“Why Can’t You Learn a Bit of Autism?”

The Benefits of Peer Support Groups for Autistic Adults from the Perspective of Participants

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Abstract

An increasing body of research literature indicates that adults on the autism spectrum continue to experience difficulties with communication, social interaction, and social inclusion throughout their lifetimes. The question of what support is needed for Autistic adults is recognised to be an important area of concern, but to date, has been relatively neglected. This study set out to explore the benefits of peer support for Autistic adults from their perspective. The secondary aim, was to consider how this knowledge might inform the way we develop supports and services for current and future generations. Four adults who self-identified as Autistic, participated in semi-structured interviews, and answered questions about their experiences of peer support. Data was analysed using an Interpretative Phenomenological Analysis approach, which places emphasis on the meaning participants attribute to life experiences, and is presented in the form of a reflective engagement with the researcher. Results yielded a number of themes across participants, clustered around the following topics: connection, communication, community, mental health, environments, and self-growth. All participants saw participation in Autistic peer support as being of benefit to themselves and an opportunity to help and educate others. Peer support was conceptualised as a place of safety, transformation and self-growth. Participant descriptions were at variance with a medical model of autism but aligned with theories of autism as a social and cultural construct. Participants spoke of claiming Autistic self-identity and identified with Autistic culture. Implications for practice include the importance of (1) recognising the value of expertise from experience; (2) including the perspectives of Autistic people in research and practice; (3) considering autism in the context of cultural competency; and (4) ensuring professionals working with, and alongside, people in the Autistic community are as well informed about autism as those they seek to help. A number of novel and unexpected research outcomes are also discussed.

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Researcher's note on language used in this report

> Being attentive to how we use language to describe people, that is, 'being aware, for example, of how different words impact on different speech partners in different situations' (Lee, 1997, p. 448) – in the research laboratory, in the clinic, in schools and in the community – should go some way towards improving society's understanding of autism and the well-being of those on the autism spectrum. (Kenny et al., 2015, p. 1)

Some researchers and authors writing on the topic of autism are choosing to introduce their work by providing a rationale for their choice of terminology used to describe it. This is partly in response to tensions surrounding the language of autism that will be discussed in depth later in this report, but also as a way of acknowledging the author's social and ideological perspective to the reader.

This research project will be informed by the social model of disability.[1] Identity first language[2] (i.e. "Autistic person") and "on the autism spectrum", will be used as default terms to refer to people on the autism spectrum. In a stance related to that taken by the Deaf community, some Autistic advocates have chosen to capitalise the word "autistic" as a sign of respect for their community as a distinct and valued entity (Wrong Planet, 2014). Out of respect for this position, capitalisation of the word "Autistic" will be adopted when referring to an Autistic individual, Autistic culture, or to the Autistic community. For the sake of clarity and consistency, the term Autism Spectrum Disorder (ASD) will be used when referring to a clinical diagnosis of autism. However pathologising terms, such as "disorder" or "condition", will not otherwise be used, unless they appear in quoted material. Quotation marks will be used to indicate that sensitive terms, such as "mentally retarded" or "feeble minded", are being referenced in relation to a specific historical context, and to acknowledge how the sense conveyed by each has shifted over time. Many of these terms were themselves introduced as euphemisms, and as concepts of "disability", "gender", "sexuality", "ethnicity" and "normality" continue to be challenged and shift, the language we use to describe each other will also certainly evolve.

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[1] More information about the social model of disability will be provided in the introduction

[2] Further discussion of identity first language and person-first language will be provided in the introduction

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Introduction

Parents/caregivers of children given a diagnosis of Autism Spectrum Disorder (ASD), often first seek help because of concerns about speech and language development, therefore a speech language therapist (SLT) is often one of the first professionals they come into contact with (Ministries of Health and Education (MOHE), 2016; Shepherd, Landon, Goedeke, Ty, & Csako, 2018). As social communication difficulties are a core diagnostic feature of autism, SLTs are uniquely qualified to offer support at all stages of a person's life, and best practice guidelines around the world recommend SLTs are included in any multi-disciplinary team involved with assessment, diagnosis or intervention (ASHA, 2019; Ministries of Health and Education [MOHE], 2016; National Institute for Health and Care Excellence [NICE], 2019).

Based on overseas data, the *New Zealand Autism Spectrum Disorder Guidelines* suggest there may be more than 40,000 people in New Zealand (NZ) who have ASD (MOHE, 2016, p. 11). More males are diagnosed than females, with a commonly reported male:female ratio of approximately 4:1 (Loomes, Hull, & Mandy, 2017). However as it is increasingly being recognised that girls are going undiagnosed, or are being misdiagnosed, it is likely the overall numbers are much higher (Loomes, Hull, & Mandy, 2017; Pellicano, Dinsmore & Charman, 2014; Satchell, 2016). Young people with the diagnosis are moving into adulthood, and as awareness of autism becomes more widespread, a growing number of adults are self-identifying or seeking diagnosis later in life (Lewis, 2017; MOHE, 2016).

An increasing body of research literature indicates that adults on the autism spectrum continue to experience difficulties with communication, social interaction, and social inclusion throughout their lifetimes (Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016; Howlin et al., 2015; Magiati, Tay, & Howlin, 2014; Muller, Schuler, & Yates, 2008); higher rates of unemployment than their peers (Hendricks, 2010; Roux et al., 2013); and higher rates of suicide and mental health problems such as anxiety and depression (Hirvikoski et al., 2016). The question of what support is needed for Autistic adults is recognised to be an important area of concern, but to date, has been relatively neglected (Howlin et al., 2015; Pellicano et al., 2014).

In my role as an SLT, but also as a teacher aide and voluntary buddy in the community, I have met and worked with children and young people on the autism spectrum, with a wide range of abilities. Many of these young people have experienced bullying, exclusion and social rejection, and I have seen how their response is often to “act up” or “shut down”. I have also met parents who report feelings of frustration at not being able to get their teens “out of their bedrooms”, and have expressed fears about how they will fare in adult life without them.

Out of a desire to learn more about how SLTs might better support these families and young people into adulthood, I attended the 2017 “Transitions Altogether Autism Conference”. Altogether Autism is an information and advisory service that, along with Autism New Zealand, is one of the largest charity organisations providing education for families and community members nationwide (Altogether Autism, 2019a; Autism New Zealand, 2019). In his conference handbook welcome note, Mark Brown (2017), Chief Executive of disability support charity Life Unlimited, described this as “a unique opportunity to be immersed in autistic culture, as well as being updated on recent research, new initiatives and best practice in support for autistic people and families” (p. 2).

I was to learn a lot over my two days at the conference, but two things struck me straight away. Firstly, I found myself surprised to see the number of adults on the autism spectrum, who were hosting presentations and workshops. Nine of these presentations concerned peer support initiatives set up by and for Autistic people, in the United Kingdom (UK) and Australia, as well as here in NZ. This was something that, until then, I had heard little about.

Secondly, I noted that while some people were using the person-first language I was used to hearing in my professional work (i.e. “person with autism”), many others - notably those speaking from the point-of-view of lived experience - were using identity-first language (i.e. “autistic person”). The language we use to describe ourselves and others is important, as it embodies our sense of identity, but also reflects and helps change societal attitudes and stereotypes, so I was curious about what had prompted this “divide”.

Person-first language was first advocated for by health and disability rights organisations in the late 1980s, in an attempt to reduce stigma and social subordination (Dunn & Andrews, 2015). The rationale was to restore humanity to those who felt they were being defined by a condition, diagnosis, or trait (e.g. “a homeless man”), by putting the condition or disability second, so it is something the person *has*, rather than *is* (e.g. “a man who has experienced homelessness”). Person-first language has since been adopted by many academics, professionals, and government organisations worldwide (Kirszenbaum, 2015) and in the *New Zealand Autism Spectrum Disorder Guidelines* (MOHE, 2016), “individuals/person with ASD” is the terminology currently used.

In contrast, the Office for Disability Issues (ODI) outlines a process of consultation that led to their decision to use identity first language in the recently revised *New Zealand Disability Strategy* (ODI, 2019). The authors state: “For some of us the term ‘disabled people’ has come to be a source of pride, identity and recognition that disabling barriers exist within society and not within us as individuals” (ODI, 2019, p. 13). This perspective is aligned with a reaction against a medical model of disability, which “views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals….to 'correct' the problem with the individual” (World Health Organisation (WHO), 2002, p. 8). And a shift towards a social model of disability that sees:

> … disability as a socially- created problem and not at all an attribute of an individual. On the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment. (WHO, 2002, p. 9)

Autistic advocate Lydia X. Z. Brown (2011), summarises how these two perspectives inform the way we describe autism, raising important questions about power and self-identity:

> When we say “person with autism,” we say that it is unfortunate and an accident that a person is Autistic. We affirm that the person has value and worth, and that autism is entirely separate from what gives him or her value and worth. In fact, we are saying that autism is detrimental to value and worth as a person, which is why we separate the condition with the word “with” or “has.” Ultimately, what we are saying when we say “person with autism” is that the person would be better off if not Autistic, and that it would have been better if he or she had been born typical. We

> suppress the individual's identity as an Autistic person because we are saying that autism is something inherently bad like a disease.
>
> Yet, when we say "Autistic person," we recognize, affirm, and validate an individual's identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual's potential to grow and mature, to overcome challenges and disability, and to live a meaningful life as an Autistic. Ultimately, we are accepting that the individual is different from non-Autistic people — and that that's not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference. (p. 1).

In the UK, the National Autistic Society (NAS), the Royal College of GPs, and the UCL College of Education, recently conducted research to explore which words people prefer to use to describe people on the autism spectrum (Kenny et al., 2015). A sample of 3,470 people, including Autistic adults, friends and families of children and adults on the autism spectrum, and relevant professionals were surveyed. Their results showed that professionals liked the term ASD. Autistic adults liked the identity-first terms "Autistic" and "Aspie". Families didn't like "Aspie". All groups liked the terms "on the autism spectrum" and "Asperger syndrome", and some terms were strongly disliked or no longer used, particularly "low functioning", "Kanner's autism" and "classic autism" (NAS, 2018a).

A clinical diagnosis of ASD necessarily requires evidence that a person is "abnormal" or "atypical" in a number of ways (Volkmar, 2019). This in turn implies there are other people who are "typical" or "normal". In their media guide, "How to talk about autism", (NAS, 2018c) advised against using the word "normal", suggesting instead a term I also heard in frequent use at the Altogether Autism conference: "neurotypical" (NT). The origin of the term NT is attributed to Autistic forums in the mid-1990s, where it was used to describe people who were not on the autism spectrum (Silberman, 2015). Autistic advocate and scholar, Nick Walker (2014), offers an expanded definition of NT as those with a style of neurocognitive functioning that falls within the dominant societal standards of "normal", as opposed to "neurodivergent", which refers to those who are on the autism spectrum, or have any other developmental neurological difference (p. 1). While the term NT is not yet accepted in medical circles, it has gradually become more mainstream (Healthline, 2018). How language and the experience of being "labelled" can inform a person's sense of self, and have both negative and positive influences, was the subject of several presentations at the Altogether Autism conference, notably Jason Edgecombe's "Shattering Your Cage" (Altogether Autism, 2017, p.68), and Madison Ward's, "What about me. I'm normal 2" (Ward, 2017).

During one of my breaks I reflected on having discovered that a much wider discussion was taking place about autism in my own community than I had previously been a part of. In order to better understand the position Autistic adults find themselves in, I recognised I needed to better understand the issues they face, from their point of view. By chance I met a young adult wearing a badge that read: "Ask me about my autism", and so I did. He told me about a cluster of peer support initiatives he was involved with. One of these, was a social group for Autistic adults that has been meeting for almost 10 years, and has grown from six participants to nearly 100. The group is now forming a trust to advance pilot schemes around work, housing and advocacy. Participants of the group include some of our first generations of Autistic adults who have grown up with a clinical diagnosis, and others who are "late-diagnosis" adults, or who have "self-identified".

Learning more about how - and why - Autistic adults were coming together to support each other as peers, and the benefits of this from their perspective, seemed to warrant further investigation.

What is autism?

> In order to understand what we think childhood isn't we need first to understand what we believe childhood is. Put another way, to appreciate how we define what makes an abnormal child (such as the ASD child) we need to understand how we define a 'normal' child. (Timimi, Gardner, & McCabe, 2011, p. 45)

The term "autism" derives from the Greek *auto* (self) and *ismos* (condition) (Grinker, 2007). Frith (1991) attributes the first use of the term to Swiss psychiatrist Eugen Bleuler, who used it to describe the type of "loss of contact with reality" (p. 38) he observed in those diagnosed with schizophrenia. While in the first half of the 20th century, a number of workers in the field of "abnormal child development" were attempting to define subgroups within what was commonly called "childhood psychoses" (Wing, 1997, p. 15), the discovery of autism as a distinct condition, is generally attributed to two papers published within a year of each another: “Autistic Disturbances of Affective Contact” by US-based physician Leo Kanner (1943), and “Autistic Psychopathy in Childhood” by Austrian pediatrician Hans Asperger (1944).

It is worth revisiting Kanner and Asperger’s original texts as, while some of the language used may be confronting to a modern reader, they provide rich and detailed information, not only about the “peculiarities” of the subjects they came to know, but also illuminating the complexities of trying to understand and categorise other people through observation of their behaviour.

For Kanner (1985), what distinguished the 11 children he studied from those otherwise labelled “feeble minded”, “schizophrenic”, or “emotionally disturbed”, was an inability to relate in the “ordinary way” to people and situations, which was present from birth:

> … these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps. (p. 50)

Kanner noted that many of the children in his sample demonstrated an “excellent rote memory” and could recite long nursery rhymes or lists, but seemed to lack interest in, or even an understanding of, language as a tool for receiving and imparting meaningful messages. At the core of Kanner’s “disorder of affective contact” is what he terms an “*extreme autistic aloneness”* that wherever possible disregards, ignores, shuts out anything that comes to the child from outside:

> Direct physical contact or such motion or noise as threatens to disrupt the aloneness is either treated ‘as if it weren’t there’ or if this is no longer sufficient, resented painfully as distressing interference. (p. 41)

Kanner also observed what he described as “an anxiously obsessive desire for sameness” (p. 44) and felt, overall, that the children demonstrated better engagement with objects than with people:

> Objects that do not change their appearance and position, that retain their sameness and never threaten to interfere with the child’s aloneness, are readily accepted by the autistic child. (p. 46)

Asperger (1991) presented four case studies of "a particularly interesting and highly recognisable type of child" (p. 37) whom he describes as "Autistic":

> The children I will present all have in common a fundamental disturbance which manifests itself in their physical appearance, expressive functions, and indeed, their whole behaviour. This disturbance results in severe and characteristic difficulties of social integration. In many cases the social problems are so profound that they overshadow everything else. In some cases, however, the problems are compensated by a high level of original thought and experience. This can often lead to exceptional achievements in later life. (p. 37)

Asperger attempted to summarise characteristics that Autistic children have in common but also acknowledged ways in which they may be different and distinguished from each other, "not only by the degree of contact disturbance and the degree of intellectual ability, but also by their personality and their special interests, which are often outstandingly varied and original." (p. 67). Notably, Asperger also acknowledged the "potential value" of Autistic people to society, and introduced the idea of "Autistic intelligence":

> Behind the originality of language formulations stands the originality of experience. Autistic children have the ability to see things and events around them from a new point of view, which often shows surprising maturity. (p. 71)

Asperger also gives examples of how individualised teaching strategies can improve outcomes, to "demonstrate the truth of the claim that exceptional human beings must be given exceptional educational treatment" (p. 37) and "show that despite abnormality human beings can fulfil their social role within the community, especially if they find understanding, love and guidance" (p. 37).

Kanner and Asperger both considered atypical social behaviour to be a core attribute of the children they studied, however they interpreted the cause of this behaviour somewhat differently. Kanner believed Autistic children are not only disinterested in other people, but are fundamentally *unable* to form emotional connections with others:

> When with other children, he does not play with them. He plays alone while they are around, maintaining no bodily, physiognomic, or verbal contact with them. He does not take part in competitive games. He just is there, and if sometimes he happens to stroll as far as the periphery of the group, he soon removes himself and remains alone. (Kanner, 1985, p. 47)

Kanner also highlighted instances of these traits in some of the children's parents, and influenced by psychoanalytic theories that were prevalent in the psychiatric profession at the time, suggested their children's condition might be due to cold, detached parenting (Kanner, 1985; Wing, 1997).

Asperger, on the other hand, noted the children he observed experienced "social problems", but described these as "difficulties in social *integration* [emphasis added]" (Asperger, 1991, p. 37). He went on to give examples of "odd" behaviour which resulted in communication breakdowns, but attributed this to a "lack of understanding" on both sides, and noted how this can compound the child's other difficulties, resulting in feelings of "failure and frustration in the practical matters of life" giving rise to "scenes" and to "negativistic and malicious reactions" (pp. 78-79). He also observed "that autistic children are often tormented and rejected by their classmates simply because they are different and stand out from the crowd" (p. 79), and gave examples of how all of these problems can further compromise a child's ability to learn from others. Asperger acknowledged that socialising is a process, and is relational, thereby created a picture of Autistic social difficulties that was more multi-dimensional than Kanner's.

Interestingly, Asperger also described a "kind of introspection" in the children he studied, which rather than making them oblivious to others, gave them a certain "clear sightedness" in judging character:

> Just as these children observe themselves to a high degree, so they also often have surprisingly accurate and mature observations about people in their environment. They know who means them well and who does not, even when he feigns differently. They have a particular sensitivity for the abnormalities of other children. Indeed, abnormal as they themselves may be, they are almost over-sensitive in this respect. (Asperger, 1991, p. 74).

While there are some important differences between the children described by Kanner and Asperger, they clearly shared many of the same characteristics. Despite this, Kanner's name came to be associated with the term "classic" autism ("Kanner's autism"), a more "severe" form of autism, associated with those who appear "withdrawn", are non-speaking, or have "intellectual disability" (Silberman, 2015; Wing, 1997). Asperger's name, on the other hand, came to be associated with those often described as "mildly autistic", who might be highly verbal, or have savant skills (Barahona-Correa & Filipe, 2015; Wing, 1997).

Major contributions to the scientific study of autism in the 1960s and 1970s, included the first epidemiological study of “Kanner’s autism” (Lotter, 1966); a series of studies by Rutter (1970), who created profiles including clinical features, intelligence testing, and follow-ups into adolescence and adult life; and notably a series of studies by DeMeyer (1975, 1979) who studied the parents of Autistic children, and found no evidence they caused their children to be Autistic through abnormal childrearing practices (Wing, 1997). Wing and Gould (1979) conducted prevalence studies, but looked for children who had any feature of “autistic behaviour”, not just those who had typical Kanner’s autism, and as a result of this, broadened the criteria for autism and went on to develop the hypothesis of a spectrum of autistic conditions (Wing, 1996).

It wasn’t however until 1980, that the *Diagnostic and Statistical Manual of Mental Disorders 3rd Edition (DSM-III)* gave autism diagnostic status for the first time, when “infantile autism” was included in a new class of disorders termed “Pervasive Developmental Disorders” (American Psychiatric Association [APA], 1980). The *DSM* manual was an attempt by the APA to standardise the diagnosis of “mental disorders”, partly in response to the need for mental health services after World War II. The first edition was published in 1952, and was intended for use in clinical, research or administrative settings (APA 2018; Silberman, 2015). The most recent edition, the *DSM-5* (APA, 2013), has aligned its “billable codes” for various disorders with the WHO (2016) *International Statistical Classification of Diseases and Related Health Problems (ICD-10)* (APA, 2019). The ICD-10 is the more commonly used diagnostic reference in the United Kingdom (NAS, 2018b).

Currently, most professionals’ understanding of autism is related to the “triad of impairments”, namely: impairment of social interaction; impairment of social communication; and restricted and repetitive patterns of interests/activities (Wing, Gould, & Gillberg, 2011). First formulated by Wing and Gould (1979), the “triad” was considered a clinical and theoretical breakthrough, bringing clarity and coherence to otherwise very heterogeneous and seemingly unrelated clinical phenomena, and paving the way for the recognition of “high-functioning” forms of autism (Happe & Baron-Cohen, 2014). The concept of the “triad of impairments” has had a long-lasting impact on diagnostic and assessment methods, and formed the basis of the diagnostic criteria for “Autistic Disorder” in the revised *DSM-IV* (APA, 1994), when Asperger’s Syndrome (AS) was also listed for the first time as a separate diagnosis (Barahona-Correa & Filipe, 2015). AS was later removed from *DSM-5* (APA, 2013), when the idea of autism as a “spectrum” was first introduced, and in clinical terms, autism is currently described as “Autism Spectrum Disorder (ASD)” (Wing, Gould, & Gillberg, 2011).

While a clinical diagnosis of ASD is currently made on the basis of the *DSM-5*, or the *ICD-10*, it is by no means clear that autism is either a mental disorder, a disease, or even a health problem at all. It should also be noted that while the *DSM* manual is widely used, it has also been the subject of controversy, even within the health professions themselves. In his 2013 book, *Saving normal: An insider’s revolt against out-of-control psychiatric diagnosis, DSM-5, big pharma, and the medicalization of ordinary life*, psychiatrist Allen Frances, who was Chair of the Task Force that published *DSM-IV*, critiqued the role of *DSM* codes as increasingly “stigmatizing” what he sees as healthy people, as mentally ill. In a review of Frances’ (2013) book for USA Today (Jayson, 2013), Stuart Kirk, a Professor Emeritus of Social Welfare at UCLA, who has been tracking the *DSM* for decades, was quoted as saying:

> The whole disease model that underlies the DSM has been an utter scientific failure. There's not a single biological marker for any of the 300-plus disorders. What we do instead is descriptive. This describing is creating a disorder and pretending it's a medical illness rather than just human behavior. (p. 1)

A UK National Health Service (NHS) (2013) news analysis, provided a review of both criticism and praise for the *DSM-5*, but concluded by advising its readers: “Rather than seeing the DSM-5 as the ‘Psychiatric Bible’, it may be better to think of it as a rudimentary travel guide to a land we have barely begun to explore” (p. 1).

A clinical diagnosis of autism has always been - and still is - made solely on the basis of behavioural observation which may be supported by self- or parent/caregiver reports (MOHE, 2016; NAS, 2018b; Prior & Ozonoff, 2007). Since the early days of autism being recognised as a distinct syndrome, attempts to definitively link autism to any given set of physical, biological, neurological, or genetic markers have remained elusive (Arnett, Trinh, & Bernier, 2019; Jumah, Ghannam, Jaber, Adeeb, & Tubbs, 2016; Modabbernia, Velthorst, & Reichenberg, 2017).

The current consensus is that autism is related to neurological differences and that these emerge from a genetic predisposition. However all that is known with any certainty is that those with a diagnosis of autism have an increased risk of epilepsy (Sundelin et al., 2016), and that children are more likely to be diagnosed in families where autism is already present (Arnett et al., 2019; Jumah et al., 2016). Epidemiologist Grether (2006) explains how this is a confounding factor for both research methodology and in establishing prevalence:

> Achieving accurate, complete, and unbiased ascertainment of individuals affected with ASD is challenging. Because diagnosis depends on clinical recognition of the behavioral characteristics that define the disorder, diagnoses typically cannot be made until early childhood and are based on application of behavioral criteria that are inevitably somewhat subjective. Children are commonly assessed in outpatient settings not amenable to standardized application of diagnostic procedures or to centralized record keeping. Lacking a reliable, objective diagnostic test or biomarker, it is probably inevitable that there will be biases in diagnosis associated with cultural factors and eligibility requirements for available services. In addition, restrictions on access to confidential medical or educational records in some settings can severely hamper efforts to achieve complete and unbiased ascertainment. Within these constraints, it is difficult to apply a consistent surveillance case definition for comparison of prevalence across time and/or geography. (pp. 119-120)

Despite this, the numbers of people diagnosed with autism have grown exponentially, along with a steady stream of newspaper headlines announcing “scientific breakthroughs” based on “promising” or “speculative” studies, such as a hearing test that could diagnose new-born babies (NHS, 2019a), research that suggests “rain” could “trigger autism” (NHS, 2019b), and new theories about the influence of gut bacteria (Newman, 2018). There is also a long history of cases of people using scaremongering and pseudoscientific claims to support false causes and harmful “cures” and “treatments” for autism, such as Jim Humble who is currently distributing an increasingly popular bleach enema “solution” to parents seeking to cure their children’s autism, and most famously, discredited former UK doctor Andrew Wakefield, who has been charged with serious professional misconduct for fraudulently suggesting links between the MMR vaccine and autism (Grimes, 2015; Offit, 2008). Wakefield continues to be active in the US, where he is at the forefront of a movement of “anti-vaxxers” who campaign against vaccinations, in the mistaken belief that they are responsible for the “autism epidemic” (Buncombe, 2018; Silberman, 2015). Comprehensive studies have failed to prove any link between autism and vaccines (Altogether Autism, 2019b; Center for Disease Control and Prevention [CDC], 2018a; Maglione et al., 2014) and there is no conclusive evidence of a link between autism and environmental factors such as diet, or toxins such as lead or mercury (Modabberniaet al., 2017).

While most researchers believe the increase is the result of a broadening of diagnostic criteria, and more widely available access to diagnosis, leading to higher rates of people being diagnosed (prevalence) rather than an increase in population numbers (incidence), autism is frequently referred to as a threat or a national emergency. President Bush’s Combating Autism Act, passed by congress in 2006, was reported as “a federal declaration of war on the epidemic of autism” (O’Keefe, 2006, p. 1), and saw almost $1 billion dollars pledged to track and help find cures for the “health crisis”, which, the CDC continues to describe as a “significant economic burden” to the country (CDC, 2018b, p. 1). In 2009, Autistic advocates and allies reacted swiftly and passionately to an advertising campaign run by Autism Speaks, which included an ominous voice-over, warning: "I am Autism ... I know where you live ... I live there too ... I work faster than pediatric AIDS, cancer and diabetes combined ... And if you are happily married, I will make sure that your marriage fails." (Wallis, 2009, p.1). Autism Speaks continues to be named a “hate group” by many in the Autistic community for promoting “hostility” and “malice” against disabled people (Sequenzia, 2014, p. 1).

The majority of research funding for autism continues to be focussed on establishing a genetic, neurological or biological cause (Zwicker & Emery, 2014). Pellicano et al. (2014) conducted a comparative survey of United States (US) and United Kingdom (UK) autism research grants and priorities between 2007 and 2011, and found that projects in the areas of biology, brain and cognition far outstripped all other areas of autism research both in terms of awards made and money spent. Comparatively little research funding was targeted towards identifying effective services for Autistic people and their families or societal issues (Strauss, 2018). A recent report on behalf of the US Interagency Autism Coordinating Committee (IACC) (2019) identified nine US federal agencies and nine private providers, who in 2016, invested over $364 million in ASD research. Projects targeting screening and diagnosis, genetics and biology, risk factors, treatment and surveillance received a total of 83% of the funding, and those concerned with services and lifespan issues received only 17% (IACC, 2019).

Claims that intensive early intervention will save millions of dollars in subsequent decades by reducing the "symptoms" of autism also remain unsupported by any direct evidence (French & Kennedy, 2018; Green & Garg, 2018). A recent round table report by Howlin et al. (2015) summarised a number of studies and reviews that show highly variable trajectories even among Autistic individuals "with normal IQ", and while the authors acknowledged diagnostic and intervention services have improved for children over the decades, they concluded that "almost nothing is known about the factors that determine outcomes" (Howlin et al., 2015, p. 389):

> Although cognitive and communication skills clearly have some impact, there is a lack of information on the role of other characteristics such as social competence, early ASD severity, personality and temperament, or physical and mental health. The long-term impact of external factors including family stress, cultural or ethnic background, social support networks, or access to specific interventions or educational programs as children is also unknown. (p. 389)

While efforts to define a medical model of autism are ongoing, another discussion has been taking place from the perspective of anthropology, cultural studies, philosophy, and the social sciences, questioning whether autism is in fact a contemporary epidemic, has always been amongst us, or even exists at all.

Silverman (2012), Director of the US Center for Science, Technology and Society, is concerned with social practices as symbolic systems, in particular, she is interested in the emotional content of scientific and biomedical practices (pp. 2-6). In *Understanding autism: Parents, doctors, and the history of a disorder*, Silverman (2012) considered the ethics of "treating" autism, the construction of "illness based identities" and who has the authority to decide whether something is a pathology or a normal difference. Silverman explored how decisions about the “treatment” and care of people with autism may be presented as “evidence based”, but have always had an ethical dimension (pp. 8-9):

> Scientists have adopted styles of observation that emphasize impartiality and objectivity…As scientific work became more collaborative the problem of knowing whether or not to trust an individual’s observations or experimental results became a crucial one. (pp. 5-6)

Silverman outlined a history of attempts to attribute to Autistic children various “failures”, such as an inability to “love”, an “abnormal personality structure”, a lack of “theory of mind” (or “mindreading”), or “weak central coherence” (the ability to organise and synthesise information), to illustrate the history of this “modern disorder” as “resolutely experimental”. Silverman acknowledged the growing number of Autistic adults arguing for the validity of Autistic experience and Autistic culture, and the need to “address what treating autism can mean in terms of respecting and acknowledging the personhood and rights of people with disabilities” (p. 7). Silverman concluded with a call for more “empathetic scholarship” and reciprocal investment in research:

> Scientific work involves interpersonal relationships, and in order to comprehend these relationships we have to form some ourselves. Mark Osteen, in confronting this problem, has proposed what he calls “empathetic scholarship”. Researchers should try “speaking with those unable to communicate entirely on their own,” by combining rigorous scholarship with the experiential knowledge” acquired through kinship and friendships with autistic people. (p. 233)

In his book *Unstrange Minds: Remapping the World of Autism*, cultural anthropologist Grinker (2007), father of an Autistic daughter, presented the perspectives of people he interviewed in America, South Korea, South Africa, Peru and India, interwoven with the parallel story of his own family coming to know their Autistic daughter and sibling, to demonstrate how: “autism, like all disorders, does not exist outside of culture. It is culture that sees something as abnormal or wrong, names it, and does something about it, and all cultures respond to illness differently” (pp. 11-12). Grinker argued that by shifting the focus from “data” and “reasoning”, to the primacy of experience, new insights might be gained into what any given culture considers normal:

> Ironically the process of understanding autism itself parallels the work that anthropologists do, since the minds of people with autism are sometimes as hard to understand as foreign cultures…Our goal is to make the strange familiar. Indeed,

> with every day that passes, as autism advocates, parents, and researchers teach us about the complexity of human behaviour, autism seems less exotic and more "unstrange"….But cultural anthropologists also try to make the familiar strange, seeking to turn our gaze homeward and see our own culture in a new light….As we'll see, the discovery of autism wasn't so much a discovery of new truths as a new way of seeing a group of cognitive and social differences. Although it's likely that autism has existed among humans for at least hundreds of years, until very recently no one thought to create a distinct category for it because our culture - our social, educational, and medical systems - was not ready for it. (p. 13)

In *Autism and the Edges of the Known World: Sensitivities, Language and Constructed Reality*, Bogdashina (2010) gave examples of how "unusual sensory responses" have been identified and reported from the earliest descriptions of autism, including "bizarre reactions" to sound, touch, sights, taste and smell (p. 17). A linguist and autism researcher with a special interest in sensory-perceptual problems, Bogdashina cited the work of a number of psychologists, psychiatrists and Autistic people themselves, who have suggested that it is this higher degree of sensory sensitivity which causes people to acquire defensive strategies to protect themselves from overload, which, in turn, results in the developmental distortions that are reflected in the "autistic condition" (p. 17).

Bogdashina argued that while we accept some animals have sensory receptors that are alien to humans, we are generally less open to the possibility that within our own species there may many different sensory realities, and ways of interpreting those realities, which in turn might contribute to us living in fundamentally different perceptual worlds. Bogdashina describes how Autistic people have reported relying on "intuition", and developed their own theories , rather than accept what they are told by others, because they recognised they just didn't "see" things the same way (pp. 88-89). Bogdashina also suggested the types of sensory "hypersensivities" described by Autistic people - including being hypersensitive to the emotions of others - are likely to have been present in our culture throughout time, but may have been variously described as premonition, precognition, telepathy, or the paranormal:

> …we have to admit given the way we interpret what we see that our "normally" functioning senses and brain reveal an extremely limited range of reality. The question is: is the "normal" interpretation necessarily the "correct" one? (p. 26)

Interestingly, Bogdashina explored how differences in sensory perception might affect the way a person integrates information to form concepts, such as those related to language acquisition. In support of this, Bogdashina cited the work of Autistic artist and writer Donna Williams, who devised her own theories of "autism and sensing" (p. 114). Williams distinguished between what she described as "the language of sensing" and the "language of interpretation". Williams argued that if the cultural concepts we exchange are related to agreed meanings based on shared perception, then when those perceptions are fundamentally different, communication breakdowns are bound to occur (pp. 114-115). In her own life, Williams stated that she "struggled to use the 'world' language to describe a way of thinking and being and experiencing for which this world gives you no words or concepts" (p. 115).

Bogdashina also considered how Autistic people who are non-verbal might "think", and referred to the work of Temple Grandin, who described being able to "think in pictures without words", something Grandin believed enables Autistic people to "directly access primary parts of the brain that are not accessible to verbal thinkers" (p. 121):

> So many professionals and non-professionals have ignored sensory issues because some people just can't imagine that an alternate sensory reality exists if they have not experienced it personally….That type of narrow perception, however, does nothing to help individuals who do have these very real issues in their lives. Even if they don't understand it on a personal level, it's time they put aside their personal ideas. (p. 19)

Barry Prizant is a Speech Pathologist from the US, with over 40 years' experience providing "hands-on" support to children on the autism spectrum, and co-developer of the SCERTS© Model (Social Communication, Emotional Regulation and Transactional Support) intervention framework and resource (Dr. Barry M. Prizant, 2019). In his 2015 book, *Uniquely Human: A Different Way of Seeing Autism*, Prizant gave first-hand examples of the experiences that have shaped his theory that, while autism is defined by a person's behaviour, there are in fact "no such thing as autistic behaviors. These are all *human* behaviors and *human* responses based on a person's experience" (p. 5). Prizant went on to state his belief autism can best be understood as "a disability of trust" (p. 84):

> When our sense of trust is challenged and we feel frightened and anxious, our natural response is to try to exert control. Some autism professionals speak of control in

> negative terms….But when you understand the underlying motivations, it becomes clear that many of these behaviors represent strategies to cope with anxiety or dysregulation. (p.84)

Prizant suggested that the need for control might also express itself as a preference for certain foods, how they are served, and rituals surrounding eating which make the world feel safer and more dependable, thus adding to a growing acknowledgement of the associations between sensory issues in Autistic people, and sensitivities around eating and drinking (Taylor, 2016). Prizant explained this is why he believes the strategies Autistic people use to "self-regulate" should be shown more respect. He argued that when the ultimate goal of professionals is to reduce or eliminate these behaviours, this can actually result in making things worse for an Autistic person. They should instead be asking *why* a person is behaving a certain way (p. 27).

In an article for the UK *Independent*, "*ADHD: Being different is not an illness*", Sutcliff (2011) stated that in America, Attention Deficit Hyperactivity Disorder (ADHD) is "now the second most frequent long-term diagnosis made in children, narrowly trailing asthma, and generating pharmaceutical sales worth US$9 billion per year. Yet clinical proof of ADHD as a genuine illness has never been found" (p. 1). In the same article, Timimi, Consultant Child Psychiatrist at Lincolnshire NHS Trust, was quoted as saying:

> We see ourselves as being increasingly tolerant towards children, but the rise in medication for the young is an indication of the opposite trend. "In some cultures children are loved unconditionally," he [Timimi] says, but in the West we have a more "performance oriented approach, where children are valued primarily for their achievements. At the same time, educational demands are rising." This is an approach that we are now exporting to the East, and with it, a medical "solution" for those children who can't keep up with the rising pressures. (Sutcliff, 2015, p. 1)

In *The Myth of Autism: Medicalising men's and boy's social and emotional competence* Timimi et al. (2011) set out to explore the history of autism from the perspective of science, politics and personal experience. Timimi et al. examined how the construct of autism has not only been subject to the "changing whims of influential academics and researchers", but has also been influenced by the dominant beliefs in a given culture, and that certain forces - in particular economic and political - have a big hand in shaping the nature of these beliefs and associated practices over time (p. ix). For example, the authors suggested that in the context of contemporary neo-liberal politics, the high rate of men and boys diagnosed with autism and ADHD, may in part be related to a stigmatising of those who don't meet the needs of a changing 21st-century workplace:

> The dominant competitive, narcissistic, masculine [neoliberal] culture led to ideas such as cultivating "emotional intelligence" in management and working relations becoming more popular in the 1990s, as a way of developing "better" ways to motivate the workforce and manipulate the consumer. Thus, modern Western culture demands more convoluted and complicated forms of socialising than in the past or in many other modern cultures. These new demands for strong "people skills" in the workforce contrast with "traditional" male labour that revolved around solidarity in a community of men doing jobs that didn't require strong empathising skills. These changing roles mean there is greater political and personal demand for men to have enhanced social competence. Finally, we noted the paradox that being able to use "empathy" to manipulate others is desirable, while being compassionate and responsible, but lacking the above "social skills" to express this in society's terms, is more likely to be labelled as disordered - as being autistic. (pp. 232-233)

In this context, the authors argued "diagnostic labelling" could be seen as a type of "therapeutic violence" that contributed to social inequality, self-blame, non-acceptance, and the practise of eugenics (p. 286). After examining scientific literature in the field, Timimi et al. reported being "stunned" at the extent of the absence of any real science that supported either the narrow or the broad construct of autism, and "shocked at the ease with which academics alike have accepted the validity of the diagnosis" (p. 285). While acknowledging that many seek a diagnosis because they are experiencing difficulties, and despite having diagnoses of their own, the authors summed up by saying the only logical conclusion they could come to was that "there is no such thing as autism and the label should be abolished" (p. 286):

> Perhaps the increasing problem of epidemic numbers of children in the West receiving diagnoses of autism is a symptom not of something "wrong" that we should try and cure in the individual, but that it has become a broader barometer pointing to something wrong in the culture/society that invented this. (p. 283)

In *The autism matrix: The social origins of the autism epidemic*, authors Eyal, Hart, Onculer, Oren, and Rossi (2010) consider autism from the perspective of medical anthropology, sociology, and sociomedical sciences. The authors described the rise in the "visibility" of autism as an "aftershock" of the deinstitutionalisation of "mental retardation" that began in the late 1960s, resulting in "a great undifferentiated mass of atypical children" (p. 3) being released into the world, from which gradually new "categories" emerged. The authors noted these changes took place during a post-war period in the West, when the middle-class family was on the rise and "having healthy and normal children became an ethical goal, and adult life fulfillment was seen as a matter of successful parenting" (p. 85). This in turn "saddled parents with the task of representing, advocating for, and translating their children for neighbours, teachers and many others on a daily basis" (p. 233), but also resulted in the promise of "a universal surveillance and placement system that could minimize the risks posed by all childhood ailments…and maximise the potential of each child." (p. 87)

Deinstitutionalisation, Eyal et al. argued, also opened the door for a new class of "experts" dedicated to achieving these goals. The authors describe Kanner as one such "scientific entrepreneur" (p. 87), whose new "category" autism permitted modern child psychiatry to "lay claim at once to the lower-class feeble minded and the middle class 'problem child' and unify them with a single observational field." (p. 88):

> …[autistic children] were in need of careful diagnosis and therapy, which would help them "re-enter the world" and which would "not only bring hidden potentialities to light but can also do something to turn the discovered potentialities into realized actualities." They were not, therefore, "institutional material" but "clinical material" [Kanner, 1949, 4, 10-11, 17-20]. (p. 88)

Eyal et al. argued these "massive" changes in the social organisation of expertise resulted in the formation of a new institutional matrix, that in time, also included community treatment, special education, early intervention programmes, parents and activists, who sought to undermine the dominance of a psychiatric profession they believed had ignored or belittled their experiences (p. 4). Autism is as a result, not only highly visible, "it's become the center of a social world, a universe of discourse complete with its own idioms, modes of seeing and judging, its own objects and devices" (p. 2).

In *Representing Autism: Culture, Narrative, Fascination*, Stuart Murray (2008), an English lecturer and parent to an Autistic son, looked at autism from the point-of-view of storytelling, and noted how an earlier fascination with the "mysteries" of schizophrenia, has been eclipsed by a contemporary obsession with the "mysteries" of autism. Murray explored narratives in what he described as the "acceptance versus cure battleground"

(p. 211) and gave examples of how autism could be figured as either a “threatening and destructive force…[or] a catalyst for love and connection” (p. 165). Murray highlighted the power of storytelling as a way of building bridges between “difference”, and summed up by suggesting that the most pressing issue, is a break-down in our “ability to care”, which he described as “a process of acknowledging, of thinking about, of admitting, debating, listening and sharing” (p. 212):

> There are still too many easy assumptions made, and casual stories told, about this condition. Caring about autism - what we know of it and how we put it in our narratives - is something from which all manner of people can and must benefit. (p. 212)

But as academics and professionals continue to explore what autism is - and means - others, including parents, caregivers, and those in the community who have been diagnosed or identify as Autistic, have been having discussions and debates of their own.

The rise of Autistic advocacy was associated initially with parents and caregivers who formed support groups in an effort to share knowledge and fight for better lives for their children. In the early days many of these parent groups began to invite Autistic adults to conferences to share insights that might help them understand the behaviour of their autistic children, including those who were not able to “speak for themselves” (Eyal et al., 2010, Silberman, 2015; Silverman, 2010). Jim Sinclair (2005) described how he and other Autistic adults attended these events as a way of meeting others like themselves, and as a result began building advocacy movements of their own. However, over time differences between parents and Autistic advocates grew. Sinclair’s 1993 essay, “Don’t mourn for us”, was first presented at an International Conference on Autism in the same year, and is considered by many to be a pivotal moment for the autism rights movement (Silberman, 2015). Sinclair (1993) rejected the “tragedy” narrative he had heard put forward by many parents, counselled them to let go of their “mourning”, and instead to embrace autism as a “way of being”:

> Continuing focus on the child's autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them. For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means. (p. 1)

Sinclair, along with Kathy Grant and Donna Williams, formed Autism International Network (ANI) in 1992, and since 2012 have been hosting their own annual retreat and conference for Autistic people, known as "Autreat" (Silberman, 2015). Other early Autistic advocates include Temple Grandin (1996; 2008), Liane Holliday Willey (1999), John Elder Robison (2007), and New Zealander Jen Birch (2003), who all shared their life stories in books. Many of these have become best-sellers, opening the door for the many Autistic autobiographies (sometimes known as 'autie-biographies') that have followed, which taken together have made a significant contribution to a more progressive understanding of autism (Nadesan, 2005; Silberman, 2015; Van Goldsenhoven, 2017).

The invention of the internet has taken place during the historical period in which autism became more visible, and in parallel, another discussion has been taking place on a growing number of online forums and Facebook groups, such as *Wrong Planet*, *Autistic Women*, and *Autistics Worldwide*, created by, and for, those in the Autistic community (Benford & Standen, 2009; Jordan, 2010; Silberman, 2015). With the advantage of bringing people together globally, this connectivity has also been at the forefront of the Autistic advocacy movement as a social and political force. While many see their diagnoses as cause for celebration, others report negative experiences, (Autism Eye, 2018; Grimes, 2015; Ward, 2018).

The internet has been used to share information and awareness about the abuse of Autistic people through sites such as *International Badass Activists* [IBA] (2019a) and the Facebook group *Âûtistic News Feed* (2019). A number of high profile Autistic advocates such as Ari Ne'eman (co-founder of the Autistic Self-Advocacy Network [ASAN]), Lydia X. Z. Brown (blogging as Autistic Hoya), Emma Dalmayne, Eve Reiland (#autisticandproud), and New Zealander John Greally (The Autistic Cooperative), are considered leaders in what has been described as the "Neurodiversity Civil Rights Movement" (IBA, 2019b). The continued use of seclusion, shock treatment, and Applied Behaviour Analysis (ABA), to "treat" Autistic people are frequent topics on forums, and many of these "front line" advocates have been influential in organising real-world protests, and contributing to legislative change (Brown, 2018; IBA, 2019a; Ryan, 2016, Silberman, 2015).

While some may consider headlines such as “It’s illegal to torture prisoners and animals, but not disabled people” (Brown, 2014) or “#StopTheShock: What’s happening at the Judge Rotenberg Center?” (ASAN, 2019a) to be at the extreme end of advocacy, it is important to note that these practices are lawful and currently taking place. A 2009 US Government Accountability Office (GAO) investigation found there are no federal rules restricting the use of restraints and seclusions in schools, and reported thousands of documented cases of children being handcuffed, locked in closets and subjected to other acts of violence, which in some cases have ended in death (U.S. GAO, 2009). The Judge Rotenberg Educational Center in the US has won a series of legal challenges allowing it to continue to use shock treatment on its students, including a law suit brought by the Massachusetts governor’s office, which first sued to stop the practice in 2013 (Delfin, 2018). The centre, founded in 1971 as the Behavior Research Institute, serves “emotionally disturbed” individuals and those with learning disabilities, many of whom are Autistic. Since its inception it has used the graduated electronic decelerator (GED), an electric shock device developed by the centre’s founder, Matthew Israel (Brown, 2014; Delfin, 2018). In NZ, Ashley Peacock, an Autistic man, was incarcerated as a compulsory treatment patient in an isolated mental health unit, and kept mostly in seclusion. At one point he was reported to have been locked in for two and a half years continuously, allowed out for 30 minutes a day (Johnstone, 2018, p. 1). Despite his parents, allies in parliament, the Human Rights Commission, and Ombudsman advocating for his right to freedom, it took eight years to secure his release, in 2018 (Johnstone, 2018; Stace, 2017). And recently even the UK’s leading Autistic charity organisation, NAS, was forced to take disciplinary action after disability rights campaigners revealed it had been covering up serious abuse at one of its residential homes over a number of years (Autism Eye, 2018; Ward, 2018).

Interventions based on Applied Behavioural Analysis (ABA) are also a target for many Autistic advocates, and some Autistic forums will not allow promotion of ABA, or mention of ABA without a trigger warning (ABA Controversy Autism Discussion, 2017). ABA is considered to be one of the “treatments” for autism that has the best scientific evidence base, and is therefore included in best practice recommendations around the world (ASHA, 2019; MOHE, 2016). ABA is an applied science dedicated to developing procedures that will produce observable changes in behaviour. It is based on the principles of "operant conditioning" and "behavioural modification", through use of reinforcers (aka rewards) and consequeunces (aka punishments). ABA builds on earlier forms of behavioural modification, by first assessing the functional relationship between a targeted behaviour and the environment, then using prompts, modelling and positive reinforcement to motivate learning and reduce "non-desired behaviours". ABA techniques have been used in a wide range of interventions for children on the autism spectrum, such as Discrete Trial Instruction, the Early Start Denver Model, and the Picture Exchange Communication System (PECS) (ASHA, 2019). However many in the Autistic community question the ethics of behavioural modification, citing a recent study by Kuperferstein (2018) as preliminary evidence in support of anecdotal reports that ABA may be associated with the experience of post traumatic stress disorder (PTSD), and are actively opposed to its use (ABA Controversy Autism Discussion, 2017; Dawson, 2004; Parker, 2015).

The call for the right of Autistic people to live authentically as themselves, with a rejection of treatments and "cures", has seen analogies made between the Autistic rights movement and Gay and Deaf rights movements, with many embracing the slogan: "Nothing about us without us" (ASAN, 2019b; Silberman, 2015). It has not gone without notice that the first edition of the *DSM* (APA, 1952) listed homosexuality as a "sociopathic personality disorder", which at the time was described as a disease or condition deviating from normal heterosexual development that required medical help, commonly in the form of behavioural modification treatments (Dreschler, 2015, p. 566). The diagnosis remained until it was removed from the *DSM-III* in 1973, as a result of a change in societal attitudes (Dreschler, 2015; Silberman, 2015). However articles such as "Homosexuality: Treatment by Behaviour Modification" (Pradhan, Ayyar, & Bagadia, 1982), published by the *Indian Journal of Psychiatry*, remain in circulation (retrieved from PubMed February 16, 2019):

> We present here the treatment of thirteen homosexuals by behaviour modification techniques. With classical electrical aversion and positive conditioning 8(61%) out of thirteen patients showed a change in orientation lasting on a six-month 1 year follow up. A marriageable age and indirect social pressures were positively correlated with improvement whereas the presence of a steady homosexual partner and habitual passive anal intercourse indicated a poor response. The techniques, the assessments, the onset and course of improvement and complications arc discussed. (p. 80)

Byrd and Nicolosi (2002) authors of “A Meta-Analytic Review of Treatment of Homosexuality” summarised the results of 14 studies published between 1969 and 1982, 13 of which utilised a behavioural approach to treatment. While the authors acknowledged controversy over whether homosexuality was a disorder and should be treated, they also expressed concern about of the removal of the diagnosis from the *DSM,* which they attributed to limiting research in this field (p. 1149).

> Political, legislative, and psychotherapeutic issues concerned with homosexuality are debated regularly. Within the various mental health professions, psychotherapy for homosexuals is being challenged, and many have described it as unethical (Haldeman, 1994) suggesting that it does not produce change and that it does more harm than good. This meta-analysis is pertinent to that political debate and provides empirical evidence, based on the literature, that treatment interventions can be successful with individuals identified as homosexual. (p. 1149)

It should be noted that Nicolosi was one of the founders of The National Association for Research and Therapy of Homosexuality (NARTH), a charity organisation that supported conversion therapy. Nicolosi is active today as a private practitioner and includes endorsements from two former American Psychological Association presidents on his website (JosephNicolosi, 2019). Since 2014 NARTH has operated under the name Alliance for Therapeutic Choice and Scientific Integrity (Sutton, 2015).

In a complete reversal of their previous position, alongside other organisations such as the American Medical Association, and the American Psychological Association (Human Rights Campaign [HRC], 2019), the APA’s current position on the use of conversion therapy is as follows:

> Psychotherapeutic modalities to convert or ‘repair’ homosexuality are based on developmental theories whose scientific validity is questionable. Furthermore, anecdotal reports of ‘cures’ are counterbalanced by anecdotal claims of psychological harm. In the last four decades, ‘reparative’ therapists have not produced any rigorous scientific research to substantiate their claims of cure. Until there is such research available, [the American Psychiatric Association] recommends that ethical practitioners refrain from attempts to change individuals’ sexual orientation, keeping in mind the medical dictum to first, do no harm.
>
> The potential risks of reparative therapy are great, including depression, anxiety and self-destructive behavior, since therapist alignment with societal prejudices against homosexuality may reinforce self-hatred already experienced by the patient. Many patients who have undergone reparative therapy relate that they were inaccurately

> told that homosexuals are lonely, unhappy individuals who never achieve acceptance or satisfaction. The possibility that the person might achieve happiness and satisfying interpersonal relationships as a gay man or lesbian is not presented, nor are alternative approaches to dealing with the effects of societal stigmatization discussed.
>
> Therefore, the American Psychiatric Association opposes any psychiatric treatment such as reparative or conversion therapy which is based upon the assumption that homosexuality per se is a mental disorder or based upon the a priori assumption that a patient should change his/her sexual homosexual orientation. (HRC, 2019, p. 1)

The purpose of including this information, is not to re-ignite the debate over conversion therapy, but to illustrate, as Silverman (2012) claimed, the ways in which even "evidence based practice" is shaped by social, emotional and ethical context. The above extract also highlights what might be at stake, if professionals - and indeed Autistic people and their families - do not question the social validity of treatment approaches based on behavioural modification. In particular, the question of who decides which behaviours are "negative" and need replacing or "extinguishing". In light of this, it is concerning to note, that for a recent systematic review of research evidence pertaining to "The Effectiveness of Applied Behaviour Analysis Interventions for People with Autism Spectrum Disorder" (New Zealand Living Guidelines Group, 2009), commissioned by the NZ MOHE, studies that were "not deemed appropriate to the research question or nature of review…[included] those reporting on outcomes solely relating to safety; the acceptability of, or ethical, economic or legal considerations relating to ABA" (p. 3).

Controversies around different stances and alliances in the context of autism, particularly between those advocating Autistic acceptance, versus those who promote "treatment and cure", have at times been so passionate they have been described both inside and outside the Autistic community, as "The Autism Wars" (Çevik, 2018; Harmen, 2012; Silberman, 2015). Some Autistic people have taken to using the hashtag "#ActuallyAutistic" as a tag for people who are themselves autistic to post in, and draw support from, significantly as a response to feeling unsafe:

> The tumblr autistic community developed this tag because the autism and autistic tags were full of parents and siblings, many of whom expressed opinions that made people feel unsafe and in some cases could make people actively unsafe. In order to build community together, there was some conversation on tumblr that resulted in the actually autistic tags being developed. (ASAN, 2019c, p. 1).

Others are incorporating "Âû" in their names, or as a coda, to indicate they support the 10 points of the "Autistic Union", under the banner of "The International Charter of Autists Human Rights" (IBA, 2019b):

> **THE 10 POINTS OF Âû (The Autistic Union)**
> 1. I am Autistic. [or] I support those who are Autistic.
> 2. I embrace my Autism as a very significant part of my identity.
> 3. I embrace those who would sacrifice to protect all Autistic life.
> 4. I embrace the belief that Autism does not need any "curing".
> 5. I embrace the self-advocacy goal of "Everything about us, with us".
> 6. I embrace the definition of Autism as a neuro-social difference.
> 7. I embrace measures directed at protecting Autistics from attack.
> 8. I embrace a person-centred approach to all Autism issues.
> 9. I embrace rigorous scientific approaches to co-occurring conditions.
> 10. I embrace Autistics leading their own welfare organisations.
>
> (IBA, 2019b, p. 1)

With a foreword by Oliver Sacks, journalist Steve Silberman's 2015 book, *Neurotribes: The Legacy of Autism and How to Think Smarter About People Who Think Differently*, has become a touchstone for many in the Autistic rights movement, as it is considered the first cross-disciplinary history of autism that has included in its account the voices of Autistic people (Greally, 2019; Humble, 2018; Turner, 2015). Silberman also charted the "secret history of autism" in the context of eugenics, identified historical figures who may have been Autistic, and is credited with introducing the concept of "neurodiversity" to a wider audience (Baron-Cohen, 2017).

Neurodiversity is a term first used in the 1990s by advocates who argued that neurocognitive differences, such as autism, dyslexia or bipolar, should be accepted as natural forms of human diversity, rather than "disorders" that need to be fixed or cured (Baron-Cohen, 2017; Silberman, 2015; Walker, 2014). The term is now also being talked about in the context of science and education, and as researchers shift their attention to evidence of strengths associated with the many "disorders" of the human brain or mind, some suggest these may offer an evolutionary explanation for why these "disorders" are still in the gene pool (Armstrong, 2015; Brune et al., 2012; Polimanti & Gelernter, 2017):

> Without variation, no evolution by natural selection could take place. Mainstream psychiatry has largely ignored the fact that variation is the rule, not the exception, and this creates conceptual tensions. Psychiatry conceptualizes "disorder" as a

> statistical deviation from a normative statistical mean, yet handles it as a category. In other words, both “normalcy” as well as “disorder” with regard to psychological or behavioral functioning are burdened with the connotation of low variation. (p. 55)

With more adults “coming out” as openly Autistic, there is a growing community of Autistic academics and educators such as Michelle Dawson (2004), Stephen Shore (2003) and Damien Milton (2014) who have called for more Autistic adults to be involved in research, consultation and on advisory boards. A number of organisations, such as The Participatory Autism Research Collective (PARC) in the UK, and The Cooperative Research Centre for Living with Autism (Autism CRC, 2019) in Australia, have been set up to further these aims.

In a recent review of a study into the relationship between zinc deficiency and autism, NZ Autistic advocate, mentor, and mental health professional Paula Jessop (2017) raised questions not just about the potential relevance of research to Autistic people, but also the message it sends:

> I believe we autistic advocates, organisations such as Altogether Autism and professionals working in the field have a moral and ethical responsibility to think more critically about the potential negative effects on autistic people of research in the very early stages, which is not yet giving us enough information for real benefit.
>
> We need to go beyond having a rather superficial understanding of the impact of language where autism is described in such a general sense and continues to be portrayed as a condition which is so bad that every possible little thing which might treat it is good.
>
> We need to all be asking the questions: ‘which aspects of autism actually need treating’ and ‘which aspects of autism need support’ for autistic people to thrive in the world.
>
> Until people start thinking of autism in this way, the view that ALL of autism is bad will predominate – and that is not helpful for autistic people. (p. 21)

In her book *The Obsessive Joy of Autism*, Bascom (2015) encouraged Autistic people to express pride in who they are:

> I pity anyone who is so restrained by what is considered acceptable happiness that they will never understand when I say that sometimes being autistic in this world means walking through a crowd of silently miserable people and holding your happiness like a secret or a baby *letting it warm you* as your mind runs on familiar

> tracks of an obsession and *lights your way through the day*….All of these things autistic people are supposed to be ashamed of and stop doing? They are how we communicate our joy. (pp. 25-30)

The "autism space" is a complex one, with many different narratives around how we describe or even define it, however one thing that is consistently stated in the literature, and by parents/caregivers, educators, and Autistic people alike, is that more help is needed to support Autistic adults (Howlin et al., 2015; Gottleib, 2015; Jessop, 2017; Muller et al., 2008; Shepherd, Landon, & Goedeke, 2017).

Perspectives of Autistic adults in research literature

> I wish I could feel like I am not just trying to survive, and find the support that I need. (Baldwin & Costley, 2016, p. 491)

There is now an extensive body of literature detailing the challenges associated with autism, but very few research studies based on the perspectives of Autistic adults themselves (Howlin et al., 2015). What follows is a brief review of some recent qualitative studies, collectively offering insights into everyday challenges experienced by Autistic adults ranging from 16 to 64 years, from their point-of-view. Several of these studies focus specifically on gender issues from a female perspective, but have been included as women are otherwise under-represented in the other participant samples.

Hong et al. (2016) conducted a survey of "Factors Associated with Subjective Quality of Life of Adults with Autism Spectrum Disorder: Self-report vs. Maternal Reports". Using the WHO Quality of Life measure (WHOQOL-BREF), data was collected from 60 mothers and 60 paired children (adults on the autism spectrum of whom 76% were male) drawn from a Wisconsin/Massachusetts longitudinal study. Results indicated "adults with ASD experience relatively good subjective quality of life in terms of physical health, psychological health, social and environmental indicators" (p. 10). Family support was considered a factor contributing to resilience. However, having a history of being bullied five or more times was associated with poorer quality of life in both the adult and maternal reports. In addition, greater perceived stress, and exposure to stressful life events predicted "poorer social functioning", which the authors claim suggests an "emerging pattern of association between stress and social outcomes in this population" (p.10).

Several recent studies explored experiences of women on the autism spectrum. Drawing on the findings of an Australia-wide survey, Baldwin and Costley (2015) presented self-report data from 82 “high functioning women with ASD” in areas of health, education, employment, social and community activities. Key findings included a high prevalence of self-reported mental health conditions, with a large majority experiencing “on-going feelings of worry and stress that seriously impacted on their everyday functioning” (p. 492). Despite the fact the participant group expressed a “strong interest in learning”, many reported “significant struggles” during their time in education relating to “victimisation and exclusion” by fellow students, and felt their learning needs had gone unrecognised (p. 488). Unemployment and underemployment (over education) were also significant issues for this group. The authors concluded there is “a common perception among women with high-functioning ASD that their support needs tend to be overlooked or disregarded because they do not fit into conventional social constructions of ‘disability’ and are belied by a normal or above-average level of intelligence” (p. 492).

Bargiela, Steward and Mandy, in their 2016 UK study, set out to investigate “autism spectrum condition (ASC)” gender differences and how these might lead to girls/women being overlooked for diagnosis. Semi-structured interviews were conducted with 14 participants, along with several screening tools to gather data on general and mental health, along with “verbal IQ”. Participants spoke of making a deliberate effort to learn and use “neurotypical” social skills, sometimes describing this as “putting on a mask”. This “camouflaging” was associated with various disadvantages including “a sense of exhaustion and confusion about one’s true identity” (p. 3293). Results also included a high incidence of sexual abuse and experiences of victimisation. Almost all of the young women reported having experienced one or more mental health difficultly, most commonly anxiety, depression, and/or eating disorders. Most of the participants felt health professionals had not noticed their issues might be related to ASC, and that a delayed diagnosis had been detrimental to their wellbeing and education. Authors conclude their data suggests “some of the challenges of being a female with ASC do not come directly from the individual’s autistic difficulties; but rather reflect how these difficulties play out within a culture that has specific expectations for females” (p. 3293).

Seven women in the UK were interviewed by Kanfiszer, Davies, and Collins (2017) for a study based on semi-structured interviews to explore a broad range of life experiences, and a narrative method of analysis. Authors reported two overarching themes emerged, namely gender identity and social relationships:

> The women were united in how challenging they found social relationships and their experiences of maltreatment from others. Their lack of skills and confidence interacting with other people, paired with odd behaviour or different interests, resulted in a shared sense of others being disinterested in them and uncomfortable in their company. In making sense of their experiences, the women drew upon notions of 'normalcy' in how they internalised a representation of the self. The definition of 'normal', from which they all believed they deviated, was created by their peers as children and an ideological frame of gendered expectations. As adults, their perceived difference stemmed from a cultural expectation that they would be feminine (defined by their interests and appearance) and would want to have children. Nonconformity with these representations resulted in questions around their gender identity and the comfort they felt in their own body. (p. 67)

In "'Something Needs to Change': Mental Health Experiences of Young Autistic Adults in England", Crane, Adams, Harper, Welch, and Pellicano (2018) used a five-part online survey, with some interviews, to gain insights into 130 young Autistic adults' (aged from 16 to 26 years) experiences of mental health problems and perspectives on any help they sought. Participants identified as, female/transgender female (56), male/transgender male (33), non-binary (17), and "prefer not to say" (3). Key themes included: (Not) understanding my normal, stigma, barriers to support, and relationships. The research identified the participants "generally felt unhappy and depressed, worthless, under strain, unable to overcome their difficulties, unable to face up to problems and lacking in confidence" (p. 11). They also rated their quality of life to be poor, and these difficulties were felt to be exacerbated by co-occurring mental health problems, which were present in approximately 80% of the sample. Overall participants reported being generally unhappy with the services they had received:

> 'I wasn't very happy with any way that my mental health was handled my whole entire life really'. In spite of this, they were made to feel that should express gratitude that they were receiving any support at all: 'I just felt like a burden 'cause I didn't get as much as I wanted to but I was made to feel that that was more than I deserved'. (p. 10)

Participant reports indicated that feeling there were “high levels of stigma associated with both autism and mental health problems” made them less likely to seek personal or professional help for the difficulties they were experiencing. Authors also suggest that a lack of services “tailored to different cultural needs” may present a further barrier to those from “minority ethnic” or “non-white” backgrounds (p. 12), further compounding communication difficulties associated with cognitive differences:

> You’ve got to deal with being autistic and having a mental health issue as opposed to just being neurotypical and having a mental health issue, which is difficult enough. You’ve got to work twice as hard because you’ve got to interpret things and understand things, as everybody does, but you’ve got to interpret and understand things from the perspective of somebody who doesn’t have autism and quite often people won’t communicate to us as autistic people, we’ve got to adapt and conform to their ways of communication, their ways of doing things. (p. 9)

In their study, “Social Challenges and Supports from the Perspective of Adults with Asperger Syndrome and other Autism Spectrum Disabilities”, Muller et al. (2008), interviewed five women and 13 men from San Francisco, USA. Participants were asked to describe their experiences of navigating their social worlds, and to recommend effective social supports and strategies for improving social connectedness. Major themes that emerged included: (1) intense isolation, (2) difficulty initiating social interactions, (3) challenges relating to communication, (4) longing for intimacy and social connectedness, (5) desire to contribute to one’s community, and (6) effort to develop greater social/self-awareness. All participants emphasised the importance of the following externally implemented supports: (a) joint focus and shared interest activities, (b) structured social activities, (c) small groups and dyads, (d) facilitated social interactions and opportunities for ‘tracking off’ others, and (e) opportunities to observe/model socially appropriate behaviours. Attitudinal supports, such as time with people who “understood” them and were patient and caring; non-judgmental attitudes; and having friends who were prepared to “take the initiative”, were also valued. Researchers reported that some of the most surprising findings, were the numerous self-initiated supports which participants used to manage social anxiety and stress. These included creative outlets; physical and outdoor activities; spirituality and religion; mediating objects; and alone time.

While together these studies capture some of the struggles experienced by their participants, data also included information about factors that contributed positively to people's lives. Reported sources of resilience and support that were common between all of the above studies included: relationships with people who were open and non-judgmental; opportunities for social connection; tolerance of a person's "differences" amongst teachers, family and peers; diagnosis as validation and an opportunity for self-growth; and developing more mature coping skills such as becoming more confident and assertive over time (Baldwin & Costley, 2015; Bargiela et al., 2016; Crane et al., 2018; Hong et al., 2016; Kanfiszer et al., 2017; Muller et al., 2008).

A number of participants across studies, reflected a desire for access to professional support, but this was frequently given with the proviso that it was the right kind of support. Crane et al. (2018) present a good summary of common themes:

> The young people emphasised the importance of having strong, trusting relationships with friends and family members, and strived for this with professionals too. However, concerns were often raised about seeking support from professionals who did not have high levels of expertise and knowledge relating to autism. Some young people highlighted, though, that this very much 'depends on the person you get'; and, encouragingly, examples of good practice were noted. Ultimately, there were a number of qualities that young people felt professionals needed to display, which centred on the principles of trust and respect. Furthermore, while many young people highlighted the importance of having strong personal support, they felt strongly that this should not take the place of professional support: 'What I'd like is somebody I can trust, someone to talk to and someone who understands autism; a professional person'. (p. 10)

Notably, some of the young people in Crane et al.'s 2018 study, stated they wanted to be able to "bridge the gap" between formal support (such as provided by health professionals) and personal support (such as from friends) and suggested peer support as a compromise between the two. However they also expressed a desire that it be individualised (rather then just access to a "generic group") and be "facilitated by a specially trained autistic people" (p. 10).

Three of these studies (Crane et al., 2018; Kanfiszer et al., 2017; Bargiela et al., 2016) acknowledged their research focus has been influenced by a study by Pellicano et al. (2014), which sought views from four "stakeholder groups" in the UK community, including Autistic persons, immediate family members, professionals and researchers, on what the priorities for autism research should be:

> To our knowledge, this is the first attempt to investigate the views of a wide stakeholder group about UK autism research. The results suggest that there is a large discrepancy between the research priorities identified by participants and the current UK research portfolio. This research activity should be broadened to reflect the priorities of the UK autism community, focusing in particular on research that helps people live with autism. Our results suggest the importance of making autism research more democratic…including greater involvement of the autism community in priority-setting exercises. (Pellicano et al., 2014, p. 768)

The researchers involved with all the studies examined above, echoed this call by acknowledging the value of expertise by experience, and stating as a priority, that the perspectives of individuals on the autism spectrum should be included in future research efforts, and in identifying and developing appropriate strategies for improving social connectedness, mental health services, and provision of and access to support (Baldwin & Costley, 2015; Bargiela et al., 2016; Breen, 2017; Crane et al., 2018; Hong et al., 2016; Kanfiszer et al., 2017; Muller et al., 2008).

Research in the New Zealand context

An electronic database search performed in the University of Auckland library catalogue (last search February 18, 2019, all ITEMs, language ENGLISH, any YEAR) of books, articles and theses using combinations of keywords: autism; ASD; Asperger syndrome; AS; adults; and New Zealand revealed the following qualitative study that specifically included the perspectives of Autistic adults in our local context:

"A Qualitative Study of Noise Sensitivity in Adults with Autism Spectrum Disorder" (Landon, Shepherd, & Lodhia, 2016). Conducted by researchers at Auckland University of Technology, 10 adults were interviewed about their experiences of noise sensitivity. Themes identified included an association between noise sensitivity and anxiety; accounts of being "overloaded" by auditory stimuli making it hard to maintain control over attention; and the presence of coping strategies such as avoidance or escape.

It is worth noting that Altogether Autism, in partnership with Life Unlimited charitable trust, publish a free quarterly journal, *Altogether Autism Journal*, for which they solicit and present numerous articles written by Autistic adults about their lived experience. The journals and many individual articles are accessible from their website (Altogether Autism, 2019c). Topics explored include diagnosis, autistic identity, mental health, tertiary education, parenting, employment and experiences with services (Altogether Autism, 2019d). Themes in these articles echoed those identified in the literature previously discussed, such as an overall lack of supports for adults; feelings of loneliness, isolation, and issues with mental health; but also stories of individual resilience and survival. While this is not a peer-reviewed journal, and the reports are anecdotal, these testimonies provide a rich resource in our local context where the perspectives of Autistic adults are rarely sought.

There is very little NZ research that considers autism from Māori or Pasifika perspectives, or from culturally diverse backgrounds (MOHE, 2016). One notable exception is the work of academic and educator Jill Bevan-Brown, who is herself of Māori heritage. Bevan-Brown's 2004 report prepared for the Ministry of Education, "Māori Perspectives of Autism Spectrum Disorder", focussed on the views of parents and whānau of 19 Māori children on the autism spectrum, and in face-to-face interviews shared stories of raising their children. Overall, the report echoed commonly expressed concerns relating to a lack of support and services, and concerns for their children's future, but also captured some culturally specific issues and concerns, such as dealing with staying on the marae (noho marae), being included in kapa haka (performing arts groups), participating in bi-lingual education; and the need for parent support groups which incorporated tikanga Māori (Māori customs and obligations).

In another more recent study, Bevan-Brown (2013) explored her own research output (including the above study) in the context of different cultural concepts around disability and inclusion. Bevan-Brown acknowledged that "Māori, like any other people, are a diverse group" but that by incorporating Māori values such as "manaakitanga" which requires a person to be welcoming, nurturing, hospitable and inclusive; "āwhinatanga" or an obligation not to "trample on people's mana [value, power, prestige]" by excluding them; and "wairuatanga", which involves a recognition, respect and embracing of the spiritual dimension in others, into services and assessment procedures, will contribute to greater inclusion of all disabled people, regardless of their ethnic identity (p. 580).

Rochelle Nafatali (2017) provided an insight into a Pasifika Perspective on autism, in her presentation titled: “A Pasifika Parent’s Journey”, at the 2017 Altogether Autism conference, including insights into Samoan language and concepts that might impact on diagnosis, and cultural issues relating to traditions of caring for family members “in-house”.

There is also a small but growing number of openly Autistic professionals in NZ contributing to the field, one of whom, Dr Ava Ruth Baker (2019) has written prolifically about topics including diagnosis; “autistic-friendly practice”; different historical and social “approaches” to autism; and issues relating to being an Autistic professional working in a career that requires empathy. Baker’s experience in autism is both professional and personal, as both she and her son have been diagnosed with Asperger’s Syndrome. Baker describes herself as “an anthroposophic GP” and her private practice is one of only several in the country that specialises in adult diagnosis of autism (Baker, 2019).

It should be noted that while the *New Zealand Autism Spectrum Guideline* provides comprehensive information on best-practice recommendations, this is based primarily on reviews of existing literature, predominantly from overseas. However, due to the lack of research evidence available, the section relating to Māori and Pacific perspectives, involved consultation with experts and community leaders (MOHE, 2016, pp. 280-285).

Depending on their specialisation, most SLTs offering government funded support for children and young people on the autism spectrum are employed by either The Ministry of Education, working in schools or early education; the Ministry of Health, working in hospitals or community care; or for ACC, supporting rehabilitation. In some areas SLT services are also available through community providers contracted by the Ministry such as Spectrum Care, Explore, McKenzie Centre (Hamilton), and the Champion Centre (Christchurch) (Horrocks, 2018). Government funded SLT services are currently only available for children from pre-school to 8 years old. Children with “high” or “very high needs” may be eligible for support for the entire period of their schooling, through the

Ongoing Resourcing Scheme (ORS). However this funding is capped, and at 1 July 2018 there were 9,377 students receiving ORS funding, representing only 1.2% of the total schooling population (Education Counts, 2019). Autistic adults who require support for communication needs or problems with swallowing (dysphagia), or eating and drinking, would generally be referred to community health services, through their local Department of Health Board, where specialist training in autism may vary (MOH, 2019a).

Support provided by SLTs is generally aligned with best-practice guidelines around the world (MOHE, 2016; New Zealand Speech-language Therapists' Association (NZSTA), 2018). Recommended "treatments" and "interventions" for autism generally include strengths-based, individualised, and functional approaches, using strategies such as ABA, social-skills training, social scripts, multi-modal communication strategies, visual supports and parent/caregiver mediated language interventions (ASHA, 2019; Bevan-Brown & Dharan, 2016; MOHE, 2016).

In NZ the majority of autism *specific* national funding is directed towards providing parent/caregiver information and education, and behavioural support services for help managing "problem behaviour". Currently, Explore hold the government contract for behaviour services (Healthcare New Zealand, 2019; Jones, 2017). Almost all of these services are focussed on children and early years, with very little state-funded support available for Autistic adolescents or adults (Altogether Autism, 2019e; MOH, 2019a; MOHE, 2016). Adults with very high needs may be eligible for a Supported Living Payment, and there are a small number of charity organisations throughout the country (such as PHAB, Ranfurly Care Society, or Māpura Art Studios) offering day care and activities. However these are not necessarily autism specific, and training and qualifications of staff vary widely.

Three additional studies will be briefly reviewed to give some insight into parent/caregiver perspectives on current and past services available to families and adults on the autism spectrum in NZ. One further study will be mentioned as it provides recent feedback, specifically on experiences with NZ mental health services.

In his 2012 thesis, “Experiences of Families of People with Autism Spectrum Disorder in the Canterbury/West Coast Area”, Rawson cites the results of a survey commissioned by the Autistic Association of New Zealand (2001), the only comprehensive study to date that specifically investigates the state of services for “people with ASD” in NZ from the point of view of service users (Rawson, 2012, p. 27). The Autistic Association of New Zealand (2001) researchers surveyed 932 families about many areas of support, ranging from obtaining an appropriate diagnosis to home support. Overall, results identified that “a lack of support was a New Zealand wide problem and the quality of services that were provided were shown to vary from place to place” (Rawson, 2012, p. 27).

Rawson’s (2012) study was intended, in part, to be a follow-up on this data. In summary, Rawson reported results that mirrored those of the earlier study, as participants reported variability in professionals’ understanding of autism, a lack of suitably qualified respite care providers, and difficulties and delays accessing diagnosis for those unable to afford private services (Rawson, 2012, pp. 146-150). Notably, long-term impacts also reported by families included “financial costs involved in catering for sensitivities or allergies, to more personal impacts arising from a lack of understanding within the extended family” (p. 155). Rawson also reported some positive feedback that reflected a shift in some areas, notably participants found carer support to be “adequate”; those eligible had access to an Individualised Education Programme; and services provided by the Canterbury branch of Autism NZ were “generally well received” (p. 150). In summary, Rawson concluded the results of his study indicated: “Further research into the lifelong needs of families is going to be critical to ensuring services remain responsive to family needs as the children with ASD and their caregivers age” (p. 156).

Shepherd, Landon, Goedeke, Ty and Csako (2018) conducted a NZ-based survey of “Parents’ Assessments of Their Child’s Autism-Related Interventions” to investigate (1) intervention helpfulness in relation to expectations, and (2) intervention impact on parenting stress. Interventions addressed included, speech language therapy (SLT), behavioural therapies (BT), intensive applied behavioural analysis (iABA), occupational therapy (OT), and dietary interventions (DI). While the research questions are not directly related to the aims of this study, data included the following information pertaining to SLT services. Participants were parents with a child with “ASD”, ranging from 2-19 years (average age 12.02 years). Of the 538 participants that had reported having received treatment of some sort, only 385 (66%) had received support from an SLT. Support was reported to be ongoing for 129 (34%) parents. However, it is interesting - and somewhat confronting - to note that 182 (47%) parents had "abandoned" SLT support, and 73 (19%) of parents reported they had "completed" support from an SLT. Based on a 7-point scale, (from 1, e.g. no improvement/not helpful, to 7, e.g. substantial improvement/very helpful) parents answered a number of questions relating to intervention targets and impact. Mean scores from parents rated the effectiveness of SLT services (2.83/7); as meeting their expectations (3.62/7). While the authors reported the highest "completion rate" for any of the services was for SLT, where approximately one-in-four parents whose child had engaged SLT in the past considered the target symptom to have been sufficiently treated, this may not in fact be cause for celebration.

Social communication difficulties are a core diagnostic feature of autism and research indicates these are present over the course of a lifetime (Magiati et al., 2014; Muller et al., 2008; Paul, 2007). In addition, while there are no reliable figures for how many children diagnosed with autism remain "non-verbal" beyond the early preschool years, a composite of recent and past studies suggest the number of people diagnosed with autism who *failed to acquire spoken language at all* may be between 30 and 50% (Bopp, Mirenda, & Zumbo, 2009; Tager-Flusberg & Kasari, 2013; Trembath, Iacono, Lyon, West, & Johnson, 2014). In light of this, the results of Shepherd et al.'s 2018 study might also be interpreted to indicate a gap between community members who are likely to benefit from ongoing SLT support, and either access to appropriate services, or awareness of how SLTs might provide this support at various stages across a person's lifetime.

In response to a call for submissions to the NZ Mental Health and Addiction Inquiry, Altogether Autism developed an "autism friendly mental health survey" (John & Trezona, 2018, p. 1). Feedback was provided anonymously by 189 community members, via an on-line survey, on what is working well with mental health and addiction services in NZ for Autistic people, what is not working well, and what could be done to improve things. While no information was given about participant demographics, in a summary of responses over 80% of participants indicated their overall experience in using mental health/and or addiction services was average, poor or very poor (John & Trezona, 2018, p.

4). Trezona (2018), National Manager of Altogether Autism, discussed the relevance of these results to Autistic adults, in a recent editorial. Trezona explained how currently young adults between the ages of 15 and 19 seeking diagnosis for autism or support, are referred to Child and Adolescent Mental Health Services, and adults over 19 years, to Adult Community Mental Health. However, if a "co-existing condition", such as autism, is identified, their mental health needs may be seen to be outside the scope of mental health services, resulting in reports of many failing to receive support at all. Trezona acknowledged that while the Ministry of Health is quoted as saying "this is incorrect" (p. 1), Altogether Autism are currently gathering data to support the claims (Trezona, 2018).

In 2016, along with over 400 parents, caregivers, advocates and professional organisations, the NZSTA contributed submissions to a report by the Education and Science Committee (2016) into the delivery of education for students with dyslexia, dyspraxia, and autism spectrum disorders. Recommendations presented to the New Zealand House of Representatives reflected community feedback and included calls for better information and access to services, more consistent provision, clearer pathways, and increased funding to support students with ASD from early years, right through into tertiary study and beyond (ESC, 2016).

The small but growing number of studies, along with government submissions, providing feedback from both parents/caregivers and Autistic adults in New Zealand (such as those summarised above) have indicated that both past and present services may not be meeting needs or expectations (Bevan-Brown, 2004; ESC, 2016; John & Trezona, 2018; Rawson, 2012; Shepherd et al., 2017). Anecdotal and media reports suggest that this, in turn, may be contributing to a breakdown in trust between community and professionals (Checkpoint, 2018; Jones, 2013; Nafatali, 2017; Newshub, 2018; Sayers, 2016). For all of these reasons, many have turned to peers for support and information.

Peer support groups

> Since the inception of self-help groups, their image has been shaped by a few simple yet powerful ideas: Ordinary people with a common problem come together in settings they own and control, share their problems, and learn form one another without the need of professionals. (Powell, 1994, p. 46)

The development of contemporary forms of self-help groups, also referred to as mutual-aid groups, is generally associated with the birth of the Alcoholics Anonymous programme in the early 1930s. Since then a diverse range of groups has grown around a huge range of issues including lesbian, gay, bisexual, transgender and intersex (LGBTI) rights, chronic illness, addiction, disability and mental health (Powell, 1994; Cowie & Wallace, 2000).

Self-help was in part seen as a reaction against the "professionalisation of disability", by which professionals make decisions "for and over the people they serve" (O'Brien & Sullivan, 2005, p. 12). In her thesis *The Experiences of Peer Support Workers in New Zealand: Benefits and Challenges*, Atlas (2011) described this as "learning to see beyond the diagnosis…and see each other as human beings" (p. 14). She included "courage" as an important component of healing, defined as "an ability to take risks, to speak in one's own voice and to step away from 'safe' routines" (p. 10). Shery Mead, founder of Intentional Peer Support (2019), is a former "mental patient" who now offers training and resources to support "ways of thinking about and inviting transformative relationships" (p. 1). Mead describes peer support as:

> … a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain. (Mead, Hilton, & Curtis, 2001, p. 135)

Atlas (2011) outlined how "consumer led support groups" around mental health in our local context have existed since the 1940s. However, since NZ developed a nationwide mental health strategy based on a "wellness and recovery model" in 1994, consumer involvement in projects such as "Like Minds, Like Mine" (MOH, 2019b) that are focussed on increasing social inclusion and reducing stigma for people with experience of mental illness, have been steadily increasing:

> Recovery is a profoundly social process and is the aspect of recovery that is to do with rejoining the social world or what some may term as 'getting a life'. Being able to forge connections with others is a result of hope, healing and empowerment. To be able to connect is to find roles to play in the world in the form of activities, relationships or occupation….These activities may help consumers find a greater purpose in their life as well as reducing the chances of suicide (Atlas, p. 11).

Te Pou o te Whakaaro Nui (2014), national centre of evidence based workforce development for the mental health, addiction and disability sectors in New Zealand, conducted an analysis of international research evidence and best-practice guidelines, alongside an evaluation of a number of New Zealand-based mental health and addiction peer support programmes, and concluded:

> The formal evidence in both mental health and addiction is growing and shows high satisfaction from services that use all kinds of peer support as well as positive outcomes for people who receive peer services. Outcomes from peer services are as good if not better than conventional services. (p.4)

Over time the boundaries between professional services and self-help have become more blurred, with some groups being led by professionally trained leaders, many of whom are paid. More recently the focus has shifted toward viewing self-help as a social movement, and self-help groups as settings that promote individual, interpersonal, and social change (Powell, 1994; O'Brien & Sullivan, 2005):

> Self-help groups are complex entities. They create experiences such as the inculcation of hope, the development of understanding, and the experience of being loved that are thought to be therapeutic. They are also cognitive restructuring systems possessing elaborate ideologies about the cause and source of difficulty and about the way individuals need to think about their dilemmas in order to be helped ….Additionally, they are social linkage systems where people form relationships, and in that sense, self-help groups provide social support. (Powell, 1994, p. 47)

Rappaport and Simkins (1991) related the processes of "identity construction" that occur in self-help groups to those in more familiar community settings such as schools, families, neighbourhoods, churches or clubs. The authors described these as: "*community joining acts* that have consequences for identity development and change (some of which will be self-imposed and some of which will be imposed by others) thorough the normal processes of social communication by means of shared narratives" (p. 124). Rappaport explored how this in turn creates a shift from individual healing to the creation of new communities with their own language and culture, something researchers are conceptualising as "communities of interest" or "communities of belief", rather than as alternative human service systems:

> Many groups are autonomous social worlds coexisting amicably within mainstream society but with their own language, customs, beliefs and social networks. The

> culture creating and transmitting aspects of groups is being explored, including how groups develop and use specialized experiential knowledge of their common problem ….Mutual help groups construct their own cultural ideas including world views or subcultures that are often discrepant in certain ways from professional ideas or from their equivalent in mainstream society. (Rappaport, 1994, p. 175)

In a recent panel discussion on the topic of "Citizenship, Belonging and Social Inclusion for Marginalised Populations of Aotearoa", Patricia Benedict (Project Director, Citizen Project) shared thoughts on how, while peer support can be about healing one person at a time, more often she has observed how it is *as a group* people begin to heal. This in turn creates community. And community gives people the power and the confidence to create social change and advocacy outside of the group (Benedict, 2018). Dave Burnside (Peer Support Manager, Odyssey House), speaking at the same event, provided support for Benedict's observations based on his own personal and professional experience. He stated: "Recovery doesn't happen within people, it happens between people" (Burnside, 2018).

Despite the reported growth of peer support initiatives in the Autistic community, very little research has been done in this context, and the small amount of research we do have relates to child and adolescent schemes, and generally in an education setting. Two studies, and one after school programme, will be briefly reviewed as they provide insights into the relative benefits of different modes of peer support.

In a recent review of literature focussing on peer-mediated intervention, Platos and Wojaczek (2018) reported that with over 60 experimental studies published to date, it is considered one of the "most supported and recommended evidence-based practices for children with ASD" (p. 747). Peer-mediated intervention is a set of practices, based on the principals of behaviouralism, in which typically developing peers are systematically taught ways of engaging children and young people on the autism spectrum in "positive and extended social interactions" (Sperry, Neitzel, & Englehardt-Wells, 2010, p. 257). While the goal is to improve social skills and increase social interaction, Platos and Wojaczek, pointed out that questions remain over whether the effects generalise out of school settings, and argued that the current focus of teaching discrete social skills limits the potential of peer involvement. The authors argued for broadening the scope of peer support interventions to include "befriending programs" based on models that have been used effectively in mental health settings, and “in particular, we argue that there is a critical need for research on PMI that focuses on friendship, social participation, and well-being of adolescents and adults with ASD, as well as engages peers in the community settings” (p. 747).

“Avoiding the ‘Brick Wall of Awkward’: Perspectives of Youth with Autism Spectrum Disorder on Social-Focused Intervention Practices” (Bottema-Beutel, Mullins, Harvey, Gustafson, & Carter, 2015), provided some interesting points about the relative benefits of peer-mediated intervention versus “natural interactions with peers”. The authors interviewed 33 “youth with autism spectrum disorders” (aged 14-24 years), about their experiences of school-based peer-mediated intervention programmes that were designed to improve their social experiences. A summary of participant responses found: (1) many considered adult-driven strategies to assist social interaction to be intrusive and undermined students’ efforts to enter peer groups; (2) participants expressed a preference for natural interactions with peers, and activity-based learning with peers, over direct instruction, whether delivered by an adult or a peer; (3) and while some adolescents viewed disclosure of their diagnosis as “an opportunity to ‘instil interactional expertise’ in their NT peers which can bridge the empathy gap created by insufficient knowledge about the autistic experience” (p. 203), others viewed disclosure as a potential source of ridicule, and expressed strong feelings about maintaining privacy.

In summary, Bottema-Beutel et al. concluded that the young people they interviewed had diverse yet strong opinions about how social interaction might be facilitated or supported, and that this should be considered when conducting future research. The need to consider the views of those whom “intervention” is targeted to help, is particularly highlighted by participant feedback expressing dissatisfaction with adults intruding on their interactions, and causing them to feel odd, or hampered in the topics they discussed with peers. Some even questioned the legitimacy of school staff in providing social support, describing adults as unapproachable or “clueless” about adolescent interactions:

> Adults without an ASD are unlikely, even with training, to *not* mess it up. If it takes this much effort to assist someone with an ASD in interacting with “neurotypicals” then where does the assumption that a “neurotypical” can understand and interact with someone with an ASD so easily come from? [24 M, AS]. (p. 202)

Finally, one other project will be briefly mentioned, as it provided insights into a very different approach. “Subway Sleuths” is an after-school programme for Autistic children run by The New York Transit Museum (Brooklyn Autism Center, 2019). The aim was to take the special interests of a group of children on the autism spectrum as the starting point, then develop the Autistic children’s talents as mentors, so that they could share this interest with peers and others in the community. The programme brought together children who shared a passion for trains and helped them develop social skills and leadership abilities. Each class had around six children who met once a week, along with a museum educator, a speech-language pathologist, and a special education teacher (Fagan, 2017). Activities were based on the child’s needs, interests and curiosities, so the programme was personalised in response to whoever turned up. This extract from a report for Spectrum News (Fagan, 2017), provided an insight into how the programme has been of benefit to one 10 year old boy, Alastair:

> Alastair’s favorite game is “Hold the Pole.” In the game, one sleuth inside a subway car calls out something he or she loves, such as the Q train, and if the other sleuths love it too, they grab a nearby pole. The game encourages children to communicate, recognize connections and build relationships, Asborno says.
>
> A shared passion creates a strong foundation for friendship. “Most friendships stem from common interests, so putting kids together who have this as a common interest seems like a really good way to build relationships,” says Somer Bishop, associate professor of psychiatry at the University of California, San Francisco.
>
> [Alastair’s mother] Farley agrees. Alastair tends to be quiet and shy. As a sleuth, however, he is ready to discuss trains with children who care about the vehicles more than his schoolmates might. Alastair began to open up and become more social around these new peers.
>
> “This is a special place where he can be himself, just be Alastair running around the trains,” Farley says.
>
> Alastair has participated in the program three times. Each time he returned, his confidence grew, Farley says. By the third session, he took on a leadership role for the first time, showing new sleuths around the museum. And he has transferred his newfound confidence to school, where teachers asked him to help his peers in math. After Alastair finishes his own work, he helps other students divide and multiply fractions. (p.1)

According to Asborno, the museum’s deputy director, “Our purpose is all about communication and building friendships” (Leland, 2018, p 1.) The Subway Sleuths programme was honoured by First Lady Michelle Obama as one of the recipients of the 2016 national Arts and Humanities Youth Program Award (Leland, 2018; Newburg, 2016).

The present study

Autistic adults are finding each other and setting up peer support groups, but to date, little is known about how these groups might be serving the need of their community. What are the perceived benefits for the participants? And what we might learn from these initiatives when considering how best to develop services for current and future generations? These are the central questions of this study, and as those with lived experience are the best placed to provide insights into what is and isn't beneficial to them, their words will be best used to convey that experience. This is most appropriate to qualitative research methods. Rather than frame research as a scientific problem, qualitative research instead embraces a naturalistic paradigm, which *assumes* that observation is inherently value-laden, and that objectivity is impossible because the human observer perceives and interprets the world through a set of lenses based on upbringing, cultural heritage, values, social position, and experiences. Therefore, instead of seeking a single "objective truth", in qualitative research, the different interpretations and meanings of people's social worlds become the focus (Davidsen, 2013; Powell, 1994; Smith, 2008; Yardley, 2000).

This project is based on an Interpretative Phenomenological Analysis (IPA) approach. IPA is a qualitative research method, that is based on a detailed analysis of a small sample, and committed to the examination of how people make sense of their life experiences (Smith, Flowers, & Larkin, 2009). IPA has its roots in phenomenology, a branch of philosophy concerned with "consciousness" and how a person experiences the world around them (Davidsen, 2013). But IPA also recognises that access to experience is always dependent on what participants tell us about that experience, and that the researcher needs to interpret that account in order to understand that experience (Smith et al., 2009). IPA also, therefore, draws from theories of "interpretation" and "symbolic interactionism", which acknowledge the ways "meaning making" is influenced by context and culture (Davidsen, 2013):

> …the IPA researcher is, in part, wanting to adopt an 'insider's perspective'…see what it is like from the participant's view, and stand in their shoes. On the other

> hand, the IPA researcher is also wanting to stand alongside the participant, to take a look at them from a different angle, ask questions and puzzle over things they are saying. Here the analysis may move away from representing what the participant would say themselves, and become more reliant on the interpretative work of the researcher. (Smith et al., p. 36)

Smith et al. describe this as a type of "double hermeneutic", placing the researcher in a "centre-ground position [that] combines a hermeneutics of empathy with a hermeneutics of 'questioning'" (p. 36). This approach is particularly relevant to health, clinical and social psychology researchers, who have an understanding of the contextual and cultural ground against which data is generated, but are interested in how the voices of those with lived experience can inform practice (Larkin, 2013; Reid, Flowers, & Larkin, 2005; Smith, 2008; Yardley, 2000).

Ethics approval

Ethics approval was sought from The University of Auckland Human Participants Ethics Committee and the project was approved on 28 May 2018, for a period of three years, reference 021199.

Method

Four adults were recruited for this study, based on the following criteria: (1) they have participated in a peer support group for Autistic adults; (2) were over 18 years of age; (3) were able to independently provide informed consent.

A combination of purposeful selection and the "snowballing" technique was used to recruit participants. Community contacts, who have had involvement in peer support in a number of voluntary capacities, were asked to forward a pamphlet advertising the research project to anyone they thought might be interested. This was an important first step in establishing trust and clarifying the purpose and intent of the research. Four people contacted the researcher directly by email and were forwarded a participant information sheet and informed consent form. All four subsequently agreed to participate. Prior to the interview, time was taken to discuss this information including issues of confidentiality, the purpose of the research, and the research approach, to ensure it was understood.

Participants were given the option of being referred to by their own name or by a pseudonym. Two participants chose to be identified using their own first names, and two participants chose to be referred to by a pseudonym (indicated in Table 1 by an asterix*). Participants also provided the following information when asked how they identify in terms of age, ethnicity/cultural identity, and gender, as shown in Table 1.

Table 1

Participant Demographics

Name	**Age**	**Ethnicity / Cultural identity**	**Gender**
Margaret*	61	New Zealand European	Female
Jackson*	40	Autistic New Zealander	Male
Tyrone	39	New Zealander	Male
Timothy	28	Frisian/English/Tauiwi	Autistic

In response to difficulties associated with creating an operational definition of autism (as previously discussed in this report) and in acknowledgement of the barriers many adults currently face when seeking diagnosis (Lewis, 2017), participants were advised that "self-identification" was all that was required and there would be no testing. Participants were not directly asked questions about their diagnostic status, however during their interviews one participant reported having been diagnosed as a school-aged child, one described receiving a clinical diagnosis as an adult, and two participants described a process of "self-identification" which included "validation by peers" in their Autistic community.

Data collection

Data collection for each participant was in the form of a single semi-structured interview conducted by the researcher. Interviews ranged from one hour, to one hour and 50 minutes. An interview schedule (see Appendix 1) was used by the researcher to guide the discussion. During the first interview, the researcher trialled use of an additional more open question (i.e. "What does peer support mean to you?") to start the conversation. This question was then used to initiate the further three interviews. Participants were asked to choose a location that was comfortable for them. This included a community space in a local library, a bar/restaurant, a bar/café, and a participant's home. Participants were offered a $40 gift card, travel card, or supermarket voucher to help cover expenses. The interviews were audio recorded and then transcribed verbatim by the researcher. All participants were given an opportunity to review and edit their data.

Analysis

Analysis of the data was based on an inductive, or "bottom up" approach. Based on an IPA framework suggested by Smith et al. (2009) this process took place over six stages:

(1) Reading and re-reading each interview

This was a first step in the process of trying to "enter the participant's world", and involved re-listening to the interviews while reading the transcripts, noting how narratives bound sections of the interview together; shifts from generic explanations to specific events; contradictions and paradoxes; and exploring the general flow of the interview from beginning, middle to end (p. 82).

(2) Initial noting

The next step involved examining the semantic content and language use in a detailed free textual analysis. The aim was to identifying specific ways each participant talked about, understands, and thinks about an issue. For each data item, a detailed set of notes was made including (a) *linguistic comments* noting language use, style of speech, tone, degree of fluency, use of pauses, laugher and repetition, etc.; (b) *descriptive comments* describing the content of participant's speech such as key words, subjects/topics, figures of speech, and significant experiences; and (c) *conceptual comments* considering each participant's over-arching understanding of the matters they are discussing, including their views at different stages of life or time frames, and thinking about participant's experiences in terms of their relationship to the important things that make up their world (p. 84).

(3) Developing emergent themes

Moving from the transcripts and initial notes, this involved a reorganisation of the data away from the narrative flow of the interview. Firstly a “thematic map” was created for each data item noting emergent themes that reflect not only the participant’s original thoughts and words, but also the researcher’s interpretations.

(4) Searching for connections across emergent themes

The primary focus of IPA is on capturing the individual voice, therefore the process of moving from interpreting chunks, to analysis of whole interviews, and then to making claims for the larger group requires care (Smith et al., 2009). The researcher took guidance from Braun and Clark (2006), in determining what might be a theme:

> A theme…represents some level of *patterned* response or meaning within the data set….A theme might be given considerable space in some data items, and little or none in others, or it might appear in relatively little of the data set. So researcher judgement is necessary to determine what a theme is….Furthermore the ‘keyness’ of a theme is not necessarily dependant on quantifiable measures - but rather on whether it captures something important in relation to the overall research question. (Braun & Clark, 2006, p. 82)

In charting and mapping themes across the data set, the researcher first looked for clusters of themes, then for patterns and connections between them, and finally for any “opposing” themes or outlier perspectives.

(5) Reflection on perceptions, conceptions and processes

A process of supervision and self-reflection was used to test and develop the coherence and plausibility of the interpretation. This included the researcher creating notes on expectations and assumed knowledge going into the research, and reflecting on data not anticipated, or that challenged preconceptions.

(6) Writing the report

The results of this analysis are presented theme by theme, with extracts chosen to support and inform their interpretation, in the form of a "reflective engagement" with the participants' accounts.

Results

Results yielded a number of themes across participants, clustered around the following topics: connection, communication, community, mental health, environments, and self-growth. Themes and sub-themes have been presented in Figure 1, in the form of a "map". Subthemes were interconnected and relational in participant testimonies, so have been explored under main theme headings, rather than as discreet topics.

At the beginning of each interview, participants were asked: "What does peer support mean to you?" All four participants initially gave succinct definition*s* of what peer support *is*, before going on to provide richly detailed narratives about what peer support *means to them* in the context of their own lives. These initial definitions are included below, to provide some context, before looking at each theme in more depth.

Despite coming from very different backgrounds, and describing very different journeys, there were very few points of divergence between participants in relation to these themes: these will be explored later.

"What is peer support?"

Margaret explained she had been involved in peer support in many different ways over the course of her lifetime, during her previous career as an educator, and as both a volunteer facilitator and participant:

> *Peer support can be one-to-one. Or it can be in a group. And it can be for specific purposes. Or it can be purely social, um, which has spinoffs of course to other things. But it's really listening and sharing, you know, and being there for other*

> *people, and, and having them be there for you too. Peer support often goes two ways. (Margaret)*

Jackson discovered peer support after seeking a diagnosis as an adult:

> *To me it's basically, I guess in its simplest form, if someone's had experience, say for example going out flatting, and someone that they know, a friend of theirs wants to go flatting, and they're just after a bit of information or guidance on what to do and what not to do — and to me that's kind of just really bare bones, just nice and easy definition of what it is. It's literally one person supporting another person in some part of their life. (Jackson)*

Peer support groups have been a part of Tyrone's life since childhood:

> *Peer support to me means, when you've got other people that are the same as you, and you've got similar life experiences, so you can go to each other and support each other. Sort of like, um, for instance, a lot of people like me have been bullied, um, when we were younger, so we can support each other in that, because it's something we share. (Tyrone)*

Timothy gave a broad definition of peer support that included friendship, and more formalised group support, reflecting his many roles as facilitator, and participant:

> *Well I suppose, anything where, any situation where Autistic people are together and are supporting each other in any kind of way. It's, um, obviously it's very broad, but it would be, um, that kind of, like even if it's like a social gathering — we had our (name of social peer group) last night, and people just sitting around chatting, and talking and stuff, and that's a form of support, you know. And then you've got the more in depth kind of — where you would sit down in a group, and you would talk about issues, and you'd try and resolve them. And somebody would say, oh, this has worked for me. And somebody else would say, you know, I'm having this issue, what's worked, and there's a korero around that. And then you've got the online stuff, you know, where there's, um, a lot of groups online for Autistic people, for Asperger's, for, um, there's specific groups, say for example, for Autistic people who are transgender, or whatever, and, and these are also forms of peer support, I suppose, yeah. But it's basically any, any time an Autistic person comes into contact with another Autistic person, and something say positive happens, or comes from that. Whether it's just a good experience, or you feel a bit better afterwards or something, because you went to the movies, you know, movies are peer support, people might not think it like that, but that's their — that's the truth. I don't know [laughs], that's my view anyway. (Timothy)*

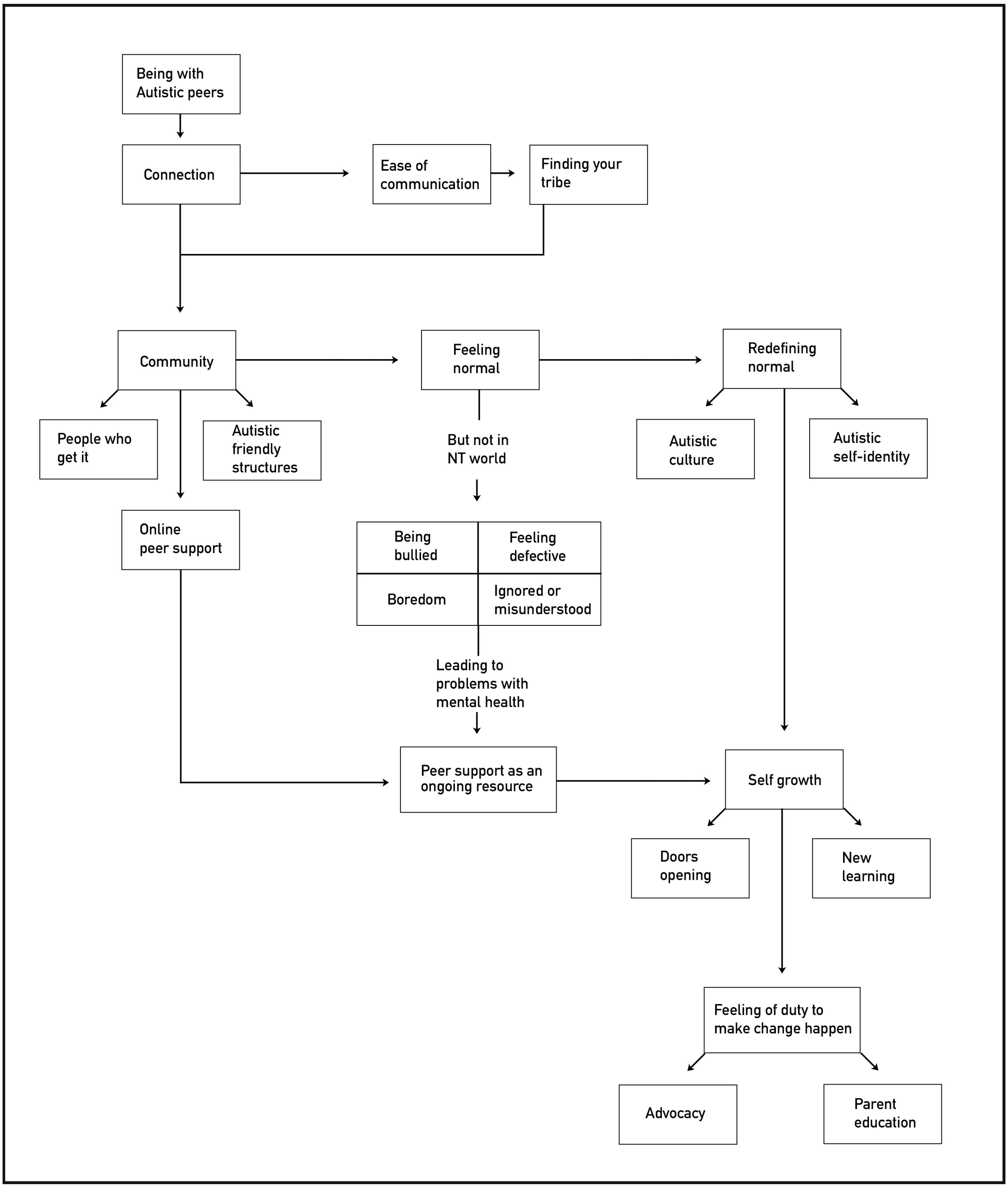

Figure 1. Summary of Themes

Connection

Participants talked about peer support in a variety of different contexts, including naturally forming friendships, youth camps, peer support groups for people experiencing mental health issues, social peer support groups, online peer groups, community groups, and the 2017 Altogether Autism conference. These events were distinguished by (1) being in the presence of other Autistic people, and (2) an *ease* of connection, that was instantaneous, and sometimes beyond words. For example, Jackson described how discovering the "quiet room" at the Altogether Autism conference, a space set up just for Autistic people who need a break from talking, was a life-changing moment for him:

> *…it was the first time in my life, that I've actually walked into a room, that had a group of people, who were five or more, and I actually felt relaxed. Like I didn't know these people from a bar of soap, but when I walked in there, no one just looks up and stares at me sort of thing, everyone's just as though — like ignored me I guess. And to me it's like, well that's quite refreshing. It's nice not having to feel self-conscious about — and I guess that's kind of the first time that I've ever felt like that in my life, and it was really nice. (Jackson)*

Timothy talked about how, when he first started working as a disability support worker, he was surprised himself, to find he could connect quite deeply with other Autistic people, even on a first encounter. He described a first meeting with a young client, that inspired him to keep doing the work:

> *…the son eventually plucked up the courage…he came out to the lounge, and then he just sat there he just sat there and listened to me for awhile, and then he just started resonating with what I was saying, and he was just like — and then he started asking questions, and then all of a sudden there's a dialogue going between, you know, him and a person he's never met before….And I was just like … I, I, I just — to me it was natural but I was still quite taken aback. But more so were his parents, because they were like, oh my gosh, he's never, ever talked to us about any of that stuff, um, but he'll talk to you about it because you're Autistic and you, quote, get it, you know, you've got that empathy there. And I was — I just found that really fascinating, you know, that you can have these moments where you can just connect and relate to somebody, um, over something as simple as being Autistic. Whether being Autistic is simple or not I don't know, but yeah [laughs]. (Timothy)*

When describing his first time at an Autistic social peer group get-together, Tyrone expressed joy at discovering people who *"speak my language"*:

> *Yeah, I was like, wow. It was exhilarating because I met others like me, and it was like, these people speak my language [laughs]. So it, it was like, um, I didn't have to pull out the dictionary to look up anything, because it was like, these people speak my language, it's all good. (Tyrone)*

All the participants associated Autistic peer support with significant first times, suggesting this ease of connection was something they did not feel on a daily basis. For Jackson to describe feeling relaxed while in the company of others, *for the first time in his life* at the age of 40, was telling. All of the participants distinguished between what it felt like trying to communicate in the NT world, compared to being with Autistic peers:

> *…it's just good because after living in a neurotypical world, like most of the week, being able to go to [name of facilitator]'s group, or [name of social peer group], and just not have to speak neurotypical, for a couple of hours is good, because it can be quite exhausting [laughs]. (Tyrone)*

The ease of connection and communication experienced with Autistic peers, was described by all participants, as being with people who "get it":

> *…if you're struggling with anything, being with peers who really understand what it's like, you don't have to explain yourself all the time. They get it. And that's really important. And you can relax more. And it takes the tension out. And you can find solutions much easier. (Margaret)*

Communication

Language, in its most fundamental form, can be described as a shared code, based on a symbolic system, that others who share knowledge of that system will be able to understand. This includes non-verbal codes such as body language and the way we look at each other, as well as spoken language and our choice of words. Language is also shaped by culture and shared experience (Justice, 2010). A shared code by necessity, implies "insider" and "outsider" perspectives, something Timothy refers to explicitly when he described how, as a peer support worker, he sometimes found himself in the position of "translating" for a young Autistic man and his mother:

> *…the son was agreeing with everything that I was saying, and saying, yeah, yeah, that's me, that's me to a tee, that's one hundred percent right. But he couldn't explain it in a language that his mum would understand. And it took the outside voice, the outsider voice, for her to understand, or gain some comprehension of. And I still go to his place, and sit down with him and his mum, and we have discussions a couple of hours a week, where we just talk about different things, and she just sits there and just — wow. And I'm just like, oh my gosh, all I'm doing is just like explaining myself in a way, um, but it's just really insightful for them, I suppose. (Timothy)*

During the course of the interviews, participants were all overtly mindful of the language they used, while sharing information. Given that participants reported frequently feeling misunderstood, it is no surprise that a lot of effort went into defining things, and being clear about “how they saw things”. Examples included Jackson considering how to describe the life crisis that led to his seeking a diagnosis: *“I don’t know quite what the word to describe it would be, um, it’s — my wife and I kind of joke it’s a bit like a kind of Autistic mid-life crisis sort of thing, like a mid-life diagnostic crisis [laughs]”*. Or Tyrone flagging the use of a word that carried negative connotations for him: *“I really do hate this word, but feel normal”*. And Timothy overtly rejecting the way professionals describe sensory issues: *“I really didn’t like the way that, um, the clinical world was talking about autism, you know, um, using the word meltdown instead of sensory overload.”*

Notably, while all four participants referred to themselves as “Autistic” and considered “autism” to be a part of their identity, what this meant for them in relation to social communication, was far more revealing and nuanced than clinical descriptions might suggest. This highlights a potential schism between the way professionals may understand the problems Autistic adults face, and how they themselves report thinking about them.

For example, while diagnostic criteria in the *DSM-5* (APA, 2013) includes “persistent deficits in social communication and social interaction across contexts” (p. 50), all participants in this study described, in rich detail, sharing interests, activities, fun, support and empathy, in a variety of social settings, some even talking place in silence, or with strangers on first meeting. Margaret provided a detailed description of all the ways her community gets together (a group of around 100 Autistic adults, of whom around 40 meet regularly), and ended by highlighting the fact that Autistic people are clearly *social*, they just prefer to do things in their own way:

> *…we go out together as a, as a larger group, to a bar, or to pubs, or restaurant or something. About once a month. And twice a month we have a venue downtown that we use. And it’s very quiet. It’s got lots, and lots, and lots of rooms and nooks and crannies where people can go and have little conversations here, there and everywhere, and do things. We do lots of, um, board games and lots of, we focus on different things, we have an anime group there, and things like that, but we tend to — there’s lots of chat, you know. It’s just getting together and letting people support each other, and make friends, build, um, you know, friendships and stuff like that.*
>
> *And we have other groups during the weeks now like — that are very small, and get-togethers, like we had a café group. Now we’ve got quiz group which is quite popular, a few of us love our quiz nights, um, and that’s down at one of the local bars. And we have a couple of, um, different movie get-togethers at two different*

> *places, two different guys' places, um, and what else do we do? There's adventurers club, they've been off rock climbing and doing things, um, just different things like that…[exhales]*
>
> *People keep saying, you know, we should be mainstreamed, we should be mainstream, go to the mainstream things. But they don't set up things that are quite Autistic friendly. And some times you get sick of doing things their way all the time. It'd be very nice to relax and do it our way sometimes. And that's what this is about. (Margaret)*

Online Autistic internet groups and forums were also described by all participants as an extension of their community. Margaret acknowledged the value of online peer support as being *"really, important, because it's something that connects us…it is amazing how without the physical stuff, you can be yourself."* But she has also seen how *"a couple of our guys get bullied online"*, so *"it can be very, very good if it's used carefully"*:

Margaret also pointed out that as a lot of Autistic people are on benefits, it's more difficult for them to physically travel, so online communication opens up possibilities for connection, that might not otherwise be possible:

> *There's definitely a movement gathering. We've got some really strong people up and down the country, and that's where, um, you know they get connected via online and stuff like that. Because most people on the spectrum are pretty broke. So they can't travel everywhere. Doesn't cost money to travel online, you know, so they can do that. And it's the best way to communicate anyway. We say what we mean. We don't have to worry about body language. We say what we mean. It's a good form of communication for people on the spectrum. Yeah. (Margaret)*

Notably for Jackson, spending time with Autistic peers and feeling relaxed was also associated, in part, with a *reversal* of what most people might consider social norms, such as no one looking at him, and being ignored.

Diagnostic criteria for ASD in the *DSM-5* (APA, 2013) also includes: "deficits in developing, maintaining, and understanding relationships" (p. 50). Participants all reported problems with relationships, but notably, distinguished between the issues they had when relating to people in the NT world, as opposed to those in the Autistic community. Jackson gave multiple examples of how communication difficulties in the NT world, had caused confusion and difficulties throughout his early life, including contributing to him losing the *"only job I was ever good at"*:

> *…the boss had heaps of weird conversations with me, and I could never understand what he was trying to tell me. And it basically turns out he was trying to tell me to start doing a bad job, because when I left, there was about 200 outstanding trouble tickets, because I was doing* <u>*too*</u> *good a job, because I'm quite detail oriented and … so, it was quite interesting [laughs]. (Jackson)*

Jackson also described how frustrating it was to converse with NT people, because it takes a really long time to get past the *"small talk"*, but with Autistic peers *"we can discuss topics in depth, with just saying, oh hi how are you, and then just launch straight into whatever, at a really in-depth level."*

While Margaret also reported communication breakdowns in earlier life, she didn't consider the fact she saw and did things differently as a negative. She described herself as a social person, but said that *"the mainstream bored her."*

As a peer support worker, Timothy acknowledged that part of his work was supporting people with communication, however he didn't attribute this to a "social deficit" in Autistic people:

> *…it's weird to say I suppose but, um, Autistic people, a lot of people don't get this, but we're actually pretty good at picking up on other people's energy. So, um when you're with somebody, you know, you can pick up on body cues, on, on, um, whatever their energy output is, you know, the emotional state of somebody, you know… (Timothy)*

Timothy is also a musician and has drawn on this knowledge, as well as his many years experience working with and alongside other Autistic people, to develop his own theories about communication, which he saw as multi-modal, and based on a transference of energy:

> *The only way when I was a kid I could process emotions was to play them on the piano, and one of my friends, when I first met her, and she asked me to play her something, and I said well I don't play songs, I play emotions [laughs], you know, like what does that mean. But, um, that was the only way I could get that energy out there was, was through music, and it's always been that way for me, so, um … I've struggled a lot with expressing certain emotions, but I can express them musically, um, which a lot of people struggle to do, you know. Your more neurotypical musicians, you hear them play, and you go, it just sounds plain, it sounds normal, it doesn't — there's no feeling in it. But then when you hear a musician play with*

> *feeling, and you just go wow, I can, I can resonate with that energy, I can gravitate towards that energy, I'm feeling it, you know,*
>
> *So why not look at it as, as a form of — you've got energy, I've got energy and we're transferring energy through conversation. And not necessarily, you know, audible and verbal. We could sit here in utter silence and still have a conversation, you know, we could, we could, um, we could totally like be blindfolded, and close our eyes, and not even have a facial expression in conversation, we could just sit in silence, and still have a conversation through energy, you know, transferring of energy can still happen. And it's very much like that for Autistic people, you know, you talk about Autistic people being non-verbal, and there's ones that don't speak in the traditional sense, but they still have energy going in and coming out okay, so how do you find a form of energy that they can translate and understand, and voila, you've got yourself a form of communication, you know. So energy, um, that's probably where a lot of my language comes from, also being a musician, but, um, a lot of my language comes from this, this, um, concept of energy. So that's why I use words like resonate, and, um, attachment, and all these different things, you know, um, it's because it's, yeah, energy. (Timothy)*

Tyrone also highlighted the importance of having access to different modes of communication while talking about the relative benefits of online, and real-world, peer support groups:

> *...I always tell people, never tell your child that they cannot use the internet, because that's their way of communicating. We had one guy, he ended up in the [name of mental health facility], and he was pretty much told, no sorry, no phone, no internet, can't use — and it's like, well hello, that's his mode of communication, cause any other time he pretty much locks himself away, and he's communicating with other people, you should be promoting that for his health, not saying no, you can't. (Tyrone)*

DSM-5 (APA, 2013) diagnostic criteria for ASD also includes: "deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions" (p. 50). Participants in the study reported many examples of sharing their interests with others:

> *...some of us will take the opportunity too, to go and have a bowl. One of our guys, he is a Special Olympics ten pin bowler. So he'll bring his own bowling ball, um, and he's also into photography as well, so him and [name of person in peer group] often get talking about their photos. And there's a lot, a few of us on our group too, have had involvement in the Launched Festival too, which happens every year, so they'll either be behind the scenes or part of a group that's performing... (Tyrone)*

Participants did also describe occasions when they, or others in the community, would withdraw or avoid others. This was sometimes associated with the need to manage energy overload or to desensitise. But on other occasions avoidance was associated with "rejection" or people "trying to trigger us", and participants saw what might be interpreted as a "lack of social-emotional reciprocity", either as their response to something that was done to them, or as something that went "both ways".

Social-emotional reciprocity was also acknowledged by participants to be something you can choose to invest in*, or not*. For example Timothy said he was less motivated to form friendships with neurotypical people, because unlike Autistic people whose need to manage energy and sensory issues makes them more creative about the way they live, neurotypicals are *"some of the most boring people you will ever meet"*. On the other hand, Tyrone described how neurotypicals appeared to be bored by things that interested him: *"like if I start talking about Startrek, or cats…they'll be like, oh, have that bored look on their face, and they'll be like will he shut up."*

The question of where "dysfunction" might lie in the area of social-emotional reciprocity was also highlighted by Jackson, who reported profound discomfort around the way fellow "tradies", in his past work life, talked about women:

> *…it's just, you know, pretty unbelievable just the amount of crap I've heard a lot of workmates talk about, it's just, it's just...sometimes it kind of makes me a bit concerned about being male in this world. (Jackson)*

Jackson saw this as a *"minefield"* for young Autistic people learning to *"feel comfortable in themselves and their sexuality"*. Jackson also talked about having several recent experiences where it was okay to let the *"waterworks"* go (while on a noho marae and while attending a peer support group), which made him question the tyranny of the *"tradie hold"*, or the social pressure for men to hold in their feelings, something he now saw as dysfunctional, and having had a negative effect on his *"coping ability"*:

> *I would just go away to a quiet space and just, um, let it work its way through, and then when I was ready I'd just re-engage with the group, and just no one batted an eyelid, and I just felt really included, and even though this just continually happened, just because of all the stress, it was just a really nice environment to be in. And that's the first time as well, that I've ever been under huge amounts of stress, and I guess*

> *sort of breaking lots of times, and still able to re-engage, and no one cares. And that was, that was also quite nice. Just like it sort of — I didn't expect that, I expected to have lots of, I guess, throwback, like I mean, just from my trades background — tradies are normally pretty rough, and rugged, and don't show any feelings and, you know, that sort of stuff and [laughs]. (Jackson)*

When asked if in all the years he had been involved with peer support, he had a "high point", Tyrone returned to the theme of being understood:

> *…probably knowing that I'm understood, like, um, knowing that if I had to say, right I need a break, I need to go outside, they're all going to go, oh yeah, sweet, we understand, we got it. Where if I'm with, say my mum for instance, she doesn't get it — oh you'll be right, we're only going to be here five minutes — yeah well in five minutes there could be a full on meltdown, which do you want [laughs]. So, yeah I think that's the high point, that everybody gets me, and I get them. (Tyrone)*

Tyrone's answer also throws light on what not being understood - *being misunderstood* - might mean for him. Being misunderstood was a recurring theme for all participants, something that was associated with exhaustion, negative outcomes in life, mental health problems, lost opportunity and anger. All of the participants talked about Autistics and NTs not "speaking the same language". As communication is by definition a two-way street, this poses the question of whether breakdowns might be related to different world views, or agendas, rather than "deficits" on one side of the conversation:

> *You don't expect a deaf person to come into a room and have a conversation with you verbally, it's not going to happen, they're deaf. Okay, what do you do, you learn sign language, right. So why can't you learn a bit of autism? And that way you can have a conversation with me and we'll all get along fine. Otherwise I'm not even going to bother with you and then you're going to say, oh, he's non-social, he doesn't want to talk to anyone. No, it's not that I don't want to talk to anyone, it's just that no one's bothered to learn my language. (Timothy)*

Community

All of the participants associated Autistic peer support with community. A community, or "tribe", implies a group of people with shared attributes and a sense of belonging. Margaret equated this, quite simply, with *"being at home"*:

> *Being involved in peer support's really important, because it's like, it's like being at home. It's like being accepted for who you are. (Margaret)*

Jackson’s introduction to the Autistic community came later in life than the other participants. He described how walking into the quiet room at the Altogether Autism conference, and feeling relaxed in a group for the first time, was a before-and-after moment for him. Jackson related how he felt, to the concept of *tūrangawaewae*, or having a *“place to stand”*:

> *I’ve just finished doing a noho marae, for a, um, Te Ao Māori in social practice, and they had a noho marae in [name of city], about three weeks ago, um, and we learnt about, I think it’s tūrangawaewae, it’s like a place to stand. And literally up to that point in time, I’ve struggled my entire life to do anything. And it turns out there’s mix of executive function issues and a lot of other stuff. And I’ve just had to fight to do even just basic simple stuff, and it’s just always effort, and it’s really tiring and, it was sort of, I guess the first time in my life that I knew that I wasn’t alone, that there are other people out there like me, that they have their lives and struggles as well, and just being able to launch into conversations with complete Autistic strangers, and they don’t really care about where I come from, or what I do, they’re not like looking at me, and you know, like judging me sort of thing. (Jackson)*

Jackson found himself questioning whether the problems he had been experiencing were because he was *“defective”*, or instead were the consequence of having been and cut off from his *“tribe”*:

> *Yeah, and [name of social group facilitator] always talked about it, sort of, you need to find your tribe, and I didn’t really get what she said initially, the first few times she mentioned that, um, but it’s completely like that….I see disenfranchised Māori that have been, basically that don’t have tūrangawaewae anymore, they have no place to stand, they, they’ve got no roots to go back to — the worst happens there’s something to fall back on, and it’s, sort of, I want to start developing that, cause it’s just a community, and it’s sort of, I think it’s quite an important thing to have. (Jackson)*

Collective terms were used by all participants when discussing the group, for example, *“our guys”*, *“we as an Autistic community”*, and *“us Autistics”*. All of the participants used identity first language to describe themselves and other people on the autism spectrum, and were overt about rejecting a medical model of autism. Functioning terms were occasionally used, but the group were unanimous in immediately highlighting their dislike of them.

Margaret introduced another perspective by stating she did not consider autism to be a disability at all, but a *“culture”* with a *“disability sector within us”*:

> *I don't see autism as a disability…I think as a population of Autistic people we have a disability sector within us, every culture does, but I see autism as a culture in its own right. So we will have that section. But I see a lot of, or most of the Autistic culture, as not having a disability as such, and a lot of those people are hidden still, because why would you come out, you know? But as people talk, and talk, and talk, and don't put that negativity on autism, you'll find more people coming out and saying well actually yeah, I feel this way too. And maybe neurodiverse is the way to go, it's recognising it as that, and getting rid of that stigma. But we've got to stop looking on autism as a bad thing. We've got to. It's not a bad thing at all. (Margaret)*

Margaret associated this *"disability sector"* within the community, as those with *"co-morbidities"* such as intellectual disability, ADHD, post traumatic stress disorder, and *"full-blown OCD"*:

> *…I think that's what a lot of, um, the problem's been in the past is that, they stopped diagnosing when they got to autism….and it'll be like, this isn't fair, because if you've just got autism, I don't mean just autism but you know what I mean, if you're an Autistic person, you don't want to be labelled the same as all these other, this person who's got all these other conditions. And it's not true autism. It's autism plus. …And I think that's where a lot of the negative, um, ideas around autism have come from. They've come from people that have observed very complicated, very stressed people, um, who've got multiple, multiple things going on. I'm not trying to, um, undermine how difficult it can be living with autism for some people. I'm not trying to do that at all, um, because for some people their — it can impact on them quite severely. But for a lot of people on the autism spectrum it doesn't at all. (Margaret)*

Participant perspectives also drew on the language and constructs of colonisation and cross-cultural relationships. Participants referred to "mixed" Autistic/neurotypical families in the way people might refer to cross-cultural marriages or adoptions. For example Jackson referred to *"an entire Autistic family with one neurotypical daughter"* and the difficulties the parents were having seeing things from her perspective. They were able to relate to an Autistic child who was *"getting into trouble"* at school, but couldn't understand the neurotypical daughter who *"wants to play with dolls and things all the time, and it's just quite weird."* Jackson recognised that in this clash of "cultures", the neurotypical child might just as well be the one that needed support, rather than the Autistic sibling.

Redefining what is considered normal was a recurring theme for all participants. Jackson spoke about how since being diagnosed, and discovering the Autistic community: *"I think basically I've had to pick apart my entire life and look at it from a completely different* *world view."* "Identity politics", or the way a person's social and political views are shaped by their sense of personal identity, has been, and continues to be, an important social force over the last century (Nadesan, 2005). Participants all used the language of "exclusion" and "inclusion", and an awareness of the different boundaries and barriers in their everyday lives. The stigma of being associated with a narrative of "impairment" or "dysfunction", or not being able to "fit" someone else's idea of "normal", was seen as the most disabling feature of being Autistic, and while each participants background and journey to peer support was different, this shared experience was clearly unifying.

> *I liken it a lot to the other cultures within cultures, um, like the Gay rights and things like that. We're very much following along that sort of path. From trying to cure the so-called disease, yeah right, to ... [laughs] Sorry! To changing and realising that it isn't that. And then going through their whole awareness thing. Into the acceptance. And then getting rid of the discrimination. But until we get proper acceptance we won't get rid of the discrimination. Because people still treat you as different. But when you get down to being accepted, they then go, okay, we'll stop treating you like that. It will come. It will come. But it's going to take a long time. (Margaret)*

These perspectives reflect research which focuses on mutual help groups as "communities of interest" or "communities of belief", rather than just "alternative service providers", recognising the culture creating and transmitting aspects of groups, and the ways groups develop and use specialised experiential knowledge of their common problems as an asset and source of power (Powell, 1994). Timothy spoke about how being Autistic was not just fundamental to who he was as a person, but a source of strength:

> *Well I would not have such a strong sense of identity if I was not part of the Autistic community, or didn't identify with being Autistic. And that sense of self-identity, like taking ownership of being Autistic, has been really vital for me because, um, I would probably not be as open and strong an individual if I was unsure of who I was, you know. And obviously we're all, we're all on, you know, never ending journeys of self discovery. We're all trying to figure out who we are, and what our purpose is, and all that sort of thing, and how can we contribute more, and all these sorts of things, you know, what can I do to make myself happy, um, there's — that's a never ending process. But, um, you can, you can do that in a, in a passive way, or a more active way, and if you have a bit more of a sense of identity and ownership of self then, you know, you can be a little bit more active in your self-discovery, and your self-recovery, you know. (Timothy)*

Jackson described how embracing his autism, and developing relationships within the Autistic community, has changed his perception of self so profoundly that he now considers it part of his *"ethnicity"*:

> *…on the census for example, recently I identified my ethnicity as an Autistic New Zealander, it's like this, to me it's like, well that is my culture, it's sort of been my culture my whole life, I've just sort of just never realised it, and I'm currently in the process of continuing to define what that is for me, who I am … (Jackson)*

Environments

The importance of adapting structures and environments to meet the needs of people, rather than changing or fixing people so that they can fit into the system, was a theme all participants returned to time and again:

> *…some people are quite disabled by their autism, and that's understandable (…) but maybe it's environmental for them as well, if you get them in the right — I've seen it so many times, and you know, especially with adult services….you put them in the right living environment, and their behaviour will settle down because they're happy, and then you know, then that's an environmental issue. And if it's an environmental issue, it's about that, not about the person themselves, and therefore maybe it's not their autism that's the problem, it's the environment. (Margaret)*

Margaret described how her interest in support services for Autistic adults, came about after she retired from teaching and moved to a new city, because she was curious about what had happened to the many Autistic children she had taught:

> *I wanted to know where the kids went, so when I came back to [name of city] I just went and, um, decided that I was going to follow, and see where they went. And I went and had a look at the adult services and it scared the hell out of me. It really scared me. It was terrible. (Margaret)*

Margaret also expressed concern about statistics that point to negative outcomes for Autistic people and their families, and shared that she had her own fears for future generations, including for herself and *"people coming through our family too"*:

> *…we have horrific stats. We've got terrible stats. I mean they reckon about 85 percent of people on the spectrum are depressed and, you know, have anxiety and things like that, it's disgusting, and the amount of homelessness, and the amount of, ah, woah — scares the living daylights out of you. And the amount of unemployment and the, the trap of being on a benefit (…) And we've got a new issue now that the*

> *adults are talking. And the parents of the adults are talking. And we've found that there's this huge swell of people who've been supported by their parents, and their families, who are getting older. And their families are sweating. Because they're going, what happens when we die? And there's another issue. Under normal circumstances, not normal but you know what I mean, under the usual way of life, as parents age their needs change and they need support. And who do they get the support from? The children. Now if they're supporting their children, how do we support their kids to support their parents? Do you understand what I mean? All those issues are coming up. And that's peer support stuff. We have to get out there and do it. We have to talk about these issues." (Margaret)*

Margaret went on to explain that she believes this is *"peer support stuff"* because *"society's very good at isolating people and keeping them away from each other."* She used WINZ as an example:

> *…the structure of our society, let's take WINZ for example, right, everybody's isolated. They keep giving you a benefit. You stay over there. You're on your benefit, we've sorted you out? Okay, you're fine. Stay over there. Right. This one, we'll deal with this one now, right? You're okay? Got you sorted out? Right. You stay over there. They isolate you. Away from each other. So you can't get together and discuss together. (Margaret)*

Margaret demonstrated a deep interest in the "nuts and bolts" of how to make things accessible to Autistic people, and how social structures can bring people to together or keep them apart. Transforming things from the ground up is something she described (somewhat shyly) as her *"obsession"*. For example after discussing the problems experienced by people at WINZ, Margaret went on to propose how it might be addressed, *"together as peers"*:

> *…well you know the stats aye, 42,000 people, Autistic people, are on WINZ books. They don't know that. They don't know that….And WINZ has no specialised staff trained in autism. It's like, no wonder they don't get it. But we, as an Autistic community, when we come together, we can deal with that. We can then go in bulk, and say right WINZ, this is how we want it organised. Because it's not WINZ's fault. It isn't their fault. I mean it is to some degree. But they don't know what they don't know. And they don't know how to deal with it because they don't — nobody's telling them. Because nobody knows how to do it. So we can do it, we — and that's part of peer support, when you get together as peers, together, you can support each other to make a change, and yeah, so that's where we're heading [laughs]. (Margaret)*

Margaret spoke most passionately about her long term involvement in another project that is clearly very personal to her, a local grass roots initiative (the "social peer group"), which started as a small group of *"about six people on the spectrum"* who used to get together socially, but has grown through word of mouth alone, and expanded exponentially, to become a community resource, a social experiment, and what she described as a *"movement"* in its own right, She shared a wealth of detailed information about how the different initiatives she is involved with have been set up to be *"Autistic friendly"*:

> *…we just want a safe place that we don't have to adapt ourselves all the time, which is what you usually have to do when you go anywhere else…and that forms a natural peer support. Because it's the place to be. Where you can be yourself. And when you get together with people, and start talking, you find out that there's so many issues that are common issues ….and then you think, yeah, I'm normal, you know, it's quite nice to be normal [laughs] but people don't usually talk about it you know. (Margaret)*

Margaret repeatedly linked people *"getting together and discussing things"* with problem solving and positive outcomes, and for all the participants, being in a group was associated with having the power to make change happen.

All participants shared thoughts and ideas about what makes things Autistic friendly; this included the size of groups, control over the physical environment (particularly noise/music), who was allowed to be there, and who made decisions. Keeping a place "safe" for any given community relies in part on a power dynamic, and a common theme was the environment having to adapt, not them. For example, one of the things Jackson, and Tyrone particularly valued about the social peer support group they attended was the way the group would take over a venue (usually a bar or café/restaurant), which given their numbers, would usually result in the venue having to accommodate them. Tyrone expressed pleasure in recounting this, suggesting that having this kind of power, was not an everyday thing:

> *Just our large group, um, they've got to be able to [laughs], have the room to handle us all, and most places, we're getting to the point where we can't. Also we will pick places that we've been to and we know can cater for our different sensory needs. We had one place that we went to, and, we went to them and said, um, would you mind turning your music down? And they did. I can't remember what it was, I think it might have been in [name of café restaurant], I can't remember, but someone did for us. (Tyrone)*

When discussing how the social peer group operated, Margaret consistently used the collective terms *"we"* and *"us"*. For example when listing different activities, she said, *"what else do we do?"*; or in response to a problem, *"so we thought"*. She also referred to *"our guys"* (as opposed to *"their guys"*); *"our people"*; and *"us as a community"*. Despite taking on an organisational role, Margaret clearly placed herself firmly on the "inside" of the group, and while she identified herself as a facilitator and co-facilitator in the group, she believes it is fundamentally important for everyone in "the group" to be actively involved in making decisions:

> *...it's really important that the guys decide what they're going to do with that group. It's really important. It's not my decisions. I can run things past them and say what do you think, you know, but they usually agree with me anyway, which is, which is fine, but it's also scary, because you know what the yes-men are like. They're trained to be yes-men when they're young. So we're always trying to give them opportunities and make them think about things, you know. A lot of our people are trained to be yes-men. I never was [laughs]. I don't have trouble being a no-man [laughs]. Sorry mm [laughs] but yeah, maybe...And that's part of good peer support, is making sure that you're actually really listening to the people, and that's where the small groups are important, because they get heard better, yeah. (Margaret)*

Margaret identified with others in the Autistic community who had limited resources, and/or barriers to employment or opportunities in the wider (or NT) world, and had experienced the frustration and the *"trap"* of being on a benefit or supported living where:

> *...you're not allowed to have treats because if you have too much money then you're penalised for it. So you can't save to do something nice for yourself, like go on a trip or go on, you know, you're not allowed to, and that really sucks big time. In the disability sector, many people also become used to having things done and decided for them. (Margaret)*

Empowering people by letting them make choices was in this context a significant and conscious choice. Tyrone recounted how having a facilitator take *"direction from us"* distinguished this Autistic-run group, from others run by non-Autistic people:

> *So each group decides what they're going to do. And with [name of social peer group], [name of facilitator] takes direction from us, so every [name of social peer group] she'll be like where do you want to go next time? And we all, all decide where we want to go, and she'll organise it. She said she wanted a group where it was run by us entirely, so like some groups you'll find the non-Autistic person will take over, and they'll make all the decisions, um, where she's like, no, you guys decide where you go, you guys decide what to do. (Tyrone)*

Each group had its own guidelines in terms of who could join, and boundaries were set by a "gate-keeper" who dealt with enquiries, that were said to come mostly by *"word of mouth"* through other community members. For Margaret, it was important the door was open to all who needed it:

> *…the nature of our group is that you just come if you want to. And you don't come if you don't want to. It's just open door policy and, um, we don't have any fees or anything like that, it's purely because all they need is an email address, and then they can get our information and where we meet up. That's all. (Margaret)*

However, as the social peer group met in bars and restaurants, Tyrone explained how people who joined this group were required to be "independent", especially with money:

> *…the main thing for going is, you must be able to go and be independent, um, and especially financial independence because otherwise that makes you vulnerable, um, because if you have to trust someone else with your money you can imagine all the — what could go down, so… (Tyrone)*

Margaret also talked about how this decision was, in part, in response to the need for more "independent" Autistic people in her local community, to have a space just for them:

> *We've got other social groups that I know of, um, I know quite a few actually around town, um, that have been set up, and they will have staff, and have major facilitation and things like that, because their guys have, um, higher needs than we do. And our guys used to go to those groups. But they found that when they went along, they ended up as helpers. And their needs weren't met. Their social needs weren't met. They were — I don't mean dumbing down, I don't mean that, they were, um, helping other people, instead of being there for themselves. So we thought, right, we need something that's for them. So they can be themselves. And it's been quite successful. Because they've needed a place as well. (Margaret)*

Tyrone also explained how a few non-Autistic "allies" have been allowed to join in:

> *And we've got a couple of people in our [name of social peer group] that are not Autistic, but they've been invited by the Autistic member, and of course, for our safety [name of facilitator] screens each person, and these two people have fitted in, and the guys like them, so we've allowed them to stay, because we like them, they fit in well, you know, they don't cause trouble. (Tyrone)*

Timothy also has many years' experience setting up and facilitating Autistic peer support groups, and also contributed ideas about how to make things Autistic friendly. Timothy described how he recently challenged fellow support workers, employed by the service he works for, to consider whether they might also qualify for some of the services they offered. Many of them would, or did. He went on to highlight the importance of how we talk about *"service users"*, and providers:

> *And I said to them, so when you're talking about clients, or service users, or people we serve, or however you want to word it, you're talking about yourself, so you have to be really careful around language [laughs]. And all of a sudden people stopped and were like, ah, oh, okay, yeah okay I get it [laughs]. So yeah, that was a bit of an eye opener for some people, because it's not an us and them, never has been, it's a we as a community, supporting ourselves to be a better community. (Timothy)*

Timothy described how he actively sought opportunities to model *"we"*, rather than *"us and them",* and described how when members of one support group he facilitates, told him they didn't like doing paperwork at the meeting, he agreed to do this in his own time:

> *…because, um, that's just one barrier that's been broken. And if I'm in with a group of other Autistic people, it doesn't make me any less Autistic, I'm still Autistic you know. I might be there in a professional sense but I'm still Autistic. And I can't forget that I'm Autistic and I'm a professional. So I'm, I'm sort of, um, I don't want to say like, um, darting the fine line or anything like that, because it's not a, you know, it's not a conflict of interests to be Autistic and on an Autistic group. People might look at it that way, or people might look at it as in, you know, you are either a professional or you are Autistic, you can't be both at the same time, you know. Or the fact that there is no both at the same time, it's one and the same thing, you know. (Timothy)*

This inclusive approach to organising and structuring things enabled the peer groups to be fluid and responsive to the needs and interests of the participants over time. An example of this was how the social peer group responded to problems relating to "sensory issues" or "sensory stuff", that was a frequently recurring topic amongst all participants. Jackson explained how he was particularly sensitive to noise, even within the social peer group itself, *"just because there's so many people, and like, we actually make, there's so many of us, we actually make enough noise that I start having sensory issues"*. Margaret reported that the growing size of the group was also making it more difficult for group decision making to take place. In response to this, alongside get-togethers in local pubs and cafés, the social peer group decided to also start using a hired venue twice a month, as it is *"very quiet"*, and has got *"lots of rooms and nooks and crannies where people can go and have little conversations"*. But as the need for a bigger venue has arisen, so has the need for funds to pay for it:

> *The new venue is really, really good, it's huge, we have to bill — I mean it costs us almost 300 dollars a night, it's that big. But we have to hire out the whole thing because we need it all. There might only be 30 or 40 of us there but we need it all, um, and that's the nature of it, and so… (Margaret)*

Margaret saw this as an opportunity, not a barrier, and finding an environmental solution that provided some control over noise, rather than have people drop out or feel excluded, was a clear sign of how important sensory issues were recognised to be for her community. Margaret also explained how she saw this as an opportunity to develop skills in the group, as they are now in the process of evolving into a trust and registering as a charity, with an all-Autistic management team: *"And that's a really important part of the peer support, because people can do a lot more of it, in different ways."*

While the physical environment was seen to be important, having an Autistic person/s facilitating was also seen as contributing to a group's safety and comfort, in both real world and online groups. Tyrone felt this was particularly important to the online groups, where without moderators: *"there'd be all sorts of troubles, just wouldn't be able to have groups because they'd just … crumble."* When asked if there had been any problems in the groups, and how she had dealt with them, Margaret described a few occasions when she felt *"co-morbid conditions get in the way"*, and acknowledges there may be *"a bit of mental health going on there"*, such as people feeling a bit *"paranoid sometimes"*, or disagreements over *"pedantic things"* where *"we have to step in sometimes just to help them deal with moving on with that"*:

> *Sometimes because our guys get quite hurt, if they're bullied or if they perceive a wrong, they can get quite hurt, and sometimes we have to step in and help, um, re-frame that. See it in context. Or help them realise that it's such a big group, that if they don't particularly like a person, they don't have to talk to that person, and there's so many other people to talk to [laughs], that there's room for everybody, you know, and that's been quite hard for a couple of our guys, um, who have had disagreements in the past, when they were younger, and they've got to maturity, but they find it hard letting go. (Margaret)*

Time and again, in response to problems or potential conflicts within the group, strategies were described that involved recognising aspects of a person that needed respecting and/or accommodating, and "softening" or bending to the needs of Autistic people, rather than expecting them to conform to the desires of an "outsider". Two examples, provided by

Tyrone, have been included in full, as they demonstrate his awareness of the interplay between different social expectations and codes, but also of how responses are shaped by different social/cultural expectations. This is of note, as difficulties with perspective-taking have often been associated with autism in a clinical context. At no time is the behaviour of the Autistic person described as a problem, rather a person's responses are accepted as valid communication, of valid needs. Having the Autistic person's needs met, even at the inconvenience of an "outsider", and/or transgression of their social codes, was seen as a positive outcome. The first instance involved a young man who wanted to go home early:

> *There's one guy that, um — he is Autistic, he sometimes — his mum will have to take him, because when he wants to go home, he wants to go home, no if buts or maybes, he's nope, not waiting, I want to go home. And sometimes they bring another guy with them. So, one time he was — or he has a broken elbow, that he broke, um, when he was at school, and it still gives him trouble, and he said I'm in pain, and I want to go home. And they said, well what about [name of person]? He might not want to go home. And then [name of facilitator] suggested to his mother, okay, why don't you take him home, and come back. And, so she did. She took this guy home, and then turned round, and came back. And then that meant that [name of person] got to stay and enjoy himself, because he didn't want to go home yet. And, um, we could tell that the guy's mother didn't really want to go home yet, so, um, so that happened. He's very, he can be — they always say that we Autistics think black and white, which is pretty much true, but this guy seriously, he is black ... he'll talk about one subject, and pretty much anything else he'll just…[laughs]. (Tyrone)*

In the second example, Tyrone described how the group dealt with an "outsider" who touched him inappropriately. Notably, he concludes by suggesting problems rarely happen within the group, but are generally caused by outsiders:

> *... one time a guy who wasn't Autistic, and rather drunk, came off the streets — and we were at the [name of pub], and, ah, he decided that, oh, he's a very friendly looking guy I'll go and give this guy a hug. And I'm sitting there going, go away ... And [name of facilitator]'s like, Tyrone doesn't like to be touched. And he's like, oh, (matey tone of voice) he's alright, don't worry about them, they're not your friends, I'm all good, aye. And I'm sitting there trying to get away. And, um, this guy, (name of person in peer group) got up, cause [name of facilitator] was going to, and she said, she noticed [name of person in peer group] get up, and walk behind her, and then calmly came and stood in between me and this guy, and pulled out his phone and called the cops [laughs]. And just before he got to me, I said to this guy, don't touch me! So of course the [name of pub] people had to come, and they got him out the door, and managed to shut the door and lock it, so [laughs] ... and, um, not so much that our guys cause trouble, it's more, other people that cause trouble for us. (Tyrone)*

Margaret explained how, for her, peer support was about *"making friends, and breaking that social isolation that, ah, Autistic people can feel"*, and recognised the importance of building self-esteem:

> *We see a, we see a lot of our guys come into the (name of social peer group), ah, yeah, the [name of social peer group] groups when they first start, and you see them come in and they're so — their self-esteems are low, they've been beaten over the years with not quite fitting in, and maybe being, most of them being bullied….And if they're isolated, they come in, and they're very low. And then they find their — and they go, oh my gosh, these guys are cool, these guys don't put any expectations on me, they accept me for who I am. They like me for who I am. I'm okay. And there's — you can see their self-esteems going up. And the things they then try, by talking to each other — and somebody's gone flatting and they've been quite, you know, they've been flatting for years. And then they think well I might try that, or I might, you know, and they support each other, you know. (Margaret)*

In recognition of the fact many of their community had experienced negative social encounters, both Margaret and Tyrone shared how important they felt it was to scaffold interactions, and facilitate introductions, particularly when someone was entering a group for the first time. Margaret referred to this as helping people "flow", and described her approach based on matching people according to their interests:

> *…when people first come, I ask them what, what they're interested in, and what they like to do, and that will tell me where, whose, to pair them up with. And then when I introduce them to that person I say "Oh look this is so-and-so and he's really into da-da-da-da", and lead them into that discussion, so they've instantly got to sit down and talk about something. And then usually they guys are flowing on from there. And we usually just keep an eye out, I've now got several people that are watching all the time too. And we're training people up and that'll be part of the advocates role too, you know the helper's role is just to make sure everybody's flowing, and there's nobody sitting by themselves. Unless they want to be sitting by themselves … sometimes people take themselves off to have a little bit of desensitisation time [laughs] you know, quiet time to themselves for a few minutes, and, um, or if they just want to talk to just one person instead of a small group or something like that we might do that. (Margaret)*

Timothy's approach to facilitating introductions, acknowledged how the size of a conversational group might help or hinder connection, and drew on theories of energy exchange that suggested a kind of "alchemy":

> *…you know you can't just put two Autistic people in a room together, and all of a sudden you've got something magical happening, you know. But if you put the — if*

> *you have the right Autistic people who have compatible energy in the room together, then yeah, magic happens, you know, and you have a really ... you know, you can spark a life long friendship.... like when I, when I went to the [name of social peer group].... and there was one Autistic guy there when I turned up ...and he was the only one there, so I sat down at the same table as him, but he still didn't talk to me, he just kept to himself. And it wasn't until there was a lot of different people there, and a whole bunch of people sat at his table, that he found somebody he was comfortable with talking to and you know, he kind of came out of his shell a little bit. But just because I was there and I was Autistic, it didn't mean all of a sudden that he was comfortable, you know. Because we probably have different energy, or we haven't discovered each other's energy yet, you know, and that's cool, you know I understand that, you know I don't want to hang around all Autistic people all the time, um, because the energies can be quite intense, or it can be pretty, um, not intense enough [laughs]. (Timothy)*

A further two extracts, building on Timothy's theories of "*energy input and output*" have been included in full, as they demonstrate a very nuanced picture of social interaction. Once again these highlight limitations in the scope of the *DSM-5* (2013) as a tool for understanding autism, specifically in relation to "a failure to initiate or respond to social interactions" and "difficulties adjusting behavior to suit various social contexts" (p. 50). Timothy used the example of Japanese *hikikomori*, as an analogy to explain how Autistic people are constantly having to make adjustments to their environments and lifestyles in order to manage their "*energy input and output*":

> *So, um, in Japan they have a social phenomenon called hikikomori, which you might be familiar with, and, ah, hikikomori is where people lock themselves in their rooms for six months or more, and they'll just literally live on their computers, and sleep, and live on their computers, and they only go out to go to the toilet, and get food, and then they come back into their rooms again. And that is very appealing, that lifestyle is very appealing for Autistic people, because, um, our whole life is trying to reduce sensory input, you know, to make things comfortable for us. And if we're in an environment that is completely controlled i.e. our room, we control our own space, and we can control what happens on the computer by our actions, by — if it gets too much we hit the X button, and we close the window, you know, or we pause the video or something. So all of that stuff is things that we can control, but if we're in a room with somebody else, we can't control what that other person's going to do. So energy input and output. (Timothy)*

Timothy went on to explain that, while removing yourself from others gave you more control, *"sometimes we do crave the energy of other people"*, and that one of the benefits of meeting people in person (as opposed to online support) was *"that you can be a lot more specific with your empathy"*:

> *So if I'm with somebody else who's Autistic, I then have the opportunity to say to them, um, how's things going, what's working, what's not working, you know, you can have an actual discussion, you know, that is energy based. Because as much as we're trying to reduce or control the sensory input, sometimes we need that other person near, for energy, you know, because sometimes we don't have enough energy coming in, and we need somebody there, you know, um, and you can't get that in your room. Hence the fact a lot of hikikomori people suffer from depression, or I should say, experience depression, you know, um, because there's that imbalance of energy, right. The, the energy balance has got to kind of even out a little bit somehow, and, um, so if we can find somebody, or some people, that have a compatible energy that is in a right balance, you know, because some Autistic people are very loud and out there, and, um, have a lot of energy, and you've got to prepare yourself for that, because otherwise it could be too much. Other Autistic people, um, are really quiet, and shy, and reserved and they hardly talk at all, and that's not enough energy, and you want to find somebody who's in the middle there, who has the right kind of energy for you, so that you can have that balance there. (Timothy)*

Margaret shared that *"almost all"* of the people who have found their way to the social peer group have "*had diagnoses"*, and grown up knowing they were Autistic, but a few had come as adults seeking, or are post late-diagnosis. Margaret went on to flag some of the negatives associated with seeking a clinical diagnosis, and explained how time with Autistic peers, may provide an alternative to a clinical diagnosis, something she described as *"validation by peers"*:

> *I mean the thought of going in and actually getting diagnosed is actually really scary. Because to get diagnosed, you're going down that whole medical model, that goes there's something wrong with you, and where there may actually not be. You may just be Autistic and that's okay. But the medical model implies that there's a negative, you know. There's actually something wrong. And it's, yeah, that's really hard for a lot of us to accept, and a lot of us adults are going, nah. If you've got a lot of Autistic peers around you that that accept you as Autistic as well, how more validated do you need? Because they actually know what they're talking about. They live it. They see these characteristics. They know. And why go for an interview with a professional who'll only see you as a snapshot on this particular thing, where these people know you, really, really well. (Margaret)*

Margaret went on to explain that *"for people that aren't really diagnosed as such, we tend to use more the term neurodiverse, and then it sits really well and easily with them, because we're all neurodiverse anyway….and that's usually where we all end up.*"

All participants described their peer support groups, and the Autistic community in general, as neurodiverse, and despite differences in backgrounds, interests and sometimes opinions, essentially inclusive to all who identified as Autistic. Margaret described the social peer group she was involved with as being *"open"* to diversity in general, but acknowledged, *"we're still learning about our women"*, and that cultural barriers were taking taken longer to break down:

> *We've got quite a few women now coming along. Quite a few mothers who actually brought their sons along initially and then they've found themselves at home here, funny that, aye. We've got a few Autistic women that've come in that way, um, and they've stayed on their own right, and they've made their own little clique in there, you know, which is quite nice…really, this, our group is very, very — compared to general society it's actually much more inclusive in the sense of we've got several transgenders, we've got asexuals, and we've got all sorts of people in there. And it doesn't matter. We're all just who we are, you know, um, and that's really cool, I like that about the group. Always have. Always loved that about the group. That we don't sort of place any — and we've got all, starting to get different ethnic groups too. But as I said we've never advertised so we haven't — It's interesting how they're coming out of the woodwork slowly. Different cultures do things differently so you don't see some cultures. And it's not because they haven't got the Autistic population, it's because their culture is organised differently and, um, they cater for their Autistic population better, or they may hide them to the point where we don't see them either, that happens, um, so yeah. (Margaret)*

Margaret repeatedly placed her focus on others, and what she would love to see happen for others, often remarking that she was *"getting side-tracked"* if the conversation became too personal. She demonstrated her optimism, and passion for transforming things from the ground up by describing future projects and "structures" she wants to see put in place. For example, after talking about how so many Autistic people are under employed, and often lack the resources needed to leave home, she shared plans to harness the power of the trust to set up a number of pilot schemes, to support and showcase Autistic talent:

> *We want to set up co-ops. We want to set up micro-businesses. We want to set up all sorts of things, look at accommodation, we want to set up all sorts of things that are Autistic friendly. So that they can shine. Because our structures in our society are not friendly. They're not Autistic friendly. Unless you can skimmy under the radar like I did, you know, but when you come out as an Autistic person they're not friendly at all, and it's frustrating, and, um, we can do it better than that. And it's coming. Because now the adults are talking. And they're getting together and they're organising. Some amazing stuff will — and then it'll go mainstream, it's like anything you know, so yeah it'll go mainstream in time. It'll come. I have a great positiveness about the future if the Autistic community can organise themselves. (Margaret)*

Mental health

All participants associated Autistic peer support with positive experiences, but also went one step further, in describing these groups as a *"resource"* or *"place to go"* that once discovered, had become essential to their well-being. Most significantly, all participants spoke of the negative effects on their mental health of stigmatisation, bullying and struggles with aspects of daily living, and how peer support had helped them.

Both Tyrone and Jackson first discovered Autistic peer support groups while seeking help for issues relating to mental health, and not finding it elsewhere. While Jackson had received a diagnosis of ASD from his local adult mental health services, he felt he had had to fight for it, and was left feeling he knew more about autism than the professional he consulted:

> *…when I initially went for a diagnosis, the psychiatrist asked me, well you're an adult, at sort of what point would a diagnosis lead you? And that sort of made me think, and I was like well, that actually explains that things that have happened in my life, were out of my control, and it's not me that's defective, it's, and it's yeah that's a huge thing for me, and he just didn't seem to understand that. And they downloaded some information about autism off the internet and gave that me, and I was like well, I've already read all this. (Jackson)*

Jackson went on to explain how *"after I got diagnosed, it was about early 2016, I started searching for some sort of support, and I literally could find nothing."* By chance someone in the community directed him to a local Autistic-led group that had been set up specifically in response to a perceived lack of formal support for Autistic people's mental health needs. Jackson described his experience of peer support as *"invaluable"* and expressed anger about two years of his life *"spent medicated off my trolley on anti-depressants"*, after what he now saw, in hindsight, as *"Autistic overload"*. He felt this was a missed opportunity for diagnosis as a younger man, when he could have been given the *"right kind of support"*, which he felt he had to fight for later in life, and has since found in the company of Autistic peers:

> *... that was basically the first time that I've ever been in a social circle where it's considered normal to have a psychiatrist, or be seeing a psychiatrist, or a counsellor, and that's okay, and people just talk about it as though it's like, oh we*

> *just went down to the pub, it's literally the same, and it was quite odd and disconcerting at first, um, but it rapidly became quite easy… (Jackson)*

Tyrone also described how he felt local mental health services were not meeting the needs of Autistic people, despite problems with depression and anxiety being so prevalent in this community:

> *I didn't actually realise that I could possibly be on the spectrum until I was a bit older, and, um, and then I met [name of facilitator], and, so yeah, he introduced me to [name of social peer group]. And then he was like, ah, he saw a need for a support group for people who've — for mental health support, because we, a lot of us on the spectrum have had at some point, a mental health issue. And of course you go to mental health, and they're like, oh you're Autistic so we can't help you, we'll put you on this side of the basket. (Tyrone)*

Jackson also described a less helpful experience, at what he called a "traditional" support group, which included NT people. He explained how sensory issues, and not being in sync with other people's conversational rhythms, were a significant barrier to his participation. Jackson's description is in stark contrast to Timothy's earlier reference to Autistic people "resonating" with each other:

> *I started attending a [name of mental health trust] support group, basically anxiety and depression support group….and basically just — there was heaps of neurotypical people there, and there was sort of 20 other people, and I don't do new places and lots of new people well at all, and I wasn't in a great place at the time myself, and just, yeah, it was a pretty horrible experience really. Once I'd basically managed to get the waterworks under control, I just found it really hard to participate in anything, because literally it's like there's, imagine little train sets going around and round the table, and that was just the conversation between everyone, and literally I normally don't have any issues, but because there was so many people, I couldn't actually time the gap where it's okay to start talking about something. And I just found that really frustrating, and it sort of — I guess that's one negative thing about the traditional support groups, just the noise and stuff as well. (Jackson)*

Keeping the *"waterworks under control"* was something Jackson referred to several times, and had clearly been a source of difficulty for him in his earlier life, particularly in the context of his work as an electrician, where *"tradies are normally pretty rough, and rugged, and don't show any feelings and, you know, that sort of stuff and [laughs]"*:

> *I don't have meltdowns, I have I think what's called shutdowns, so like waterworks [laughs], and it's quite embarrassing. That's happened once here actually, at [name*

> *of social peer group], and I basically realised after that happened that — so in 2006 I did Outward Bound's 10 day adult thing, and the first night that I was there, just before tea time, I was in the room with some great big, about 50 or 60 odd other people, and I had a shutdown, and just pouring my brains out, and in the corner, and it's like, what the hell is that all about, sort of thing. And after the tears I was completely fine, and just looking back it was several times in my life where that's occurred, and I've never known why, and it's like panic attacks and having a shut down, and just sort of being able to manage myself, and it's just the whole self — Autistic self-awareness, rather than just purely self-awareness… (Jackson)*

Being in an environment where "meltdowns" and other issues such as depression and anxiety were normalised, had contributed to Jackson developing what he described as *"Autistic self-awareness"* which has resulted in him being able to advocate for himself in daily life:

> *And so recently at my noho marae in Wellington, like I knew that it was like three days, that it would be extremely intense, I'd have all these new people, a whole new place, and I would be assessed the entire time I was there, and I got an exception to not have to sleep on the marae which otherwise I wouldn't have coped with. But even with all of that, and my anti-anxiety tablets, I was having shutdowns probably every couple of hours. But because it was a, just a lot of social things, I announced when I introduced myself that I was Autistic. Pretty much everyone was extremely supportive when I basically had a bit of a shutdown, I would just go away to a quiet space and just, um, let it work its way through, and then when I was ready I'd just re-engage with the group, and just no one batted an eyelid, and I just felt really included, and even though this just continually happened, just because of all the stress, it was just a really nice environment to be in. And that's the first time as well, that I've ever been under huge amounts of stress, and I guess sort of breaking lots of times, and still able to re-engage, and no one cares. And that was, that was also quite nice. (Jackson)*

Timothy reflected on how sensory sensitivities, and the challenge of managing these, fostered creativity in Autistic people - a source of resilience - and something he saw as a deficiency in NT people:

> *There's a threshold right, every human being has a threshold of how much energy they can handle, okay, um, your, your neurotypicals can handle more energy than your neurodiverse. Now the thing is with the neurodiverse people, because we, we — I don't like to use the words, but we can't handle as much energy coming in, right. So we, we have to, um, be more creative about how we do things, so that we make sure that not so much energy is coming in. Hence the fact that, ah, neurotypicals are some of the most [laughs] boring people you've ever met because, um, they're, they're not creative, and they've never had to be creative. Whereas neurodiverse people, we've got to be constantly thinking how do we do this, how do we that, how*

> *do we make sure that this can happen without me going into this negative space. So that's where a lot of our creativity comes from, you know. (Timothy)*

Tyrone thought peer support systems had *"changed me in the fact that I'm a lot more calmer, um, because it's like I know I've got other people I can talk to."* He also felt that online was both an important way to stay connected, but also a form of respite when the *"real world"* gets too much:

> *The real world is good for like — I can handle so much of the real world, so I'll go out to these peer supports, and the rest of the time I'll be on online, communicating. (Tyrone)*

Jackson also described how it was reassuring to be able to dip in and out of these various groups over time, without any of that "*[aggressive tone of voice] <u>oh where have you been, or where have you been hiding</u>, and all that sort of stuff*". And that online support groups meant he could access others in the Autistic community at any time of day or night, and was able to communicate in his own *"space and time"*:

> *And I've also found that, once again, really valuable, just sort of being able to connect with someone that actually gets what it's like being Autistic in a neurotypical world, and even just being neurodiverse in a neurotypical world. And it's just nice being able to ask questions, sort of, I've got this scenario, how is — has anyone had the same thing and how did they deal with it and ... I haven't done too much of that, um, yeah. I definitely wouldn't want to be without, I guess, that resource. And just the fact that you can ask a question, and you don't have to respond then and there, which is sort — it's like I can do it in my own space and time. (Jackson)*

Margaret has been instrumental in setting up peer support groups specifically to support Autistic adults with mental health. She talked about the many factors a facilitator needed to consider when providing support in this context, and her own approach, which reflects professional training, as well as personal experience:

> *We have a separate group for our Autistic people if they want to come to that because we keep that particular group quite small, one or two people. Because it allows for catering for your sensory stuff. And very personal stuff. And we tend to get quite focussed on a particular topic. And in doing that we really just talk about what people want to talk about. And we learn skills. Cause it's about depression and anxiety. So we learn lots of skills about mindfulness and, um, self-care, and how to cope with general — yeah the whole the thing. And everybody's journey's different. Everybody's medication journey. Everybody's counselling journey. Everybody's,*

> *everybody's — the whole, their lives are different so, you know, it's a matter of respect and letting them go. You know. We just listen a lot and share ideas without telling people what to do, because what their — is right for them, is what's right for them, it may not be right for us, you know. (Margaret)*

All four participants reported having attended social peer support groups, as well as smaller groups specifically set up to support those experiencing anxiety and depression, but saw *all* of the different types of "informal" peer support (including informal friendships and online groups) as contributing positively to their mental health.

Timothy also reflected on why he thought peer support, itself, also needed to be *"healthy"*, and how he felt organisations often got that wrong. Timothy highlighted the importance of "entering someone else's world", rather than making assumptions about them, and of being genuinely interested in what you might learn. He referred again, to his first-ever encounter with another Autistic kid, a pivotal moment in his own life, and one that has informed his professional approach:

> *…and this is the biggest thing that I always say, why do organisations, specifically organisations that call themselves Autistic organisations, or autism organisations, or whatever, I won't name any of them, but when they run groups for Autistic people they always fail. And why is it? It's because it's not organic, okay. Being organic is the healthiest option, to chuck the old food references in there, right, being organic is one of the healthiest options, right, so if you want to survive, and to grow, you've got to eat healthy. If you want a group to survive, and grow, it's got to be organic to be healthy. And when I met this Autistic kid for the first time, it was — he was just another kid at school, I met him at lunchtime, you know. It was not something that was presented to me, he wasn't put in front of me, he wasn't introduced to me by anyone, I just saw him and thought he's an interesting character, I'll go and have a chat with him. And that's, that's, that's the key point. I asked him, I said, can I enter your world? And amazingly he said yes. And that was the beginning of, of, you know, however many years of, at High School, of friendship, um, you know. We used to annoy each other a lot with our really cheesy jokes and things like that, and I'm still pretty bad [laughs], ah, but it was a sense of, I don't know who you are, but I know that you're like me, and that's a start. Yeah. (Jackson)*

Self-growth

For all participants, being involved with peer support was associated with self-discovery, new learning, and transformation. They talked of feeling no longer alone; of stumbling into or discovering a new world; of finding a tribe of people like themselves; a community that speaks the same language and shares the same issues. They described doors opening, a feeling of being home, and of finding a place to stand. For all participants, this led to new opportunities, and most significantly, a shift in how they saw themselves, and how they saw themselves in relation to the non-Autistic world. Jackson described the shift that had occurred for him, as a *"change of life"*:

> *I've had to basically take a whole lot of, not really preconceptions, I don't think is the right word but it's kind of there, it's basically like, this is what being normal is, so working a 40 hour work week, I don't think I'll ever actually be able to do that again completely, and sort of realising that, and then coming to kind of, I guess accept that well, what is normal for other people, is not actually doable for me, unless I basically want to destroy myself in the process, which is what's happened in the past. (Jackson)*

Words and phrases Jackson used to describe life before his diagnosis included: *"struggle", "massive issues", "huge issues", "not very confident", "stress", "anxiety", "depression", "Autistic overload", "basically just get in get out get in get out", "crashed and burned", "medicated off my trolley", "weird conversations", "put down", "rejection", "defective", "pressure", and "alone"*. Jackson talked about being *"led"* to try and figure things out, *"pursuing"* a diagnosis, and *"searching"* for support.

The language Jackson used to describe life post-diagnosis, included: *"piece together my path", "re-define", "realise", "accept", "new life", "easy", "potential", "skills", "experience", "share", "culture", "community", "mutually beneficial", "friendships", "relationships", "relate", "relaxed", "comfortable", "helping", and "teaching"*. He described how from the very first connections he made with the Autistic community, opportunities have just *"kind of snowballed from there"*.

Jackson also reflected on how re-defining what was normal, and gaining an understanding of what was normal for him, had illuminated strengths and qualities of resilience he had not appreciated before. For example, Jackson recognised that while *"persistence"* was the quality that pushed him to breaking point in his past life, it was also the trait that brought him to the point of change:

> *I'm generalising a bit here, but I think it does apply to a lot of Autistic people, is just the whole persistence thing, and just that ability to keep at something….I think that's a trait that a lot of people see as negative, but actually it can be really positive, and*

> *that's probably why I managed to become a sparky finally. I just kept on hitting my head against that brick wall until I fell apart and — so once in awhile, I guess it's like everything in life, how good points can be bad points, and the bad points can be good points, and that just depends in the context and, yeah. (Jackson)*

After initially having *"crashed and burned"* while a student in early adulthood, Jackson had come full circle, and returned to tertiary study so that he could enter the social services and offer peer mentoring himself. Having an opportunity to better understand his strengths has also enabled Jackson to redefine success:

> *And so I've discovered along the way, that success is what I define it as, not what society defines it as, so it's sort of, if I try and live up to society's definitions of that, I'm just doomed to spend a lifetime of failing, it's like well, I'd rather succeed my way. (Jackson)*

All of the participants expressed an interest in human behaviour, and a desire to understand themselves and others better. Being involved in peer support was seen as a valuable resource and source of knowledge. For example, Timothy associated his earliest experience of meeting an Autistic peer at school with a sense of wonder, and described having the opportunity to learn from others as something he appreciated every day:

> *So when I'm running an Autistic support group for example, I'm gaining just as much, if not more, from what the other participants are feeling and expressing…so, um, I don't go there and do it, and come back and go, wow that was really cool, they learnt a lot, you know. Ninety nine percent of the time I'm going, wow I learnt a lot from that, that was amazing. And so I'm gaining just as much. And that kind of self-awareness and self-growth, um, through these things is really important as well….but what I'm gaining is not a sense of pride and accomplishment because I helped somebody, it's a sense of, wow, I learnt so much from somebody, you know. And that's, that's really what it comes — what it is for me, it's learning, like I see the world as my teacher, you know, everyone's my teacher, everyone and everything, nature, um, the house that I live in, the people that I surround myself with, they're all, they're all my teachers, yeah. Even if I — the only thing I learn from them is to avoid them, I learnt something [laughs], so yeah. (Timothy)*

For Tyrone and Margaret, involvement with peer support groups had been pivotal in recognising, and accepting, they themselves were Autistic. Margaret reflected on how, while for most of her life she has been able to *"skimmy under the radar"*, recent awareness campaigns highlighting Autistic women's stories, contributed to her decision that the *"time was right"* to *"come out"*:

> *…for a long, long time I had a lot of Autistic friends that were saying, yeah, but you're Autistic too. And I'd go yeah, sure, yeah right, I don't know — didn't matter, you know. But now it matters. I like to acknowledge now because I think the time is right to acknowledge that you're Autistic. It's really important for women now. And more so since the, the last, um, awareness campaign…where they've focussed on women and women's stories, and it's allowed women to recognise themselves in it, and come out as, yup, I'm definitely sitting there. I think that is what happened with me really. I sort of knew, but I didn't really, you know. And then when I saw these other women talking, I was like yep, yep, yep I get that! [laughs]. (Margaret)*

Margaret shared that she had *"only just started putting myself out there, in those closed [online] groups"*, and admitted that she still felt *"vulnerable in the sense of when you put yourself out there you have to be prepared for all the people that will give you advice that doesn't pertain to you."* However when sharing a story about an online post she had made, asking if anyone else had sensory issues with *"wind on them"*, she laughed and had a brightness to her tone of voice. Margaret agreed that getting responses from people who feel the same way was a positive experience: *"it validates what you're like."*

The reported emotional connections formed within the community (and for the community) along with risks identified to people's lives and well-being (from those outside of the community), were potent and personal enough that participants expressed a shift from feeling victimised, or dysfunctional, to feeling a sense of duty to future generations of Autistics. Sharing these fears also contributed to their feeling empowered to create change in the world, and recognising their life experience and knowledge as expertise, that may be of value to others. When asked whether there has been a "low point" for her, in relation to her involvement with peer support, Margaret talked at length about how *"really, really sad"* she felt about *"talents being wasted"*, and all the *"bright guys"* she knows that are badly treated and misunderstood. Margaret was deeply concerned about *"what emotional damage is done to my friends"*, and mental health issues experienced by those in the community:

> *…we all need to be safe, every single one of us has to be safe, and if you're out there being victimised and bullied and stuff for being different, it's not acceptable. And let's face it, we've got huge suicide rates in New Zealand. We know that we are the worst for teen suicide and stuff like that. You know all of our guys are right on that verge. We don't need that crap. We don't need that crap at all. We can do better than that. We can do better. (Margaret)*

Margaret saw this as an important time historically, but also - as someone who had also expressed a life-long love of learning - an opportunity for self-growth too:

> *This is the first generation that we've ever had, of adults that can actually turn round and say "I'm Autistic and this is what it's like for me, this is what it's like, this is what I have come through in the services, et cetera, et cetera, and this is, you know." We can now say what it's like, and [exhales] it's really interesting what's coming out. We're learning. I look back at what we used to, cause I used to do a lot training in autism and stuff like that, um, do training packages and things like that, and education and things like that, and the things we used to teach ten years ago I wouldn't do it that way now, no way, we've learnt so much in the last ten years. So it will be interesting to see what happens in ten years time, because we will have all this other knowledge as well, and just keep growing and growing. (Margaret)*

All participants had made an active shift from "giving and taking peer support" to advocacy in the wider community. One area singled out for special concern, was the need to educate NT parents of Autistic children, and the need to keep those children safe:

> *I'm really keen to start up a group of people that would be willing to talk to neurotypical parents that have just had their children diagnosed. So that they know they don't have to panic, that they don't have to worry so much, that things will be okay and, and that their child is going to turn out to be this wonderful, wonderful person, and they don't have to put them through horrible programmes and, you know, um, stress the child out so much by doing strange things to it, which has happened in the past. And I think that's a different sort of peer support. That's a really important one for the kids that are coming through. (Margaret)*

Tyrone talked about how he was contributing to online forums, where parents were now being given permission to join, so they could ask Autistic adults for advice:

> *…a lot of parents are now wanting to listen to us, to help their child, so they'll come and ask us questions — where many years ago they'd be like, no, you're too high-functioning, what can you, um, say to help my child, you know, you can talk, you can do all this stuff, so go away. Where now they will listen to us, and, um, ask questions like, I've been recommended ABA for my child, what's your experiences? And of course, a lot of Autistic adults have had bad experiences with ABA, so they will say, okay it might work for your child but I found that it's traumatising, and a lot of these people have now got PTSD from ABA. (Tyrone)*

In other contexts, Tyrone had experienced how "outsiders" in the community could make assumptions about him that had left him feeling powerless, for example he explained:

> *I don't like being touched by strangers. Once I get to know you, and you know how I work, I'm all good, because usually the touching that you need to do is to help me. But I am sometimes in a wheelchair, and for some reason, people have this thing about being attracted to people in wheelchairs, and I don't know why, and so they tend to come and touch me. (Tyrone)*

Finding a place where he was considered an "expert", and the respect of the wider community, was clearly empowering for Tyrone - and for all the participants.

Jackson described how, through involvement with his son's activities, he had become part of an *"unofficial support group"* made up of parents he had met that *"are undiagnosed and they're known Autistic themselves"*, and was also surprised to find, that being open about Autistic, meant NT parents were seeking him out for advice:

> *I guess kind of understanding even one tiny little perspective, it just helps them gain, like I mean, they just seem extremely grateful even with me sharing my experiences, and why I do or don't think about something, it kind of just helps them have a bit more understanding, and yeah, I think peer support to neurotypical people is actually quite an important role as well, for neurodiverse people….And I guess….I kind of feel like I have a duty to the Autistic community, and actually to the world, to try and get some more of that understanding out there, it's sort of, I've spent my whole life building up this huge body of knowledge, even though I didn't even know it, um, and just yeah, there's a lot of good that I can actually do out in the world, just, um, helping people understand each other. I would never have thought of myself as being able to do that at all, but, yeah. (Jackson)*

The participants of this study, all embraced their Autistic identity and associated it with positive attributes in their lives, but expressed concern about others who, as Timothy put it, *"just sort of, they live, but they don't like <u>really</u> live, you know, in the way that they could"*:

> *… the thing that sort of frustrates me the most is, is that I know we have a huge community of Autistic people out there, in [name of city] there must be two, three hundred people at least, at least, that are Autistic, and yet the majority of them you just never see or hear anything from, and I'd like that culture to change, you know. I'd like Autistic people to be able to gain a sense of identity and ownership of their autism….We need, we need to — we need more knowledge around who we are as a people, and as a community, so that we can actually, you know, um, start to gain a little bit more confidence and understanding….And that sense of self-identity, like taking ownership of being Autistic, has been really vital for me because, um, I would probably not be as open and strong an individual if I was unsure of who I was, you know. And obviously we're all, we're all on, you know, never-ending journeys of self discovery. We're all trying to figure out who we are, and what our purpose is, and*

> *all that sort of thing, and how can we contribute more, and all these sorts of things, you know, what can I do to make myself happy, um, there's — that's a never-ending process. But, um, you can, you can do that in a, in a passive way, or a more active way, and if you have a bit more of a sense of identity and ownership of self then, you know, you can be a little bit more active in your self-discovery, and your self-recovery, you know. (Timothy)*

All participants were asked if, during their involvement with peer support initiatives, there'd been a highlight for them. For Tyrone it was *"being understood"*. For Jackson it was for the first time feeling *"really comfortable, and…it's not just me alone in the world"*. Timothy described the moment he discovered that *"just talking about my own life"* had the power to help others. Margaret answered without hesitation:

> *Friendships. It has to be. I've got so many friends, that are just amazing, amazing people on the spectrum….And some of our guys are just so generous, and they are just so wonderful, kind hearted people. I mean I look at the two I live with. We're all Autistic in my household. The other two aren't like me personality-wise, they're very quiet people, I'm very outgoing, and — but my two are the kindest people in the world. They are so kind. And so generous. And so nice. And I, I guess from my point-of-view it frustrates me sometimes that people can't see it. And I look at my friends, and [name of social peer group], and, and the [name of social peer group] groups, and I think, God I wish the world could see you guys, you know, how wonderful you really are, you know. And so many of them are so quiet, and so … and you think, oh my gosh you know, we're under-selling these guys. They've so many talents and so much to offer. Just not given the opportunity. Watch this space though. It's coming. (Margaret)*

Notably, the *DSM-5* (APA, 2013) also includes "an absence of interest in peers" (p. 50) as one of their diagnostic criteria, certainly for all four participants in this study, this was clearly not the case. Perhaps - as Timothy points out - this raises the issue of who is really interested in who?

Divergences

There were three main ways in which material relating to the central themes, diverged between participants. The main differences related to their early years, reasons for becoming involved in peer support, and individual interests.

(1) Early years

Differences in early experiences, including family relationships, school, and peer support, appeared to have influenced whether participants had internalised a feeling they were "defective" (such as for Jackson and Tyrone), or whether they had moved into adult life and, thinking their problems were external to them, were more able to recognise their positive attributes, and feel they could "make things happen" (such as for Margaret and Timothy).

In particular, Margaret stood out as being confident in herself as someone who thinks *"outside the box"*. She explained how she learnt "*really, really young"* how to *"get things going and how to set up groups"* because she *"didn't quite fit anywhere".* An optimism, not accepting the "status quo", and a belief that "we" (notably Margaret almost never used the word "I" in relation to her involvement with the group) can contribute to change happening, appeared to be personal traits, or resilience, that Margaret traced back to childhood.

Margaret was the only participant who didn't remember being bullied, something she attributed partly to being *"cushioned"* by a *"very supportive family".* She also said she had lots of brothers, and parents who *"didn't have time to treat me like a girl…so I got treated like everybody else. Like I did whatever I wanted…and that bound in my brain"*. She went on to tell a story about wanting to do technical drawing at school, but was told by the teacher, that subject was just for boys. Her response was, *"well that's not acceptable"*, and challenged this by convincing another girl to join her (as proof girls also wanted to do tech drawing), then getting the school to agree to let them do it, becoming, she thought, *"the first girl to take tech drawing in the biggest school in New Zealand"*. She said she was also partly inspired by one of her brothers, who was one of the very few boys who *"managed to go in and do typing"*. Margaret went on to say, *"it never occurred to us that we couldn't",* and looking back now, she attributes this partly to her having *"no filters"*:

> *…and it was like my brothers all did it so why can't I? You know. And I guess I was used to sort of — no filters [laughs]. There were no social filters. It never occurred to me that maybe socially I shouldn't be doing something, or you know, there just*

> *wasn't those filters there, and, um, in a way that can be a really positive thing, because, you know, for me it was a positive thing (Margaret)*

Margaret recalled being at university, and hanging out with other students experimenting with early computers. In hindsight, she said, *"So many of those guys were Autistic. They were."* She related how several of them have come to her since then, and asked if she thinks they might have Asperger's: *"It was like, 'yeah'. 'Yeah!' 'Yeah, good okay' (laughs). It's like, we saw the best in it, you know? It was never a negative thing to us."* When reflecting on her years as a teacher, Margaret shared that the mainstream *"bored"* her, because she liked *"unusual people"*, and how when she discovered special education she *"just fell right into it"*. Margaret discussed how this teaching environment allowed her to use her ability to think *"outside the box"*, explore adapting *"structures"*, and developing teaching strategies that *"met the needs of the child*".

A common pattern in Margaret's responses, was to start with something she personally felt passionate about (such as her friends), widen the circle by shifting the focus to a need in her immediate community (such as their wasted talents), and then see it as an opportunity for connection and change (create opportunities for them to *"shine"*). Despite her frustration with current services, Margaret says she tries not to get *"too political"* because she has as strong belief that *"we have to change things from the ground up, I don't think you can change them from the top down, it has to come from the people and go upwards"*. Margaret attributed this sense of confidence and agency to growing up without a perceived sense of boundaries (related to gender or neurology), and feeling safe and supported within her community (at home and at work).

(2) Reasons for seeking peer support

Many people seek support because they are experiencing problems. For Jackson it was *"a mid-life diagnostic crisis"* that led to his seeking help, and his testimony was the most focussed on the transformative nature of peer support. Discovering autism later in life, meant that he was in the process of retrospectively evaluating himself, through a new lens. Jackson was the only participant who identified himself as having to deal with *"an internal mindset that I'm defective"*, which is described by many in the disability community as "internalised ableism". Ableism is a form of discrimination in favour of non-disabled people, and when that stigma causes a person to internalise negative thoughts about themselves, the result is internalised ableism (Campbell, 2009; Grace, 2015):

> *I think it's basically my entire life I, I've never been looked up to, I've always been put down, so I don't really — my entire working life, you're working too slow, speed up, you've got to hurry up, you're not trying hard enough, you're not applying yourself, um, that goes back to like primary school even. And despite my best efforts, it's sort of really was the best I could do. I guess just that whole mind-set of that, I guess the inherent value in myself, I still struggle to sort of see that, if that make sense? (Jackson)*

Unlike Margaret, Jackson's experiences in the world of work were less accommodating. He described a *"bang, bang, bang, get it out, get it done, cut corners, even if it's actually a safety risk to yourself"* environment that caused him *"massive issues"*. Jackson referred to *takiwātanga*, a word that has recently been added to *te reo Māori* for autism, to describe what he felt he needed to be able to function. Takiwātanga has been defined as "own time and space" (Te Pou o te Whakaaro Nui. (2019, p. 15):

> *…it's like well actually that's just me to a tee, it's sort of — so fifty years ago Autistic people would have been master craftsmen, and speed wasn't a concern back then, whereas now it's becoming an issue. (Jackson)*

Tyrone was also introduced to a group set up to support mental health, however other disabilities contributed to his having less control over his living situation, and mobility than the other participants. Tyrone was the participant who placed the most emphasis on peer support as an opportunity to make choices and have fun, and reported that peer support had *"widened my social circle. Otherwise the only other place really that I would socialise would probably be church"*.

For Margaret, involvement in peer support came about because of a desire to use her skills and professional experience to support and connect with friends and others she already knew in the community. And for Timothy, while he talked about a formative experience at school, it was through professional work in the disability sector that he first started meeting Autistic people. Margaret and Timothy's perspectives were, therefore, mostly directed at how they might facilitate change in others. They also both had professional training and experience that informed their approaches. For example, as Timothy had been to music school before getting his job, he drew from music theory, and was interested in how autism fostered creativity.

(3) Individual interests

Notably, in part because of his interest in communication as energy input and output, Timothy was the only participant who talked directly about Autistic people who don't use speech as primary form of communication. This topic was otherwise absent from participant testimonies.

Discussion

This study set out to explore the benefits of peer support for Autistic adults, from their perspective. The primary aim was to gain a better understanding of the position Autistic adults find themselves in, and how as peers, they were supporting each other. The secondary aim was to consider how this knowledge might inform the way we develop services for current and future generations.

The introductory section of this report explored the wider discussion around autism, from academic, community and research perspectives. What was striking in that conversation was (1) the divide between those who identify with the medical model of autism and those who embrace the social model of disability; (2) the intensity of the conflict between those two stances and (3) how differences in perspectives might influence the way Autistic people are treated, supported and/or accommodated.

Many of the problems and challenges Autistic adults reported in this study mirrored those in the literature and anecdotal reports previously discussed, including (1) bullying; (2) experiences of depression and anxiety; (3) access to support for mental health needs; (4) a lack of professionals with sufficient understanding of autism; (5) barriers to diagnosis; (6) stigma and discrimination; (7) environmental and structural barriers to participation; (8) barriers to employment; (9) poverty; and (10) social isolation.

A number of other problems and challenges were identified that had either not been anticipated, or were less reported in previous studies, including (1) being misunderstood; (2) own time and space/differences matching other people's rhythm of communication or working speed; (3) fears for Autistic children and future generations; (4) sensory sensitivities; (5) shutdown/meltdowns; (6) managing energy input and output; (7) feeling unsafe; (8) internalised ableism; (9) no "place to stand" (dispossessed from community); (10) people not "speaking my language"/people not "getting it".

Results of this study also include perspectives on how these issues might be addressed, including (1) use of Autistic intermediaries or "translators" to facilitate understanding between those in the NT world and the Autistic community; (2) redefining normal to accommodate different ways of being social; (3) acceptance of difference; (4) sharing and listening but not "fixing"; (5) multi-modal methods of communication; (6) on-line and real world peer-facilitated support groups; (7) "natural peer support"/opportunities to connect with others in the Autistic community; (8) environmental accommodations; (9) own time and space/communicating or working at own pace; (10) matching people's energies to aid communication/connection; (11) access to professionals with an understanding of autism; (12) autism-specific support for mental health issues; (13) educating and advising NT parents of Autistic children; (14) "learn a bit of autism"; (15) tūrangawaewae/a place to stand.

A summary of the reported benefits of peer support for Autistic adults include: (1) an ease of connection; (2) "people who speak my language"/multi-modal communication; (3) people who get it; (4) "finding my tribe"/community; (5) tūrangawaewae/a place to stand; (6) feeling safe; (7) being heard/being understood; (8) having the opportunity to make choices; (9) fun; (10) friendship; (11) new learning (12) self-growth/developing "Autistic self-identity"; (13) influence over the environment; (14) improved mental health; (15) access to 24/7 global support via online groups; (16) opportunities to help others; (17) discovering life experience is of value to others/expertise from experience; (18) wider social circle; (19) people who know you well; (20) acknowledgement of and accommodations for sensory needs; (21) respect from others in the community including NTs; (22) feeling normal; (23) doing things "our way" for a change; (24) feeling relaxed and comfortable; (25) Autistic culture; (26) advocacy; (27) power and a sense of agency;

(28) new opportunities; (29) paid employment; (30) volunteer work; (31) a desire and duty to affect change in the world; (32) diagnosis/validation by peers; (33) not feeling alone.

Taken overall, the results of this study provide evidence for the perspective that autism is a difference not a disorder. Analysis of themes common to all participants painted a complex and nuanced picture of how Autistic adults connect, communicate and foster community. Data also provides rich information about how Autistic adults think about autism, both in terms of how *they see the world,* but also in terms of how *others* might see them. Results show that being part of a group was something participants actively sought, and invested in. All participants saw participation in Autistic peer support as being of benefit to themselves, but also as an opportunity to help and support others. Going one step further, participants all expressed a belief and commitment to community, giving their time as volunteers, looking out for future generations, and making sacrifices for each other. This is social reciprocity at its best. The results of this study suggest the presence - not of a communication disorder - but of a communication *breakdown*. This was seen by participants to be related to (1) a lack of effort or interest from NTs in connecting with Autistic people; (2) a limited understanding of how, why, and where people might choose to be social; (3) not "speaking the same language"; and (4) cultural differences. This raises the question of why Autistic people have been categorised as socially deficient.

Autistic people are often thought of as loners who don't like to join in. As the introduction to this report shows, historically, Autistic people have been attributed a series of different failings, including but not limited to, a lack of empathy for others, an inability to recognise that other people have their own minds, an inability to form affective or emotional bonds, deficits in imagination, and a lack of interest in peers (Kanner, 1944; Silverman, 2012; APA, 2013). Participant descriptions of autism did not reflect diagnostic criteria in the DSM-5, or support a medical model of autism based on an inability to relate to others (Kanner, 1944). Instead, the results of the study provide support for theories that consider autism as a social and cultural construct (Eyal et al., 2010; Grinker, 2007;. Nadesan, 2005; Silverman, 2012; Timimi et al., 2011). If, after all, autism is a social or as the results of this study also suggest - even cultural issue - related to the diverse ways that a group of people fit in with their social environments, this throws the question of whose behaviour is dysfunctional into a new light, and forces us to consider other factors that may be contributing to the problems and challenges Autistic adults describe.

Timimi et al. (2011) have described what they see, as an increasing tendency in Western cultures to label as dysfunctional those who don't fit in any given dominant social agenda. Therefore autism, when seen in this context, may be seen to be a "barometer pointing to something wrong in the culture" (p. 283). Putting community before self is distinctly at odds with a prevailing Western neoliberal agenda of individualism, which seeks to atomise people, and promote the philosophy that you are responsible for your own happiness. Creating structures that bring people together, is empowering: results of this study provide evidence for the many ways Autistic people are doing just this.

Timimi et al. (2011) also described how "labelling" people, with the resulting effect of stigma and discrimination, could be seen as an act of therapeutic violence. Results of this study support this perspective with participant reports of feeling *"judged"* for being different, discriminated against for being *"out of the box"* thinkers, and penalised for working, or communicating in, their *"own space and time".*

Could, as Timimi et al. (2011) suggest, a rejection of individualism and an inability to conform to given social norms be considered a threat? Threatening enough to evoke the spectre of social engineering and eugenics? While this theory, once again, seems extreme, Silberman (2105) has outlined the very real ways eugenics is currently being practised in health and social policy. Results of this study echo these fears, with participant reports of how discrimination and internalised ableism have contributed to negative, and sometimes destructive, outcomes for some participants. Collectively, participants conveyed real fears for their community, based on "horrific stats", high rates of suicide, reported (and observed) abuse of Autistic children, and threats to their own well-being.

Cultural anthropologist Grinker (2007) talked about the ways disabled people were often better absorbed into cultures that favoured smaller communities with larger, more extended families, and someone at home who is available to care for or watch over people who need support. In our increasingly faster, less accommodating - and some might say less caring Western societies, perhaps it is the very need to care, or to look after others with higher support needs, that is seen as the problem. Certainly that is the message implied by the White House press release that declared war on autism, and supporting material on the CDC website citing the cost of caring for this population (CDC, 2018b.; O'Keefe, 2006).

If as this research suggests, Autistic adults perceive there to be an absence of caring in the wider community, it appears Autistic-run and led peer support groups are forming in response to that need, and meeting it with an abundance of caring, that is inclusive and future focussed:

> *... the medical profession has a long way to go to become Autistic friendly. And once again I think it's sort of...it's from the grass roots up, it's just, yeah we're growing from our bootstraps, and look out world here we come. (Jackson)*

Researcher reflections

One unexpected topic that emerged from this study was the amount of information provided by participants on the subject of connection and communication. I had not expected so many thoughtful, in-depth observations about the minutiae of communication, both between both other Autistic people and NTs, or original theories, such as "energy input and output", to explain communicative interaction. As an SLT, I was both surprised by the depth and richness of these participant observations, and amused to hear participants talk about finding the "mainstream", and NT people, boring and uncreative. The fact that this stood out for me was telling, and demonstrated how used I was to being the "expert" and the one to assign deficits to others, and how uncomfortable it was for me to hear that being reversed. Participants of this study also talked about issues relating to rhythm and resonance, and how being in "sync" with others or not, impacts on our ability to connect and participate. As previously discussed in the introduction, Bogdashina (2010) and Williams (1992) stands out as being amongst the few researchers to have explored these issues in the context of autism.

These perspectives may be of particular interest to SLTs and those who work with people who have communication difficulties. In an assessment of a person's speech and language abilities, professionals often include information about what is described as their cognitive "processing speed". People with processing speeds, or speaking rates, faster or slower than typical may experience difficulties in daily life. These deficits are often grouped under umbrella terms such as Specific Language Disorder, ADHD, or fluency disorders. Timothy's preference for describing these differences using the language of music brings to the fore other musical terms such as tempo, harmony, disharmony, and discord. Using these terms is both de-pathologising and also encourages us all to truly *listen* to others, in the way we do to different types of music. Slowing down or speeding up in response to the energy of the song. Shifting the perspective to the way we interact (resonate) with others, even as listeners, and recognising whether or not we are in sync with them, is something that could have profound consequences in enabling or disabling connection.

To sum up, results demonstrated that the participants of this study associated Autistic peer support groups with access to, not just support, but to a *whole world*, with its own community, culture, and different ways of doing things; it's own leaders, language and tribes; and most importantly, a place where they felt empowered, respected, motivated, understood and included. These perspectives support research presented in the introduction to this study, which focused on mutual help groups as communities of interest or communities of belief, rather than just alternative service providers (Powell, 1994). Importantly they also reflect a growth of connectivity in the Autistic community globally, something that has been accelerated by the internet, and is fostering Autistic culture. At times, while immersed in participant testimonies, I too felt as if I had stumbled through a portal into a new world, but a world of *functionality* - not dysfunctionality as I had expected.

Limitations of this study

The total word count for all four interview transcripts combined, was 48,510. Within the constraints of the word limit required for this report, it was impossible to do justice to the complexity, detail and nuance in the participants' answers, and at times I felt overwhelmed not just by the amount of data, but also by the importance of every word. All participants pre-warned me they had tendency to *"go off topic"*. Margaret frequently apologised for getting *"side-tracked"*. On the one hand this demonstrated an awareness of differences in conversational styles and good self-advocacy. On the other hand, feeling the need to apologise suggested participants anticipated I might consider this a problem (which I didn't), and/or a feeling of discomfort about "being themselves" with an "outsider". Interestingly, these "off topic" conversations were rarely in fact off topic, but more often related to participants sharing more nuanced observations, or their own theories about a topic, demonstrating a depth of thinking and engagement, rather than a loss of attention. As all participants had reported the negative consequences in their lives of being misunderstood, I was aware of the importance participants placed on being able to tell their story - their way - and keenly felt the responsibility of deciding which of their words were "relevant" and which could be edited out. I recalled Timothy feeling he was sometimes involved in acts of translation, between NTs and Autistic people, as a kind of cultural interpreter. I wondered if the pressure to reduce these long, detailed answers into "pithy statements" was in its own way, a type of cultural appropriation - or transgression. If word limits had allowed, I would have felt more comfortable if I had been able to include the full interviews as an Appendix to this project. This would allow readers to follow up on anything they wanted to explore in more depth, provide context for the choices I made in terms of selection and editing, but most importantly, provide supporting evidence that honoured the integrity of each participant's communication style.

To date, the voices of Autistic adults have seldom been included in research, therefore on setting out on this project, I felt the pressure to capture as many voices as possible. The IPA was a good choice, as it allowed me to focus on participant perspectives, and involved detailed analysis of their testimonies. One down side of this was that I ended up with too much detail, much of which got lost in the attempt to amalgamate material into overarching themes. In future, particularly if working within time constraint (in this case of one year), to enable a deeper exploration of a participant's actual words and meanings, I would consider one participant sufficient.

Implications for practice

> …if we see more autism around us than at any time in history, and if we think of the consequences of knowing it to be a lifelong condition, then we can also admit that we have a greater opportunity for dialogue than has ever existed. Listening to those with autism has never been a more available option, and it is one that those who are in the business of making cultural representations of the condition need to take up. (Murray, 2008, p. 212)

First and foremost, this research has demonstrated the value of seeking the perspectives of Autistic people when considering (1) the challenges they face; (2)what supports might be needed and; (3) how those needs might best be met. Participants provided a wealth of information about the issues they have faced, ideas about the cause of these problems, and practical information about structures, accommodations, and solutions they consider "Autistically friendly". In addition, participants made it clear that while many in the community do experience difficulties, there is also amongst them a rich vein of knowledge and expertise by experience, including (in this sample) professional qualifications, and training in education and social work, and that solutions are being found within the community itself. However feedback from literature, and the results of this study, also suggested that many Autistic people do want access to experienced professionals, but reported their having knowledge and experience of autism was considered essential to avoid communication breakdowns and to facilitate appropriate care (Crane et al. 2018; Howlin et al., 2015).

All of the participants in this study demonstrated they were self-directed learners; were actively engaged with complex, multi-layered discussions about what autism is and means; were familiar with historical, social, philosophical and political perspectives; and were also developing, and articulating some of their own theories (e.g. Timothy on autism and creativity; Margaret on talent; Jackson on seeing in 3-D, etc.). Researchers and professionals working with and alongside people in the Autistic community, may need to consider whether they are more, or less, informed than those they seek to help.

If, as suggested by the results of this study, the disconnection many in the Autistic community experience is related to cultural difference, professionals may also need to reflect on their own "cultural competency" in relation to autism. A commitment to monitoring cultural competency is an on-going requirement for those working in the health and education professions, and something of particular relevance to SLTs when working in a cross-cultural context (Arlidge, Hand & Lee, 2012). Brewer and Andrews (2016) remind us that delivery of services is "influenced by the culture of the healthcare discipline and the unique cultural, social and political history of the country" (p. 87). In New Zealand:

> … issues arise because the Aotearoa SLT workforce is not representative of the population it serves. Because of te Tiriti, it is necessary to begin by addressing issues facing Māori, the indigenous peoples of Aotearoa. These include health inequities, racism, color-blindness and white privilege. (p. 88)

Hand (2006) highlighted the importance of "rapport" between client and therapist, and in a study which examined power dynamics between SLTs and clients from culturally diverse backgrounds, discovered that despite being communication experts, "even the more experienced clinicians were not necessarily informing the client in a way that opened the door to full two-way communication" (p. 263).

> This information-sharing process is particularly delicate during initial contacts when the knowledge of the parent about the purpose of the questions cannot be assumed, particularly when clients come from nondominant-culture backgrounds where shared understandings are likely to be less predictable (p. 262).

The ways in which social and political realities feed in to the way we construct narratives around deficit and disorder, and shape professional practice, have also been highlighted by a series of recent studies in the health sciences in South Africa. Pillay and Kathard (2018) explore how the "reverberations of coloniality" can also be found when certain epistemologies of science are privileged over others as ways of establishing versions of "clinical reality":

> These positivistic influences undergird even clinicians' use of more person-centered approaches. For example, professionals tend to describe peoples' speech/language functions, annotating their deficits by listening to illness narratives, and classifying their communication/hearing (or eating/feeding) within pathological frameworks. Practitioners assign diagnostic labels to, essentially, describe what is wrong with a person's communication. This process is one we refer to as disothering…where practitioners contribute to creating persons with pathologies as societies' "Others" or as a marginalized subaltern….Therefore, professional power—which is closely associated with positivistic, empirical science—is used to engage a form of colonization of Others' lives. (p. 145).

Certainly the participants of this study all described ways in which they have been made to feel "other", and have felt marginalised by the NT world, using language that referenced colonisation, such as: accommodation, segregation, discrimination, assimilation, and what was considered the very real threat of annihilation. Could attempts to modify the behaviour of Autistic people, or to force them to conform - however well-meaning this may be - also be seen as a form of colonisation? Again, this may sound extreme, but the many negative effects of their being misunderstood or discriminated against, reported by participants of this study mirrored those reported by other marginalised communities.

Results from this study remind us that despite not having - or choosing not to disclose - a diagnosis, many of the family members of Autistic people who come to their attention, and those in their social community (such as caregivers or advocates), may also be Autistic. Some of the participants of this study were also themselves professionals working in the disability sector, so, as Timothy reminds us, it's important to remember, *"it's not an us and them, never has been, it's a we as a community".*

While participants associated involvement in peer support groups with positive and meaningful change, and described multi-dimensional benefits that impacted on many areas of their life, replicating/building a peer support model raises some complex issues. All participants acknowledged the role of Autistic facilitators as being key to the success, sustainability and safety of the group. This is a role that demands a mixture of different skills, experience, training, and personal characteristics, including a deep empathy for and knowledge of the community, without which, as Tyrone suggests, things would *"implode"* or fall apart. Facilitator skills and experience described in the study include knowledge of "mindfulness training", experience with Work and Income New Zealand (WINZ) and other disability and social services, knowledge of medications and *"sensory stuff"*, professional training in education and social work, as well as life experience, community knowledge, the ability to be responsive to the individual as well as being able to manage the "alchemy" of connecting others and matching their energies. It is therefore a VERY skilled role, and of course, very responsible. In all groups discussed in this study, the facilitator was working as a volunteer, and all were very unique and different individuals with very different approaches. In this community, there is no place for templates or a "one size fits all approach", this is therefore not an easy role to "cast".

When participants are both "givers" and "receivers" of support, questions of accountability and responsibility are also raised. Constructing a peer support organisation as a "provider of services", under a funding umbrella, with the need to provide measurable outcomes, equating positive or negative results with "change", may also be problematic:

> *These organisations might be better understood as voluntary communities rather than as social service agencies. When membership leads to significant change in a person's identity and behaviour, it could be understood as a change in community of membership and lifestyle rather than as a "treatment outcome*". (Powell, 1994, p. 124)

When groups grow from the "grassroots up", with structures that are fluid and responsive, they certainly meet "best practice" criteria of being individualised and functional, however this too requires expertise along with "out of the box" thinking. Remembering Timothy's insights into the need for peer support to be organic to be healthy, perhaps as professionals it might be of more value to consider how we might support such grass-roots initiatives rather than aim to replicate them. Examples could include sharing relevant knowledge when needed, training community members in specific skills such as supporting multi-modal communication, or providing supervision for peer buddies and mentors.

If, as results of this study indicate, many aspects of our current systems and services for Autistic adults are failing, then we as professionals need to work at finding solutions. No better place to start than to ask ourselves:

What would it mean to learn a bit of autism?

Future directions

> The history of diagnosis and classification in this field [autism] can be expressed in an analogy from music. It is as if some groups of people believe they are singing the same song but each singer has chosen a different key and some have changed the keys over time, while other groups are really singing the same song but each singer has called it by a different name. (Wing, 1991, p. 107)

The richly detailed descriptions of what autism meant to the participants of this study were at odds with current diagnostic criteria as quoted in the *DSM-5* (APA, 2013). Overall, while there were some significant differences in the specifics, the way participants talked about their autism had more in common with early descriptions by Kanner (1944), and Asperger (1943), than with the more current *DSM-5*. It appears that the more we try and distil or simplify what autism *is*, the less meaningful these descriptions become. This suggests that an individualised, qualitative, and ideally longitudinal approach to furthering our understanding of autism may be of more value than trying to refine a “tick-box” list of features.

One benefit of Autistic peer support, which had not been anticipated by the researcher, was access to an alternative way of diagnosing autism, referred to as self-identification and *“validation by peers”*. Participants reported having a *“knack of spotting Autistic people”* because *“they actually know what they’re talking about. They live it. They see these characteristics. They know.”* As previously discussed, the majority of funding for autism research, to date, has gone towards trying to establish a biological, neurological, or genetic cause for autism; in other words, a robust scientific way of identifying it. But as yet, a medical model of autism remains inconclusive. If as Asperger (1991) suggests, some Autistic people have “an ability to see things and events around them from a new point of view” (p. 71), and an ability to “observe themselves to a high degree…and [make] mature observations about people in their environment” (p. 74), might it be of benefit to further explore this ability to “spot” autism in others. What are the *“characteristics”* that provide this validation? How do *“they know”?* Research focussed on understanding this ability to recognise autism in other Autistic people - from an Autistic point-of-view - has the potential to further our knowledge of what autism is and, more importantly, *means* to Autistic people.

Appendix 1 - Interview Schedule

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

SCIENCE
SCHOOL OF PSYCHOLOGY

Interview schedule

Project title: *Facilitated peer support groups for adults on the autism spectrum.*

Name of researchers: Simone Horrocks and Dr. Linda Hand.

1.	Could you tell me how you came to join a peer support group? *Possible prompts*: How did you hear about it? How long ago? Why were you interested?
2.	Can you describe the first time you went to a group meeting? *Possible prompts*: What happened? Was it what you expected? How did you feel at the beginning? How did you feel at the end? Did you want to go again?
3.	Can you tell me a bit more about support group meetings you have attended? *Possible prompts*: How many have you been to? What makes them different? How often do you go? Where do you meet? How many people go? What do you do when you are there?
4.	How do you mostly spend your time when you are not with the support group? *Possible prompts*: What would be a typical day for you? What do you do with other people? What do you enjoy doing most?
5.	Could you tell me about your best experience in a support group? *Possible prompts*: Why? Why is/was this so special? Could you tell me more?
6.	Could you tell me about your worst experience in a support group? *Possible prompts*: Why was this a negative experience for you? How did it affect you? How did you cope? What did you do about it? Is there anything you think could be improved?
7.	How do you think being a part of the peer support group has changed the way you think or feel about yourself? *Possible prompts*: What have you learnt from the group/from others in the group? Do you see yourself differently now than before you started going? In what ways? Have you made any changes in your life? Would your life had been different if you had not gone? Could you tell me more about this?
8.	Is there anything else you would like to share?

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