picoult’s novels for their literary device of perspective taking, providing insight into social functioning. However, although she went to great lengths to garner greater insight, she, like most autistic people, experienced school as a milieu where she was primarily misunderstood, with very few people around her going to any length to understand her autistic perspective.

Despite the scarcity of friendships in high school for autists, ‘peer support’ is thought to provide safety from bully perpetrators, companionship, and protection from being rejected, or being made to feel as though excluded and on the ‘outer’ (Bauminger, et al., 2003; Daniel & Billingsley, 2010; Schroeder et al., 2014). Both Grace and Emily [ter] developed an awareness that being ‘in proximity’ (as though ‘friends’) was different from having the type of friendship connections they desired throughout their intermediate and high school years. Their *only* option was other ‘outer’ members, or ‘outer’ groups of ‘misfits’:

> *we all were kind of friends because we were the misfits as opposed to getting [along]* (Grace [ter], pp. 42-43).

Emily [ter] for example, recalled a time when she hung out with the ‘naughty’ kids in intermediate school, sneaking into the library at lunch time when they weren't supposed to: “so the only reason I hung out with them, was because the other girls were quite ‘cliquey’” (p. 2). Grace [ter] also experienced being on the ‘outer’ in intermediate school, at a time when others began to advance socially, leaving her behind.

> *As children, social rules are something you can kind of learn, to these very in depth […] it became incredibly complex* (Grace [ter], p. 6).

> *... the other girls were too 'cliquey' [...] and those girls made me feel nervous about hanging out with people at high school* (Emily [ter], p.2).

Some autists therefore described being in proximity to others who were more like non-friends, united by their oddities, various diagnoses, social naivety, and exclusion from the lifeworld of their neurotypically developing peers.

> *You get these kids and they all…the one's they call 'geeks'… and they all end up because they, maybe because they're too sensory overloaded out in the playground or whatever and they end up congregating in the library at morning tea and break and 'oh, there's another person that is like me that is into this and into that' and then you've got 'geeks united', or you know what I mean. But actually, they've been forced together due to their disability* (Paddy [adv], p. 43).

Grace [ter] reflexively hesitated to even employ the term 'friends' to characterise the group of (non)friends she spent most of her high school time with at one school. Rather, it was more of a partnership to provide 'pack protection' from potential bullies. She recognises other peoples' developmental expectations and 'positions' herself and her friends at the lower end of the social developmental continuum:

> *I had a group of friends. 'Friends' is probably debatable! There was a group of five of us who, essentially, were all the social outcasts. You had me on the autism spectrum, you had another girl with ADD, one with Trichotillomania - pulled her hair out, the one who came back from primary school, so 'selective mute', and another girl with ADHD. My dad used to lovingly call her 'the ferret on speed', because she was very, very, very much… And also had dyslexia as well; quite severe dyslexia and another girl who came from quite a religious family and had a whole bunch of anger management issues and there was some strange things that went on in her house […] So, we were an incredibly dysfunctional group; we had nothing in common at all except for the fact that everyone else hated us, but we were all in some ways on quite a similar social level. We were all well below our peers who were all talking about boys and make-up and gossip and talking about each other and we were still sitting there playing with soft toys* (Grace [ter], p. 17).

For Taylor [adol], being in proximity to a regular group of peers in the SSC in high school, constituted her friendship network, or peer support group. Although she described people as a source of anxiety that left her unable to talk to her 'friends', she nonetheless had “about 10” friends (p. 10), one of whom was leaving, creating a ‘gap’ in the SSC, as much as causing a felt loss:

> *Taylor (to Mrs Smith who had just entered the room): did you know that it is Becky's last day tomorrow?*
> *Mrs Smith: it definitely is, isn't it.*
> *Taylor: I’m going to miss her. It's sad. It seems like all of my friends move all the time* (Taylor [adol], p. 27).

Other participants, like Chris [adol], preferred to remain alone, having limited options for joining a ‘group’ of individuals in a similar social predicament being in a smaller rural school. Chris had one person though who he referred to as a ‘friend’; someone who started off as a ‘companion’ in a ‘social skills class’ for ‘loners’, and became ‘a friend’ over time, through their familiarity. Their level of engagement and interrelatedness did not equate to the type of socialising neurotypicals might believe characterises a friendship, however, ‘being friends’ provided a sense of inclusion when their paths crossed, and it was these little moments that meant much to autists in high school.

> *Well at first it was more like a companionship or something, but I guess over a few meetings, well, a few of our sessions later, and we [Harry and I] started to become friends. We don’t talk to each other often because I don’t talk with much of my friends, but we do talk to each other and we did get to hang around in a few classes together and those classes were drama. I don’t really learn drama, but I did visit drama every now and then [...] I’m not too good on explaining friendship or understanding friendship [...] I didn’t really hang around him [Harry]. In the breaks, I just wondered around until my last year when I could sit in the special place with the year 13’s. I did sit in there, but it was still boring, so I just preferred to wander around* (Chris [adol], p. 9).

Whilst Brad [adol] was socially connected to many people through school, sport and theatre, alluding to them all as ‘friends’, like Chris [adol], he didn’t have any ‘close friends’ (p.13) and struggled to explain the characteristics pertaining to ‘friendships’. ‘Friends’ appeared to be an uncomfortable theme for Brad, bringing to the fore once more the importance of watching body language and listening for changes in tone and tempo of the interview, in order to discern ‘consent’. Brad began to gather the cushions scattered along the length of the couch, hugging them to himself, whilst his language, which up to this point, had been reasonably articulate, also began to change. Sentences began to be filled with nonsensical, non-lexical fillers, reflecting his hesitancy and difficulty in grappling with the theme of close friends:

> *Brad: I don't know if I have any close friends, hmmm.*
>
> Sharon: is there someone you like the most then?
>
> *I'm not sure at the moment, I'm just trying to think…blah, blah, blah, blah, la, la, la ….*
>
> Sharon: do you see anyone out of school [and not connected to sports or theatre] to socialise with?
>
> *Brad: nah, nah, nah not really. Ah la, la, la, la, I don't know* (Brad [adol], p. 13).

At this point, I directed the conversation away from friendships, to that of parties and socialising in general, and during the transition to this conversation, Brad began returning the cushions to their usual location and resumed his typical, well-articulated replies. The contrasting non-lexical 'fillers' left the impression that 'being close friends' was interpreted as a social gauge for also measuring personal 'worth' and as such, was a 'marker' he wanted to literally hide from me, being personally painful and socially shameful.

9.1.2 Sharing interests and being 'gamers'

Orsmond and Kuo's (2011) small study investigating how high-functioning autistic adolescents used their discretionary time, revealed that more time was spent watching TV, than being on the computer. A comparatively insignificant amount of time was spent visiting friends or relatives. However, as Attwood (2007) attests, many autistic young people develop friendships through special interests, especially on-line computer gaming.

Some time ago, one local community hub offered autistic adolescents the chance to socialise through the medium of computer gaming in an "extremely popular" once-a-month Saturday session (Grant [adv], p. 2). Grant noted the value in providing community 'space' for younger adolescent 'gamers', whereby 20-40 young autistic teens would attend, interacting indirectly. The gaming session was moderated, providing additional opportunities for aiding *in vivo* social engagement too. Similar success has also been noted by Carter et al. (2004) with 'The Friendship Club', whereby game-like activities facilitated indirect interactions with peers:

> *and they stood at the table, but it's just being in the room with other people and they are actually interacting with all those people because it all goes through a LAN, it doesn't go through the internet. It's only people in that*

> *room, so that guy over there who's got a 'game' name and you've got one, you are actually talking to each other, and you can see the guy and it doesn't happen often but sometimes you have a bit of a blowout because somebody has stolen your castle or whatever they do, you know…destroyed something. So, we had rules and they break the rules and then we have an admin guy who monitors all that to make sure they don't overstep the boundaries, or they get penalised; they get 15 minutes downtime* (Grant [adv], p. 4).

Whilst none of the autistic participants in this study mentioned attending this group, one lamented, like Grant [adv], that this center had closed, and closure occurred around the time they wanted to go along!

Some parents of autistic 'gaming' teens have considered this form of interrelating to represent 'poor quality friendships' (e.g., O'Hagan & Hebron, 2017). Kym[par] (Liam's mum) restricted Liam's [adol] gaming time because she perceived it as frivolous and wanted Liam to spend time on other pursuits. However, Liam claimed to have no other 'pursuits' that interested him like 'gaming'. He was not currently involved in any other activity. Michelle [adv] also noted the rise of parents undervaluing the importance of computer use as a source of quality down-time for autistic teens, advocating instead for increasingly busy schedules that might enhance socialisation opportunities but are more tiring and potentially jeopardise a balanced approach to life. She recalled a specific incident involving a current high-functioning client:

> *music was his special interest and so the parents were nurturing that and this young person was involved in different kinds of music recitals and bands and stuff like that […] he wasn't particularly social at school and he was more social with music people […], so that was a good way for him to have social contact. Really sensible stuff…* ***but*** *he got home from high school at about 4 o'clock and then from about 5.30 onwards, every night of the week he was involved in something to do with music […] and he wanted to play computers and his mum would get mad with him* (Michelle [adv], p. 22).

Whilst parents might perceive 'gaming' as lacking 'real' social value for their autistic teens and contributing to a truncated social existence, teens had a lived experience of being connected to others in ways that were meaningful to them. Gaming facilitated social connections and enabled James [ter] and Liam [adol] to feel as though they belonged in a social group, despite persistent communication difficulties on- and off-line for Liam [adol]. In addition, James [ter] credited gaming with getting him out of bed and interested in life again; it was not ‘the game’ *per se*, but the friendships he began to form and interactions he enjoyed with others that increased his motivation to ‘participate’ and interact. On-line games typically enable on-screen text or voice chatting within the play zone or in private (Griffiths, et al., 2004) and so these opportunities for interpersonal interactions, gained through gaming with likeminded people, enabled Liam and James to feel like they belonged and thus were able to say they had become part of a ‘we’.

> *James: my brother introduced me […] to a game and […] I came across these guys my age and they were having a great time. One of the guys was the funniest guy I’ve ever met. And so they said ‘hey, like just join us I guess, for a bit of fun.’ And Yeah, so ever since then I’ve had the best group of friends I’ve ever had on-line.*
> Sharon: so have you met them?
> *James: yeah, yeah […] The first time I met them was a couple of years back. There’s a group of like three of them in [the city]. We’re like Australasian though, from anywhere from Perth to Blenheim to Dunedin. I’ve met them a few times now in real life. But we speak everyday on-line* (James [ter], pp. 10-11).
>
> Sharon: can you recall what you did in breaks at school; in lunchtimes?
> *Liam: I’d mainly just hang out with my friends really […] just talking […]*
> Sharon: what did you mostly talk about?
> *Kym [par] & Liam [adol] (simultaneously and animatedly):* ***gaming!*** *(we all laugh)*
> *Kym: [His sister] walked past them one day and said it’s crazy - they were all so hyped up and chatty, chatty and chatting so fast and you never see them chatting like that but when they are in game mode and they are talking…*
> *Liam: it’s like another language* (Liam [adol], p. 21).

In their small study involving three autistic adolescents, O’Hagan and Hebron (2017) noted that ‘gaming’ held friendships together at school too, therefore positively influencing students' social interactions and presumably, sense of belonging. Liam [adol], like the participants in O’Hagan and Hebron’s study, gamed online with known peers, enabling him to continue conversing off-line, at school, in this ‘other language’.

Experts, generally, are distinguishable from novices by a range of characteristics that pertain to shared language, including superiority in organised knowledge, computational speed, advanced perceptual processing of domain-specific scenes and objects, as well as being able to detect variations in triviality, so as to discern what might be atypical and thus deploy their 'expertise' (Kim, Bae, Nho, & Lee, 2011). This might account for not only why gamers might be perceived as though 'speaking another language', but why, when they do, they may become animated, as witnessed by Liam's sister, of Liam during break time. Liam and his peers were engrossed in the tasks of strategising and analysing, which are motivational for subsequent participation in gaming sessions. When the same social group moved into other topics of conversation, the import of the shared interest is most evident:

> Sharon: when you're gaming, do you chat as well?
> *Liam: oh yeah, definitely […]*
> Sharon: and do you talk about other things or is it always related to the game?
> *Liam: there's this friend who keeps talking about University and I don't know how to respond, because it's just like… Can you just talk about the game!*
> (Liam [adol], p. 17).

Regardless of some difficulties, it seems that James [ter] and Liam [adol] received enough feedback from their gaming friends to make positive self-references about their own identity as 'gamers' and as belonging to a social group of friends. Shared interests play an important role in identity development (Renninger, 2009) and this contributes to a positive sense of well-being. Online gaming gave personal meaning to James' [ter] life. His motivation increased and these positive interrelations aided his decision to 'get up', which eventually lead to 'getting out' and getting involved - firstly by engaging a psychologist, and then by enrolling in a tertiary program of study, with support, to navigate the 'offline' social curriculum.

Whilst these were positive outcomes, gaming research has previously revealed that gaming can be addictive, contain violent content, and when engaged in excessively, can led to negative consequences for people's lives (Griffiths, et al., 2004). Whilst Nellie [adv] posited that a student's happiness and wellbeing must be considered before their learning, she interpreted online gaming through the normative, dominant lens, like that taken up by Griffiths and colleagues. She had noted one high-functioning autistic adolescent was slipping behind in NCEA, losing interest in school in general, and was becoming increasingly angry and therefore difficult to engage with in learning:

> *He'll come to school stressed out, like last week because Mum wouldn't buy him a Game Boy game. And he was just angry all day and he couldn't engage in any form of learning anything* (Nellie [adv], p. 11).

When Nellie eventually phoned the mother, the complexity of the 'gaming issue' emerged.

> *I rang his mother and she said, "I'm just having such a battle with him at home." So I hadn't really looked into his home life too much [lately] and she said he's very disruptive in the morning when she's trying to get the other three off, ready for school and she said "Knives are coming out of the drawer" […] If I take him away quietly and say "What is it?" He'll, say "Oh, teacher aide is being annoying" or "I want to leave school." So, this is the latest that I've got. "I want to leave school". And of course, he does! But his mum's argument is he'll just sit on Game Boy all day if he stays home (Nellie [adv], p. 12).*

Nellie [adv] sensed the danger of the situation, mobilised a support service and highlighted the importance of specialised mesosystem level connections between home and school, to make sense of the student's lifeworld. However, what was not explored or considered, is the way 'gamers' construct 'virtual communities' and live 'socially' on-line and the importance of this sense of connection, for well-being.

This thesis has already alluded to the sociocultural pressures on parents to prioritise 'active participation' in life; thus, it is deemed normative to prioritise music lessons over gaming. From the autists' perspective, having downtime is essential and having online gaming friends, highly desirable and enjoyable. It may be that autists have not been able to convey the experience and joy of 'being social' in 'gaming', because of their communication difficulties (O'Hagan & Hebron, 2017). Meanwhile parents lack faith in there being a future for their adolescent, with few programs or initiatives in place for assisting autists in transitioning out of high school and into off-line community life. There is a general perception, which is supported in psychological practice too, that many autists struggle to find work, move out, and generally 'move on' (e.g., Wehman, et al., 2014). Instead, they devote their time and talents to gaming, where they are being socially active, despite the lack of acknowledgement that this could be socially fulfilling.

> *[…] and they can't get a job and they get stuck and they get stuck typically in front of the computer screen and when they get to be about 29 or 30, their parents are going crazy - how can we move our son on?* (Michelle [adv], p. 15).

Whilst transitioning out of high school was a salient concern for participants in this study, it is worth noting again, that in phenomenological and ideographical studies, wisdom does not need to be harvested from repetition or from a ‘saturation point’, but rather, can be left to emerge via a single insight. To that end, Grant [adv] noted, as a parent to a ‘gamer’ and community advocate for autists in general, that the popularity, sociality, and safety of facilitated gaming opportunities for high-functioning autistic teens, makes organised gaming a potential form of enjoyable socialising, with some boundaries that may assist in curtailing excessive gaming (Griffiths, Davies, & Chappell, 2004) whilst facilitating establishment of on- and off-line friendships for high school teens.

9.1.3 Social media: making and unmaking friends

Dominant definitions of friendship have failed to account for autistic people’s experiences of online friendships (Bertilsdotter Rosqvist, Brownlow, & O'Dell, 2013; Brownlow, Bertilsdotter Rosqvist, & O'Dell, 2015). Engaging with offline friends online, and strangers online, has however, had a very short history (Subrahmanyam & Greenfield, 2008). As such, there has been scant research comparing the quality of friendships made online with those made offline. It appears that people who meet on-line can “initiate meaningful and satisfying conversations, and build stable, long-term relationships, similar to face-to-face interactions” (Yum & Hara, 2006, p.133) as James [ter] attested to in becoming friends with a small number of on-line stranger gamers. Despite the normative assumption that it is ‘risky’ to establish online ‘stranger’ friendships, a small body of research suggests that establishing online relationships with strangers has a positive impact on the lives of adolescents who have experienced social anxiety and social rejection (Subrahmanyam & Greenfield, 2008). This may be because online friendships move at a different pace, are not subject to nonverbal communication ‘interference’, and enable an orderly progression of disclosure (Yum & Hara, 2006).

In this study, Catherine [adol] recalled how she developed an online friendship with a young couple in America, through her online presence as a fanfiction writer. Catherine communicated with her friends during school lunch breaks, when she wasn't reading, and on the weekends. Unlike Liam [adol] and James [ter], her online friends were not part of her small ‘offline’ network. However, like many people who ‘meet’ online and develop a ‘friendship’, Catherine sometimes Skyped her American friends, for face-to-face interactions. The ordinariness of this type of friendship is well-captured by the fact that their conversations spanned not only their common writing interests but ventured into the trivial and mundane aspects of each other's lives. For example, Catherine noted how her friends were “always pleasantly surprised at the fact that NZ cafeterias sell decent food” (p. 8). Whilst this may not be indicative of the depth and breadth of their relationship, it does highlight the normality of a friendship that goes beyond a common interest into the types of mundane disclosures and declarations we make about our culture and habits, with our friends.

All the autists in this study used social media to varying degrees, (predominately Facebook, Instagram and Snapchat) to follow offline friends and acquaintances, in addition to monitoring and/or contributing to posts within various groups. Most participants used smart phones or laptops, however, Liam [adol] and Chris [adol] did not have a cell phone, being unable to see the point in them. Unlike other teens, in her adolescence, Grace [ter] couldn't see the point in any social media:

> *I was very antisocial media as a teenager - why would you want to be talking to other people outside of school? We have to spend so much time inside school talking to other people, why on earth would you want to do that outside of school?* (Grace [ter], p. 46).

It is thought that most Facebook users do one of three things, namely maintain their relationships, use Facebook for entertainment, or to ‘pass time’ (Moore & McElory, 2012; Sheldon, 2008). However, it is also increasingly used as a platform to facilitate mentoring (McCarthy, 2012), overcoming geographical and time boundaries, and bringing mutual benefits to mentee and mentor in a reciprocal and bi-directional relationship (Bierema & Merriam, 2002). As Grace [ter] moved into young adulthood however, she began to use Facebook, suggesting a changing perspective over time. She used this to mentor others, as well as joining ‘aspie’ groups, thus helping and engaging with others on ‘the spectrum’. It was comparatively purposeful.

Other participants predominately followed others on Facebook, rather than contributing to relationship maintenance. This enabled them to stay informed, without having to reciprocate. For example, autists mentioned following known peers, teachers, and even their deputy principal, highlighting the unidirectional nature of the ‘relationship’. Like many NZ teens, participants regularly checked their social media accounts for updates:

> *I use social media like every night and morning before I go to bed and after I hop out of bed just to check notifications and stories and all that. And I check what people have posted there* (Brad [adol], p. 14).
>
> Sharon: how often would you go on Facebook?

> *Liam: I generally just log on and just look at a few things and then just leave it on and carry on with gaming and look back on it after a little while. I don't really type anything […] I just leave it on and check whenever I'm just searching for a game or something (Liam [adol], p. 22).*

In their 'following' of their peers, autists predominately 'monitored' posts, rather than contributing their own posts, preferring nonetheless, a morally sound newsfeed. This resulted in their active removal of offensive material. This highlights however, that they were also considering social etiquette and were navigating the social implications of their online actions. Moreover, they were also choosing 'friends' that best fit their values, in a manageable way:

> *If they have posted rude things about kids [on Facebook] that are not like really positive then I'm just like "oh gawd, keep it to yourself why don't you" and I just defriend them. I learnt that it is better to defriend someone on social media, better than block them because if you block them it will come up on their notification and they can get mad at you really easy* (Brad [adol], p. 14).
>
> Sharon: do you take a lot of notice of the type of things that your friends are posting?
> *Liam: oh yeah, I've actually unfriended some people because of that, yeah, I don't want that stuff on my timeline.*
> Sharon: what sort of stuff were they posting in order that you got rid of them?
> *Liam: um, mmm, there's just stuff I just generally didn't like. It's…*
> *Kym [par]: swearing, sexual, what is it?*
> *Liam: stuff like that, yeah* (Liam [adol], p. 22).

Facebook and other social media applications are commonly used for adolescent fun, including the organisation, and recording of, student parties (Sheldon, 2008). Brad [adol] and Emily [adol] followed live events using Facebook and snapchat. This reinforced and contributed to Emily's sense of being on the 'outer' of her peers, especially when they began uploading photos during special events, like pre-ball parties leading up to the High School Ball. In this way, social media functioned to facilitate Emily's internalisation of being a 'damaged identity', through the power of normative forms of adolescent socialisation. This finding regarding using Facebook as a form of adolescent social surveillance, is not too different from that of Tiggerman and Slater's (2013) finding, whereby avid Australian female adolescent Facebook users, had comparatively higher negative body image scores, than their non-user peers, thought to be the result of ‘surveillance’.

> *When I saw it [the ‘Pre-ball’ party] on Facebook and it looked like most of the year 13’s who went to the ball went, I was like ‘I felt so dis-included’. I just felt stink and like I didn’t really know how… I just felt stink thinking about it. It wasn’t the nicest thing to think about. It made me feel how like dis-included I was at high school in seeing that* (Emily [ter], p. 13).

Brad [adol] also experienced the adverse impact of social media use when he posted a message on his Facebook newsfeed about a teacher after he received a ‘Not Achieved’ grade. He felt so angry that he couldn’t resist posting the message, which his Deputy Principal saw, told him to delete, and disciplined him for, including asking him to post an apology online! Brad’s Facebook peers added to the public shaming and humiliation of this episode by adding negatively valanced comments, which functioned to silence him and restrict his voice in the public arena of social media if ever moved to anger again:

> *If I was going to post on social media, I would think ‘arrggg, just go through it a lot of times and then you realise, it’s bad, so if you still feel like posting it on social media, just write it on paper and hang it up on your wall…and then pretend that people see it and then they say nothing - that’s what it is* (Brad [adol], p. 32).

Parents also raised concerns about the nature of retaliation on social media and how this contributed to the offline (anti)social experiences in high school:

> *Paddy: on social media, I mean you’ve got social media now you know and she’ll [16yo high-functioning autistic daughter] will write things and I’ll look at the Facebook and I’ll think ‘oh no. Or, 'somebody is going to see this!'*
> *Rachel: you know, she has no understanding*
> *Paddy: they’re going to take the p#ss out of you*
> *Rachel: but she’ll say, ‘but they said it was awesome’ but I’ll say, ‘did you read that comment afterwards?’ You know, it’s like, all she wants is to be a popular girl, but she is never going to mix with the popular girls* (Paddy [adv]; Rachel [adv], p. 42)

Paddy and Rachel [adv’s] suggested their daughter failed to recognise her peers’ comments and responses as intimidating. This may be one reason why participants report fewer incidences of cyberbullying, in this and other studies (e.g., Saggers et al., 2017). However, two other reasons can be gleaned from this study. Firstly, given literary difficulties, autists may post less because they cannot express themselves easily. Secondly, in the following section, some autists describe how being bullied led to them becoming increasingly vigilant, perhaps curtailing desire to put themselves ‘on [the] line’; keeping silent is like staying out of the way. It is a protective factor.

9.2 Being bullied and abused

Adams, Taylor, Duncan, and Bishop (2016) suggest that educational outcomes are related to experiences of victimisation for students with ASD in mainstream schools, like typically developing children. It is therefore relevant, if not necessary to consider peer support in conjunction with the phenomenological experience of being victimised and bullied as autistic adolescents in high school. During the interviews, participants referred to bullying in high school. In the literature, a bully is defined “as an individual who perpetrates emotional or physical power over the victim” and is distinguished from peers of the same strength and social standing who may be involved in physical or verbal altercations (Rose, Monda-Amaya, & Esplelage, 2011, p. 115). Bullying typically involves verbal or physical forms of aggression and can escalate from teasing to violence, as power is exerted over the other. Two additional key elements pertinent to an understanding of bullying behaviour in NZ high schools, is that behaviours must be deemed deliberately harmful and repetitive (New Zealand Council for Educational Research, 2011).

Unlike student experiences in special education settings (Hebron & Humphrey, 2014; Zablotsky, Bradshaw, Anderson, & Law, 2014), autistic students in mainstream schools are at increased risk of being punished by a larger contingent of their cohort, for ‘being different’ (Schroeder et al., 2014); they may be comparatively isolated and thus lack protection, being more vulnerable. This is consistent with numerous studies highlighting higher rates of bullying for children with disabilities, with some being more likely to be victims, whilst others are more likely to be bullies, leaving them with less friends and more experiences of social rejection (Mishna, 2003; Smith, 2016).

With respect to being bullied, the power imbalance seems to be in reference to ‘social’ power. Having a peer group is therefore thought to serve as a ‘buffer’ to reduce exposure to bullying and victimisation (Bauminger, et al., 2003; Daniel & Billingsley, 2010). Several participants noted that they did find protection from bully perpetrators in other people and ‘safe places’ within high school, however, at best, it was only ‘partial protection’:

> *[Despite protection offered via membership with 'the outcasts'] I was still very badly bullied, but I would imagine it would have been even worse, had I sat*

> *alone at lunchtimes […] It was often when people got me alone or I was at school earlier* (Grace [ter], p. 45).

> *[Using the SSC enabled] staying away from the other kids since I was too wary; I didn't want to run into bullies or anything or come across double-crossing friends* (Chris [adol], p.5).

> *I would be in the computer lab and there would be a group of four of us, but there was a couple of times where some other guys would come in and start unplugging computers, whilst we were working on things* (James [ter], p.7).

Whilst some participants recalled specific incidents of bullying, like having the computer cords pulled, the majority referred to general episodes that were repetitive in nature and persisted throughout high school. Liam [adol] noted that his experiences of bullying had typically been 'seasonal', heightened at the beginning of the school year and tapering off in the latter months of the year, suggesting that his 'differences' were a novelty to exploit, until habituation reduced their social currency. Chris [adol] and Brad [adol] recalled that their earliest memories of bullying dated to primary school, whilst Emily [ter] and Grace [ter] became aware of 'cliquey' cliques during late primary and particularly in intermediate. Grace [ter] was around 12yo when she began perceiving herself as being a target of verbal victimisation, whilst Catherine [adol] and Liam [adol] also recalled repeated incidents of being interrupted and 'questioned', experiencing this as a form of verbal victimisation, beginning in high school and persisting into their senior years. They all perceived this to be deliberate forms of intrusion, often for entertainment purposes. Catherine for example, did not perceive social interactions initiated by her peers, or invitations to parties as an 'invitation' to be social.

> *Like I'm sitting there trying to read a thing and follow it and kids are like how's [online friends] "***Why are you asking, I was trying to read!***"* It's just annoying! It's like can you just stop asking me all these questions and they keep inviting me to parties and **I don't want to go to parties!** […] but they keep asking me to parties and describing the parties to me and it's like **I don't want to go to these parties!** (Catherine [adol], p. 26)

Grace [ter] drew on a developmental narrative to suggest that social rules 'mutated' suddenly and became complex, coinciding with the driving forces of nature that propel puberty, and result in a social movement beyond the prepubescent 'play' stage "where you have to share with the person next to you – quite simplistic" (p.6). At this time, Grace became increasingly aware of others and realised her own social inequality and communication differences:

> *... as lots of the other kids learnt innuendo and all of that, it went straight over my head and one of the ways lots of the other girls loved to torment me, in many ways was they would ask me questions and I wouldn't understand that either it was a question you are not supposed to answer, or I didn't understand what they were asking, so I would get really confused and ask and then they would get all giggly because I'm asking about concepts that are obviously - they are talking about them at 12 and 13 - they were talking probably about sex and other things like that - that are kind of much older concepts, but they are laughing because they had an understanding and I had no clue at all* (Grace [ter], p. 43).

Fisher and Lounds Taylor (2016) have noted that understanding is lacking as to why peer victimisation in autistic adolescents occurs. Grace's [ter] 'victimisers' exerted their social power of shared understandings, isolating Grace's 'differences' and leaving her with a lived experience of 'being inferior' and a nonconsenting target for 'entertainment'. By taking up the 'interpretative' freedom that IPA offers, it is possible that Grace's perception of the phenomenon, functions to illumine something notoriously innate about our (fallen) human nature. Early Egyptian tomb paintings depict dwarfs 'employed' for entertainment purposes, whilst the court jesters and 'fools' (the developmentally disabled) of the 1600-1800s, gave way to the market-place 'freak shows' and museum attractions (Gerber, 1992). Grace's perpetrators are like the 'showmen' "learning how to make people who simply looked different into 'freaks'" in order to better 'entertain' and capitalise on someone's differences (Gerber, 1992, p.59). This interpretation also resonates with Liam's [adol] lived experience that bullying tended to be 'seasonal'; it lost currency commensurate with commonality.

Similar to Catherine [adol] and Liam [ado] who were repeatedly questioned about parties and books, Grace perceived at least some of her victimisers as loving the task of tormenting her, where their satisfaction came from making her 'differences' stand out to appear more 'freakish'. Doing so enabled perpetrators to build up their 'social' capital as onlookers and bystanders (being the audience), were 'entertained'.

James [ter] and Brad [adol] had similar insights regarding the cause of bullying, suggesting that their ‘differences’ were cause enough. Sadly, whilst Brad fails to look beyond his own person to locate ‘blame’, James emphasises how the past ‘freakshows’ have been superseded by the genre of Reality TV. He believes these have penetrated our social fabric (Bagdasarov, et al., 2010). So, what continues to get illumined is, thanks to the producer (or modern-day ‘showmen’), that which is most ‘freakish’, laughable, or outlandish. This not only drives up capital through viewer appeal but keeping the culture of ‘difference’ very much ‘alive and well’ in the modern age.

> *Brad: I have been bullied at school, but I have kind of learnt that the main reason I have been bullied is because I have created some of my…I’ve created bullies because I have been like, being stupid at my friends […].*
> Sharon: why do you think they are mean to you?
> *Brad: they just think I’m different or something; they just think I’m rude* (Brad [adol], p. 15).

> *James: I’ve just had issues all through my life – it’s like “hey, it’s fun to wind this kid up”. That is something that…there’s an autism group around here which I used to go to and that just seems to be a common occurrence in schools, that people liked winding the autistic kids up and getting them to throw chairs and...*
> Sharon: just to watch for the reaction?
> *James: yeah. It’s one thing I’ve never really got, like Americans are big on that kind of thing and media and stuff is like, they will film reactions of people rather than the action and it’s kind of boring…it’s like, ‘what’s so interesting about their reaction?’* (James [ter], p. 7).

The reactions to being bullied varied, ranging from walking away, to name calling, to being physically violent. For example, James ([ter], p. 7) said that he “never wanted to hurt anyone” and the “reason I was violent, basically always was ‘would someone who was feeling okay, do this?’” Other participants also recalled reacting in a physically violent ways, particularly when frustration levels rose. For example, being interrupted whilst reading was irritating for Liam and Catherine [adol’s]; however, these constant interruptions elicited increasing levels of frustration so that they were embodied reactions, interpreted as the consequences of bullying, to which some participants eventually reacted to.

> *If it is a fight or someone frustrating you and you just shove them up the wall when they are like upsetting you, that's happened to me* (Brad [adol], p. 41).

> *Liam: I throw quite a temper and I would probably just physically punch them […]*
> Sharon: on a regular basis?
> *Liam: not on a regular basis but when we are in the same class or something…*
> Sharon: always as a result of being bullied?
> *Liam: oh yeah*
> *Kym: did you punch them because you are being bullied or was it for other things?*
> *Liam: oh no, they wouldn't leave me alone. Generally, I would be reading a book and they would just be like 'hey what are you reading' and I'd be like 'just go away, go'[…] just go 'be irritating somewhere else'. Yeah!* (Liam [ado]; Kym [par], pp. 13-14).

Aside from depression and anxiety in general, several participants believed that a specific and detrimental repercussion of their being bullied was the development of what they called 'paranoia', taken here to mean the increasing tendency to be hypervigilant. This functioned to further inhibit opportunities for socialising, making new friends, and developing peer support networks.

> *It [being on the 'outer' of cliques] made me feel really nervous about what I said and it made me feel like I couldn't be myself because of those girls* (Emily [ter], p.2).

This led to the realisation for Grace [ter] that she also alienated others.

> *I was very paranoid in many ways because I couldn't understand the difference between someone teasing me and someone being genuinely nice because what lots of them liked to do to me was pretend to be nice and then lull me into a false sense of...yeah,. And so, I became **incredibly** paranoid and then, yeah and mum said it was part of the problem in the end as to why I didn't make friends. It was because I was so convinced that everyone was out to get me* (Grace [adol], p. 14).

> *Yeah, you always tried to avoid the people who were going to 'get you'. But again, that whole paranoia thing - that then it created people that maybe weren't trying to be nasty necessarily and it meant that I put a lot of them off because I became very paranoid* (Grace [ter], p. 32).

> *And I would answer them honestly because they asked a question - why wouldn't I? - and that's again where that paranoia came from, which then meant that any question that someone asked me, it got to the point of where it would be 'why are you asking me that; what do you want; why do you want to know that?' And so, then I put off a whole bunch of people so, yeah I was kind of permanently damaged by this set of people that actively were trying to get a reaction, which meant probably when people who I might have got along with… I was unwilling to try and even make those connections* (Grace [ter], p. 20).

> *[…] staying away from the other kids since I was too wary; I didn't want to run into bullies or anything or come across double-crossing friends. I've already had a bad experience with that kind of thing in my previous school* (Chris [adol], p. 5).

Chris [adol], Emily [ter], and Grace [ter] avoided people because of fear. Grace's father adjusted his working conditions, in order to drive her to school. Whilst this limited opportunities for bullying *en route,* it highlights the impact extending beyond the adolescent to the family. Whilst Grace reported bullying to her family, it is thought that because of their social difficulties, autists may have difficulty reporting bullying or pressing for additional assistance if their initial effort garners insufficient relief (Humphrey & Symes, 2010). Chris [adol] for example, recalled 'paranoia' setting in following his experiences in primary school in his recollection of reporting being bullied on a regular basis, with assurances of assistance, but no actual relief.

> *…well they say they are going to stop bullying but bullying continues no matter what they do, and they don't ever change that. They just say things, but they don't do things* (Chris [adol], p. 5).

Emily's [ter] reports of bullying to her high school teachers led to the suggestion that she hang out with other students in 'the block'. The problem with this, was that Emily interpreted those students having less social currency than herself; consequently, like other autistic students, she perceived teachers as being insensitive and doing little to respond to reports of bullying (Saggers, et al., 2017). Like other adolescents (e.g., Humphrey & Lewis, 2008a), Emily wanted to be perceived as 'normal'. Instead, like the neurotypical students who excluded her, she too avoided making friends with those she perceived as socially and intellectually inferior to herself. The inclination we have toward making downward social comparisons to boost self-esteem (Festinger, 1954), no doubt contributed to not only Emily's social isolation, but many autistic people's social isolation and lived experiences of being unsupported by peers in mainstream high schools.

Aside from physically retaliating because of being bullied, a small number of participants engaged in aggressive or bullying type behaviours themselves, predominately within the context of defending others and recognising injustice. Whilst this led to the school taking disciplinary action against them, the irony of their recollection is that disciplinary action was not forthcoming when they were the targets and victims of 'being bullied' by neurotypical students. It is possible that autists' reports were trivialised, whilst their bullying actions obvious. Neither Brad [adol], nor Chris [adol] however, wanted to think of themselves as 'bullies', but rather as defenders of social justice, who went about things in the 'wrong way'.

> *Well, I was going to see if one of my friends was okay and then she was like sprinkling water at the idiot and I thought the idiot was messing with her so I just shoved him up the wall and I just told him that I don't like jokes or his teasing and 'you just stop it!' […] Then I had to deal with it with the Deans […] I know I did something wrong as well, so which wasn't really my fault, it was actually his fault because he is like, he is winding up people* (Brad [adol], p. 41).
>
> *Chris: My friend Jaydan was being bullied by some girls and I got so angry that I threatened to stab one of them with a pen. Of course, that particular individual I threatened, she was having problems of her own, but I didn't know that, but I'm not trying to… Well okay I'm trying to defend my knowledge of her having anxiety. She didn't want to go to college because of me for a few days. […] They were all just laughing at Jaydan.*
> Sharon: is Jaydan on the autistic spectrum too?
> *Chris: ah, no. But he had depression, he was having some little anxiety issues himself, so no, he was just more of a victim of bullying than I could ever be*

> *and they just kept laughing at him and I kept calling them mean names* ***to shut them up****. It wasn't going so well then along comes the Down Syndrome boy and he just hits Jaydan or something and I just went… I just snapped; I just chased after him, grabbed him and went* ***"go over and apologise right now"*** *and he kept trying to run away and I have to say, I don't care if you have Down Syndrome, this kid, he was a naughty boy at times* [Chris [adol], p. 7).

In summary, whilst some participants in this study did enjoy some positive interactions with others, most experienced a heightened sense of social exclusion, bullying, and victimisation. Some participants noted that this led to becoming hypervigilant, limiting opportunities for socialising and likelihood of making friends. It seemed to be 'luck of the draw' to find peer support, be that via shared interests or diversity of diagnoses. Autists were perhaps no different from their neurotypical peers who excluded them, not wanting to engage with those lower in social skills and perceived social currency. On this premise, students are potentially preserving their sense of human dignity; they wanted to be included with the 'higher kind' (neurotypical), would settle for 'the same kind' (for example ADHD, trichotillomania), but actually enjoyed the 'like-minded' (those with shared interests).

9.2.1 Being (victims) in intimate relationships

Western culture has increasingly normalised the period of adolescence as a time of striving for independence, particularly from parents, in order to begin exploring identity and intimacy within the context of relationships, and to explore and pursue dreams. Adolescence, particularly mid-adolescence, is a time when many high school students begin to form intimate relationships. Romantic relationships are typically considered to differ from close friendships in terms of passion, love, and anticipated or actual, sexual activity (Collins & Sroufe, 1999). However, since the emergence of the 'tween' period in the 2000's, there has been a blurring of boundaries "between child/teen and innocent/sexual" (Vares & Jackson, 2015, p. 701); and within a sexualised culture, an increased negation of one's sexual identity and sexual engagement. Nonetheless, whilst previous research suggests autistic adolescents desire intimate relationships, there have been minimal studies investigating intimate relationship experiences (Stokes & Kaur, 2005; Stokes, Newton, Kaur, 2007).

Whilst it was not the aim of this study to specifically explore autists experiences of intimate partner relationships, most participants made some reference to these types of relationships in the context of normative ‘everyday’ mainstream high school experiences. Most expressed no desire to be in an intimate relationship, though seem to have considered the idea:

> *Catherine: […] dating? No! I’m a-romantic, a-sexual. I’m not actually dating […]*
>
> Sharon: and so you are not keen on boys or
>
> *Catherine:* ***noooo, I’m not keen on boys and I’m not keen on girls!***
>
> (Catherine [adol], pp.10-11).

> *Liam: [regarding girlfriends]: well, I’m not interested; not at the moment!*
>
> (Liam [adol], p. 13).

> *I wasn’t that interested in boys and this and that [in high school] and I was interested in reading books and reading encyclopedias and learning and doing things like that* (Grace [ter], p. 20).

Brad [adol] however, was interested in girls! He had had girlfriends in the past and has a current girlfriend. He made it emphatically clear though, that this was not a ‘subject’ for us to engage in and hence explicitly conveyed the limitations of ‘consent’, despite dwelling on the fringes of ‘consenting’ for a few moments longer.

> *Brad: [when his friends ask about ‘girlfriends’] now that really annoys me the most.*
>
> Sharon: Why is that?
>
> *Brad: ohhh…. the moment they ask me how many girls I’ve been out with, it just becomes…it just becomes embarrassing. And, I don’t want to say [laughing and hiding behind his hands]. I don’t want to talk about it [laughing and hiding still].*
>
> Sharon: you don’t have to!
>
> *Brad: I don’t want to talk about girlfriends because….*
>
> Sharon: it's not your favourite subject?
>
> *Brad: [laughs and laughs and laughs]. You call that…imagine that…if girlfriend and boyfriend was a ‘subject’ [continues laughing and I laugh too!]*
>
> Sharon: I don’t mean it like that [laughing]!

> *Brad: You mean like – is it my hobby or something? Nah, I'm just […'joking', perhaps?]…When I first heard of like 'loving someone', it was just like 'oh, it's just love, love, kissing, all that', and love blinded me too much. By the time I was 13, I just decided to know more about love and relationships – just take it in…some relationships just take it slow and all that. Yeah! That's all I have to say about girlfriends and relationships and all that. And you know the school rule for relationships is no PDA! Yeah you know if you are doing smoochies or, I don't know, probably holding hands…you know…*
> *I don't want to talk about it in this interview! Ok, let's move on to something else. Yes!* (Brad [adol], p. 16).

Whilst Brad [adol] conveys a basic understanding of, and respect for, taking relationships slowly, it has been noted that some individuals with ASD have 'crossed' this boundary and in pursuit of an interpersonal relationship, have, possibly naively, stalked target individuals (Stokes & Newton, 2004). Whilst there is little research about the lived experiences of autists being sexually abused in adolescent intimate relationships, it has been reported (Attwood, 2007; Hendrickx, 2015). It is thought that autists may be at 'double risk', lacking social protection and risk awareness (Fisher, Moskowitz, & Hodapp, 2013) and that autistic young women are more vulnerable to unwanted sexual advances and succumb to social pressure, engaging in unwanted sexual activity. For example, of the 14 participants in Bargiela, et al.'s (2016) study, nine reported sexual abuse, half of which occurred within the context of 'a relationship', primarily the result of being pressured and 'pestered'. Three participants (21%) reported having been raped by a stranger, as young autistic women, which is consistent with lifetime experiences of sexual violence for women in Aotearoa, New Zealand, being 24% (Ministry of Justice, 2020).

During these interviews, without provocation, two autists, James [ter] and Taylor [adol], disclosed experiences of sexual, physical, and psychological abuse, one of which was in the context of an intimate relationship.

James [ter] disclosed being the victim of sexual abuse in school on two occasions, once in his early primary school years, and again in year eight; these events occurred in two different schools, geographically distal. Whilst he had reported these incidents to "two or three people", he believed his 'story' was not dissimilar from other autistic young people's accounts. As he came to understand and make sense of this during adolescence, he conveys a sense of the normativity; of 'being a sexual abuse victim' because you lack power and agency. This is not dissimilar to heteronormative assertions that masculinity is superior to femininity, where “men are perceived as dominant and domineering and women as subordinate and in need of protection” (Aghtaie, et al., 2018, p.295). Following this gender-based notion of the structures facilitating violence, ‘being autistic’ is also interpreted as ‘being inferior’; ‘disabled’; or, weaker and thus ‘vulnerable’.

> *I have heard similar stories [from others in the autistic community] and it’s probably because they’ve been abused themselves. That’s one of the main reasons why I didn’t really follow it up* (James [ter], p. 23).

Unlike the discreet incidents of abuse James revealed very early on in our interview, Taylor [adol] revealed she had been in two intimate relationships, one of which was characterised by violence and abuse, namely sexual, physical, and psychological violence. This had occurred over a period of several months, during her senior years in high school. Simone (2010, p. 82) notes that ‘Aspergirls’ are “easy targets for abusers and Svengali-type partners”, sensing “that we might be easy to mould or manipulate.” Taylor began her account of what had transpired characterising the severity and grotesqueness of her sexual abuse experiences as “bad things that you don't want to know about”. She noted the severity of the physical abuse (“he hit me and punched me and all of that”), and her perception of how dangerous, and thus psychologically damaging this pattern of violence became (“he just about killed me”).

Before I had a chance to process what Taylor [adol] had revealed, much less empathise with how this might have impacted her life, Taylor elaborated on what she meant by the things 'you don't want to know about'. She immediately disclosed the specific acts of sexual abuse she had been subjected to and tortured by, terminating by depicting the physical acts of violence. Looking at me, she asked: “would you like to see my scars?” Then, before I could respond, she thrust her outstretched arms towards me, pulling up her sleeves, to reveal a myriad of scars, the result of two instruments used as weapons of violence. She bore the scars of aggression and violence, in their shockingness, for all to see; for me to see!

In a subsequent interview, Taylor [adol] drew my attention to a nearby photo of her old ‘boyfriend’. She asked me “does he look ‘right’ or does he look evil?” (pp. 37-38). I understood that by staying with this story and listening to Taylor, she was exercising her agency, telling what was important to her; what she wanted known. Taylor was conveying that the abuse was not simply about a ‘perpetrator’ of violence and the hideous acts inflicted, but rather this was her story of the violence she suffered, as a ‘girlfriend’. She had wanted a boyfriend to be like everyone else at school. Now, she didn’t just carry the physical scars of the relationship, but even more demoralising scars of knowing that she “can't keep a boyfriend” because she hadn’t been able ‘to say much to them’; it was ‘her deficits’ which contributed ‘to the problem’. Thus, she was trying to convey that ‘being autistic’ can be a very serious deficit! However, as highlighted above, simply being a woman can also be a serious risk factor when it comes to sexual abuse (Ministry of Justice, 2015).

When these experiences of violence occur in the context of high school relationships, the memories and embodied scars are not the only reminders victims have; they are written into the fabric of high school, being ‘everywhere’, from school walls, to school yearbooks. These seemingly innocuous recordings of ‘school life’ can also become the invisible ways in which exclusion just ‘gets done’.

Whilst Taylor [adol] was engaging with support personnel at the time of these interviews and the perpetrator was being prosecuted, she had subsequently entered into, and terminated, another intimate relationship. With a paucity of familial relationships and difficulty experienced in talking to her friends, Taylor disclosed the abuse to her only other significant relationship and that was her favourite teacher. In sum, relational support is a salient factor in the lives of autistic teens, including for most, familial support.

Throughout their interviews however, parents repeatedly highlighted that there are limits to the support they were able to provide, being enabled and constrained by access to services and financial means (Bevan-Brown, 2004), as well as richness of mesosystem relationships with school staff. In the final section of this chapter familial support is considered; from a parental perspective it is difficult to give what you have not got yourself.

9.3 Parental support – you can(‘t) give what you have(n’t) got!

It is well documented that parenting a child or teen with an ASD can be particularly stressful (Brobst, Clopton, & Hendrick, 2009). The perception and experience of being unsupported as a parent can also have a detrimental impact on home-life and a subsequent impact on school-life for their student offspring. At present there is a lack of research focusing specifically on parental struggles and difficulties (Gupta & Singhal, 2005). However, it is thought that mothers are impacted more than fathers (Gray, 2003), though that possibly depends on who the primary caregiver is. As a result of challenges being overwhelming at times, family members are at increased risk of experiencing trauma and developing PTSD (Oberleitner, et al., 2006).

Parents lamented the sheer number of referrals they endured during the time they sought a diagnosis. Not only did their children have unmet needs and considerable pressure upon them to ‘perform’ like other children in school, but parents were dissatisfied with the level of care, if any, that they received. This lack of care and support is consistent with other qualitative studies on parents' lived experiences of raising a child with ASD (e.g., Hall & Graff, 2010; Russell & McCloskey, 2015).

Despite the difficulties parents may have had in seeking a diagnosis and accessing various support services, all student participants in this study, except Taylor [adol), alluded to 'being supported' by their parents, in various ways, and to a more or lesser degree. Brad [adol] for example, proudly recollected his mum's confrontation with his intimidating rugby opponent on the side lines, and her visits to school, especially accompanying him during disciplinary procedures. James [ter] recalled his dad as always being there for him and taking on extra work for his benefit. Grace [ter], Catherine [adol] and Emily [ter] were all cognisant of their reliance on parental support, consistent with the autism literature that posits autists as having greater reliance on parents for day-to-day support, including into the teen years (Fong, Wilgosh, & Sobsey, 1993). Grace [ter] repeatedly expounded on how parental 'support' enabled her to succeed in high school, particularly in completing NCEA Level 3 and obtaining University Entrance.

Looking back, Grace [ter] recalled how pivotal her parents were in providing or obtaining ecological forms of support, social support, academic support, and emotional or psychological support. Her parents were proactive in meeting her teachers prior to the commencement of each new year in high school. This contrasts to Kym's [par] experiences of parent-teacher interviews, which left her feeling as though she were the cause of all Liam's [adol] 'failures'. Grace noted how her dad adjusted his work schedule to reduce her exposure to bullies en route to school and how her mum reduced her work hours at a pivotal point during her NCEA. This contrasts starkly to Taylor's [adol] experiences of her dad going from work to the pub and 'never being there for her', and then how her stepmother 'gave her a really hard time.'

Grace [ter] also acknowledged the role her mum and dad played in 'coaching' her socially by being "the devil's advocate" (p.25) and, how they provided the rubrics for her NCEA papers. Then, when she "was at a crisis point again in year 13" (p. 35), mis-managing diabetic medication and struggling with depression and anxiety, she notes how their support extended to providing a needed 'intervention opportunity' by way of private psychologist, whereas Taylor [adol] lamented the implications of so little support, believing with more she may have obtained her " level one [NCEA] by now" (p. 8). Grace credits rich, personalised forms of support, as contributing to her success, without which she "would have missed year 13 NCEA completely and would have failed NCEA" (p. 35).

Just as a lack of peer support and peer victimisation is thought to negatively impact education attainment (Adams, et al., 2016), so too does a lack of familial support, highlighting the complexity of influences. Grace [ter] perceived benefits in the rich mesosystem connections between her parents and school, and parents and health professionals, particularly when her parents were able to draw on their own resources to overcome exosystem limitations, such as delays within the public mental health system, which may have resulted 'in another eight month wait for assistance'. The significance of the chronosystem cannot be underestimated in her narrative, where 'timing' (of needed support), was deemed essential to her good outcomes (Muus, 1996).

Although parents typically try to respond to the special needs of their children with developmental disorders (Seltzer, et al., 2001), they are always constrained and enabled by their position(s) in life. In this case, Grace [ter] noted how well-educated her parents were; how they had a good understanding of the NCEA curriculum; how they were able to give her their time; and, when public support was difficult to access in a timely manner, how they drew on their own financial resources to access private support when it was needed the most:

> *I have two parents that love me very much […] I see myself as kind of, in some ways a very good case scenario of if the right supports are in place and it doesn't mean it makes it easy, but it means that you can achieve what you want to be achieving* (Grace [ter], p. 35).

Some parents however find that their own lack of support so overwhelming at times, that they are unable to focus on their high-functioning autistic teen in high school. The following analysis, though disturbing in content, elucidates on what is like to live in crises.

9.3.1 Families in crisis: living with violence

Seligman and Darling (1997) assert that parents who have enough support and resources to help their child, tend to be more relaxed, whilst those who feel helpless and/or require police intervention, are at increased risk of trauma. When parents perceive their child's disability to be particularly severe and behaviours intense, parental stress escalates (Brobst, et al., 2009; Gray, 2003; Gupta & Singhal, 2005; Hastings & Johnson, 2001; Konstantareas & Homatidis, 1989).

At various times, Danny and Victoria [par's] found parenting extremely stressful, marked by behavioural challenges, for which they lacked support, compromising their ability to 'cope'. Both recalled times when getting their teen to school became secondary to the more pressing demands and challenges that they faced as parents:

> *I couldn't get him up in the mornings* - *again I was feeling incredibly torn. I have got a job to do, I've got another kid, what do I do? So it got to the point where I just left him […] I did try hard, but we just couldn't get him out of bed […] it's very easy to get lost in the system; really easy* (Danny [par], p. 8).
>
> *And then when I came inside, I thought 'awwweee what is that smell' and Harry [Chris's older autist brother] had got the chlorine […] he poured all [of it] in his room and then tipped his drink on it. I didn't know that it was dangerous […] I rang my husband and he says,* ***'for goodness sake, ring the fire brigade!'*** *and I was like 'Oh no! I've just had the police here [to calm Harry who had lashed out violently towards her] and now I've got to have the fire brigade here', so I rang 111* ***AGAIN!!*** *[…]. Then Chris refused to go to school, so I had to ring up the school and say, 'Chris is refusing to come to school, I'm really sorry'* (Victoria [par], p. 8).

Danny and Victoria regularly drew on the police services as primary sources of support in their 'battles':

> *We […] called the police, which was our plan […] he was throwing… pointing knives, you know […] I had knives going through doors and things like that, so we are talking potentially quite …* (Danny [par], pp. 12-13).

Paddy [adv] also noted, that in his experience of aggressive autistic teens, police were often regularly involved and became primary forms of support for critically stressed parents.

> *Paddy: The police come and the police can't do anything you know, so they decide… they're not sure how to work with autistic kids so they think to calm them down, 'oh we'll take him'; "oh come on we'll take you an' drive around town"*
> *Rachel: and get an ice-cream*
> *Paddy: oh yes, so what happens next time the kids wants to drive around town, he kicks the sh#t out of his mum, like you know, so the police get called again, 'oh, come on'. He doesn't ask: "oh mum can you call the police…"* (Paddy [adv]; Rachel [adv], p.54).

Very little research attention has been given to the problem of adolescent-to-parent abuse (Cottrell & Monk, 2004; Kennair & Mellor, 2007), including families with mental health disabilities (Charles, 1986). However, according to Cottrell (2001), even for parents of otherwise typically developing teens, it can be difficult to obtain support for teen-to-parent abuse. Examples of abuse, commensurate with Victoria's [par] lived experiences, include “hitting, punching, and kicking” (Kennair & Mellor, 2007, p.204). Victoria also experienced having her hair pulled out, objects thrown at her, and being woken to abuse in the night by her older, more profoundly autistic son.

It is thought that parents may minimise the impact of violence experienced, due to their lack of support and sense of shame (Arrigo, 1982; Evans & Warren-Sohlberg, 1998). Some may want to protect their children from the consequences of the law, or organisations commissioned with child welfare and protection (like Oranga Tamariki in NZ) (Dumbrill, 2006). Additionally, it takes time and trust for people to ‘open up’ and discuss distressing and personal experiences. Similar to the problem’s parents encountered during the diagnostic process, parents lacked opportunities to build rapport and speak about *their* need for support, impacting their ability to cope and support their adolescent during the high school years. This too is a barrier to inclusion: exhausted parents “really just try to survive” (Danny [par], p. 19); building mesosystem relationships between home and school takes effort and understanding.

9.3.2 Filicide: When car rides and ice-creams are not enough

Filicide refers to the death of one’s own child, usually aged 0-17 years, and in Australia accounts for 10% of all homicides (The Conversation Media Group Ltd, 2019). Between 2009 and 2015 in NZ, there were 56 children killed. Approximately 25% of these deaths (14 children) were attributed to filicide (Family Violence Death Review Committee, 2017, p.68).

‘Altruistic filicide’ refers to a murder ‘committed out of love’. It is the type of homicide more commonly associated with the murder of a developmentally delayed child (Palermo, 2003). The filicide offender is typically the caregiver with the closest relationship to the victim (Brown, et al., 2019). It is thought that the lived experience of extreme distress over prolonged periods, without support networks, increases the risk parents will commit filicide (Rimmerman & Duvdevani, 1996). However, Palermo (2003, p. 53) notes that “the impact of support and stress on filicide is still not well understood, although common sense would dictate that there is clearly a relationship if other pathoplastic circumstances (depression, loneliness, parental discord, blame and guilt) common in autism families are present”.

There has been a steady stream of 'altruistic' murders over the last two decades in NZ. Recently, a mother was thought to have drowned her autistic son (Moger, 2019). In another case, Donella Knox murdered her autistic daughter commenting afterwards that she felt "alone in a battle that [will] never end" (Eder, 2017). Donella was described as a "'strong and caring mother' for 20 years but was broken, mentally and physically" (Eder, 2017). Victoria [par], also described herself as a 'fighter'; not wanting to give her eldest non-verbal autistic child up to residential or institutionalised 'care'. However, she was unable to find the support she needed and like Donella, she also reached 'breaking point'.

> *I was going to kill my son, Harry [...] Mental Health weren't interested. They said they were going to help. All these places that deal with children that have extreme behaviours and autism and others "oh, we don't want him! He'll disrupt the flow!" And yet, that is what they're there for. The only ones that were helping were the police and I would ring them and they would come up and take my son for a drive and bring him back and he would be calm enough, I could give him dinner, [and when my husband] would get home, then I would sort of just hide for a bit. But I mean we didn't sleep* (Victoria [par], p. 3).

> *Rachel: I've got a family at the moment that he's saying that his son is so aggressive he's actually taken him to CYFS; taken his son to CYFS and said 'if you don't take him off my hands, I will kill him; I am telling you now, I will kill him' and they've said 'oh you won't do that, don't worry about it – we haven't got anybody to look after your son, off you go'*
> *Paddy: I've sat in Strengthening Families meetings; I've sat in Family Group Conferences and you've got the top people from CYFS and all these places – IDEA services and whatever and you're there and saying 'well what can you do with this person; where can we go?'* (Paddy [adv]; Rachel [adv], p. 51).

> *And I looked at the police officer and said "am I going crazy because it feels like I am suffocating and the only future I see for my son is six foot under the ground because there is no future for him.' That was like pounded into me constantly. Everyone said we can help BUT…we can help BUT. You know, he hadn't been at school for three years because 'if Harry can't control himself then he is a danger to everyone', and so BUT…so he stopped going to school, you know.*

> *[…] There was no one interested. Everybody knew he was no longer at school and not one person did anything about it. By this stage, I had given up asking for help because it was like, you know…it was like what was the point* (Victoria [par], pp. 6-7).

Victoria [par] felt increasingly isolated, overwhelmed, and alone as a parent. As Harry's abuse escalated, support provision diminished as providers feared injury. Victoria became too tired to socialise with friends, and family members distanced themselves. One support worker had already experienced an injury, jeopardising availability of future caregivers, whilst Victoria's parents, who lived close by, labelled her two sons, Harry and Chris [adol], derogatorily as 'loopy'. They distanced themselves from their grandsons. Chris [adol] being several years younger, and protective of his mother, was often her only source of support whilst her husband was away working. He would physically step in between his mum and Harry during violent incidents, adding to Victoria's sense of guilt, anguish, and trauma. Victoria believed these experiences contributed to Chris's generalised anxiety and depressed mood, curtailing any desire he might have otherwise had to explore roles and settings beyond the home and school.

> *Victoria: it screwed Chris [adol] up! The repercussions are immense, and nobody seems to get that. They think I talk out of my a###*
> Sharon: what repercussions do you see for Chris; what are the main things?
> *Victoria: Chris is still at home, isn't he? Do you think he's ever going to leave? I don't think so. It's the only safe place he has. He has seen what the world does and how it treats people like Harry and that's what he is afraid of; that's why it took us a long time to get him to go into a shop by himself. And now, he will walk into town by himself – that's not scary – but going into a shop by himself – that is scary; that is terrifying. He would have such massive panic attacks* (Victoria [par], p.15).

As a result of years of 'fighting the battle' and constantly being met with rejection for support, Victoria began to increasingly consider filicide. She spoke openly and directly regarding systems-level failure to meet her needs and had started to self-harm. Chris's [adol] educational experiences became secondary concerns.

Whilst the Ministries of Education and Health (2016, p.79) recognise the need for "service coordination and case management for individuals with ASD", this was not the experience of participants in this study. Instead, over time, and through repeated callouts, Victoria [par] developed a rapport with the local police officer. This led to being able to reveal the truth about her struggles, through the building up of trust, and the assurance that if she ever felt like she'd reached 'breaking point', she was to call him.

Looking back, Victoria [par] recollected that she "could never understand how someone could do that [kill] to their own child" (p. 33). In a desperate moment, with knife in hand, waiting for the police officer to arrive, she turned it in on herself and spared her son's life. Despite the years that have since elapsed between that event and this interview, her mum asking her not to talk about this dark point in her life. Victoria said she refused to be silenced by the shame and stigma of not 'coping' and of having reached 'breaking point' and shared her story.

Danny [par] and Victoria [par] both experienced the limitations of 'governmentality', which they apprehended as the indifference of 'organisations' being not only cold and impersonal, but out of touch with the degree of trauma they were in, and thus, disconnected from the 'lived experiences' of parenting an autistic child or teen and 'being in trauma'.

> *I mean to me the government department should have nothing to do with children on the autistic spectrum and those with other disabilities that are difficult because they don't deal with them, they throw them out; they are too hard. […] I could never understand how someone could do that [murder] to their own child. Being in that position myself, my mum told me not to tell anyone I was going to kill my son. I don't think it is shameful. I think the situation of what these organisations did that pushed me to where I was […] I saw nothing [no future]* (Victoria [par], p.33).

Victoria [par], like Danny [par] is yet to fully explore the impact of the 'trauma' they experienced as parents, highlighting not only additional limitations of mental health services, but the fragility of 'being human' with its limitations to 'cope', especially in isolation. Like Victoria, Danny also had extremely limited family or social support and continues to wait for counselling as he endures post-traumatic stress disorder symptoms. Relief only came for Victoria after she was 'sectioned' to psychological care, following her self-inflicted stabbing. This was the impetus for relocating Harry into full-time residential care.

Although there are few qualitative studies regarding family life, including the well-being of mothers (Lounds, Seltzer, Greenber, & Shattuck, 2007), it has been postulated that in families comprising a neurotypical and an ASD member, the neurotypical sibling typically engages in caregiving responsibilities, whilst receiving less parental support (Cridland, et al., 2016). Whilst there have been a variety of studies regarding adjustment and 'risk' for neurotypical siblings, findings have been mixed (Rodrigue, Geffken, & Morgan, 1993).

However, typical coping mechanisms, such as increased reliance on parents for support, is diminished when parents are experiencing trauma and distress (O'Brien, 2016). Less is known about the lived experiences of a high-functioning autistic adolescent in a family also comprising a non-verbal autist, like Chris [adol] and Harry's family.

Sexual violence, self-harm, filicide, and institutional ‘indifference’ may well seem far removed from themes of academic success and student wellbeing. However, participants in this study repeatedly highlighted that the brutal consequences of ‘violence’ (personal and/or institutional) impinged upon every facet of life, including academic. Ecological influences are therefore truly multidimensional, with tentacles of influence permeating to the heart and soul of people, impacting their roles as much as the settings and milieus in which they are embedded within, or interact with. The complexity of institutional support is thus entwined with the ‘institutional’ rhetoric and the personal experience of ‘inclusion’.

9.4 Chapter summary and transformative potential

Most autistic participants in this study considered their social life at school. Most alluded to the notion that whilst they have friends, their friendships might be constituted differently or held together differently than that of their peer friendship groups, including composition especially through shared denominators, such as gaming or fan-fiction writing; through sharing of a common space like the SCC; or, through a meeting within a group specific to their ‘disability’. The use of computer gaming and/or on-line chatting functions facilitated a sense of belonging and enabled autists to develop a stronger sense of being connected to others. This sometimes spilled over into their off-line relationships and highlighted the benefit of the internet for linking lives, aiding development of self-esteem, and providing a sense of belonging.

By contrast, social media also functioned to elucidate one’s differences and make autists feel an even greater sense of being dis-connected and isolated from their mainstream peers. Another painful way in which the dominant ‘mob’ illuminated autists as ‘different’, was regarding how they sought to bring out into the open their differences through questioning, as though they were a ‘novelty’ to be exploited. To be transformative, ‘normally’ developing peers would need to increase their understanding of autism and the implications of how disabling and painful it is to have one’s differences, or weaknesses, make public and ‘spot lighted’. This requires capitalising on neurotypical students’ perspective taking skills and postulating the severity of the consequences for ‘invisible [forms of] bullying’. In the workplace ‘invisible bullying’ is often innuendo (blink and you’ve missed it!). Increased knowledge of autism is therefore needed to not only illuminate what constitutes ‘invisible bullying’ regarding autists, but also equipping well-meaning peers with the knowledge and know-how, for how they might prevent seemingly innocuous banter from being ‘felt’ as bullying, thus equipping more peers to function as natural mentors, bridging the social cracks and gaps currently enabling these ‘Q & A’ episodes.

There is also transformative potential to be had from simply listening to autistic senior high school students, given their ability to articulate their experiences, often with eloquence. They understood the many barriers and limitations hindering success as an autistic student in a mainstream school, whilst also perceiving themselves as being people with strengths. Strengths included having the tenacity to work hard and to be motivated to achieve all they could within what at times seemed to them as a ‘rigid’ and uncompromising ‘system’. Their insight into their own plight and the institutions’ (in)ability to meet their needs and ensure an inclusive educational experience was well-articulated. What worked for them and what didn’t were stories they could tell. Autists had insights into their social relationships and insights regarding what it was they liked about teachers and how they functioned to make a difference. They were conversant with ambient environments, school culture, and the problems of NCEA.

Whilst the DSM provides a reductionistic and narrow lens through which we might consider autism in general and the autist more specifically, Bronfenbrenner's ecological systems theory highlights the need to take “into account aspects of the environment beyond the immediate situation containing the subject” in order to understand human development (Bronfenbrenner, 1977, p. 514). When support was not forthcoming, families had to find ways to provide extra assistance. Whilst most students perceived their parents as being a salient form of support, some home environments were particularly stressful. Some parents felt unsupported and this hampered their ability to be support providers and proactive mesosystem links between home and school. Having few peers for support and being confronted with isolation, bullying, and abuse adds to one’s vulnerability and sense of exclusion within school. In this situation, teacher-student relationships become pivotal, particularly when familial support is lacking. Like all students, autistic people’s development, successes, and failures, cannot be considered outside of the ecological levels of influence permeating the contexts in which they live, move, and have their ‘being’.

Similar to other countries, systems of public support exist in NZ, but these are experienced like 'silos' (Sarrett, 2015) consistent with a macrosystem deeply fragmented in its understanding of, and empathy for, the needs of people with autism and disability in general.

At its most extreme, family members were driven to the brink of despair, dialling '111' and dealing with police for immediate support. As despair increased and forms of support failed, one mother was driven to the brink of 'breaking point'. She perceived others as not just failing to help but perceiving her as being accountable for her child's behaviour and for *her* own 'madness' too. Given the number of autism-related murders in this country, it is comforting to think that 'madness' is better than 'murder'; however, it is timely to once again recall that "there is no motiveless murder" (Hammond, 1888, p. 629) and filicide is no exception.

The un-doubtable tone of parents' diverse array of experiences and encounters with professionals and agencies was cold. Their accounts of entering in and out of the mental health system on their autism 'journey' left them feeling as though 'the system' is 'heartless'. A cold and heartless system has previously been described as a by-product of neoliberalism; agencies can no longer factor in to 'transactions,' the heart of people resulting in a general sense that the state has abnegated its sense of social responsibility; citizens are stripped of citizenship and clothed instead as 'consumers' who engage in 'transactions'. Whilst there is widespread awareness of the social and relational implications of a pervasive economic model that has the best interests of the market in mind, human service agencies are paraded *as though* non-biased, non-corrupt, and even 'wiser' than humans (Esposito, 2011), for example the Plunket Society and Dr Spock's parenting practices. In short, the neoliberal marketplace provides a ubiquitous practice of economic calculations to govern human life (Rose, 1989). Parents felt that the health services, like the educational service, did not have the heart of autists in mind. There was no notion for calculating what was needed to see autists 'thrive' or flourish' and at most, it was simply hoped 'they'd get by'. Those who had the resources, were taking matters into their own hands, potentially paving quite different outcomes for their autistic adolescents.

Chapter Ten
Discussing, considering, reflecting: (Un)stranger-ing the 'stranger(s)' in a *strange* land

"If I could distil it down into one concept that we are pursuing in New Zealand
it is simple and it is this: Kindness"
(Rt Hon Jacinda Ardern, Prime Minister of New Zealand & Leader of the New Zealand Labour Party)
https://www.labour.org.nz/jacindaardern

10.1 Introduction

This final Chapter summarises the findings, suggests future research, considers transformative implications, and reflects on the methodological processes of this research.

The aims articulated in Chapter Three were summarised in the three research questions that pertained to:

1. How senior students with (high-functioning) ASD, in mainstream NZ high schools, understand and experience in/ex-clusiveness (belonging, acceptance, achievement, and participation);
2. How every day in/ex-clusive schooling experiences contribute to perceptions of (autistic) identity and wellbeing; and,
3. How the co-articulated autism discourses of strengths, problems, and tensions, experienced by adolescents, converge or diverge from that experienced by parents and advocates.

The first two questions guided the interviews with adolescent and tertiary students, but also helped to 'shape' the focus of interviews with parents and advocates. The third question, however, was not specifically directed *at* participants per se, but rather acted as a guide for drawing attention to salient issues based on multi-perspective analysis.

10.2 Summary of research findings and suggestions for future research

The five analysis chapters highlighted that there were a range of salient themes and experiences contributing to wellbeing and experiences of in/ex-clusion for autists. These included:

- Parents' engagement with Mental Health and the diagnostic 'journey'
- Parents' understanding of autism

- Students' understanding and acceptance of autism as an identity; an 'autistic self'
- Meaningfulness of the school space, governance, and culture, with opportunities for success and recognition
- Having strategies, support and space for de-escalating arousal and anxiety
- The curriculum's 'fit', leading to the accumulation of credits and desired academic goals
- The importance of autism knowledge, narratives, and discourses
- Having academic support
- Having some good relationships; rapport with peers and teachers
- Having family support

Autistic participants made sense of their experiences by regularly drawing attention to the importance of autism knowledge, the ontological differences between neurotypical and autistic people, and neoliberal influences, particularly at the exosystem and macrosystem level, over which they have no control. This chapter discusses these findings, integrating them under three broad headings, pertaining to:

- Problems of autism narratives
- Inclusion and motivation through school governance and the NCEA curriculum
- Relationships and support

10.3 Autism: the problems of narratives and discourses.

The review in Chapter Two, alongside the findings presented in Chapter Five, provided background for considering how 'being autistic' comes to be experienced as a 'mental health disorder'. Parents' observations of behaviours considered 'deviations from the norm' were astute. 'Read' in this way, the social and cultural mores of Plunket books, the 'well-child' movement, and urgency surrounding 'early interventions', have fostered a state of parental alertness or vigilance. Thus, certain cultural and scientific conditions comprising our sociohistorical and cultural milieu, have functioned to position parents to take responsibility for the monitoring of their child's development against normative standards. In addition to understanding and experiencing the pressure of 'doing parenting', without a diagnosis parents experienced an array of injustices including substitute derogatory labelling of their child by teachers, school staff, and 'professionals', and an inability to access needed school or community support services, which depend on an 'official' diagnosis. This led to intense feelings of frustration; parents felt a sense of responsibility for obtaining help and *explaining* their child.

Parents were perplexed by their child's behavioural differences and pursued many avenues for making sense of them over an extended period, consistent with research highlighting that obtaining a diagnosis can take a long time (DePape & Lindsay, 2015b). Gaining understanding and making sense were priorities. Obstacles to diagnosis included 'being a girl' and having a history of trauma. Parents' experiences of misinformation (no diagnosis) and referrals gave parents the impression that 'experts' were seemingly independent, disconnected agents, constrained by governance in their service provision; 'experts' were perceived as though 'cold', distant observers, objectively 'gazing' upon 'their subject', who happened to be the children parents loved and protected. Being unable to tell their story, including the intensity of their suffering, increased the experience of isolation parents felt; many had no support at all and had to keep things going, impacting how they could support their child or teen.

In the process of discovering 'autism', some parents encountered 'experts' who encouraged medications as a form of 'experimentation' aimed at alleviating symptoms of depression, anxiety, and 'odd' behaviours, including medicating calm children with ADHD medicine, Ritalin. Previous research by Aman, Lam, and Collier-Crespin (2003) highlighted that there is a gap in understanding the reasons why prescription medications are given to those diagnosed ASD. Parents in this study believed it was sometimes used as a method of experimentation, with little support or monitoring being offered afterwards. Alternative interpretations might suggest that the aim is to bring children's behaviour closer to societal norms, and in doing so, relieve some parental distress.

Parents generally believed that the cause of so much misinformation, was a lack of autism knowledge in general and a failure of the (neoliberal) 'system' preventing them from being able to tell their story. In order to tell a story, one must build up rapport and be given time. Parents perceived too many obstacles to this, including being made to feel as though they were not the expert of their child, limiting how they could share their story. Additional confounding factors like previous trauma, were also experienced as obstacles; clinicians were looking at the 'wrong' things. The actual diagnostic experience, therefore, stood in stark contrast to previous encounters with clinicians and professionals.

For most parents (or parent-advocates), diagnosis occurred after many referrals. Parents invariably met *someone* within 'mental health'; an (autism) 'expert' prepared to step 'outside the box' to engage with them. They emphasised the intersubjective nature of the relationship, contrasting this with the ‘clinical’ encounters that led to one referral after another. In this encounter, time was given to telling their story. They felt ‘listened to’. The relational aspect was experienced as transformative. Their story was made sense of, and the diagnosis was not simply the end-goal.

These findings have implications for how diagnosing gets done. It is consistent with research investigating the benefits and therapeutic effects of health consultations based on building rapport (e.g., Adler, 1997). Empathy forms part of the ‘hidden curriculum’ of health care (Hafferty & Franks, 1994), is essential for rapport, and becomes the soil from which first-person accounts spring. Having empathy is necessary for motivating *action* (doing all in one’s power to alleviate distress, disability, or illness) (Garden, 2008), which in this study, was experienced as ‘going beyond the call of duty’ or ‘stepping outside the box’. Parents wanted to engage with ‘experts’ who would do “systematically with a stranger, what people do intuitively with friends and relatives” (Adler, 1997, p. 28)! The implication is that this requires turning from policy and governance-dominated-praxis to a consideration of philosophy; particularly those undergirded by defence of human dignity. At stake is the importance and centrality of the person, as opposed to services whose clinical work is foremost predicated on its analysis of ‘data’, including ‘risk assessment’.

10.3.1 Diagnosis:

Parents had mixed reactions to an autism diagnosis, with most finding relief in the increased understanding the label gave them. Only one parent reported ‘doors flying open’ specifically in response to the diagnosis, consistent with research highlighting that few parents receive direct help ‘with practical management issues’ (Howlin & More, 1997). In comparison to parents, younger autistic participants generally had scant recollections of the time preceding diagnosis, the process, or their reaction to it. The diagnosis was a welcome relief for those diagnosed in their teens; it was the ‘missing piece of the puzzle’ in self-understanding, and, even a defining moment. In this sense, the categorical label brought understanding to one’s experiences, behaviours, and their lifeworld, generally. The label provided autistic teens with a simplified way to make sense of much that had hitherto been confusing, enabling them to (re)examine and (re)interpret their identity. For some, it marked a point in time whereby they could reinterpret ‘being’; where ‘I’ now ‘belonged’ to a certain ‘type’ of human ‘being’. Although we don’t normally understand humans as having ‘types’ like other species, older autists appealed to their characteristics as being ontological; salient, permeating every aspect of life; bound up with their ‘essence’ of being; they apprehended ‘being autistic’ as an identity. For James [ter], the diagnosis meant the end of a ‘violent era’; he began to fathom alternative, and less destructive methods for making his distress (born out of confusion and frustration) ‘evident’.

Tertiary students felt it was more detrimental to perceive oneself as ‘different’, but not know why than to learn you are ‘autistic’. This finding contributes to a growing body of evidence that suggests the diagnosis provides autists with a sense of normality; of belonging through the sharing a common identity (Mogensen & Mason, 2015). Whilst teens thought it opened understanding and should not be hidden, advocates noted that parents sometimes ‘hid’ the diagnosis from their child. James [ter] challenged parents to refrain from ‘buying into’ dominant discourses, challenging our understanding of deviance, versus ‘different’. From a philosophical phenomenological and even Catholic, Personalistic perspective, this *act* points to a worrying notion of ‘disorder’ that has its roots in denying the inherent beauty and dignity of the soul of *each* person, diminishing personal value and attributing worth, to those considered ‘normal’ and those esteemed by the majority for their conformity (sameness) and economic potential.

Reactions to the diagnosis predominately pertained to the labels ‘goodness of fit’. Grace [ter] believed the ‘experts’ misinterpreted salient characteristics of her experience of autism due to gender-related assumptions. However, from a medical model perspective, the mentally ‘ill’ are rarely considered decision makers (Silverman, 2012), much less collaborators in discerning a diagnosis or its ‘goodness of fit’. Although most participants apprehended the diagnosis as enabling increased self-understanding (“it makes sense”), it was also perceived and experienced for its negative, medicalised connotations and implications too. Two high school participants felt that ‘autism’ was synonymous with ‘retardation’ and a disability that needed a ‘cure’. They had learnt that being autistic meant not being able to participate in life normally because of a ‘disability’. These students disdained their diagnosis attributing it to their being unable to communicate well and having high levels of anxiety; characteristics experienced as ‘disabling’.

Because autism was predominately assumed a medical ‘disorder’ or disability, it impacted how autists initially understood themselves. Despite perhaps disclosing their diagnosis prior to high school, they wanted it concealed in high school, consistent with developmental maturation leading towards exploration of identity; wanting to ‘fit’ and not wanting to be ‘othered’. Some felt their peers would not understand what autism meant. James [ter] however disclosed his diagnosis to his on-line peers, among whom he had a sense of being among ‘equals’ where his differences were acceptable. He, and his peers, shared an understanding that high-functioning autism was more synonymous with intelligence than ‘retardation’; more of a ‘culture’ than a disability or liability.

Understanding autism in non-medical ways occurred beyond high school for tertiary students. In new settings, they learnt to differentiate between a medical model and social model understanding of autism and had been reflecting on the implications these understandings had on their lives. This was transformative because it enabled autists to (re)consider and challenge how they could be ‘known’. Some postulated ‘alternative discourses’ (Alatas, 2000) to make sense of their ‘autism-ness’; their perception of other people’s understanding of autism; and, in a bid to expand thinking generally, about autism. Their desire to participate in this research was one chance to tell this aspect of their story in order to ‘educate’ others about autism; thus, they were now functioning as the ‘experts’, having expertise, and advocating.

Whilst prominent autism researchers have advocated that autism be considered a ‘difference’ and not a ‘disorder’ (e.g., Baron-Cohen, 2017; Malloy & Vasil, 2002) autists postulated various ways that autism (and hence themselves) could be understood, including *being like* a ‘third culture’; *being like* an ice-cream sundae; and *being (un)like* an ‘extreme male brain’. By ‘giving voice’ to the ‘subaltern’, and by drawing on the interpretative freedom of IPA, the analysis explored these discourses as an attempt by autists to use simile to invigorate and expand other people’s potential for understanding their lifeworld in more complex and nuanced ways. There is a rich literary tradition of preferentially elucidating upon more complex understandings in this way; for example, Jesus’ use of parables, or Homer’s oral tradition, eight centuries earlier in the *Iliad* and the *Odyssey* (Coffey, 1957). These storied approaches do not necessarily challenge traditional understandings of autistic symptoms pertaining to categorical identity, given that participants appreciated these simplified understandings. However, they challenge the constraints of being pathologised.

10.4 ‘Governance’ in mainstream spaces

From Bronfenbrenner’s ecological perspective, there are three pathways that inclusion can be understood, namely personal characteristics, contexts and functioning of the space in which students are embedded, and meaningful relationships (Bronfenbrenner & Morris, 1998). Chapters Six and Seven were domiciled around ‘the problems’ autistic students revealed regarding being an embodied autistic person, within physical settings, permeated by (sub)cultural contexts. Because the same environment - with its objects and technological tools - can afford different people different things, there were salient differences between participants' experiences, however, there was convergence of understanding that the mainstream 'space' has not been designed with autists in mind.

McAllister (2010) notes that from a design perspective, space should function to make others feel 'pleasure and protection'; an embodied experience of resonating with the space (McAllister, 2010). Whilst architects have begun to take note how disabling and disorienting 'space' can be for autists (Coffee, 2018), most countries have excluded development of architectural design codes for this purpose. They have failed to customise space to overcome the challenges autistic people experience (Mostafa, 2014). This has been a neglected area of study and one needed if NZ mainstream high schools are to become increasingly inclusive.

As seniors, autists were especially concerned with finding safe spaces where they could be with like-minded peers or pass time in solo pursuits interesting to them. They were using space to avoid bullies and places that elicited too much sensory stimulation, especially noise, through acoustic amplification in school halls and music suites. They felt as though they had little influence over the governance of space and although some safe spaces existed, getting to them was problematic at times. Several participants spent regular time in spaces they were not meant to be in, in order to meet their need for safety. Managing within mainstream spaces required additional forms of support as noted by Grace [ter] who had a private psychologist in Year 13 for this purpose.

As a 'space' within mainstream schools, the SSC was predominately viewed negatively by those outside it. Some autists believed it was a place for the 'abnormal' and therefore a space to avoid. Autists elsewhere have thought similarly (e.g., Carrington & Graham, 2001; Humphrey & Lewis, 2008a), wanting to avoid being associated with the 'disabled'. This is also consistent with politicised research positing that schools are sites for 'normalisation', whilst segregated spaces in mainstream schools are places where (autists and other 'disabled') 'subjects' "are subject to intensified regimes of normalisation to render them normal and facilitate inclusion into the mainstream" (Holt, Lea, & Bowlby, 2012, p. 2193).

Before 'belonging' in the SSC, two students experienced exclusion in the mainstream school space; they failed at 'being normal'. Whereas the mainstream environment had instilled terror in Chris [adol], the smaller unit felt safe and enabled a quieter working space, where he could calm down. For Taylor [adol], the SSC provided companionship, and a sense of belonging and being accepted by teachers and peers. Both students developed a very good rapport with their teacher, who facilitated practical forms of help around personalised strengths and interests, giving value and meaning to school and to learning, providing order and predictability to their day, and a safe space to retreat to. From Bronfenbrenner's perspective, it was possible that the macrosystem aspects of culture permeating mainstream spaces failed to dominate in this sphere, whilst exosystem influences were geared towards providing personalised forms of assistance, enhancing microsystem relationships, and fostering higher levels of mesosystem connections between home and school.

This study challenges assumptions about the place of smaller units in mainstream schools and their importance in the lives of some high-functioning autists. The inclusion literature posits segregation as inhibiting ‘inclusion’ (Ravet, 2011). However, lived experiences of autists in both spaces point to the ways in which the school’s ‘culture’ can be experienced as ‘exclusive’ in mainstream spaces, but inclusive in the SSC space. This is consistent with Holt, Lea, and Bowlby’s (2012) findings positing that ‘special units’ within mainstream schools can foster genuine ‘inclusion’ for students on the autistic spectrum and the more recent findings of Goodall (2018) who suggests that students’ sense of inclusion, stems from their overall feelings of how accepted they feel within a particular setting. By taking what works well in smaller units, policy and practice might be challenged in mainstream settings. Future research should continue to explore the lived experience of autists straddling these two settings, given how common these segregated spaces are in mainstream NZ high schools.

10.4.1 En-culturating (mainstream) students

Autists focused on the *culture* of sport (especially rugby) within school to demonstrate how they experienced in/ex-clusion through its permeating forces in mainstream spaces. Several autists and some advocates referred to ways in which the ‘culture of rugby’ dominated school life, including the way it was talked about, ‘celebrated’, and assumed to be a shared interest. This provided an important insight into how autists came to experience success or marginalisation through participation in, and adoption of, a macrosystem level influence, enforced and normalised by ‘management’ at the exosystem level. NZ rugby is considered “an ingrained aspect of everyday life” (Neo Prime Sport, 2020); an “ideal vehicle for promoting ‘character training’” (Crawford, 1985, p.78). It was not surprising that ‘rugby culture’ should therefore be apprehended by autists as playing a dominant role in school life.

The analysis highlighted how Brad [adol] was ‘rugby mad’ and his interest contributed to the construction of his identity as a ‘sports person’ and a ‘kiwi’. He entwined *playing* rugby with *doing* the kapa haka, drawing on our ‘cultural capital’ to boost his credibility, not only as student, but as ‘one of the boys’. He had a notion of himself as being, and being seen by others, as something more than his autistic characteristics. Nonetheless he alluded to his autism-ness in relation to rugby training and did not attempt to shake off or set aside his ‘being’ ontologically different.

Other autistic participants felt excluded and disconnected from the taken-for-granted invisible culture of school. They used rugby as a way of storying a norm of school life to demonstrate how ‘school culture’ might be understood and experienced as a force to ‘other’ them in the reproductive task of producing the ‘good and successful citizen’. Phenomenologically, the experience of being included or excluded stemmed from recognising shared dominant values within the school community, and either taking these up or rejecting their ‘essence’.

Advocates converged with the belief some autists held regarding school’s failure to take seriously the need to recognise other students for their successes. It was generally believed more emphasis should be given to recognising diverse fields in which autists were currently being successful, beyond academics and rugby. This may cause tensions however, for schools who compete to achieve ‘status’. Advocates nonetheless posited that dominance of rugby is not just ‘cultural’, but a ‘problem’ of school ‘leadership’. The implication for mainstream schools is that if the lifeworld of autists is not taken seriously, and the school’s culture and ‘norms’ are not challenged, then school management are complicit in doing ‘othering’. Advocates believed principals had greater freedoms to diversify the ‘school’s culture’, and thus challenged them to make inclusion something more than ‘mere rhetoric’, or ‘doing drivel’.

In a similar way, some autists felt a sense of exclusion from the dominant culture of school when they couldn’t understand school rules. Whilst these unspoken rules may not be ‘valued’ by all members of the community, they are at least understood as the means for being ‘good citizens’; they can be taken up and valued (or not); accepted or rejected. One autist lamented the lack of effort teachers made to elaborate on the purpose for rules; she was frustrated by encountering silences even when asked. This is worrying given that ignorance leads to violating subtle hidden, or implicit rules and understandings and increases one’s profile as ‘odd’ (Myles & Simpson, 2001). Mintz (2013) has considered how software applications for personal devices could be developed to support inclusion by overcoming these types of obstacles, making visible what is taken-for-granted by staff and neurotypical students.

10.4.2 Navigating 'safety' in the mainstream

A major problem for autists was the school's tendency to fail to provide adequate solutions for managing their distress, anxiety, and discomfort within school. Sensory overload was considered by autists in relation to noise and painful school uniform items, whilst anxiety was considered in relation to social encounters, failing grades, and comportment of teachers.

Whilst the provision of safe spaces for stress reduction is common in NZ schools, entering them was difficult, and not without recourse to one's 'abnormality' if they were to successfully navigate entry and exit of these spaces. Encountering others *en route* who demanded attention and verbal responses, exacerbated distress to the point of overwhelming James [ter] entirely. He was unable to co-constitute intersubjectivity in these encounters, lashing out on one occasion, causing physical harm, resulting in his expulsion. Following his diagnosis, he and his father reflected on the grave injustices being inflicted on those who are the least understood.

Autists and parents proffered solutions. James's [ter] father suggested that teachers be more trusting of students; Catherine [adol] wanted increased education so that teachers might understand the implications of being 'overwhelmed' and becoming non-verbal; and, Grace [ter] highlighted the benefits for herself of learning strategies to tolerate unpleasant feelings before she became overwhelmed. These solutions come out of lived experiences whereby governance had restricted access to safe spaces, limited agency, and the school had failed to acknowledge and support the implications of experiencing one's body in diverse ways. Participants collectively advocated for increased teacher knowledge to reduce the 'disabling' effects of becoming overwhelmed within the school space, especially to prevent further experiences of injustice and harm.

10.4.3 Being motivated and being educated

Motivation to participate in and achieve in NCEA, or specific subjects varied substantially between students and at different times during students' high school careers. Some autists felt the leap from Years 9 and 10 to Level 1 NCEA (Year 11), too great and they were unprepared for the experience of 'failure' through 'Not Achieved' grades. The repeated dictum that 'seniors' must strive to accumulate credits was internalised as an overwhelming pressure for some; for others it meant nothing, and one student disengaged entirely. Those trying to engage in NCEA often felt overwhelmed due to failing papers or achieving lower than expected grades, particularly if they had been achieving and perceiving themselves to be successful in Years 9 and 10. These experiences gave the impression that academic success was going to be a battle. It reduced motivation and increased frustration, leading autists to question the tenets of school as places for ‘being educated’ as opposed to ‘demonstrating a particular learning’. The types of academic tensions between perceived (normative) expectations and autists’ executive functioning differences, functioned to ‘other’ some participants, contributing to a lack of motivation and a developing sense of being excluded.

Regardless of one’s motivation to garner credits, autistic students predominantly chose subjects that were of interest or contained an element to be enjoyed. Whilst some lamented how certain vocational subjects decreased their ability to garner endorsed credits, others discerned subjects in relation to personal values. These values did not always align with the overall value of education per se. For example, one participant took horticulture because it also meant being able to use ‘class time’ to go for a walk out among the sheep; he valued the solitude and safety of being outdoors without peers whom he perceived as ‘potential bullies’.

Some students benefited from the diversity of subjects on offer, including cultural science, and arts. Several amassed large numbers of credits from subjects they were good at, using these to make up for credits more difficult to obtain, constrained by a-synchronous scholastic abilities. Future research is needed to determine the impact to high-functioning autists if limitations are imposed on the accumulation of credits from single subjects. This could have a detrimental impact on post-secondary opportunities and long-term educational outcomes for autists who have interests and/or skills in specialised areas. Advocates repeatedly warned that autists are rarely ‘generalists’, so could be ‘set up’ by NCEA policy for failure.

Participants experienced other obstacles to achieving, including the need to demonstrate mastery of pre-requisites and the need to demonstrate problem-solving in order to obtain all the credits on offer in a ‘unit’. They challenged policy and praxis, especially underlying assumptions that intelligent people think in similar ways, delegitimising their style of executive functioning. ‘Doing’ numeracy and literacy presented an array of problems for autists. These are typically considered difficult subject areas for autistic people (Myles & Simpson, 2002). Some found numeracy easy, others hard. This is consistent with the contradictory outcomes of numeracy studies within this population (Chiang & Lin, 2007). Some believed the limited focus around descriptive literacy and domination of metaphorical and perspective-taking forms of social storying, highlighted another ‘narrowness’ of the NCEA curriculum. This inequality of the education system was not only perceived, but ‘felt’ wherever literacy permeated embedded tasks within other subjects, especially factual and numerical subjects, like some forms of history and math.

Some autists believed that a fairer educational system would be one that offers diversity in assessment types, including quizzes and multi-choice, allowing them to demonstrate acquired knowledge, without necessarily compromising the importance of learning how to write essays and expressing one’s thoughts in storied ways. From this perspective, autists suggested that an ‘inclusive’ *and* just education is one that doesn’t necessarily ‘water the curriculum down’ but caters for diversity of learners and considers the impact on autistic people’s sense of dignity. This was especially important for autists when the subject was fact based, but prosaically assessed because it left their knowledge as though invisible (Bourke, Mentis, & Todd, 2011).

Participants reasoned that bureaucracy undermines many problems pertaining to autistic people’s achievement. Many drew on ‘bureaucratic tools’ like ‘tick-the-box’, to indicate how curriculum is designed for neurotypical students and is not only a ‘normative’ curriculum but contains inbuilt rewards for teachers whose learners meet ‘normative standards’. Several participants therefore perceived curricula as having ‘right boxes’ to tick, being an allusion to ‘education’ as having nullified personalised goals. This directly challenges the meaning of ‘education’ and the purpose for ‘learning’ (to ‘tick a box’). School was perceived by some to be in the business of producing ‘average’ students, not students educated to reach their highest potential. Thus, some autists challenged the ‘real purpose’ and meaningfulness of education.

To validate their perception that ‘education’ is subjective, some autists provided examples to illustrate how ‘normative’ educational procedures can specifically challenge their executive functioning skills to leave them ‘looking’ comparatively stupid. James [ter] drew on specific memories of ‘speed tests’ in primary school to illuminate how his intelligence was compromised by ‘time’. He used a novel solution to overcome this limitation in Year 11 by pairing with a ‘classmate’ who computed those aspects of algebraic computations, which slowed him down. This enabled him then to focus on other aspects of the equation, reliant upon having a higher than average understanding. Several students similarly considered the problems essay writing posed for assessing one’s knowledge of historical facts. And, two students drew on homework to demonstrate how something may seem straight forward in one context but confusing in another.

Autists articulated the implications of these experiences and provided solutions to consider. They highlighted that when ‘education’ (teachers and their tasks) failed to take their ontological differences (executive functioning differences) into account, then ‘differences’ are illuminated as ‘disabilities’ and an injustice is being done. Several noted the need for an education that was meaningful and pedagogically flexible to accommodate greater (neuro)diversity. They wanted to be valued for their more flexible and insightful ways of thinking in high school, as opposed to ticking boxes like others. Grace [ter] and Emily [ter] believed that university valued ‘thinking outside the square’. Whilst it could be argued that this is ticking a different type of box in university - one that rewards the success of novel solutions, views, perceptions, and innovations - it represents the desire to be rewarded for doing things ‘their way’ and for allowing one to excel in narrow areas of interest. Some tertiary students saw themselves excelling because of their executive functioning differences, narrow interests, and single-minded focus that are valued in university, but not in high school. And, essential for conceptualising that which is typically inaccessible (at least without considerable effort) for average (‘normal’) students.

Similar to Norwich and Lewis’s (2005) recommendation that pedagogic needs must be understood in regard to that which is *common to all*, that which is *specific to a group* (for example autists), and that which is *unique to the individual*, to be transformative, learning cannot (and ought not) always be ‘assessed’ as though one could directly map what is learnt to what is produced in the assessment. Radical transformation of disciplinary epistemology is therefore needed if achievement in NCEA is to become sufficiently flexible and cater for a diversity of learners. Hipkins, et al. (2016, p. 207) make two suggestions regarding NCEA in the future, one as though an ‘afterthought’. They suggest that teachers might consider how a ‘portfolio of evidence’ could better reflect *evidence of learning* against a set of predetermined standards; and, secondly, how “standards would be selected as the formal assessment for the course, on the basis of the evidence of achievement that a teacher expects to be elicited by the tasks and activities” (Hipkins, et al., 2016, p. 207). To be successful for autists, this would necessarily mean that teachers have a good understanding of autism. However, without addressing the problems of ‘support’ for students, it would be destined to fail.

Several autistic students spent their evenings reflecting on their failures, especially social and academic. This became a vicious circle, impacting homework and time for study, as well as enjoyable leisure activities. However, these ‘thematic’ reflections (Borden Sharkey, 2018) were also windows into the meaningful phenomenon of lived experience. In this sense, the daily experiences of ‘failing’, being confused, and ‘Not Achieving’, played significantly on autists’ minds. These problems demanded their attention, due to their degrading effect on well-being. Thus, ‘education’ (including its tests and credit system) was understood by some autists as having the power to affirm or nullify one's value and worth. Identity was impacted as students came to refer to themselves as 'different, disabled, and retarded' or they referred to themselves as 'being intelligent' but made to look 'retarded'.

10.5 The 3 R's (relationships, relationships, relationships): the importance of relationships in support, learning, and well-being

Whilst the findings of Chapters Six and Seven hinted at the importance of student-teacher relationships, Chapters Eight and Nine focused more predominately on the heart and soul of the autistic person and the meaning of interpersonal engagements and intersubjectivities, in relation to being supported: generally, as well as in regard to educational and teacher support, peers, and family. Following the diagnosis, parents assumed that the label would enable teachers to draw on their knowledge of autism, skills, and relational abilities to work with a diversity of learners. These findings contribute to contemporary discussions of how autists experience in/ex-clusion as a lived experience of being (ab)normalised, and 'othered' through support (or lack of), and intersubjectivity.

Although access to support services was experienced as difficult to obtain, advocates opined that all autistic students need support to reach their potential. Without it they cannot hope to receive an equally 'good' education, given sensory, social and communicative (as well as executive functioning) difficulties. Limiting eligibility for support to 'low functioning autists', was, according to participants, especially advocates, to leave high-functioning autists under-supported and under-achieving. Some autists however, even after acknowledging their need for support in order to achieve, did not want explicit or overt support in class, perceiving hovering teachers as primarily detracting from social capital, like Humphrey and Lewis's (2008a) participants. This has implications for development of supports which are 'invisible' (at least to others), relying on increased teacher knowledge of not only autism, but *the student's* autism-ness, and their desires. This would be consistent with the normative developmental stage of adolescence, whereby they want to be honoured for their expertise and ability yet are prepared to work collaboratively with adults to be supported, in ways they deem appropriate.

Because of their earlier experiences in primary and middle school, some autists believed their brain was so confused and 'messed up', that it would be impossible to help them academically now. One participant recalled how confused he felt in primary school and the lack of support he experienced there. Others believed that autism knowledge was so lacking in teachers that it would be impossible for them to know *how* to help. One autist suggested that teachers possibly wanted to offer more support but were restrained by their own lack of support at the exosystem level. This being another allusion to the prioritisation of ‘the institution’, which is to focus on ticking the right boxes, hampering opportunities, even if teachers desired otherwise. To date, there have been very few studies eliciting the voice of younger autists (Armstrong, 2003), however many in this study reflected on their primary school experiences to make sense of their current predicament. One recent study seeking the voices of primary school autists, highlighted similar lived experiences (Cunningham, 2020).

10.5.1 Teacher support and care

Almost all participants shared *particular* stories of how specific teachers had supported them or failed to. These experiences provided important insights into the impact of teachers on their learning and motivation, including characteristics perceived as (un)helpful. A small number of autistic students felt endeared to specific teachers because they were personally available and caring, demonstrating care in practical ways, including providing a drive home on a rainy day; a lunch when they’d forgotten theirs; some time to talk or ask a question; or, having additional school work available for enjoyment. These were experienced as not only positive and motivating aspects of schooling but were interpreted as though they were highlights to share suggesting a route to ‘inclusion’ that is relational and personal. Many of these experiences were contextualised by participants as taking place within the SSC, enabling increased individual planning and personalised support. These experiences were perceived as promulgating feelings of acceptance and a sense of belonging. This enabled participation and contributions to the school in meaningful ways, including creative and academic pursuits, like art or hospitality.

Positive educational experiences were experienced in relation to *someone* caring, providing support or ensuring a good atmosphere. When support was conceived of in terms of academic work, it was the relational aspect students perceived as making learning possible and/or class enjoyable. Autists generally favoured teachers who were ‘open’, relaxed and positive, and thus emotionally available to all students, and providing a calm atmosphere. Teachers were experienced as setting the tone in which learning *could* take place, and/or in which class enjoyment *could* be had. Autists especially enjoyed teachers who were easy to listen to. ‘Good’ teachers demonstrated their ‘openness’ and made themselves likeable by sharing personal stories, which were considered ‘off task’. The pervading atmosphere was one of enjoyment and was linked to feeling as though you belonged, were accepted, and thus included. This finding sits well within current research highlighting that good teacher-student relationships influence not only academic performance, but wellbeing (Conner, Miles, & Pope, 2014; Harvey, 2004; Harvey et al., 2012; Suldo, et al., 2008). These experiences contributed to feelings of belonging and being accepted, however, they did not necessarily translate into the production of academic work for all participants. Whilst it created the ambient conditions conducive for work, one student continued to (silently) opt out altogether in the production of written work.

The emotional state of some teachers, however, was also experienced as a barrier to learning and motivation. Whereas 'relaxed and positive' teachers brought joy, other teachers were experienced as being emotionally 'out of control'; they were described as 'emotional', raising their voice, making demands, or articulating threat, leading to sensory overload. This also contributed to feelings of frustration, agitation, and anger. Brad [adol] repeatedly referred to his teacher's mood as impacting his ability to focus and think and thus garner credits and achieve like he wanted to. He was aware of his own emotional state resulting from 'emotional contagion' (Harvey et al., 2012), but was typically unable to reduce his emotional arousal easily. Thus, he expected that his teacher should be able to 'manage' her emotions given the detrimental impact they had on him. In sum, he was alluding to a way of teaching like that promulgated by St John Boscoe, whereby teachers "must not give the impression that [they] are simply asserting [their] authority or giving vent to [their] anger," but rather, should "correct them [students] patiently with firmness and gentleness" (Catholic Church, 1974, p.16*). He repeatedly lamented, that the problems she caused, dominated his thoughts during the evening. His reactions were embodied, and *she* became an obstacle to achieving.

These reactions are consistent with neurotypical research, highlighting the damaging nature of a teacher's emotional outbursts (Harvey, 2004; Nizielski, Hallum, Lopes, & Schütz, 2012). However, unlike neurotypical students, autists in this study had difficulty obtaining help for this problem; Brad [adol] was not taken seriously. Eventually, he took matters into his own hands and vented on social media. He was disciplined for this, and his learning and achievement suffered further injury. 'His' problem morphed into one about his 'disability' and 'abnormal' behaviour. This resulted in rendering the problem invisible, so 'no problem' at all, challenging notions of 'agency' to enact change. It implicates how rigid, and neurotypically-oriented exosystem policies might come to silence autists and cause these types of experiences of injustice.

10.5.2 Unequal distribution of love and care

Some autists were moved by one-off encounters with teachers who demonstrated an interest in them, asking how they were, or approaching them and enquiring about their learning. Generally, advocates discerned a poverty of interest, commitment, and ability of teachers to form caring microsystem relationships with autists. They attributed this to the demands of their vocation and specialised interests, limited time with the student, ratio of students to teachers, and lack of teacher support within school, along with a lack of autism knowledge.   Although some autistic students like Grace [ter], felt loved and cared for at home and in relation to some teachers, not all were so lucky, having impoverished relationships in both contexts.

This led to questions like ‘why is it that others do not like us’, where ‘us’ referred to autists in general. One’s sense of ‘inclusion’ was entwined with a feeling of being known and made to feel valued. Despite some caring teachers and one-off meaningful encounters, or student-teacher relationships, most participants perceived that love, and care, was not something equally distributed in school, being typically reserved for neurotypical students. However, the two students working within the ‘special unit’ both perceived their SSC teachers as being comparatively more caring.

10.5.3 Practical support

Practical forms of support were particularly important for students who occupied the SSC as opposed to those in mainstream education, who focused on academic and social support. Advocates highlighted mundane interactions with autistic students, listing rides home and after-hour phone calls, as forms of practical support. These practical examples, however ordinary and mundane, were personal, caring, and specific to the needs of these autists. Advocates drew on these practical examples to illumine their ‘openness to personal availability’ as evidence of what ‘being supportive’ means. It was based on building rapport and having respect for the needs of students. This too can be understood in terms of treating autists with dignity.

Advocates noted that there are pockets of schools growing in understanding and becoming more able to fathom ways to support their autistic students and to make them feel safe and included. This converged with the lived experiences of students who were being supported in novel (No. 8 wire) types of ways. The practical forms of support most appreciated included returning to school in Year 14, having jobs that made breaks safe and meaningful, such as filing and serving in the tuck shop during sporting events; and utilising one's artistic skills to produce resources. However, these were sometimes experienced as token forms of support and dependent upon someone initiating these opportunities. Thus, specific teachers were breaking down some of the exosystem level barriers by enriching microsystem settings and connections for autists.

Advocates believed that SENCOs in some schools, like supportive principals 'opened up' support opportunities in general, especially aiding development of good IEPs. Advocates considered them a noteworthy means for fostering and monitoring effectiveness of teaching, learning, and support needs. However, they also noted limitations; namely, that the autist often had a limited voice regarding their goals, sometimes being over-ridden by the academic goals that teachers prioritised. One autist spoke about their IEP, providing an almost verbatim convergence in her reflection that school prioritised academic goals over her social goals, posteriorising these as though 'inferior'. Emily [ter] believed her social goals would contribute to making school feel like a place in which she belonged. She posited however, that she hadn't yet met anyone who could help her achieve her social goals, highlighting the limitations of IEPs if the expertise is not available.

Parents and advocates opined external forms of support were difficult to access, due to the constantly changing political landscape in NZ, which determines agency funding and availability. However, advocates exhibited tenacity to follow loose ends hoping to obtain appropriate service providers. After exhausting considerable effort to obtain support, obstacles and barriers were sometimes also subsequently encountered. One parent/advocate described the relationship between his son and the supporting assistant as so 'off beat', that it became the final straw in his school career. He was unable to build-up a learning relationship with her, nor was the aide able to bring his son any closer to the 'learning community' (Lebech, 2015); this was interpreted as the penultimate lived experience of exclusion. Another barrier was the frequency at which workers were replaced, being perceived as detrimental to the autist's progress and highlighting the importance of building rapport for happiness and success.

Despite their experiences of predominantly lacking support in high school, one tertiary autist was now providing practical support for younger people, acting as an 'expert' by drawing on their past experiences. Grace [ter] had developed a natural mentor relationship with other autists. She was interested in policy and praxis of school, community, and mental health, and had been attending lectures, and giving talks, indicative of having reached an 'authentic' sense of (autistic) self (Vannini & Franzese, 2008). She drew on insight and experience fathoming how to support others. This adds to the notion that older autistic individuals have valuable ‘expertise’ and insight, not only because of categorical membership, but because of the work they subsequently undertake *as members.*

Whilst it is thought that natural mentoring relationships have long-lasting advantages for adolescents (Grossman & Rhodes, 2002), including protection from depression (Hurd & Zimmerman, 2010), research regarding the lived experience of mentor/mentee relationships has garnered little research attention (Ridout & Edmondson, 2017). The findings of this study have implications for how mainstream schools might approach individualised support and manage intersubjective engagement with adolescent autistic students. With increased social media presence, access to mentor/mentee relationships may enable future researchers to focus on discerning what mentees value most about their relationships and experiences with mentors, to inform policy around supporting autists in high school and its impact on identity development.

10.5.4 Private support

James [ter] and Grace [ter], accessed a private psychologist for support. Grace needed support in her final year of high school, particularly regarding anxiety, whilst James wanted support to attend a tertiary setting. They provided insight into what they meant by ‘support’: having someone who understood autism and thus autistic people, and having someone who listened, took their goals seriously, and provided practical, implementable plans. In sum, both students emphasised that unlike other professionals, their private psychologist ‘got them’; their psychologist found meaningful ‘solutions’ without recourse to making them feel ‘broken’, deficient, disordered, or mentally ill. Solutions were practical, simple, logical, measurable, and reportable, highlighting those aspects of professional help most valued by autists. These experiences of being understood and feeling as though being treated with dignity, led to life-changing outcomes for James and Grace. These positive support experiences can be understood in terms of the politics of identity, because they led to being able to consolidate a positive autistic identity by reworking difficulties to tackle the embodied experiences and structural forces experienced as problematic, which previously led to feelings consistent with exclusion.

10.5.5 Social support and peer support

In addition to academic support, every autist wanted more social support. Young women participants especially noted their growing awareness of cliques developing during middle school years, resulting in a sense of being excluded. The solution for these students was to congregate in clusters comprising the ‘odd bods’ and/or ‘naughty kids’ who provided safety in the form of ‘pack protection’. It did not result in a sense of being understood or emotionally supported in healthy ways.

School spaces were relevant for understanding ‘friendship’. One autist considered friendship in terms of her membership in the SSC, where she enjoyed the companionship of other students. However, she wanted support for learning how to communicate better. Nonetheless, companionship in the SSC added to her sense of belonging, providing her with a deep sense of commitment to school; she could not envisage another place in which she *could* belong quite like this one, containing as it did, at least one teacher who liked her and a number of peers who accepted her, regardless of how well or not she conversed with them.

Like being in the SSC, which enabled social encounters in a safe space, other autistic students enjoyed the ‘common room’ in Year 13. They believed the ‘common room’ facilitated additional opportunities to be ‘in community’, to experience ‘inclusion’ through snippets of conversations and intersubjective engagement. This points to innate desires, to our humanity, namely, our desire to be wanted, spoken to, listened to, and to feel as though we belong within a community by connecting socially with others. Autists equated this period in their life with a reduction in ridicule and bullying. They postulated that if something similar had been offered during other year levels, it would have aided social collegiality and reduced their need for hiding from bullies and having ‘friends’ they did not really like.

Some peer friendships straddled the real space of school and the virtual world of gaming. ‘Gaming’ provided enjoyment and companionship for some autists, given in-built communication platforms. One student benefited from his on-line gaming when his peers gathered at school during breaks, to carry on their ‘gaming talk’. Whilst he remained unsure as to how to respond in either context if the interaction was removed from gaming, it gave him a sense of belonging with his peers at school. Another student had no real friends at school but enjoyed connecting with a couple of fanfiction writers during break times. Her virtual friends often face-timed, providing real-ness to the encounters. These experiences challenge how we understand ‘friendships’ in school, particularly when they traverse geographical boundaries. Group membership through shared interests provided a sense of acceptance, enabling participation - the hallmarks of inclusion and an important contribution to one’s sense of well-being.

Unlike their neurotypical peers, who are postulated as spending comparatively more time engaging on social media, autists in this study, were more reserved, consistent with recent findings (Macoun, Bedir, Runions, Barker, Halliday, & Lewis, 2021; van Schalkwyk et al., 2017). Most of the autistic participants in this study had a cell-phone, and most used social media to 'follow' acquaintances, including teachers, school staff, and peers. However, whilst they viewed newsfeeds, they rarely posted on any platform, or rarely posted without being sanctioned in some way for it, causing anxiety. Morally clean newsfeeds were particularly important for autists in this study and most took steps to prevent inappropriate posts from appearing, navigating the implications of account management and its subsequent repercussions for 'being friends'.

Some autists found it demoralising to see popular peers partying and uploading photos and comments on social media whilst they followed from the 'side-lines'. This was experienced as a form of exclusion, leaving one feeling as though 'dis-included'; a painful plight further emphasising their peripheral social position and comparative isolation within the school 'community'. When social exchanges were projected as real-time social images, via snap-chat, the lived experience of 'exclusion' was not simply interpreted as an accurate reflection of what one experienced and witnessed in the lifeworld. Rather, feelings pertaining to 'exclusion' were illumined more explicitly, being enabled technologically, to linger longer before one's eyes. Thus, the pain was expressed in terms of it being 'etched a little deeper'.

10.5.6 Bullying: no support at all

Bullying was experienced as an ongoing problem for most autistic students, throughout their school years, easing somewhat over time. One student highlighted it was a 'seasonal' problem, waning towards year end. These findings are also commensurate with Aristotle's notion of pleasure, enjoyment and entertainment, whereby "novelty commands effortless attention and therefore enjoyment, but when novelty wears off, the attention wanders and enjoyment wanes" (Urmson, 1967, p. 324).

Participants in this research contributed to the current scant literature (see Humphrey & Symes, 2010) regarding *why* they think they might be bullied. Like DeNigris et al. (2018), high-functioning autists attributed the bully's behaviour to noticing how autists 'differed'. Most participants believed peers liked to hone-in on these differences, having 'fun', illuminating their 'odd responses' for others to 'see'. In the context of everyday exchanges between autists and their cohort, these 'differences' were often provocatively drawn out, through question and answer (Q & A) sessions, mediated by the provocateur. This is 'invisible bullying'; on the surface it seems innocuous given the ordinary nature of questions and the non-conspicuous way in which it occurred. For some autists, these 'Q & A' sessions were annoying; whilst others experienced them as a form of bullying, which was painful, ongoing, and demanded constant reflection and examination to determine where *they* 'went wrong'. This finding dovetails Dennis, Lockyer, and Lazenby's (2000), suggesting an inability to discern the deceiving and malevolent nature of other people's behaviour towards them.

Humphrey and Lewis (2008) and Carrington and Graham (2001) also suggest naïve autists complained of being exploited for their lack of social knowledge, and ridiculed. Autists in this study described the impact of these experiences in terms of increased paranoid thinking, very much in line with Freeman et al's (2008, p. 258) definition of paranoia: "the unfounded fear that others intend to cause you harm". This closed access to the wider school community of potential peers for autists, and thus limited their microsystem connections. Their contribution to the literature helps to shed light on previous efforts to discern how paranoia, observed in AS, differs from that observed in those with schizophrenia (Blackshaw, Kinderman, Hare, & Hatton, 2001), namely, in *how* one is socially conditioned and 'othered'.

Transformative potential exists in helping autists discern threats and fathoming ways for mitigating the subsequent damage it does to their dignity. Whilst whole school approaches have been previously suggested as a remedy for bullying in general (Olweus & Limber, 2010), including components directed at the school-level, classroom-level, individual-level, and community-level, some programmes barely reduce bullying (Smith, 2016). It is thought that by focusing more specifically on verbal victimisation, programmes would target the bulk of bullies (Volk, Craig, Boyce, & King, 2006). This research suggests however, that more emphasis must be placed on how power-imbalance comes to be experienced as 'bullying', regardless of its malicious intent or exhibitory value; it can be perpetuated in quiet exchanges between two people and still be experienced as bullying, thus on the surface seems trivial.

Some autists lacked support within school when they reported bullying, leaving them with recourse to their parents. Whilst Grace [ter] highlighted the benefits of having parents who played the 'devil's advocate' for helping make sense of her social encounters, most students highlighted they were not in the habit of disclosing everyday social experiences (including bullying) to parents. This effectively meant suffering in silence, like the autists in Saggers' et al. (2017) Australian research.

10.5.7 Abuse and violence

Interest in, and experience of, intimate relationships varied widely, with most autistic participants not interested, and a few engaging in heterosexual relationships. This is consistent with previous research positing high rates of disinterest in sexual relationships (Magiati, Tay & Howlin, 2014) and asexuality among autistic people (Marriage, Woverton & Marriage, 2009).

Little is known however, about autists' willingness to talk about sexuality, or disclosure of abuse. Sexuality education has rarely been considered regarding its relevance for those with ASD (Tarnai & Wolfe, 2008). I failed to ask regarding their experiences in these programs, however, most of the participants in this study gave the impression they did not want to talk about sexuality. This could indicate a lack of openness to the topic in general, at least, in an interview-style forum, or the ways available to them to articulate their understandings and experiences (or both). This may also limit disclosure by other participants of unwanted sexual harassment or assault; a topic which few have investigated (Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005) despite concern existing that autistic people are more vulnerable to sexual exploitation and abuse (Bargiela, et al., 2016; Brown, Peña, & Rankin, 2017).

Two participants in this study disclosed experiences of sexual abuse without provocation. James [ter] believed unwanted sexual contact, or abuse, was rampant among the autistic population to the degree that he felt it unworthy of officially reporting his experiences. This is different to the primary reason given elsewhere for failing to disclose abuse, namely as a result of "shame, guilt, and embarrassment" (Sable, Danis, Mauzy, & Gallagher, 2006, p.160).

Unlike James [ter], Taylor [adol] had disclosed sexual and physical abuse to her favourite teacher. Given that both students willingly disclosed abuse and violence during these interviews, future research might also focus on why it is that autists participate and share what they do. I believe Taylor disclosed as part of a larger narrative to demonstrate her failures at 'being normal'. Failing at 'doing boyfriend/girlfriend' relationships became an example of how disabling being autistic is. However, James, like Grace [ter] and Emily [ter] was looking back on high school experiences and participating as a way of contributing to change; they were 'doing autism advocacy', thus wanted to tell an accurate story.

The dominant sexuality narrative of the 'permissive West' contrasts to the disinterest in sexuality by participants in this study. Transformative potential may therefore exist in ensuring appropriate sexuality education for autists, including the option of non-sexual relationships. In their annual update of the NZ ASD guidelines, the supplementary 2019 'paper' on the 'effectiveness of sexuality education for young people on the autism spectrum' recommended that sexuality education be tailored specifically to autistic students (Ministry of Health, 2019b). Taylor [adol] wanted a boyfriend to be 'like others', similar to how other autists want to 'fit in' (Humphrey & Lewis, 2008a). Advocating for non-sex as a legitimate response to sexual pressure, might be protective for autistic students, providing them with an alternative normative script for refusing unwanted sexual contact. Appropriate, but explicit (social) storying of the ways in which sexual relationships can lead to violence against women may also be helpful for increasing understanding of what violence 'looks like' and what should occur if someone is sexually or physically violated. Future studies are needed to explore not only unwanted sexual contact among high school and tertiary autists in NZ and its implications, but the lived experience of participating in sexuality education and its perceived relevance.

10.5.8 Parental support

Several autists reported times in which they felt very supported by their parents' involvement in school life; assisting them socially, academically, and physically, in a myriad of ways, ranging from teaching them social skills, providing rubrics or help on projects, and going out of their way to ensure a safe passage to school. However, other parents and advocates noted that in order to be a supportive parent to an autistic adolescent, they too needed support for themselves, along with good avenues of communication at school, both of which were sometimes lacking. Advocates also noted that more was needed to enable parents to update their knowledge and expectations over time, commensurate with adolescent phases of development.

Two parents told distressing stories of how they could not obtain enough support for themselves, with consequences for *how* they could parent and provide support. Both described experiences of extreme distress, over long periods, in the absence of support outside of the police; these being the conditions deemed most likely to preclude filicide. There was convergence between the NZ literature on filicide, parents' stories, and advocates' reports, all of which highlight the feeling that some parents had of being pushed by their circumstances, to 'breaking point' because they lacked support. They experienced indifference to their plight, as if it was *their* problem.

Several years after the harrowing part of their journey had concluded, these parents continued to feel unsupported and in need of some form of support in order to tell their story and explore the impact of 'professional' (neoliberal) violence and its impact on their lives and repercussions for their family. Looking back was traumatic and looking ahead seemed problematic; they didn't feel like they could flourish until the trauma had been given a voice and explored. However, they acknowledged having made considerable gains and, in this sense, were being generative, engaging in this research as political advocacy. They wanted to share the most painful aspects of their story in the hope that their heroic struggles might be leverage for shifting the hearts of policy writers, to ensure 'something' changes in the future and history does not continue to reproduce itself. They especially challenged established 'institutions' who focus on 'data' (symptoms and characteristics) and fail to 'see' the person, being driven by 'risk assessments' and accountability, similar to how students and advocates positioned teachers as being performance-orientated, and not always, as relational and engaging.

10.6 Reflecting on 'listening': tuning into 'pain'.

When I began my PhD, I intended to develop a methodology for 'mapping' the domains of autism and pinpointing the niches within a 'mapped landscape', which autists might 'inhabit'. I was advocating for taking up the tenets of a medical model with little introspection regarding the consequences for autists; I assumed what I proposed was simply needed as an intervention. As I pondered the impact of how gazing at one's list of deficits and characteristics might impact autistic adolescents, I chose to delay my proposal until after the 'listening' process. Too few researchers have 'listened', leaving a substantial 'gap' in the autism literature. Interventions like I proposed, naturally delimits political implications, because it leaves 'blame' for failures squarely on the shoulders of autists and solutions on that of teachers. Phenomenological research based on 'listening' therefore provided an essential 'space' for considering the politics of 'being autistic'. Without considering where transformation within the 'system' is needed, the system can only reproduce (dis)ability through structures and functions that enable and constrain success.

It was my hope that by letting autists speak for themselves about their 'lived experiences' of mainstream high school, a 'space' would also be opened to consider not just their actual experiences of an academic and social nature, but their perceptions and experiences of how inclusive school seemed to them. I didn't envisage that 'listening' would be a such a painful experience, filled with distressing moments, made salient in the transcribing phase of the research. In this section, my aim is to reflect on this pain, because it has implications for the findings and therefore the need for transformative solutions.

My aim is therefore twofold. Firstly, to consider the process of *hearing* ‘pain’ and ‘distress’ (severe frustration, leading to anger, stress, depression, withdrawal, and violence), which was pervasive throughout the transcripts. And, secondly, to reflect on that pain in relation to the social and structural inequalities participants experienced and expressed. By drawing on participants’ collective point of view, I then consider, in the final section of this chapter, the limitations of the medical model for inclusion, the relevance of a social model of ‘dis-ability’, and suggest that transformative potential exists in taking up ‘difference’ differently, and in emphasising the relational over the ‘performative’; the individual human ‘being’ over their ‘otherness’.

10.6.1 Listening and ‘hearing’ pain: Doing research; ‘doing’ [secondary] distress

“Writing separates us from what we know…the text says less than we want, it does not seem to say what we want…” (van Manen, 1997a, p.127). When my writing fails me, as it often has in this project, I have wondered how will I convey what I know; how will I make it ‘transformative’, giving ‘voice’ to participants’ perspectives and experiences in ways that moves policy makers? As I reflected on this and other dilemmas of qualitative research, I considered the difference between hearing (what the participants ‘said’ in the interview) and *listening* (the phase of *processing* what was ‘heard’ when transcribing). It is in the transcribing phase that the impact of listening really ‘hits home’; thereafter, it is diluted in the process of writing…and re-writing!

There has been very little consideration given to the way in which qualitative research impacts the researcher (Bloor, Fincham, & Sampson, 2010), yet it seems significant unexpected distress occurs when research involves experiences, issues, or phenomenon related to health, death, and dying (Woodby, Williams, Wittich, & Burgio, 2011, p. 830). Researchers typically consider how *participants* might experience distress through participation in interviews, *but not themselves* (Lalor, Begley, & Devane, 2006), much less the strategies to manage distress (Dickson-Swift, James, Kippen, Liamputtong, 2008), or the impact one’s distress has on analysing.

The act of writing about one’s distress, highlights something important about the overall *nature* of the research and the lived experiences comprising the research project. My research was focused on *everyday* lived experiences; nonetheless, I listened over and over to participants talking about verbal, physical, emotional, and sexual abuse, as well as filicide. There was much pertaining to feeling different, feeling helpless, being unwanted, being lonely, being bullied, being at one's wits-end, being threatened with violence, inflicting self-harm, contemplating murder, with considerations given to causes of suicide in autistic adolescent populations.

There is a scant literature base to draw on to understand researcher distress. I therefore underestimated the implications of being distressed in the interviews, but especially in re-living such distress during the transcription phase. It is at *this* phase, that interpretation begins (Smith, et al., 2009), having consequences for what is understood, presented, and can be concluded from the research (Oliver, Serovich, & Mason, 2005).

It is recommended that researchers transcribe their own interviews (Smith, et al., 2009). This has been assumed to be 'behind the scenes' work; mundane and time-consuming (Oliver, et al., 2005). However, to treat it as 'tedious work' would underestimate its importance; it is considered the beginning interpretative stage of IPA (Smith, et al.,2009).

There has been debate around the necessity to transcribe information ill-suited to the analysis (Smith, et al., 2009), however, I chose to transcribe the totality of the first interviews, leaving aside only those sections of subsequent interviews when autists shared stories pertaining to their personal interests. As a result, I transcribed almost all of Taylor's [adol] account of being sexually abused in her first interview, but omitted Catherine's [adol] retelling of her favourite fanfiction theme in her second interview.

Smith, et al. (2009) note that the prosodic aspects of the recordings do not need transcribing, as they contribute little to meaning. However, I wanted to guard against muting the prosodic 'tone' and 'volume', because in the interviews, this seemed to give *meaning*! To date it appears that in an autistic population speech rate and fluency are atypical characteristics as opposed to acoustic volume (Dahlgren et al., 2018). I therefore used textual signalling to demonstrate commitment to privileging the participants' voice, and thus their *interpretation* and *understandings.*

There was a significant difference between the distress I experienced during interviews and that which I experienced during transcribing. I remember feeling completely numb after interviewing Taylor [adol], especially at the thought of how this innocent teen had been 'taken' for a 'girlfriend', then repeatedly wounded with multiple instruments and repeatedly sexually assaulted in the most vile and hideous of ways. Whilst I experienced distress during the interview and after, it was offset by taking in the totality of the experience.

This included the greeting I was given, the nuanced aspects of the conversation, including smiles, and the small talk either side of the interviews. Amid the distressing narrative, were other impressions, functioning to capture my attention too, preventing a dwelling on the trauma in isolation. In the transcription phrase however, distressing stories (like Taylor's) presented themselves differently: in isolation. What had previously impacted me in the interviews, now became re-presented before me, in small fragments, each detail having its turn at coming 'into focus'. My emotional distress in response to the severity of what I was listening to compounded; and compounded with other distressing things happening in the context of my 'life'. This was not dissimilar to how participants scrutinised 'snap-shots' of discouraging social realities.

Although there are various terms given to the emotional distress I experienced, including 'secondary emotional stress' and 'vicarious traumatisation' (Kiyimba & O'Reilly, 2016), it was a silent and oppressive grief, which left me feeling helpless and dismayed by the severity of lived experiences going on all around me. My supervisor said IPA can be distressing; it requires being immersed in the 'muck'; autists wanted their voices heard; they wanted the 'muck' uncovered. They wanted policy makers to hear their voices, fathom ways to ensure high schools are places where they can be safe, wanted, valued, rewarded, and successful; where they can feel like a person with human dignity and not a form of entertainment and a novelty to be exploited, harmed, abused (socially, physically, sexually, or academically), or unjustly, or indifferently treated by staff, and through curriculum demands.

When the data for analysis was transcribed and back in its textual and storied form, henceforth considered against a backdrop of contextual research literature, its power to impact, comparatively receded. My inability to capture 'distress' thereafter become more apparent with passing time. This is consistent with literature calling attention to the transcribing phase of sensitive research; where, being stripped of its 'context', it seems to garner the greatest power to cut the researcher most deeply. It is this distress that appears in its 'nakedness', which then becomes 'veiled' through the impoverished skills of the writer. The seriousness however, of distressing lived experience needs to be brought back into focus in order that transformative recommendations stand justified.

10.7 Inclusion: being transformative

Whilst some autists are pathologised as 'different' within school, by virtue of not meeting 'normal' criteria in one or more areas of academic ability, behaviour, emotion, communication, or social relations, most of the autists in the research were also officially labelled as ‘different’. This set them apart from others, through the scientific and medical disciplines they encountered for a diagnosis. Thus, autists’ experiences are appropriate to draw from to further what is known about ‘inclusion’, given that it is for the ‘labelled’ that ‘inclusion’ applies (Dunne, 2009)! However, as a philosophy, it calls schools to value and treat all students with respect. In this research, inclusion was experienced by autists as a feeling relevant to how they were valued and respected. Nonetheless, as a philosophy, ‘inclusion’ is rarely troubled or problematised; few ask whose interests are best served regarding the ways in which ‘inclusion’ is “(re)presented and talked about in education” (Dunne, 2009, p. 42).

Participants in this research rarely addressed the concept of inclusion specifically yet troubled the notion constantly. They did this by illuminating a myriad of themes about school and about their lived experiences as students within mainstream high schools; in the mainstream *and* in the segregated unit, called the SSC. Many of their experiences were of an exclusionary ‘tone’; a feeling that oftentimes resulted in a sense of injustice being done; of having been discriminated against. From the collective viewpoint of participants, school was experienced as a place that consists of hegemonic, normative structures. These are ‘invisible’ to management, teachers, and neurotypical students, through daily practices (governance [rules], support, and social-relational opportunities, and teacher-performative monitoring) and apparatus (primarily NCEA); the tools highlighted by autists as achieving the ‘othering’ by illuminating their ‘differences’; pitting ‘difference’ in opposition to ‘sameness’. The following critique summarises how participants problematised inclusion through perceived and experienced hegemonic, normative structures. This opens the ‘space’ to consider how autistic people’s lived experiences can be drawn on for transformation.

Inclusion was experienced by autists as a feeling of being accepted and valued and was linked to specific geographical spaces and the activities afforded to them within these spaces. Those occupying the SSC, felt included, safe, and cared for. This troubles perceptions that dedicated spaces for ‘special needs’ students are spaces of marginalisation and thus, exclusionary. Mainstreamed higher achieving autists perceived these spaces as though exclusionary, with potential to marginalise, ‘other’, and reduce one’s social capital. However, those within them found them to be a place of welcome relief; a safe refuge, with additional supports enabling increased participation in the life of school, through extracurricular activities like art and hospitality - activities of interest, tailored for them. The SSC was not only a safe haven from mainstream bullies, but a place where the cohort was not threatening. It was a ‘refuge’ when anxious and thus a safe space for engaging in strategies aimed at deescalating anxiety; it was a place for (re)gaining control over one's well-being. Everyone had 'differences' within the SSC, so students were not singled out, pathologised, or 'othered'; they shared in a sense of unity.

When the school demonstrates commitment to groups of students AND sub-groups of students, they create feelings of belonging for them. This was evident in this study, when one student liked rugby; but most spoke out critically regarding the infiltration of this macrosystem influence, highlighting how dominant values are taken up as 'influences' to dominate school 'culture'. They seem 'natural' and appealing to most, but not all. One advocate recollected how 'his' sub-group of autists and others, enjoyed ceramic's 'club' in a 'setting' that afforded these students an enjoyable activity, increased interactions with like-minded members, in a safe space with a teacher who cared about their well-being.

'Mainstreamed' autists, who were in year 13, similarly found that the 'common room' produced for them a greater sense of belonging, because it afforded them the chance to interact with others more; thus, they stood out less and experienced less bullying. 'Inclusion' for these autists referred to *particular* spaces and the opportunities afforded them within. If sub-cultures and sub-groups are not nurtured, entire groups of students can fail to recognise themselves within the 'culture of the school'. This further limits autists opportunities for successes and a sense of belonging.

Likewise, advocates decreed that academic spaces such as 'open classrooms' are exclusionary for some. They naturally fail to accommodate sensory-sensitive individuals, resulting in a design affording one type of student freedom, whilst limiting freedom for others. These microsystem settings are influenced at the exosystem level and require policy writers, principals and BOTs to disrupt notions about how spaces might afford one thing for the dominate 'normative' majority but fail to cater for those outside these narrow parameters.

Students who spent more time in mainstream classes felt less safe and were singled out more often, especially when they had their idiosyncratic traits illumined. In their experience of being 'othered' (especially through academic failure and bullying), they perceived neurotypical students as being rewarded for keeping to an un-written 'script' of normalcy, reinforcing the hegemonic privileging of 'being normal': accumulating curriculum credits and gaining in social capital. Whilst Glazzard (2013) notes in his 'interrogation' of 'inclusive education', when difference is visible, or created, then 'invisibly' the entire edifice of normativity is silently strengthened. Autistic participants and advocates pointed out that the work of normativity goes on literally before their eyes. Nowhere was this more evident to autists than when they were quietly questioned by peers in the hope their novel responses would provide ‘entertainment’. Or, when they failed to demonstrate their knowledge due to extraneous, and often arbitrary constraints, like prerequisites or timed assessments.

Although some students were not motivated and lacked desire to participate in a curriculum (troubling the meaning of ‘education’), for most participants NCEA was perceived as perpetuating ‘failures’ through its normative assumptions for ‘educating’. Those who failed to ‘achieve’ did so primarily in key areas of literacy and numeracy, these being mandatory subjects. Requirements within assessments were sometimes experienced as ‘normative’ in orientation, thus, critically rebuked by participants and sanctioned as forms of injustice, leaving them particularly frustrated. For example, some autists pointed out how assessments functioned as ‘normative apparatus’, by devaluing *their* way of thinking, specifically showing workings and demanding that historical facts be presented prosaically, whilst demonstrating perspective-taking skills. These prescribed assessments failed to recognise cognitive diversity and resulted in systemic failures or reduced achievement and loss of motivation, and thus, became a barrier to any sense of inclusion.

The result of failing numeracy and literacy credits was systemic hardship that impacted self-esteem. At its worst, it was experienced as contributing to the perforation of the student ‘body’ into those who ‘got it’ and the dysfunctional (‘retarded’) ‘other’. Participants, including advocates, highlighted that the academic system of NCEA needs to be transformed to disrupt assumptions about cognitive development, the ‘need’ for pre-requisite learning, and the relevance of showing prescribed routes to problem-solving. They also highlighted that more flexibility is needed for assessing what has been learned but cannot easily be expressed in the ‘traditional’ or ‘dominant’ manner. This would increase successes and reduce lived experiences of being devalued for ‘difference’ and more precisely, the painfulness of ‘being othered’. Overall, NCEA was experienced as being too rigid to potentiate ‘inclusiveness’. Future iterations of NCEA should also consider how limiting credit accumulation in specific subjects will impact the entire student body, particularly if that ‘body’ comprises ‘specialist’ learners, as some autists are wont to be.

These challenges require a political response at the exosystem level, in order to shift perceptions that the task of curriculum writers is to simply cater for one type of ‘normal’ student and therefore cognitive style. From participants’ points of view, it seems that NCEA reinforces a normative hegemony, by positioning high-functioning autists (through its rigidity and prescribed assessment modes) as ‘low achievers’. And if positioned as ‘low achievers’, the challenge is accentuated by having teachers with little knowledge of autism coupled with ‘low expectations’ for those seemingly ‘different’. The gulf between the ‘normal’ and ‘other’ increases.

Inclusiveness was also deemed hampered by performance-related restrictions impeding the time and inclination of teachers to get to know students and ensure fair educational opportunities for *all* their students. The problems of teacher-performativity (ticking boxes and being monitored) cannot be understood aside from the context of what students wanted from their teachers, relationally, which is also tied to having autism knowledge.

Performativity is neoliberal. It was experienced or understood by autists (and advocates) as contributing to the devaluing of non-normative types of students. Autists perceived that the focus of teachers was on ‘achieving’ the majority. It was assumed not to be in the best interest of teachers to ‘stoop too low’ to explain what was not easily grasped. Autists also noted the rarity of extended learning opportunities for learnings sake and when it occurred, it was welcomed. Although autists wanted to learn, most also elevated the importance of relationships with teachers, highlighting that they enjoyed some teachers more than others, especially when they seemed to like their students. Several autists wanted additional attention and time with their teacher to share their interest, whilst others delighted in the small amount of attention they received from teachers who took an interest in them. A minority had no interest in attracting the teacher’s attention, given that it could also be the cause of trouble. This creates a tension between the demands of performance and the relational and academic needs of students. The ‘performing’ teacher must quantify and objectify teaching-learning, posteriorising subjective engagement perhaps, in order to get on with the task of teaching. Whilst not all performance-orientated teachers will be ‘cold’, autists experienced authoritative teachers as being performance-focused (“do this or else…”) and were hampered by the emotional tone that was left reverberating throughout the class.

These experiences were related to lost learning opportunities; whereas, relational teachers who brought joy to the class positively impacted school life and learning opportunities. To be transformative, teacher ‘performativity’ cannot be quantified in academic results alone. Good teachers know their students, and instead of telling them what to do, cajole them into wanting to investigate, explore, and learn, all of which may be the result of relational contagion. For autists who have impoverished microsystem networks, relationships with teachers gave new meaning to being valued. The implication of performativity and neoliberal ‘demands’ on struggling teachers is that they will increasingly have less joy themselves; and thus, less to share with students, similar to the apprehensions and fears reported of staff in other higher education institutions operating under intense neoliberal influences (Di Leo, 2013).

The rhetoric of 'inclusive education' privileges a medical model perception of students with special needs. By doing so, it can pitch one 'curriculum' as though 'fit for all' with 'support' assisting those with 'needs' to reach some level of 'normality'. Tertiary participants were unaware of these concepts until they had moved on from high school. However, on reflection of the implications, they believed that schools embraced this model and failed to live up to the demands that a social model would enforce upon them, such as being asked to adapt the curriculum and its forms of governance, the cause of so much 'othering' through its disabling effects for autists. From their point of view, schools cannot aspire to inclusion and hope to raise the aspirations of all students if they perceive the problem of failure to rest solely *within* individuals. This results in systemic failure too and [re]produces disability by failing to shift the onus onto schools to accommodate *all* students. Although the establishment of the SSC is in response to 'inclusion' being derived from a medical model, what transpired within the unit, was experienced as inclusive. Fundamentally 'inclusion' was experienced when teachers and conditions addressed the needs of each student, creatively, flexibly, and relationally and took the onus off the student to 'adapt'. Nor was the emphasis on teacher performativity, nor obtainment of NCEA although they offered NCEA. Rather, everything was well-being focused. This finding furthers Codd's (2008) assertion that the 'institution of education' has turned away from collective well-being to focus on economic gain.

The findings from this research do not support the idea that schools should refrain from drawing on a medical model to inform their understanding of autism. Rather, if this is all they aspire to, to grow teacher understanding, then they will continue to reproduce disabling conditions and lived experiences of exclusion. Autists provided ways of understanding autism that move well beyond the DSM. Without official labels, autists were excluded through other forms of derogatory labelling, therefore they benefited from a diagnosis and the subsequent understandings this provided. They pointed out however, that as a model, the medical model has limited utility in isolation to inform understanding. They troubled the model because they perceived how severely it limited and restricted understanding of themselves. As a result, they experienced a myriad of injustices. They provided alternative ways of thinking about autism that satisfied their desire to be understood in more nuanced, and multifaceted ways. To be transformative, schools must consider the autists' perspectives on 'being autistic'; phenomenological experience must sit alongside the DSM.

Challenging the injustices autists in this study experienced demands a political and relational response. It was touted by advocates that autists need an equal opportunity to be educated and to be heard. Whilst others have suggested that 'inclusion' does not work (it's 'dead' in praxis [e.g., Imray & Colley, 2017]), it could, if implemented from a transformative perspective. And if policy makers, school management, BOTs and so on were to prioritise (re)considering how institutional education functionally and relationally caters for its neurodiverse student body, breaking down the binary of 'the same' and 'the other'. Fixed, rigid and inflexible curriculums, along with teaching that favours performance over relational capacity (in a milieu of 'governance' that fails to cater for cultural and sub-culture diversity [Glazzard, 2013]), will do little more than (re)produce success for predominantly normative students. The normative hegemonic regime will just continue to 'other' the 'different', reinforcing the value of 'sameness'.

From the collective perspective of participants, it seems that there are some teachers and some units within schools operating in inclusive ways. The remainder believed mainstream high schools were failing to achieve this, thus, failing to inspire autists despite the fact they too comprise the *one* student 'body'. The repercussions of exclusion were lived experiences of educational inequality, discrimination, and injustice - hence the telling of stories imbued and embedded in frustration, pain, and sometimes, violence. Educational injustice is about systemic lack of achievement and failure and is a violation of human rights. It is an unambiguous contrast to the types of experiences the MoE had in mind when they touted their rhetoric regarding student well-being. Inclusive schools should offer *all* students the chance to flourish.

There is one body, but it has many parts. But all its many parts make up one body.

(1 Corinthians 12:12)

10.8 Methodological strengths and limitations of the study

The findings and implications of this research have been derived from the lived experiences of a small number of participants. Therefore, whilst rich and significant in their contribution to the current literature, they cannot be generalised. This is a limitation of doing IPA, although IPA does not claim to be generalisable. In the following section, this limitation along with other strengths and limitations are considered, before ending with a concluding comment.

The ratio of quantitative-style autism studies published in leading journals, such as *Autism* continues to exceed those using qualitative methods *(*Bölte, 2014); therefore, qualitative studies stand to make an important contribution to the literature. Whilst IPA in qualitative research has burgeoned (Brocki & Wearden, 2006), it is particularly useful for exploring phenomenon like the lived experiences of autists in mainstream high schools. IPA can however, present challenges for psychology students lacking a philosophical background given its many theoretical underpinnings (Shinebourne, 2011) and a shortage of studies decreases student exposure to philosophical knowledge.

IPA is complex because it draws on several philosophical schools of thought, influencing how researchers can approach and explore narratives, impacting strengths and limitations of studies like this. In symbolic interactionism for example, meanings are constructed relevant to people's personal and social worlds. This philosophical school of thought enabled me to consider how autists honed in on the diagnostic processes because it impacted their ontological understanding of self and therefore identity development, especially in relation to others, and regarding their social 'position' and experiences within school. Similarly, parents honed in on the diagnosis because it impacted how they could support their adolescent.

A strength of this study was its relaxed interview schedule, enabling greater focus on how participants' personal and social lifeworlds interacted. It could be argued that the downside of opting for open-ended interviewing techniques is that it encourages diversions and side-tracking from the primary agenda of the researcher, which in this case was educative-oriented. Such widespread diversions into 'diagnosis' and 'support' suggested that participants had forged well-worn (neural) 'paths' that demanded exploration. Well-worn paths have characteristic ruts that form into deep depressions through constant traversing. Try as you might to steer your way out of a well-formed one, you soon realise the futility; you get further, easier, by staying within it; down in its hollowed-out grooves. Thus, it was with these interviews. That all parents diverged so far down into these well-worn paths on issues of diagnosis and service provisions, highlighted that these were pressing issues for these parents; burning to be spoken, and longing to be heard.

If parents were traversing well-worn 'ruts', then this *is* the soil out of which the whole family draws their 'nourishment', enabling and constraining understandings of 'being' and 'being autistic', with implications for well-being through interconnecting constraints and enablers between home, school, and mental health and support providers. Participants continuously tried to make sense of their lifeworld of 'being' autistic in a social context. They were “not passive perceivers of an object reality” (Brocki & Wearden, 2006, p. 88) but were embedded in those contexts and actively engaging to make sense of inclusion and exclusion experiences in various contexts. Open-ended interviews enabled participants to make sense of ‘inclusion’ and ‘education’ from a broader context, enhancing how the bio-ecological connection can be understood and made sense of.

IPA is often considered as much a mix of science as it is an art. To do IPA well, it requires ensuring that interpretation takes precedent over one’s preconceptions. The researcher must to do two things to aid this: they must stand (as much as is possible) in the shoes of participants; and, secondly, they must step backwards in order to ascertain what it is that (a) participant(s) might be ‘getting at’ and trying to make sense of (Smith & Eatough, 2007). ‘Standing back’ from the data can enable a richer analysis; however, it can also increase the risk of interpretative error, because our own thoughts and ideas can seep out of their ‘brackets’ and influence the shape of the critique. Whilst the method requires that we ‘spell things out’, interpretative ‘leaps’ can advance ideas for future research and in this respect, a strength of this study was the interpretative freedom to consider ‘neoliberalism’. Neoliberal ideology pertains to silent influences and is not something anyone can easily put into words. However, material and discursive practices (such as those found in the form and function of checklists with check boxes) can pertain to the ‘politics of life’ (Rose, 2001), shaping and privileging identity by defining and distinguishing ‘them from us’ (Runswick-Cole, 2014). All that the adolescent autist *could* draw on were the tools used to illuminate the ‘sifting and shifting of people’; they lacked direct access to the discursive means for politicising sameness and difference. A further strength of taking a multi-perspective approach was that convergence of these concepts by advocates and parents assisted in demonstrating validity, through triangulation of sources (Bogdan & Biklen, 2003).

IPA is idiographic, bringing strengths and limitations to the research. Its most commonly cited limitation pertains to its lack of generalisability, given the small number of participants involved (Smith, et al., 2009). Whilst the views and experiences of participants may not be representative of others in a similar situation, the goal is to encapsulate the meaning or ‘reality’ given to experiences within a specific context, in order that what is taken for granted might be disrupted or illumined. Qualitative studies generally generate greater insight into the nuances and contextualised, lived experience, which is a strength. This was particularly evident in this study when some participants provided detailed storying of how ‘Q & A’ bullying can be ‘invisible’, yet so detrimental as to perpetuate, or contribute to, feelings of paranoia. These are nuanced experiences, which may not apply to all autists, however, it is up to future researchers to explore this phenomenon further, in order to ascertain how social paranoia comes to be experienced by autists.

Likewise, having a small number of participants meant giving attention to the stories each participant tells, regardless of ‘saturation’. Either of Taylor’s [adol] nuanced experiences (of sexual abuse and sense of ‘inclusion’ in the SSC) could have been easily overlooked in a study with more participants, aimed at validating findings, through saturation.

Having fewer participants can present challenges for how knowledge can be extended by moving beyond well-known stories, in order to illuminate subjective life experiences, yet to be explored. Although ‘the battle’ for obtaining diagnosis and support *is* a well-worn autism story, it was both a strength and limitation of this study to ‘tell it again’. On one hand, it suggests that systems and structures contributing to ‘the battle’ have not changed substantially over time. However, whilst this limited the focus on exploring how parents were supporting their autist ‘in school’, it meant greater freedom to listen and build rapport, essential for asking questions about distressing experiences.

Multiple-perspective studies like this one, can lend themselves to a more in-depth analysis, providing multi-sided analysis (Flowers, Knussen, & Duncan, 2001; Smith, et al., 2009). This is one way to overcome limitations like participants’ lack of experience, or ability to articulate their experiences. In this study, it increased the analytic work; however, it helped to demonstrate validity, when multiple groups of participants revealed recurrent, salient themes. Multiple-perspective studies can also lend themselves to increasing the depth and breadth of what is known about a phenomenon. This was evident when tertiary students were able to consider how the medical model of disability constrained and enabled how they could make sense of their high school experiences. Without the input from tertiary students, the analysis would have been limited in its depth and regarding chronosystem-level influences, thus delimiting how (dis)abling narratives are experienced across ecological contexts. In sum, these additional participants aided deeper reflection on the ‘things that mattered’, enhancing quality within the qualitative design by enabling greater sensitivity to important contexts (Yardley, 2000).

In summary, there were several methodological strengths to this study and attempts were made to overcome salient limitations. Prior to considering these, I suggested that the transcription phase of research is a little-considered aspect of qualitative research. It is a phase that has an impact on the research process, interpretation, and understanding of overall findings. Reflections like that can have consequences for fellow researchers and these also need to be critiqued. For example, they could be used to inform ethics committees, appealing to members who are ‘risk averse’. It may increase the tendency towards ‘over-interference’, and compromise research opportunities by deeming everything ‘risky’ (Bloor, et al., 2010). This was not my intention; however, consideration needs to be given to how ‘everyday experiences’ of some populations, or some sensitive topics, will lead to interviews requiring researchers to dedicate a significant portion of their PhD to doing ‘distressing work’.

As qualitative research increases and broadens, more topics of a sensitive nature will be explored, and the grief and emotional distress, in all its (extra)ordinariness will continue to confront doctoral students. There is potential for this to be worse in research utilising IPA, because unlike other qualitative forms, such as discourse analysis, the focus is listening for personal meaning, and that which is personally meaningful for one, can resonate with (or elicit strong feelings in) another! I think this is especially true when research explores lived experiences of people who have been oppressed, abused, or shunned, like some autists are. I agree with Dickson-Swift et al.’s (2008) suggestion, that more attention needs to be given to preparing doctoral students for the emotional and psychological distress of being ‘shocked’ by their research. However, when they are ‘shocked’, it must be expected that their audience could also experience some sense of being unsettled; if not, the researcher must be asked how well they interpreted what they listened to, especially if the research has a transformative aim.

Despite there being few documented strategies for managing the emotional consequences of being exposed to sensitive research, most focus on personal forms of support. This includes informal networks and professional support (Dickson-Swift et al., 2008). In addition to regular supervision meetings with my two psychology supervisors who provided opportunities for debriefing, the one (in)formal form of support mentioned by Dickson-Swift et al., which resonated most with me, was the role of ‘clergy’. This was both a formal and informal source of support for me. In taking my emotional reactions to my spiritual director, I received acknowledgement of the sorrow of life, affirming that we are to ‘weep with those who weep’. In being counselled, I became more motivated to pick up my ‘Cross’ and carry on. It didn’t change the painfulness, but it helped to place the research in its meaningful context for me, and I was encouraged to persevere with it. In this respect, I was no different from the participants, who themselves thrived only when they had the ‘right’ person to share their problems with.

10.9 Conclusion

By repeatedly returning to the roots of traditional phenomenology, this thesis grappled with the task of philosophising phenomenologically regarding ‘being autistic’ as well as taking up IPA (according to Smith et al., 2009) to hone in on the *lived experience* of the phenomenon of ‘inclusion’. Keeping the work of phenomenological philosophers like Stein and Heidegger forefront, resulted in a greater occupation with autists’ exploration between objective science and subjectivity and of perceptual intentionality; thus, a focus on ‘being’ (ontologically different) and ‘being in a neoliberal milieu’ (that functioned to pathologise autism and ‘other’ the autist). It seems prudent that philosophising precedes psychologising if autists’ *lived experiences* are to be taken seriously and do more than add to the sum of current descriptors. Having little philosophical training (as a psychology doctoral candidate) resulted in drawing on Stein and Heidegger’s work in limited ways. However, no matter how limited, the sum of this effort enabled a shift beyond the problems of what ‘*school is like*’, to a grappling with ontology, scientific objectivity, and subjectivities. Future autism researchers utilising Smith et al.’s (2009) IPA, would do well to remember that IPA *is* tethered to philosophical shores. Failure to acknowledge this, risks having modern phenomenological philosophers rightfully accusing proponents of Smith’s ‘interpretation’ of philosophical phenomenology as though in jeopardy of coming adrift from its moorings (Zahavi, 2019) and this not only implicates credibility of doing this kind of qualitative research, but restricts how we can come to ‘know’.

Nonetheless, high-functioning autistic adolescents have much to contribute regarding our understanding of what high school is like for them (and why), whilst tertiary students can provide significant insights from their reflections. Autists had a good understanding of their experiences, and importantly, their needs. Many contributed to an understanding of how schools might be in/ex-clusive, derived primarily from attending mainstream classes. Their experiences differed in significant ways, given their ability and symptoms, support, interests, goals, and positions within schools, as did their academic outcomes. Some had no ambition, some struggled to achieve NCEA, some dropped out, and others made it to university. However, their insights were more similar regarding the challenges they faced including diagnostic identity, unique academic difficulties and strengths; the type of support they deemed essential, and, their social experiences.

The findings of this research suggest autists typically felt misunderstood in high school, supporting previous research involving autistic secondary students (e.g., Goodall, 2018; Humphrey & Lewis, 2008a; Saggers, et al., 2011). Some experienced the consequences of being misunderstood as an injustice, which impacted their sense of dignity and encroached on human rights, and therefore the ethics of education. This has implications for 'inclusive' NZ schools, because 'inclusion', unlike 'integration' requires schools to take actions; inclusion is 'an ethical project' (Allan, 2005); "it implies that others [e.g., principals, teachers, para-professions, BOT's etc] have an obligation to ensure that this [inclusion] happens" (Allan, 2005, p. 282).

The experience of school, as inclusive (or exclusive), seems to derive primarily from the totality of ones' salient experiences and understandings, transpiring in the quotidian of daily life. These stem from intersecting ecological contexts (home, school, mental health) and personal (digital and physical) boundaries. Thus, autistic participants made sense of a range of barriers and facilitators to inclusion from which they derived an overall sense of what school is like (or has been like) for them. Their 'overall sense' pertained to experiences, feelings, and understandings regarding belonging and being accepted, participating, contributing, and achieving ones' goals, social and academic. Personal encouters and interactions in daily life and one's reflections on them, contributed to well-being and motivation, and were the substance or 'essence' directing identity exploration and acceptance of self.

The analysis illumined that feelings and insights about inclusion and one's place in school (belonging and being accepted), are sometimes garnered by pondering more distal ecological influences within the context of school life. These include culture, governance, and the power of autism narratives. Most of the barriers to inclusion were positioned politically as tensions demarcating proclivities towards carving up the spectrum of human-being-ness into sameness and difference. Most of the facilitators to inclusion were positioned relationally, where bridges for intersubjective engagement were crossed to touch one's heart *and* mind in personally meaningful ways. These 'touches' impacted (even momentarily sometimes) one's sense of being not only accepted and valued, but as having one's learning interests indulged, thus satiated. This is the joy of learning; the 'unfolding of the person' in action, in Edith Stein's terms; the tapping into a predisposed 'kernal' in want of being noticed and cared for; thus, educated (Brenner, 2015).

Autistic people wanted to be wanted. One way to summarise and understand this desire for 'being' in school, is to consider Stein's objection to Heidegger's reduction of 'being' to its humanistic essence, where it gets "reduced to its finitude" (Lebech, 2018, p. 219). Stein opposes a Heideggerian human reality of 'being' and opens up considerations for 'Being', where in essence *Deisin* springs forth out of relationships steeped in care and love, impacting *Deisin* through the union of body and soul, which gives *Deisin* its sense of being of inestimable value. Most participants in this study lamented when this valuing (steeped in care and love) was not forthcoming from peers, teachers, and mental health workers; on this point, all the findings converged. Thus, certain one-on-one experiences, specific people, and particular settings, like the SSC, were foregrounded by participants for their contribution toward inclusion; they reflected a relational foundation for Being.

Some autists perceived that schools (the institution of education) have a moral imperative to work towards inclusion, thus valuing, caring, and teaching *all* students. Autists opined that fiscal and market (neoliberal) realities are at play, working against inclusiveness. Some students believed teachers are pressured to meet professional obligations by teaching to the majority; thus, support for learning about autism was limited, as were options for personalised forms of support for autists, including social support and support directed toward curriculum and NCEA adaptations. This provided a sense that schools generally neither cared about, or valued autists, much less loved them or embraced them (making them feel accepted and as though they belong). Similar sentiments were proffered by parents reflecting on the constraints of mental health organisations.

Some autists believed these neoliberal market demands have compromised *their* education; in order to meet autistic peoples' needs, teachers would necessarily be compromised in their 'performance' (getting the majority over the pass line). Whilst the SSC might have demonstrated negation of these issues, through personalised strategies, a 'learning unit' is not for every autist; to assume it could be, goes against the very heart of inclusive education, which is to enable students with 'needs' to attend a school of choice (Florian, 2014). Nonetheless, it provides a model; a starting point for considering the value of closer relationships that lead to a sense of belonging and acceptance, and the value of having flexibility regarding the NCEA curriculum to offset a 'retard' or 'failure' mentality through Not-Achieved or low achieving grades. Rigid curriculum rubrics and methods for assessing learning, were perceived as positioning autists as though *knowledge* inferior, when in fact they perceived themselves as *expression* inferior, being overly constrained by the conditions of NCEA. Some students were able to get by on the supports in place for them and one student even felt very supported by the ongoing adaptations schools made. However, no student believed that they were capable of being able to achieve their academic potential in the current high school milieu, without references to tailored support.

In conclusion, development of inclusion policy and praxis must be derived from a consideration of the lived experiences of autistic people, embracing all levels of ecological influence, permeating mainstream schools. Humphrey and Lewis (2008a) noted autistic peoples' everyday stories can be painful to hear; this thesis is testament to that. If the Right Honorable Jacinda Ardern is serious about 'pursuing kindness for all New Zealanders', then she has an obligation to listen to high-functioning autists and to take action, not merely as a 'human rights issue', but from an 'ethics of care' perspective. Inclusion requires 'action' and more action is needed, not from the autist, but from within and beyond the settings they are embedded within.

Participants flagged many essential starting points for mental health, curriculum writers, the MoE, BOTs, schools, and teachers to consider. Without changes across all ecological contexts, autists will continue to be 'othered', and thus found hiding in the school's nooks and crannies and falling through its academic and social cracks. More worryingly, if this problem is not tackled at all ecological and political levels, autists (and parents of autists) will remain not only the proverbial *strangers* in a *strange land*, but, 'targets' for violence - both social and academic.

> *Like I was thinking lately: I would not be able to survive in the 'wild' very easily – it is damn cruel out there and I am not sure how someone can manage to survive and make it to the end* (Chris [adol], p.26).

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Appendices

Appendix A1: Adolescent student information sheet

INFORMATION SHEET – 'Adolescent student'

Exploring everyday school experiences of high-functioning autistic adolescents.

Introduction

This is me! My name is Sharon Crooks, and I am a PhD student at Massey University. My three supervisors from the School of Psychology are Dr's Leigh Coombes, Shane Harvey and Kirsty Ross.

Aim of my research:

To learn more about the everyday high school experiences of high-functioning autistic teens. I am interested in hearing about what you like and dislike about school and what you are good at and what is difficult.

If you choose to participate in this study -

	You will be asked to sign an 'Informed Consent' which tells me you have read this sheet and feel ok about talking to me. You will be given plenty of time to think about what you want to say and won't be rushed. You can bring 'stuff' to help explain your school experiences. For example, you can bring photos, artwork, or something you've written. You can choose where we meet. Some ideas are your home, the university, or a public library.
	I will audio record our conversation so I can remember what we talk about. Later I will type up what I've recorded to show you. We will meet twice. The second time, I will show you what we talked about the first time and you can change anything you don't agree with or add some new ideas to it. Each time we meet, it will take between 1 and 1.5 hours.

	If you want to stop the discussion at any time, just say "stop". You do not have to say why you want to stop – you just can.

What you can expect from me -

	I will respect you and try to learn from you. Consent forms, with your real names on them, will be stored in my supervisor's filing cabinet. At the end of five years, she will destroy these. I will keep what you say private. I won't use your real name or your school's name. My supervisors will not tell anyone else you participated.
	I will delete the audio file when everything is typed up. The typed document will be stored in a secure file on my computer. If you want a summary of the research at the end of the project, I can email or post you a copy. You can ask me questions about this project at any time. My email and cell phone are: S.Crooks@massey.ac.nz or 027 5775223.

Thank you for taking the time to read about my autism research project on high school experiences. If you choose to participate and would like me to bring some snacks for us to share while we talk, please let me know what you like. I look forward to meeting you and learning from you.

If you need to contact my main supervisor, her name is Dr Leigh Coombes and her email address is: L.Coombes@massey.ac.nz

Sharon Crooks (PhD candidate)

"This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director (Research Ethics), email humanethics@massey.ac.nz. "

Appendix A2: Tertiary student information sheet

(Un)strangering the stranger in a strange land: exploring the everyday lived experiences and understandings of high-functioning autistic adolescents in mainstream high schools.

INFORMATION SHEET – ‘Tertiary student’

Introduction

Thank you for your interest in this research project. My name is Sharon Crooks and I am a PhD student at Massey University. For my PhD project, I am investigating the every-day experiences of high-functioning autistic adolescents in mainstream high schools. My supervisors are Drs Leigh Coombes, Shane Harvey and Kirsty Ross, from the School of Psychology at Massey University.

Background

There has been a lot of research about autism in general, but not very much is known about the kinds of experiences that adolescents have in mainstream New Zealand high schools. The aim of my PhD project is to find out more about the everyday experiences that high-functioning autistic individuals have in high school. If you choose to participate in this project, you will be asked to think about your experiences at school in years 11-13/14.

If you choose to participate in this study:

- I will ask you to sign an ‘Informed Consent’ form. This form tells me that you agree to participate in this study and that you have read this information sheet.
- We will talk about some of your experiences. To get started I will ask you some questions about what you liked about school and what you didn’t like. I will give you time to think about your answer.
- If you want, you can bring some things that remind you of your time at school but you don’t have to.
- We will meet on two occasions, either at the university in a quiet room or at your place or somewhere that you will be comfortable.
- It will take between 30mins and 1.5 hours.
- If you want to stop the discussion at any time, you can. You do not have to explain why you want to stop. You just can.
- I will record our conversation so that I can remember what you and I say and can transcribe it into a written document.
- A couple of weeks after our meeting I will arrange for us to meet again and I will show you the transcript. You will be able to change it or add to it if you want.

What can you expect from me?

- I will respect you as the ‘expert’ of your own experiences and will try and learn as much as I can from you about them.
- I will treat whatever you share with me as private and confidential and will not use your real name or the name of the school you went to. The only person who will know you participated in this project is me and my supervisor and those people that you choose to tell.
- I will use pseudonyms when transcribing our discussion and will store the transcripts within a password protected file on my computer. Once you have approved the transcript, I will delete the audio files.
- I will store consent forms, with your real names on them, in my Supervisor’s filing cabinet. At the end of five years, all documents will be destroyed following Massey University’s document destruction policies.
- If you want, I will provide you with a summary of the research findings from this project.
- You can stop me any time during our discussion to ask me questions or you can email or text me any questions you have if you think of something later on. My email and cell phone are: S.Crooks@massey.ac.nz or 027 5775223.
- You can contact my main PhD supervisor if you need to. Her name is Dr Leigh Coombes and her email is: L.Coombes@massey.ac.nz

Thank you for taking the time to read about my research project. I look to forward to talking with you if you decide that you want to participate.

Sharon Crooks (PhD candidate)

This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director (Research Ethics), email humanethics@massey.ac.nz.

Appendix A3: Parents' information sheet

(Un)strangering the stranger in a strange land: exploring the everyday lived experiences and understandings of high-functioning autistic adolescents in mainstream high schools.

INFORMATION SHEET – Parents

Introduction

Thank you for your interest in this research project. My name is Sharon Crooks and I am a PhD student at Massey University. For my PhD project, I am investigating the every-day lived experiences of high-functioning autistic adolescents in their senior years of mainstream high schools. My supervisors are Drs Leigh Coombes, Shane Harvey and Kirsty Ross, from the School of Psychology at Massey University.

Background

In 2008, our Ministries of Health and Education in New Zealand (NZ) published a set of Autistic Spectrum Disorder (ASD) guidelines. The guidelines indicated that there is a major 'gap' in research in that the 'voice' of those with ASD is missing, not just in New Zealand, but world-wide. This means there is a lot of research about people with ASD but not a lot that includes the person's views and understandings, as well as their everyday lived experiences. My overall aim is to investigate the everyday lived experiences of teens, taking into account too, the stories and experiences of post-secondary students, parents, teachers, and community advocates (those with expertise in the field of autism). My aim in meeting with parents is to learn what it is/was like supporting a child with autism during their time in high school, especially in years 11-13 (NCEA level 1-3). I am interested in learning as much as I can about the things that worked well for your child and the difficulties you encountered and perhaps overcome along the way.

What is required of me if I choose to participate?

I will aim to meet at a time that suits you, in a convenient location which is also conducive to recording our discussion. Before starting our discussion, you will be asked to sign an 'Informed Consent' form saying that you agree to participate under the conditions outlined. Our discussion may take between one and two hours, depending on what you would like to share and the direction that it goes in. Once I have had a chance to review our initial discussion, I may ask you if we can meet again to discuss particular topics in more detail. Alternatively, if it is more expedient for both of us, I may ask you to answer some specific questions, via email.

Within four weeks of our discussion(s), I will provide you with a copy of the transcript along with a request to read it and amend it (if necessary). I will ask you to sign a 'transcript release' form which authorises me to use our discussion in my research. You are able to withdraw from this study at any time, up until signing the transcript release form.

What can you expect from me?

I will respect you as the ‘expert’ on the topics we will discuss and I will treat whatever you share with me as private and confidential, notwithstanding sharing information with my three supervisors. In the course of disseminating my research findings, I will not purposefully disclose information that will easily identify you, your child, or any institution they may be associated with or have been attached to. I will seek the opinions of my supervisors regarding these descriptions. I will use pseudonyms when transcribing our discussion and will store the transcripts within a password protected file on my computer. Once you have approved the transcript, I will delete the audio files. I will store consent forms, with your real names on them, in my Supervisor’s filing cabinet. At the end of five years, all documents will be destroyed securely, following Massey University’s document destruction policies. Finally, I can provide you with a summary of the research findings from this project if you indicate your interest in receiving this, on the ‘Informed Consent’ form.

If you have any questions in relation to this project or through-out the course of this project, you can contact me via email or cell phone: S.Crooks@massey.ac.nz or 0275775223. My primary supervisor can also be contacted by email: Dr Leigh Coombes: L.Coombes@massey.ac.nz.

Thank you for taking the time to read about my research project.

Sharon Crooks

"This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director (Research Ethics), email humanethics@massey.ac.nz. "

Appendix A4: Adult informed consent (Parents and Advocates)

(Un)strangering the stranger in a strange land: exploring the everyday lived experiences and understandings of high-functioning autistic adolescents in mainstream high schools.

(Parent/Advocate) INFORMED CONSENT

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. I understand that I may ask further questions at any time about this project by contacting the researcher, Sharon Crooks (S.Crooks@Massey.ac.nz).

Please circle the option you agree with.

I agree/do not agree to the interview being sound recorded, knowing it can be turned off at any time.

I would like/would not like a summary of the research findings at the conclusion of the research project.

By signing this form, you agree to participate in this study under the conditions set out in the **Information Sheet.**

Signature: ………………………………………………. Date: ……………………...

Full name – printed

………………………………………………………………………………….

Email address (for a summary of the research findings)

………………………………………………………………………………….Contact phone number: ……………………………………………………………

"This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director (Research Ethics), email humanethics@massey.ac.nz. "

Appendix A5: Informed Consent (Adolescent and tertiary students)

Exploring everyday school experiences of high-functioning autistic students.

INFORMED CONSENT – ‘Adolescent student’

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. I understand that I may ask further questions at any time about this project by contacting the researcher, Sharon Crooks (S.Crooks@Massey.ac.nz).

I can stop this discussion at any time by pointing to this stop sign or saying "stop". I do not have to give reasons why I want to stop. I just can.

Please circle the option you agree with.

I agree *OR* ***I do not agree*** to the interview being sound recorded, knowing it can be turned off at any time.

I want *OR* ***I do not want*** a summary of the research findings at the conclusion of the research project.

By signing this form, you agree to participate in this study under the conditions set out in the **Information Sheet.**

Signature: ……………………………………………….

Date: ……………….

Full name – printed…………………………………………………………..

Email address **(if you want a summary of the research findings)**

……………………………………………………………………………

Contact phone number: ………………………………………………………………...

"This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director (Research Ethics), email humanethics@massey.ac.nz. "

Appendix A6: Authority for the release of transcript

Exploring everyday school experiences of high-functioning autistic adolescents.

AUTHORITY FOR THE RELEASE OF TRANSCIPT

I have had an opportunity to read the transcript of the interview and have made the changes I want to make to it.

I agree that Sharon Crooks can use extracts from this transcript in reports and publications arising from the research.

Signature: .... **Date:** ....

Full Name - printed ....