

ALTOGETHER AUTISM

# JOURNAL

ISSUE 3 2019

Autism  
and the  
future

ALTOGETHER  
AUTISM  
Takiwātanga



INFORMING · EMPOWERING · CONNECTING

# ALTOGETHER AUTISM

THROUGH KNOWLEDGE AND EXPERIENCE

Altogether Autism is a free, nationwide autism information and advisory service provided as a partnership between Life Unlimited and Parent to Parent New Zealand.

With the vast amount of material available online, finding credible information on autism can be a challenge.

Altogether Autism provides tailor-made, relevant, evidence-based information, individually researched and collated by our information and research team. That team has the skills and experience to provide resources from verified sources including our Consumer Reference Group, autistics and family members of people with autism.

We also refer enquiries to our Professional Expert Group, specialists from a range of professions with clinical experience in autism.

Whether you are on the autism spectrum or you are family/whānau or a professional supporting an autistic person, our service is free.



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## Stories as gifts create meaning

### I LOVE STORIES.



Steve Ballantyne, from Story IQ, ran a workshop at the recent conference on Strengthening Through Stories, hosted by Community Waikato. He described stories as gifts, with facts wrapped in emotions that create meaning. Positive stories release oxytocin, according to Steve, which is associated with empathy, compassion and connection. In this edition of our Journal, we

are delighted to give you the gift of oxytocin, as we feature Jessica Falconer's new children's story, Beth and the Bracelets, with the chance to win one of two autographed copies of this beautiful book.

I also love facts.

Our latest Journal brings you some facts about the latest autism research, as we explore the theme of this edition, The Future of Autism. Jenny Gibbs, our consultant clinical psychologist, offers a thought-provoking piece on the future of autism under the current diagnostic framework. Our researcher, Emily Acraman, discusses the latest research into the role of genetics in autism, as she reviews a new study involving more than two million children across five countries. Rebecca Flower and Rachel Jellett, postdoctoral research fellows at Olga Tennison Autism Research Centre at La Trobe University in Australia, have highlighted five areas of autism to watch in the future, including neurodiversity and participatory research, employment and mental health. We value your feedback on each of these articles.

Some of the feedback we have already received from one of our readers suggested that New Zealand could benefit from a 'specialist facility where those on the spectrum who are working through mental health issues, are able to be admitted either as day or in-patients. This would give them access to professionals who are highly trained and skilled in working with those struggling with their autism and/or co-morbidity.'

They go on to say that "currently the ASD population is not well served by mental health professionals working in public hospitals but many in the disability sector are finding they are not equipped to fully help those who are experiencing mental health issues. We are a small country so it may mean, in order to have the best services available, there can only be one specialist unit and consumers and families would have to travel as they do for those specialist providers mentioned above." We are interested in your thoughts on the benefits of autism specialist facilities, compared with investing in the upskilling and resourcing of mental health clinicians so they have a better understanding of the mental health needs of autistic people.

The theme of our next edition of the Journal is Autism, Adulthood and Ageing. We welcome your thoughts in written articles, poems, artwork, for consideration of inclusion. Email us if you would like to learn more about ways to contribute to this important topic.

Have you contacted us through Live Chat yet? This new way to ask for information celebrated its first birthday in September. If you haven't yet contacted us via Live Chat, give it a go. Click on the orange icon on our website and ask us a question. Our Live Chat agents are generally available from 7am-5pm from Monday to Friday, but you can ask us a question at any time of day or night, and all questions will be responded to as soon as we can. We love hearing from you.

Finally, we all wish you a restful and happy Christmas filled with all the things and ones you love.

Check out our website for some Christmas Survival articles, including Daniel Smith's 12 tips for surviving Christmas.

Ngā mihi o Te Wā me Te Tau Hou (Merry Christmas and a Happy New Year).

**Catherine Trezona – National Manager, Altogether Autism**



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## Books play part in girls' autism upbringing



*Beth and the Bracelets is a picture book by first-time author Jessica Falconer who describes how she came to create a character she would have needed as a child.*

**WHEN I RECENTLY** showed my five-year-old niece the newly-published book *Beth and the Bracelets* that I had written, she told me, and really meant it, that Beth would be her friend.

At its heart, the book is about exclusion, a meltdown and a kind teacher.

My niece's comment made me incredibly proud and made me wonder about my own friendships during childhood. How the complex and intricate relationships between girls often went beyond me. How I didn't know the rules. I didn't understand why things were different today than yesterday. Why it mattered what colour shoelaces you wore.

At times, I tried really hard to fit in. I tried to understand what those other girls wanted. I mimicked their behaviour. I hated having my hair brushed, so my mother kept it short. I tried to grow it, to be more like the other girls. But it just wound up being a rats' nest. I tried joining in elastics at lunchtime. But I'm really uncoordinated and couldn't concentrate enough to jump. I invited girls for playdates but they just wanted to play inside where it was boring.

At lunchtimes, I just wanted to wander around and not have people talk at me. I just wanted to escape from the world.

So I started taking my books to school. I would scurry away at lunchtime and hang out with my "real" friends. They were Sara Crewe from 'A Little Princess' and Dicey Tillerian from 'Dicey's Song'.

Dicey was a strong, independent tomboy who didn't care what anyone thought about her. She just wanted to find a home for her three younger siblings. She put in the hard yards, and stuck to her principles and in the end, found her grandmother, who loved her exactly the way she was.

Sara Crewe was a wise but spoiled only child. When her father died, she became the scullery maid at the boarding school where she used to go. She was strong, didn't let them see her cry, she worked hard and showed her mettle. In the end, her guardian found her and loved her, exactly as she was.



These two young characters were everything to me that the girls at school were not. They were strong, thoughtful and consistent. They knew what it was like to be an outsider, but then didn't let that affect them. They kept true to themselves, even when it was hard. And they didn't compromise who they were to make other people happy.

I still read both books every year. I have the same copies. There are missing pages, the paper is brown and worn but they do not deserve to be thrown out for better versions. Sara and Dicey were my true friends, I would not discard them.

I remember having a particularly hard day and getting my duvet and climbing into my wardrobe with Dicey's Song. I didn't even read it, I just held the book and rocked. Because Dicey had been through so much, been rejected so often and kept her pride. Kept her sense of who she is. Dicey would know, she would understand.

When my niece said that Beth would be her friend, my heart leapt. What if... what if I had created a friend for someone? For a little girl to see herself? What if a child took 'Beth and the Bracelets' and held it close while they hid and rocked? I feel like that would be the best full circle possible. Creating a character that I would have needed as a child. The young girl inside of me is awfully proud to have created a friend for others.

- **Beth and the Bracelets now available at bookstores**

Jessica Falconer is a lawyer, mother, director of a tech firm, minister, author, and autistic

## WIN WIN WIN

We have two autographed copies of *Beth and the Bracelets* to give away.

Email [editor@altogetherautism.org.nz](mailto:editor@altogetherautism.org.nz) by Tuesday 17 December, 2019 and tell us why you would like your own copy of *Beth and the Bracelets*. Tell us too about any books you read which saw you through childhood.

# Services should reflect symptom overlap



Long-time clinical psychologist **Jenny Gibbs** is excited about *The Future of Autism* theme for the Journal and it got her thinking about the status of Autism Spectrum Disorder as a diagnosis and about the way we provide services for children following this diagnosis.

In my ideal world we would have one integrated service for the 10 per cent of children with neurodevelopmental conditions.

These services would place the child and family in the centre and address all the issues that contribute to the picture.

My ideal world would see us continue to increase our understanding of the genetic contributors to some of the autisms and in some of these situations we would hope to find a cure.

At the same time we would treasure, celebrate and nurture some of the autisms, recognising that these are the people who are some of our most influential artists, scientists, physicists, musicians, mathematicians – and who may have the ability to truly make a difference to the global challenges we face.

We would also have a society that is accepting of neurodiversity, recognising that a healthy society for us all is one in which everyone can contribute and belong.

**AUTISM SPECTRUM DISORDER<sup>1</sup>** (ASD) as a diagnosis and the way in which we provide services for people pre and post diagnosis is a huge topic which is not easily covered in one article, but I have tried to share some of my current thinking on these issues.

This is largely informed by my clinical practice but with a nod to the extensive research on the topic and conversations amongst those who work in the field.

I am mindful that autistic people have much to say on these matters too but I have not specifically addressed this point of view here.

<sup>1</sup>Throughout this article I have used the term Autism Spectrum Disorder (or the diagnostic term which was in use at the time under discussion) when speaking about formal diagnosis.

As my working life has been spent working with young children my comments are made primarily with this group in mind but there is likely to be some relevance to adult diagnosis and service provision too.

Thinking about the future necessarily involves a revisit of the past. As a clinician who has worked in a child development service for the past 30 years I have had the pleasure of meeting a great number of children who have what are currently broadly described as the neurodevelopmental conditions– in other words differences in brain functioning that they are born with and which become apparent as the child develops and grows.

Over the years, I have seen first-hand the changes in the way in which the neurodevelopmental conditions (of which autism is currently the most well known) are described, understood and diagnosed, and the way in which services for these diagnoses are allocated and delivered. There are a number of factors that have contributed to these changes.

## History of autism as a diagnosis

The collection of characteristics we now understand as autism was first described by Leo Kanner and Hans Asperger in the 1940s. At that time autism was regarded as a rare condition, affecting just four or five people in 10,000. Rates of diagnosis did not change until the 1980s, following the publication of the third edition of the most commonly referenced diagnostic guide, the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980 (DSM-III, 1980).

Interestingly autism did not in fact feature as a formal diagnosis until the DSM-III; in the first two editions of the DSM, autism was conceptualised as childhood schizophrenia. In the DSM-III, the term “Infantile Autism” was introduced. The way the diagnosis was described meant it could only ever be a rare condition – the diagnostic criteria required a child to have “gross deficits in language development” as well as “bizarre responses to the environment.” The term “infantile” also meant that it was viewed only as a condition of early childhood. The diagnostic criteria was broadened in 1987 with a revised edition of the DSM; the DSM-III-R (DSM-III-R, 1987). “Infantile Autism” was gone, replaced by “Autistic Disorder”, a term which implied a lifelong condition and which had expanded criteria that could be applied to a much larger and more diverse group of the population.

The fourth edition of the Diagnostic and Statistical Manual (DSM-IV, 1994) introduced four different disorders; Autistic Disorder, Asperger’s Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

This meant that children of normal intelligence, with superficially normal language development and those who had some autism symptoms but not all of them could now be diagnosed.

The most recent edition of the Diagnostic and Statistical Manual, the DSM-5, published in 2013, (DSM-5, 2013) dropped the terms Autistic Disorder, Asperger's Disorder and PDDNOS diagnoses and replaced all of these with one new, overarching criterion, known simply as Autism Spectrum Disorder.

Although this change was controversial, it arose out of the prevailing view at the time that autism is best understood as a spectrum condition, with varying numbers of autism symptoms<sup>2</sup> and varying levels of functional impairment (the rather unpleasant term that is used to describe how much an individual is impacted, on a day to day basis, by their symptoms.)

The notion of a spectrum can be somewhat problematic as it leads to the question "where on 'the spectrum' is my child?" when in fact 'the spectrum' is not a single scale but encompasses several dimensions which together are what we describe as the autism spectrum – these include variances in sociability, sensory processing, intellectual ability and language ability just to name a few.

The DSM-5 for the first time, also allowed for an autism diagnosis to be made in the presence of so-called comorbid conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and intellectual disability and anxiety; previously these were either/or diagnoses, not both or several. This inclusion of comorbidities has had significant implications for services, a point I will return to later.

## Changing rates of diagnosis

As the diagnostic criteria for autism changed so did the prevalence rates. The Centre for Disease Control and Prevention (CDC) in the USA began publishing prevalence rates for autism in 2000. Rates were approximately one in 150 in 2000; one in 88 in 2008; one in 68 in 2012 and one in 59 in 2019.

These increasing rates resulted in headlines about whether we are experiencing an "autism epidemic" and spawned many theories, some speculative and some with some evidence behind them, about why this increase is occurring. The claim that the Measles Mumps and Rubella (MMR) vaccine causes autism (which has been extensively studied and debunked by the scientific community) is one of the most well known of these.

Most clinicians and researchers are of the view that the changing rates of diagnosis are primarily to do with the changing criteria over time. Essentially this view implies that these children have always existed but historically they may not have been diagnosed or if they were, they may have been diagnosed with something else. This is known as diagnostic substitution. There is much good evidence for diagnostic substitution. For example, as rates of autism have increased, rates of diagnosis of intellectual disability have correspondingly decreased (Coo, Ouellette-Kuntz, Lloyd, Kasmara, Holden, et al, 2008).

Another driver for increasing rates of diagnosis is the emergence of services specifically available for people with autism. A dramatic increase in rates of autism diagnosis occurred in the USA in 1991, when the Department of Education ruled that a diagnosis of autism qualified for special education services.

<sup>2</sup>The term "symptoms" is used here as the diagnosis of Autism Spectrum Disorder is firmly entrenched within the medical model.

Many of the children who were now diagnosed with autistic disorder had previously been diagnosed with intellectual disability.

We do not have good New Zealand data on the prevalence of ASD. However, the government announcement in February 2014 confirming that Autistic Spectrum Disorder (ASD) is eligible for needs assessment is believed to be a key driver behind the ever increasing number of new ASD clients being referred to Disability Support Services.

Growing public awareness of autism has led to an increase in the numbers of referrals. The New Zealand Autism Guidelines published in 2008 (New Zealand Autism Spectrum Disorder Guideline, 2008) and revised in 2016 (New Zealand Autism Spectrum Disorder Guideline, 2016) raised awareness amongst health and education professionals. Parents are also recognising the signs themselves and requesting referral.

## Autism diagnosis in NZ

So with New Zealand likely following similar trajectories to the USA and the UK, and with rates of diagnosis estimated at one in 100 children, what does this mean for autism diagnosis in NZ?

An obvious impact for those working in child development and paediatric services across the country are the lengthy and growing waiting lists for formal diagnosis.

Furthermore, these changes mean that the group of children receiving an ASD diagnosis are increasingly diverse.

Within the group of children being referred for an autism assessment, it means there are a substantial minority who will not get an ASD diagnosis, although they may have some significant difficulties.

These children may have some autism symptoms but do not have enough to meet full criteria for ASD. (The extended families of people with an autism diagnosis are often full of quirky people who fit into this category).

A child who does not have functional impairment from their autism symptoms across settings, for example the child who copes at school but not at home, will not meet criteria for ASD.

Similarly, older children with autistic traits presenting for assessment later in life but who have no evidence of social communication and social interaction concerns in their early years, may not meet criteria for ASD.

A child may have some ASD symptoms as well as comorbid anxiety or ADHD symptoms, and then seem to "fall between" the child mental health and developmental services, and may not meet entry criteria for either service despite having significant needs. There is pressure for clinicians to give a formal diagnosis of ASD to these children, because ASD, along with intellectual disability, is a recognised pathway by which additional services can be accessed.

Despite our best attempts to assure parents that we hear and believe their concerns, many feel their concerns have not been validated if the diagnosis of ASD is not made. Those who do get their diagnosis are often disappointed when they find that there are not specific targeted supports as they had hoped. Unfortunately, there are simply not the resources available for specific supports for all people with ASD. In NZ special education resources are guaranteed only for the most severely disabled children (usually those with a severe intellectual or physical disability).



Similarly in health, a diagnosis of ASD simply means one is eligible to be considered for disability supports; once again it is those who are the most severely disabled who can expect significant support.

There are of course other good reasons for parents to seek diagnosis for their child besides access to services—understanding for themselves and others who have a relationship with them, guidance on strategies that may be supportive and improvement of quality of life.

## Where to from here?

Given the changes in diagnosis in the past 20 years it is likely that in another 20 years there will be further changes to the way we think about autism.

The current very broad conceptualisation of autism as a spectrum condition and as a condition with many associated conditions has I believe made the current diagnosis of ASD of limited utility<sup>3</sup>.

One size does not fit all and approaching autism as a unified diagnosis with a single approach to intervention makes little sense and is not useful.

The views of Christopher Gillberg, a Swedish child psychiatrist resonate with me.

Gillberg and others believe that there is not one condition called Autism Spectrum Disorder but in fact there are many autisms (Coleman and Gillberg, 2012)

Some of these autisms bring benefit to the individual and society – think of some of our most influential artists, scientists, physicists, musicians, mathematicians who may have the ability and focus to truly make a difference.

Others have “just a little bit of autism” and not “enough” to warrant access to disability or special education supports although it can be helpful to understand the learning styles and coping styles that might come with it. These are the people who are currently described as “on the spectrum” but do not meet full criteria for ASD.

Many of the autisms have associated conditions (learning difficulties, language difficulties, ADHD, anxiety) that are more troublesome than the autism itself and need to be the focus of intervention. In fact there are very few people in the world with autism only – having “autism plus” as Gillberg describes it is the rule rather than the exception. Some of the autisms are associated with medical conditions (e.g. Fragile X, neurofibromatosis and some epilepsies).

With a focus on the diversity of the autisms we are better able to find meaningful ways to support this large and disparate group; it is only when an individual’s strengths and challenges are understood that intervention becomes meaningful. The concept of multiple autisms also enables us to address some issues that are difficult to openly discuss as they can be perceived as disabling or discriminatory or as parent blaming. For example there are a number of genetic causes for some of the severely disabling autisms that warrant research aimed at preventing the condition from occurring.

There is estimated to be around 10 per cent of the child population who present with a variety of neurodevelopmental problems – with general development, with communication and language, with social skills, with motor coordination, with attention, behaviour, mood and sleep.

<sup>3</sup>I am saying here that the diagnosis of ASD is of limited utility, not that neurodiversity and autism are of limited usefulness.

ASD is a common diagnosis in this group of children. However these children are not simple. They come from a diverse range of cultures, backgrounds, and families. Some come from well-off and well resourced families and neighbourhoods. Some grow up in situations of social adversity and may experience abuse and neglect.

Indeed, research has found that adverse childhood experiences including living with someone with an alcohol or drug problem or mental illness are associated with higher rates of autism (Hoover and Kaufman, 2018). Intervention for parents and the parent child relationship may be needed as much or more than intervention for the neurodevelopmental condition itself.

Furthermore, while it appears that around 90 per cent of children with early neurodevelopmental problems will have some difficulties later on, we are not good at picking which problem(s) will be most significant later on (and therefore what diagnosis or diagnoses are useful) or how severe the challenges will be. Early intervention is important, but early diagnosis is not always accurate.

While we may be aware of the many factors that contribute to neurodevelopmental conditions in children and the need for broad based supports, our current siloed<sup>4</sup> funding streams mean we have increasingly specialised services and clinicians. For example it is common for children to be seen in paediatric or child disability services for their autism and separately in child mental health services for their ADHD and anxiety. Clinicians in disability services do not necessarily have the skills and knowledge to adequately treat mental health conditions and mental health services are often not well-equipped to support autistic people.

Unfortunately, when services are under pressure they may try to manage overwhelming referral volumes by trying to redirect people e.g. “this child’s anxiety is arising in the context of their autism, so it should be managed within autism services.” Or conversely “this child’s autism symptoms are not enough to meet criteria for a formal diagnosis of ASD but they are anxious so they belong in mental health.”

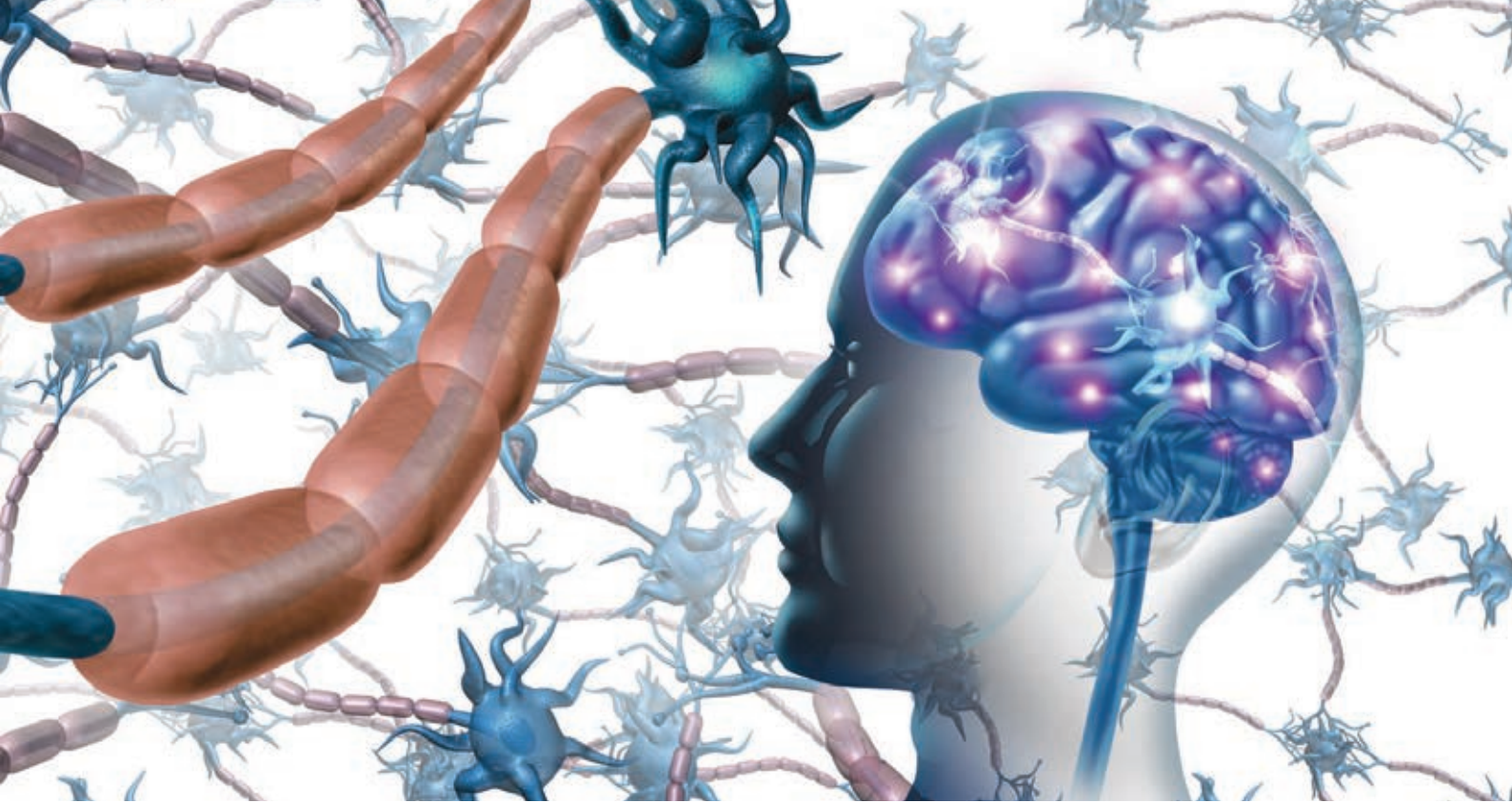
The clinical reality is that symptom overlap is the norm not the exception and our services should reflect that.

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Jenny Gibbs has been the consultant clinical psychologist for Altogether Autism for the past two years and was previously a member of the Altogether Autism Professional Expert Group.

<sup>4</sup>Silos are organisations where each department concentrates on their own objectives.



# Five areas of autism research to watch



*The field of autism research evolves as we learn more, from research findings, autistic individuals, and the broader autism community, write **Rebecca Flower and Rachel Jellett**, postdoctoral research fellows at Olga Tennison Autism Research Centre at La Trobe University in Australia.*

**THE SCOPE** of autism research has broadened significantly in recent years to include topics relevant to adolescents and adults.

We present an overview of five areas gaining researchers' attention in recent years.

The research presented below mostly relates to individuals with autism and no co-occurring intellectual disability.

We recognise this is an area of focus where more research is needed, and our team is advocating for, and pursuing research in this field, although it is not represented in this article.

Please also note that we have used a mixture of identity-first (e.g., 'autistic person') and person-first (e.g., 'person with autism') language, to reflect the diversity of preferences in the autism community. For now, here are five areas in autism research to watch:

## Neurodiversity and Participatory Research

The idea of neurodiversity is not new but has been gaining more attention recently. The essence of the term 'neurodiversity' is that *"there is no single way for a brain to be normal,"* as explained in a recently-published editorial by Simon Baron-Cohen, head of the Autism Research Centre in Cambridge. Looking at autism from a neurodiversity perspective can help promote inclusion and reduce stigma. It means broadening our understanding to see how social systems can change to be more autism friendly, rather than focusing narrowly on the individual. Supermarket 'quiet

hours' are a nice example of an environmental change that can have a positive impact for people on the autism spectrum.

*How has autistic activism contributed?* The neurodiversity movement is a social justice movement promoted by autistic autism rights advocates (see den Houting, 2019). Increasing use of words like Neurodiversity, Neurdivergent, Neurotype; hashtags such as #ActuallyAutistic, and a social media profile followed by **Âû** are indicators of some of the activism linked to the neurodiversity movement.

People who are #ActuallyAutistic are finding more channels through which their voices can be heard, which contributes to changes in how we view and understand autism. By sharing their experiences, they give us the opportunity to learn more about what autism is like from the inside.

*What is "participatory research" and why is it important?* In a recent editorial, Liz Pellicano and her colleagues (2018) explained the importance of 'participatory research', which means including autistic individuals in each stage of the research process. Some different methods of participatory research include using advisory boards, co-developing projects, and removing barriers so autistic researchers can access opportunities to contribute. Using these methods makes it more likely that research will reflect the needs of the community, and that interpretations of research data are consistent with how the autism community would view the data.

■ Continued on page 8



## Autism in Girls and Women

You might have heard that for every female diagnosed with autism there are roughly three to four males (Fombonne, 2009; Loomes et al., 2017).

But this ratio changes when you consider the person's language, cognitive abilities, and even their age. The ratio of males to females where there is a co-occurring intellectual disability has been reported at around 1.5:1 (Yeargin-Allsopp et al., 2003), for those without, around 10:1 (Fombonne, 2009), and by adulthood, about 1.8:1 (Rutherford et al., 2016). This pattern tells a two-part story. Firstly, biologically, autism might not affect males and females equally (Ecker et al., 2017). Secondly, autistic girls without co-occurring intellectual disability are being missed (Dworzynski et al., 2012), only to be diagnosed later if at all (Begeer et al., 2013; Loomes et al., 2017).

*So, what does autism look like in girls and women?* The pattern of behaviours seen in autistic girls and women is known as the 'female autism phenotype' (Kopp & Gillberg, 1992). Girls and women might be more inclined, better able, or are taught from a young age to mask their autism (Hull et al., 2019; Lai et al., 2015). They tend to desire friendships and develop strategies like watching and impersonating other girls (Tierney et al., 2016). They can be socially successful, though this becomes more difficult with age, as the complexity of the social world increases and the effort of masking (see section on Masking later in this article) comes at a cost to their wellbeing and sense of identity (Tierney et al., 2016). For these reasons, social difficulties can go unnoticed.

Some girls with autism will have a 'special interest'. Although the intensity is similar to that of boys with autism, the special interest might not stand out as being unusual (e.g., animals, Disney, creative writing, Harry Potter, manga) and might be 'gender typical' (see Lawson, 2019, for a review). Girls might show preferences for routine and struggle with transitions; their rigidity can also present as strong opinions and can mean that they can be very determined. This tendency can make autistic girls wonderful advocates; Swedish teenage environmental activist Greta Thunberg is a testament to this. Like boys, some girls with autism show differences in their sensory processing; for example, they can be sensitive to light, sounds, the feeling of some fabrics, and self-grooming (e.g., having their hair brushed).

*Why are girls missed?* Girls are less likely to be referred for assessment (Rutherford et al., 2016), and referred girls are less likely to get a diagnosis of autism (Duvekot et al., 2017). Girls might cope with strong emotions by turning them inward (internalising, anxiety, depression) rather than outward (externalising, challenging behaviour), meaning they can fly under the radar.

The diagnostic tools we use for autism have a male bias and are less effective for identifying females (Ratto et al., 2018). Diagnosticians who are unfamiliar with the female autism phenotype might carry this male bias, looking for the signs of autism they're used to seeing in males; girls don't necessarily fit the stereotype. As part of an assessment process, a range of information is gathered from clinical observations, self-, parent-, and teacher-report.

Girls can seem different in the clinic, at school, and at home, which complicates the assessment process. For girls and women, there can be a marked difference between how they seem on the outside, and what they're experiencing internally.

*What should health professionals look for?* A recent paper sums up the opinions of clinical psychologists experienced in assessing autism in girls with the title "exactly the same but completely different" (Muggleton, McMahon, & Johnston, 2019). By interviewing the psychologists, the researchers found that while the psychologists believed the underlying characteristics of autism seemed the same across girls and boys, psychologists had noticed the way these characteristics presented seemed different.

As a clinical psychologist, I (RJ) have personally found that when assessing girls and women, it can be important to look beyond surface social skills and toward deeper social understanding. Look for discrepancies between home and school; are they socially successful but then struggling at home from the effort?

Consider a combination of age, cognitive/language ability, and anxiety, as these can help to decide whether social success is coming to them naturally or is effortful compensation. For young girls, investigate their imaginative play skills by changing the idea or script and seeing if they can follow and adapt flexibly. Drop social hints about yourself and see if they pick up on the cue to ask you a question. For women, listen to their descriptions of how they learned social skills and the difficulties they encountered along the way. Look carefully at co-occurring sleep, digestive issues, mood, and anxiety. When assessing for autism, it's not just about looking, it's about listening. People's stories and experiences (including their own and those of parents and partners) can be as important as the behaviours observed in the clinic.

*What does diagnosis mean for girls?* An accurate autism diagnosis is important for girls and women. Receiving a diagnosis can give girls and women understanding, support, community, and a sense of identity, and can be liberating (Frith, 2013). Many women have received an incorrect diagnosis (Bargiela et al., 2016) on their way to identifying their autism, which can be confusing and lead to inappropriate or even harmful treatments. Increased self-awareness and understanding from others can help prevent some of the secondary difficulties (e.g., mental health concerns) associated with a lack of understanding and support.

*What about males and non-binary people?* Gender is more complicated than a simple male-female binary, and people with autism show more varied gender presentations (Strang et al., 2014). More research is needed to understand the presentation of autism across the gender spectrum and how autism presents in those who are gender diverse. Of course, there are also individual differences in how autism presents; the points made above can also apply to boys with autism and may not be exclusive to girls (Hull et al., 2019). This is because "the way autism affects individuals is highly variable" (Gould, 2017, p. 704).

## Masking, Camouflaging, and Compensating

Camouflaging, masking, blending in, compensating, impression management; we all do this to an extent. Imagine you're invited to a work dinner with your colleagues. You get ready, thinking about what's appropriate to wear, what to bring, and some topics to bring up (and avoid) if there are lulls in conversation.

In autism, the stakes are higher, and the task is more difficult. When social skills do not come intuitively, getting through this event requires cognitive effort, concentration and learning, a bit like doing complex algebra on the fly.



*How do these strategies differ?* Camouflaging and compensating are two different processes. Camouflaging and masking refer to 'hiding' autistic traits to appear more neurotypical. This can include suppressing stimming (stimming, also known as self-stimulation, is the repetition of physical movements, sounds, words, or moving objects) or talking less than you'd like to about a favourite topic to try not to stand out. Compensatory strategies involve using intellect to find new ways to read and respond to social cues, so those with autism can get by in social situations (Livingston & Happé, 2017). Compensating can be superficial (e.g., laughing along with a joke) or more sophisticated (e.g., recalling similar past experiences and adapting learned responses to a new context). Cognitively, this might be similar to children with dyslexia finding a different way to learn to read (Frith, 2013).

*What is the cost of compensation?*

A recent study found that people who engaged in compensating described it as an effortful process (Livingston, Shah, & Happé 2019). However, they explained that it gave them opportunities they might otherwise have missed. On the flip side, compensating seems to be a risk factor for mental health difficulties, and might even make it difficult to form a clear sense of self-identity. When asked whether it was worth it, many participants said that in hindsight it was, but imagine a world where there was enough awareness, acceptance, and valuing of autism that autistic people could fully participate in life without feeling compensating was required. What's exciting about this area of research is that it suggests that there is more to autism than meets the eye (Gould, 2017). In the diagnostic process for autism, it is important to consider a combination of autism traits and characteristics, as well as the level of masking/compensation (Hull et al., 2019), the underlying cognitive processes (McPartland, 2019) and subjective experience (Parrish-Morris, 2019). Having a good understanding of all these aspects of autism will enhance the provision of supports and services for those on the spectrum.

## Employment

Autistic people have a lower rate of employment than non-autistic people worldwide. While accurate and current data are difficult to collect, employment rates for autistic people in English-speaking countries are believed to be between 14% in the United States of America (Roux, Rast, Anderson, & Shattuck, 2017) and 32% in the United Kingdom (National Autistic Society, 2016). And when autistic people are employed, they are likely to be 'under-employed', working less hours than they desire, and employed in roles below their level of qualification (Baldwin, Costley, & Warren, 2014). In Australia, the best estimate for employment among individuals on the autism spectrum is only 28 per cent, which includes all employment – even if only a few hours a week, (Australian Bureau of Statistics, 2017). Unfortunately, we are not aware of any data that documents the employment rate of autistic people in New Zealand.

*Why are employment rates low among autistic people?* We know there are several barriers to meaningful employment for autistic people, and research is only beginning to investigate these. For example, the job interview is based on verbal and non-verbal communication, including communicating that you are the best person for the role and building rapport with interviewers.

This can be a challenge for autistic people given different communication styles and unwritten rules involved in a job interview that change depending on context (e.g., there may be differences in an interview for an office-based role compared to an interview for a role in the hospitality industry). Further, studies exploring community knowledge and understanding of autism have found many people have limited understanding of autism, particularly regarding workplace abilities (e.g., Jones, Akram, Murphy, Myers, & Vickers, 2019). So, is there something specific about the traditional recruitment process that is creating barriers? How are autistic candidates being perceived at job interviews? Are there changes that employers can make to reduce barriers for autistic job seekers? These are questions our team at the Olga Tennison Autism Research Centre is working on answering.

Lastly, while many of these companies aim to share their experiences via events such as regular Autism@Work summits. The majority of these programmes conduct data collection 'in-house' and thus limited objective information is available from which other companies, and researchers, can learn. So, while research has

begun to target changes that employers can make (rather than putting the onus on autistic individuals to change) there is still a long way to go.

## Mental Health

Increasingly researchers are conducting studies looking at mental health among autistic people. Recent findings have suggested that autistic adults are more likely to experience several mental health conditions than non-autistic adults. Many autistic self-advocates are speaking up about their experiences and encouraging researchers to do more work in this field.

*What do we know about mental health for autistic adults?*

There is evidence that autistic people are more likely than non-autistic people to experience conditions such as generalised anxiety, obsessive compulsive disorder, bipolar disorder, and major depressive disorder, and that these conditions are common across the lifespan (Lai et al., 2019; Uljarevic et al., 2019).

However, here's where things become a little tricky. The tools clinicians use to diagnose mental health conditions are often tools that have been designed for use among non-autistic people. This can lead to challenges, as the tools are written for a non-autistic client, and it is possible that autistic individuals may experience symptoms differently or understand questions being asked in a different way. For example, symptoms that are associated with anxiety among non-autistic people, may be a sign that the autistic individual is experiencing sensory over-stimulation rather than an anxiety disorder. It is also possible that clinicians unfamiliar with autism may misinterpret symptoms of autism as features of another clinical condition. Conversely, clinicians may ignore or overlook co-occurring conditions, assuming it is part of autism, an issue known as diagnostic overshadowing.

These challenges have prompted researchers to suggest a) mental health evaluations for autistic adults, b) diagnostic tools designed to identify mental health conditions among autistic people, and c) therapies designed specifically for autistic people (Lai et al., 2019; Uljarevic et al., 2019).

## Final points

As discussed in this article, many people with autism have had to work hard to present in a more 'neurotypical' way to succeed in social environments like the workplace. However, this can come at a cost.

It can lead to the under-identification of autism (especially in girls/women), workplace discrimination, and has an impact on mental health. This points to the stigma that continues to be experienced by autistic people.

With increasing awareness and understanding, thanks in part to the neurodiversity movement, we are hopeful that things will change quickly, and autistic people will feel they can be themselves and embrace their positive autistic identity.

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- The Olga Tennison Autism Research Centre (OTARC) is Australia's first dedicated autism research centre and is located at La Trobe University in Melbourne, Australia. OTARC works with many international partners, and lead researcher in early detection, Dr Josephine Barbaro, recently trained New Zealand's Plunket nurses. Other collaborations in New Zealand include Dr Simon Bury's work with DXC Technology and Untapped Group.



# The significant role genetics play in autism



*For decades researchers have searched for answers regarding the origins and development of autism spectrum disorder, writes Altogether Autism researcher Emily Acraman.*

**WHILE WE KNOW** autism has both genetic and environmental origins, there is still much debate about the role each factor plays in the development of the condition.

A new widespread study involving more than two million children across five different countries has revealed the variation in autism occurrence in the population is mostly due to inherited genetic influences.

The study found that inherited genes account for about 80 per cent of an individual's variance in developing autism.

They also found little to no support for contribution from maternal effects.

While genetics have always been a large known contributor to autism, this study shows just how significant a factor inherited genetics are.

It is still largely unknown what specific genes contribute to autism, and this remains an area which is still widely investigated.

However, what this study tells us, is the development of autism is largely based on an individual's genetic makeup and is not necessarily because of what a parent or individual is doing or not doing (Bai et al, 2019).

## Genes are the main contributing factor!

In the new study published in July 2019, Bai et al used population data from Denmark, Finland, Sweden, Israel, and Western Australia which included all children born between approximately 1998 and 2011 (Length of time data was gathered differed between countries).

A total of 2,001,631 individuals were included in the study, 22,156 of which were diagnosed with autism. Children in the study were followed until age 16.

The study used a multigenerational family design which involved full siblings, cousins related through their mothers, and cousins of other relations.

This allowed researchers to determine the estimated effects of genetics (heritability), maternal factors, and shared environmental factors (Bai et al, 2019). Key findings of the study are as follows:

- The median ASD heritability across the five countries was 80.8%, ranging from 50.9% (Finland) to 86.6% (Israel).
- Maternal effect was estimated to range from 0.4% to 1.6%.
- Shared environmental factors contributed minimally to the development of ASD.
- Findings were fairly consistent between the five countries, with only modest differences in the sources of ASD occurrence.

## What about the other 20%?

We know genetics account for 80 per cent of the variance in the occurrence of autism, however what makes up the remaining 20 per cent is still largely unknown.

What this study does tell us is that it is not likely due to maternal effects.

Maternal effects refer to the nongenetic influences originating from the mother beyond what is inherited by the offspring and can include both genetic and environmental factors.

Maternal effects reported in the literature to be associated with autism have included; maternal obesity, hypertension, diabetes, pre-pregnancy body mass index, polycystic ovary syndrome, maternal infection, pre-term birth and many others (Yip et al, 2017).

A notable outcome of this study is that researchers found little to no support for a contribution from maternal effects associated with the occurrence of autism (Bai et al, 2019).

This finding is important as it indicates there is no strong evidence of a maternal effect associated with autism. This finding is also consistent with previous research using population-based data in Sweden (Yip et al, 2017).

Another important point to make regarding the results of this study is that the findings put into perspective the limited role modifiable environmental factors play in the development of autism.

With genetics accounting for 80 per cent of the variance, the contribution of environmental factors is therefore significantly smaller. Interestingly however, it is the modifiable environmental factors that seem to receive the most attention as probable causes.

There is an abundance of media and public platforms which focus disproportionately on the impact of environmental factors to the development of autism, even when those factors have been overwhelmingly discredited.

In summary, this research is the largest study to date which estimates just how much of the variance in the occurrence of autism is genetic.

It is consistent with previous estimates and strengthens the conclusion that autism is mainly heritable and less likely due to environmental factors.

For many individuals, it may provide some form of comforting explanation by establishing autism is less about what a parent or individual is doing right or wrong, and largely because of an individual's pre-determined genetic makeup.

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Emily Acraman is a researcher at Altogether Autism.



**SPEAKING:** Jolene Stockman speaking at the conference ©The Pathlight School. Photo credit: Autism Resource Centre (Singapore).

# Blueprint for autistic world domination



*Since **Jolene Stockman** revealed her autism diagnosis during a TEDx Talk last year, she has spoken to many organisations, parents and autistics. But talking at the Asia Pacific Autism Conference in Singapore was a big step up. She explains what it was like.*



**THE AUDIENCE** at the Asia Pacific Autism conference (APAC) in Singapore was always going to be different to what I had previously experienced.

The culture around autism there is not as positive or supportive as it is in New Zealand.

In Singapore, autistic speakers are given the option of hiding their identity in case they are worried about the repercussions that identifying may have on their career, relationships, or social standing.

I weighed it up; I always want to inspire and educate the audience, but I wasn't going to Singapore to try and sound like everyone else.

I had been chosen for my voice and my perspective, even if it meant an unpleasant reaction to my speech. I was prepared for a potentially hostile crowd, resistant (if not adverse) to the idea of 'celebrating' autism.

So, I spoke at the conference, held in the Resorts World Convention Centre on Sentosa Island off the coast of Singapore, to my lived experience and shared concepts from my award-winning book for young adults, 'Total Blueprint for World Domination.'

**"Our greatest human gifts are time and energy. What if we took all the energy, we're spending trying to get our autistic kids to eat food that touches, look us in the eye, and pretzel themselves to fit into the current world, and spent it supporting them to find peace, to find passion, and to create the new world?"**

**– Jolene Stockman APAC19**

I told my story, and talked about autistic superpowers, the strengths and advantages. And you know what? The room was packed to overflowing.

There were people in the aisles. They nodded, laughed, and they cried (in the good way!) And no one walked out!

Even though I knew I'd be okay however the audience reacted, it was still a huge relief that it went so well.

I think it's because truth resonates, and that we all relate to finding the magic in our kids and sharing it with the world. Even if that magic doesn't look the way we thought it would.

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## Autistic-Friendly

The conference organising committee (which included autistic researcher and multi-art practitioner Dr Dawn-Joy Leong) put strategies and options in place to soften the sensory overload and support autistic delegates.

This included:

- A chill-out room that provided a quiet-zone, low light, and sensory objects for peaceful time out.
- A social space for autistics to network and have meals away from the crowds.
- Social interaction stickers – available to stick on your lanyard, letting people know if you were green (happy to speak to anyone), blue (okay to speak to people you know), or red (not wanting to talk). Imagine these in workplaces!
- Volunteer hosts (in purple shirts) everywhere: happy to smile, support, provide information, or help with anything you could think of.

The conference wasn't perfect; while the hand dryers in the restrooms were turned off (epic move APAC19 organisers!) they were labelled with an apology for the inconvenience. Autistic supports are ideals, not inconveniences.

There were still plenty of the old myths floating around, disrespectful language use in spite of the guidelines provided (identifying autistics as people who "suffer from" or "live with" autism), and lots of cringy moments for autistic delegates listening to presenters who may have forgotten we were in the room.

But overall? Huge progress.

Workshops and presentations on employment, wellbeing, mental health, digital technologies, relationships, and education. Autistic voices invited and heard alongside world-renowned doctors and guests.

I'm excited about the future of autism, not only for the things I learned in Singapore, but for the new appreciation I have for the progressive attitudes and people working together in New Zealand.

I'm humbled and honoured to be able to speak and share in this space. I've connected with some incredible people in Singapore and I'm excited to develop these relationships moving forward.

Ngā mihi nui ki Altogether Autism, Autism Connex, and the Department of Internal Affairs Lotteries Commission, for your support and for the funding that made this possible. And thank you to Pathlight Singapore for the photos. I am so honoured and appreciative.

Ngā mihi nui ki a koutou i tō tēnei taonga mīharo.

- Jolene Stockman is a multi award-winning Taranaki writer and tangata whaitakiwātanga (an autistic person).
- Since her adult diagnosis and TEDx Talk, Jolene has become a trustee for innovative not-for-profit Autism Connex and is excited to raise understanding and optimism around autism.
- The Asia Pacific Autism Conference brings together members of the international autism community to witness and discuss progress made internationally in the autism space.
- For more about Jolene and the conference, visit [www.jolenestockman.com](http://www.jolenestockman.com)



**CONNECTING:** Jolene Stockman and Theresa Tongi from Autism Connex at the APAC19 conference.





# Nikau's animated story of hope



*To look forward into the future we must reflect on where we have come from, writes Ali Cowley.*

**We hope to show better understanding and the importance of diversity and inclusion.**

**WHEN I WAS** a kid, the only thing I knew about people with autism was by watching an 80s TV show 'That's Incredible'.

They highlighted a kid that couldn't see or talk but could play music like one of the great composers such as Ludwig van Beethoven. Come to think of it, I don't even remember the show mentioning the person was autistic, but the person was referenced as an 'idiot savant'. I remember thinking this term sounded highly offensive but was a clinical description of that person's condition.

I guess these kinds of re-collections are my way of trying to reach for something that categorised someone on the autism spectrum but not actually being informed about what it was. I was just generalising an intellectual handicap (this time the second word was highly offensive to my ears), but I was starting to sense a pattern of juxtaposed clinical adjectives.

I guess I didn't really make any effort to try to know what autism was and the more media or newspaper articles covered autism, whether it was clinical or human interest stories, I found myself becoming empathetic to what autism looked like in public i.e. the said person flailing their hands around their ears with mostly loud short bursts of noise usually attached with an adult furiously fussing about them flustered and slightly embarrassed.

It wasn't until I had a child on the autism spectrum that I became that adult and inherited all that goes with the spectral world.

It was only 16 years ago that this happened when my wife Donna and I had our first-born son Nikau.

Before Nikau, we knew what our goals were.

As a couple of career minded singles, we could see what was in our line of sight. Donna achieved a Bachelor in Maori Studies and a Post Graduate Diploma in primary school teaching. I achieved my goals towards my animation career.

All of this was happening, as well as getting married in the midst of it. Our next plans were to start a family. Questions about what would it be like to be parents? Every romanticised or dramatised notion popped into our heads.

Nikau's birth was new to us. As new parents, we didn't know what to expect. Advice from friends and guidance from Donna's mum helped us both and we soon started doting over baby bassinets, clothing and everything else.

Fast forward to the delivery room and an expectant Donna had to be induced which added more anxiety but our prep work made us think we were ready or so we thought. As soon as Nikau entered the world, we had a slight feeling of uncertainty about his entrance especially because he didn't burst out in song like we had seen on television programmes. Nikau chose the mysterious silent type approach.

This was the most exciting moment for us and we were ecstatic parents. A four-year romantic period began with our first child celebrating birthday milestones. Nikau was our dream child. He played quietly all day but that uncertainty we had from his first breath became a signal that also was paired with other behavioural experiences he had at his kindergarten. After a child psychologist intervention at kindy we were referred to the Manukau SuperClinic for tests and learned of our son's condition. He had Asperger's Syndrome.

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A certain amount of relief comes with knowing and for a long time we didn't know why our son wasn't connecting with us and everyone else. He gave us huge anxiety when in public (remember the fussy adult moment but in this instance, Nikau wasn't making quirky noises) but we managed that by either having short outings or not going anywhere.

If we look at where we are now, we had no preparation for what we experienced and about the future of autism, I can tell you this. Sharing is caring!

In a world where we have information technology and popular culture, we can take ownership, to be caretakers of each other whether having this condition or not and continue to share that knowledge with those that may need it.

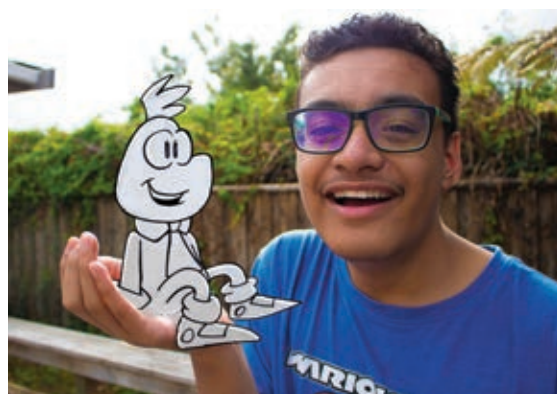
Pasifika Autism Support Group (PASG) is a parent founded initiative run by families who have spectrum kids. One thing to be said is autism affects the whole fanau and not just the child. We connected with founders Betty and Brian Pulefolau

because we could not find any support networks for Pasifika fanau. PASG exists because of this amazing couple. PASG is our community's future and it has grown exponentially over the last decade.

I recently directed a documentary called Meet Munch Jr which is part of the Loading Docs platform.

It is about my relationship with Nikau but, it's a story of hope. The documentary has had such a great response from our community, fanau and teachers and it has become a beneficial resource for PASG. We hope it will create more support groups and encourage conversations and awareness of Autism, which for me is vital.

We hope to show better understanding and the importance of diversity and inclusion. The future of autism for us has arrived and can only get better. The words that used to hurt my ears have now been thoughtfully re-worded. Neuro-diversity describes how the future looks which is bright and full of empathetic sharers of love.



- Ali Cowley (Samoan) is an Auckland based animator, Illustrator and director.
- He has worked in the industry for over 20 years and has directed music videos and short animated films for corporate videos, developed content for the Play Kindly app and specialises in storyboarding and production design for animation and film.
- He was an animation director on prime time animated show Bro'Town for four seasons and is currently working as an Art Tutor at Media Design School in the Gaming Department and is on the Pasifika Committee called "Vaega" as a Mentor to the Polynesian students. At his work, he's currently researching ways to engage his Polynesian Community with new media as a career choice. He also successfully curated an art exhibition featuring Pasifika/Maori MDS Alumni in his home town of Mangere.
- He was a participant in Script to Screen's South Shorts Screenwriting initiative and has written a short film script which he is hoping to make in the near future. Meet Munch Jr is his first short documentary.

# The Incredible Years

## Autism Group-Based Parenting Programme for Children aged 2 to 5 years



*An opinion piece by Chris McAlpine, clinical psychologist.*

### The Idea

**IN 2015** my colleague Gill Duncan, an Incredible Years facilitator, approached me about running an Incredible Years Autism Spectrum Disorder (ASD) and Language Delay Programme together.

This was a very exciting undertaking for us both because it had never been run in New Zealand.

We now know, that in early 2016 when we ran the programme, there had only been one pilot study conducted worldwide (Williams et al., 2017).

### Background

Children with autism spectrum disorders experience significant communication and social challenges and higher rates of behaviours such as aggression, atypical sleep, anxiety and difficulties regulating their emotions from a very early age.

Decades of research has shown that parents of children with autism often experience consistently higher levels of stress which in part relates to managing challenging behaviours.

Parental stress is correlated with several worrying outcomes for children and families and results in decreased effectiveness of early intervention on a child's behaviour and social skills (Webster-Stratton).

There are few empirically based interventions that address the needs of parents who have a child with autism.

Early research has shown the Incredible Years ASD and Language Delay Programme offer parents support, reduces stress and depression, promotes children's social emotional development and reduces challenging behaviours (Webster-Stratton), 2019.

### My experience in the field

In my work I am often asked of parents: "Does my pre-schooler have autism or characteristics of autism?"

A significant proportion of parents are aware from the age of 13 months that their child is developing differently.

When they express these concerns to others they can be often ignored or given reassurance e.g. "Boys are like that" or "my child does that too".

In my experience, parents can often feel blamed, judged and believe that they may have caused the problems. Advice from friends and families is not always helpful and can leave parents feeling like they have failed.

I learnt a very valuable lesson 25 years ago, mothers are usually right. It is our job as professionals to understand what is happening developmentally for children. In my opinion, we should be identifying autism much earlier.

The research is clear; the earlier we intervene the better the outcomes for children's development.

### Objectives

We wanted to determine if the Incredible Years ASD and Language Delay Programme would be appropriate in the New Zealand context.

We also wanted to determine if it would reduce children's challenging behaviours and stress in their parents. Also, would it lead to increases in adaptive behaviour skills and social behaviours?

### The Programme

The Incredible Years ASD and Language Delay Programme is a 12-week programme with weekly 2-hour sessions.

The content of the programme promotes social communication and language development, positive relationships, social skills, emotion and self-regulation and positive behaviour management. Parental goals are set after each session.

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**"There were marked improvements in the children's behaviours such as aggression, anxiety and regulating emotions."**

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We recruited the parents of eight children between the ages of 2 and 5 years, referred to the Child Development Service in Tauranga.

All children had been assessed by our Multidisciplinary Assessment Team and had received a diagnosis of autism.

### Results

The Conners Early Childhood rating scale was completed at the beginning, and at 12 months follow up.

#### Summary of main findings:

- There was an improvement in inattention/hyperactivity for 87.5 % of children.
- There were notable decreases in defiant behaviour (66% end of treatment, 66% at 12 months post treatment), defiant temper (75% end of treatment, 83% at 12 months post treatment) and aggression (50% end of treatment and 50% at 12 months' post treatment)
- Notably 75 % of children improved on the Conners Global Index Score which describes children who are moody or emotional. At 12 months post treatment 50% of the children still had an improvement.

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Lasting impacts were noted on the anxiety subscale (50% at end of treatment, 83% at 12 months post treatment) and mood (63% at end of treatment, 66 % at 12 months post treatment).

- Social functioning/atypical behaviours improved with 12.5% of children showing improved after treatment, however there was a dramatic improvement with 83% of children showing improvement at 12 months post treatment. There was a very small change in adaptive skills, communication skills, motor skills and pre-academic skills. There was no change in these at 12 months post treatment. 50% of children had improved play skills and this was maintained at 12-month post treatment.
- An unexpected finding was that 100% of the children had improved physical symptoms and 66% of children had improved sleep problems at 12 months post treatment

## Parental feedback

The following comments were made by parents during the treatment:

- "He let me play with him for the first time.... he took my hands so I could help him".
- "He said "toot toot" and "chook chook" with intonation in his voice. He is starting to talk to me"
- "My daughter has started noticing expressions on peoples' faces for example when watching the Shrek movie, she said "look he has an angry face"
- "I didn't know I had to teach my child to calm down... I thought you just knew how to do it"
- Staff from another ASD parent education programme "were awesome but the Incredible Years Programme blew it out of the water because this one is a group, with videos, group discussion and role-plays which make it all so much more effective. With the other ASD programme, the practical... what are you going to do about it is missing". (I note the other ASD programme is an educational programme not a treatment programme)
- "I think all teachers should do this Incredible Years course as part of their training".
- "This course has changed our lives... everything is so much easier since I did this course"

## Discussion

There were marked improvements in the children's behaviours such as aggression, anxiety and regulating emotions. Interestingly one of the most significant improvements was the number of children who improved on the subscale measuring inattention/hyperactivity.

Treatment gains also occurred with sleep problems and physical symptoms. Most treatment gains were maintained at 12-month follow-up.

Small changes occurred in adaptive skills, communication skills, motor skills and pre-academic skills. Improvements in play skills were maintained by 50% of the children.

At 12 months follow-up 83% of the children had an improvement in social functioning/atypical behaviours.

This was in sharp contrast to the measure immediately following treatment when only 12.5% showed an improvement. This is an extremely positive finding.

This pilot programme showed the effectiveness of the Incredible Years ASD and Language Delayed Programme. Future research is required to assess the efficacy of this programme. The data to date is extremely encouraging.



**INCREDIBLE YEARS:** Chris McAlpine with Gill Duncan.

## Final Comments

My colleague Gill Duncan is now the first accredited Autism Language Delay Programme facilitator in New Zealand.

She has now completed six Incredible Years Programmes, three in conjunction with the Ministry of Education Early Intervention Team in Tauranga.

We would strongly recommend this course to parents.

Your child does not need a formal diagnosis to participate. Check with your local ASD coordinator to see if there is a group running in your area

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Chris McAlpine is a clinical psychologist at Te Whanau Kotahi – Child Development Service, Tauranga

# How free buses for people with disabilities help our autistic community



*Waikato Regional Council recently implemented a free bus concession for people in the Waikato with disabilities, writes Emily Acraman.*

**Only around 25 per cent of adults drive independently, as opposed to 75 per cent of the whole population.**

**THE FREE TRAVEL** on all Hamilton buses, as well as on the Cambridge, Northern Connector, Morrinsville/Paeroa, Raglan and Te Awamutu services will be available to people who have an impairment (physical, intellectual, psychological, sensory or neurological), which prevents them from being able to drive.

The Waikato accessibility concession is applauded by Altogether Autism, and has also precipitated the question, “is there research to suggest autistic people experience difficulty driving, and if so, why?”

Gaining a driver licence is a notable life skill which provides opportunity for increased independence and mobility. Additionally, it can contribute to added social and economic benefits. Survey data from the United States reports that only around 25 per cent of autistic adults drive independently, as opposed to approximately 75 per cent of the population of a whole.

This suggests that autistic people may experience difficulties both driving and taking the necessary steps to gain a driver licence (Feeley, 2010).

## Let's look at the research

Research and anecdotal evidence tell us the ability to drive for autistic people is very much based on individual circumstances. Some autistic people may find the skill of driving extremely difficult, while others will be highly competent. A diagnosis of autism should not in itself be a barrier to gain a driver's licence, however simulator studies suggest that autistic individuals may find a range of specific skills involved in driving to be challenging.

The ability to identify and respond to different types of hazards on the road has been shown to present some difficulty for autistic individuals.

A study by Sheppard et al, 2010 investigated this idea by studying hazard identification performance between twenty-three adult autistic males and 21 typically developing comparison participants. Each group viewed video clips which included two types of hazards; one being a visible person (social hazard), and the other being a car (non-social hazard).

Researchers summarised that autistic participants identified fewer social hazards and were overall slower to respond than their typically developing peers. These findings suggest that although autistic people can perceive driving hazards, some may have difficulty identifying them if they involve a person (Sheppard, Ropar, Underwood & van Loon, 2010).

A further study by Sheppard et al, 2016 looked to investigate why this difficulty occurs by comparing eye movements during a hazard perception task. Researchers specifically looked at when participants first identified hazards, and whether difficulties in responding to hazards were due to delays in, or a failure to orient them.

Results of this study revealed accuracy and performance in identifying hazards was comparable between the two groups with and without autism. However, eye-tracking movements did reveal some clear differences between the groups.

Autistic participants were slower to first fixate the hazardous target than the typically developing comparison group. Those that were slower to first fixate also tended to respond to the hazards (both social and non-social) later.

This suggests that slower responses to hazards may be associated with difficulties in orienting them. As well, autistic individuals showed a significant reduction in their horizontal spread of search during stages which was not observed in comparison participants.

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While the similarities in accuracy between participant groups in this study appears promising for driver safety in autistic individuals, the subtle attentional differences observed among autistic people may lead to poorer hazard identification, especially when demands for attention are higher (Sheppard et al, 2017).

Typical eye-tracking movement patterns exhibited by autistic people have also been found to deviate from what is presumed to be the optimal safe driving behaviour. Reimer et al, 2013 carried out a driving simulation experiment with 10 males (18-24 years of age) with a diagnosis of high functioning autism and 10 age matched neuro-typical peers.

Driving behaviour, skin conductance, heart rate and eye tracking measurements were collected. Their results showed that the high functioning autistic group displayed a nominally higher heart rate compared to their neuro-typical peers.

Further, with added cognitive demand they also showed a gaze pattern which was suggestive of a diversion of visual attention away from the high stimulus areas of the road (Reimer, et al, 2013).

### What do autistic people have to say?...

There is also evidence to suggest that autistic individuals who do drive report experiencing more difficulties than neurotypical drivers.

Daly et al, 2014 surveyed 78 licensed autistic drivers and 94 typically developing comparison drivers. They found autistic drivers reported significantly lower ratings of their overall driving ability. They also reported significantly higher number of difficulties on the following subscales; intentional violations, mistakes, and slips/lapses (Daly, et al, 2014).

Anecdotal evidence also suggests a range of factors contribute to the ability and/or the decision of an autistic person to drive independently. Autistic individuals report anxiety as a large barrier to driving and gaining a licence.

Others also report difficulties with driving instructors not understanding autism, and sensory issues as significant obstacles contributing to their ability/inability and reluctance to drive.

### In summary...

Many autistic people are highly competent drivers and not only drive cars, but trucks, trains, buses and aeroplanes.

However, some autistic individuals also report experiencing huge difficulties not only driving, but also acquiring a driver licence.

Research in this area tells us autistic individuals do experience differences in simulated hazard perception tasks and, demonstrate eye-tracking patterns which deviate from the typical safe driving behaviour.

Autistic adults themselves also report a reluctance to drive due to anxiety, difficulties with driver instructors and sensory issues.

Waikato is the first region in New Zealand to provide free bus travel for people with a disability and this initiative has already received considerable attention from our autistic community.

There is an application process for the free bus concession which includes an eligibility assessment which can be undertaken by a disability agency or GP.

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**Waikato is the first region in New Zealand to provide free bus travel for people with a disability. This initiative has received considerable attention from our autistic community.**

Emily Acraman is a researcher at Altogether Autism.



**SOUTHERN NETWORK:** Attendees at the Dunedin Kids Do well if they Can network meeting. L-r back row: Deidre Dalziel, Yuchen Lin, Melanie Eady, Melissa Rongan, Michelle Tehiko, Liz Garraway, Larissa Shagalieva, Renee Koh, Benedict Tan, Joanne Lawless. Front: Sean Martin, Catherine Trezona, Sheryl Davies and Karen Keppel.

# Can autistic children benefit from yoga



*Yoga is a mind and body practice, writes researcher **Julie Peake**, that may provide a repetitive and predictable way to support your child's communication with self and others. Visual and auditory engagement, while practicing the yoga postures and associated breathing exercises, may support social and communication development.*

**Yoga can be practised individually or in groups and at home or in a formal class-led setting.**

**YOGA IS OFTEN** thought of in terms of physical postures rather than the more holistic focus of embodying mind, body and breath.

Practicing yoga may assist in strength, balance, flexibility and body awareness. Just as importantly it can support the development of coping skills, responses to stress and anxiety, and help regulate emotions.

When we are anxious or in heightened states of arousal, physiologically the sympathetic nervous system is activated. This part of our nervous system manages our responses to threat or danger – commonly referred to as the fight, flight or freeze response. Including specific breathing strategies as part of a yoga practice (along with the physical poses) can help activate the parasympathetic nervous system.

Activation of the parasympathetic nervous system can help reduce anxiety, release difficult emotions and tensions in the body, support healthy sleep, improve digestion, mood and behaviour, and overall support a healthy functioning physical body.

## What is known about children with autism and yoga?

In 2010 Radhakrishna conducted a small-scale study with six children in India who participated in a 10-month programme of regular yoga.

Practice was both at home and in a class-led setting.

Radhakrishna was interested in imitation skills in tasks such as movement, vocalisation, oral facial movements and imitating breathing exercises. The results indicated an improvement in the ability to imitate others in both body and facial movements, increased skills in eye contact, sitting tolerance, non-verbal communication and receptiveness to verbal commands and movement.

Further study was recommended to explore more fully the effectiveness yoga as an opportunity to increase imitation, cognitive and social and communication skills for autistic children.

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In 2011 Rosenblatt and others studied the effectiveness of an eight-week multimodal therapy programme with 24 children aged 3-16 years.

The programme included yoga, dance and music therapy based on supporting relaxation responses. Each session followed the same format. Children were provided with verbal instructions and pictures. Tools such as pinwheels and bubbles were used to help children experience their breath.

Children were encouraged to do whatever they were able to do in terms of the physical postures (i.e. it was a non-competitive environment). Parents were provided with a recording of the music from the class and guidelines for practicing at home. At the end of eight weeks most children could do many of the 18 postures shown.

The results showed positive changes in behaviours such as aggression, anxiety and attention for the 5-12 year old group. Further research was recommended.

Occupational therapists Koenig, Buckley-Reen & Garg (2012) conducted research when introducing a yoga programme (both breathing strategies and yoga poses) into a school setting.

They had 48 participants aged 5-12 years using a control group research design. The results of the study showed improvement of behaviours (anxiety, mood and general behaviour) in the children who practiced yoga consistently over a 16-week period. The researchers commented on the increased use of complementary and alternative medicine (CAM) therapies in the United States for both adults and children during the 2000s – namely deep breathing, meditation, massage and yoga.

Occupational therapists were found to have mirrored the trend in CAM, integrating yoga and movement programmes into clinic and school-based practice. They recommended further studies were required.

## What next?

Yoga can be practised individually or in groups and at home or in a formal class-led setting. There are numerous apps and card activities available online that make it an easily accessible and affordable way to see if yoga is something for your child and even the whole family to take part in.

## Things you may like to consider

- Age and mobility of your child/ren (yoga poses can be done standing, seated and lying down)
- Choose poses and breathing exercises that children can succeed at to build up self-esteem
- Maybe dedicate a space in the house for yoga practice?
- How might yoga be introduced in a fun way – maybe watch some You-tube clips, make it into a fun game, and/or practice yoga alongside your child/ren?
- Is there a children's yoga class nearby? (visit the studio and meet with the teacher to find out about class size and style, lighting and noise levels e.g. is music played)
- How might attending a class fit with your child's schedule?
- Is your child interested in giving it a go?

## Summary

While there are limited studies specifically relating to yoga and autistic children, the research in general indicates there may be some benefits such as: increased social-communication skills; awareness and expression of emotion; reduced anxiety; reduction in challenging behaviours; increased body awareness; and a positive sense of self.

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Julie Peake was a researcher for Altogether Autism and Parent to Parent.



 **ALTOGETHER AUTISM**

**NETWORKING:** National manager Catherine Trezona appeared on RNZ's Nine to Noon to discuss how autistic children are waiting too long for support and right, Sharron and Paul Freeman from Bay Autism support with Altogether Autism's Joanne Lawless and Catherine Trezona.

# WIN!

## The Chalk Rainbow explores difference and diversity through a family living with autism



Zane is different to other kids. He lines things up, and he's frightened of things that don't seem to bother others — like the colour black.

The Chalk Rainbow explores difference and diversity through a family living with autism. It's a story of unconditional love, of trust and of learning to look at the world through the eyes of others.

Touches on universal themes of unconditional love, trust and the importance of family

- Visually stunning, the book uses a combination of charcoal drawings with intermittent colour to bring added depth and richness to the text
- Brings together an accomplished author, with numerous picture books and chapter books to her credit, and the talented illustrator behind the highly successful *Don't Think About Purple Elephants* and the upcoming *Sugar & Spice Collection*.

### ABOUT THE AUTHOR

Deborah Kelly is the author of several popular picture books for children as well as a chapter book series. She also writes Haiku poetry, inspired by living in Japan for two years. Born in New Zealand, Deb now lives in Australia with her husband and two children.

### ABOUT THE ILLUSTRATOR

Gwynneth Jones drew all through her maths book at school, so left to study art at TAFE and then majored in Plant and Wildlife Illustration at the University of Newcastle. Since then, Gwynneth has been imagining and drawing madly, exhibiting and holding market stalls, and creating picture books.



## We have three copies to give away

Email us [editor@altogetherautism.org.nz](mailto:editor@altogetherautism.org.nz) by Tuesday 17 December 2019 and tell us why you should have a copy of *The Chalk Rainbow*.

## New CEO for Altogether Autism partner

**MEGAN THOMAS** is the new chief executive of Life Unlimited Charitable Trust, one of two partners which provide Altogether Autism's free, nationwide autism spectrum information and advisory service.

Megan's career in the health, disability and social service sectors has been in developing the leadership and skills of organisations committed to social justice and to bringing commercial skills to bear effectively in organisations.



She has held senior management roles in the not for profit sector and has been an independent facilitator/consultant to the community sector.

"I'm looking forward to and am committed to ensuring we continue to listen and respond to the autistic voice. I look forward to seeing how Altogether Autism continues to evolve and positively respond to the dreams and aspirations of those living with autism," says Megan, who started at Life Unlimited on Monday November 18.

Altogether Autism national manager Catherine Trezona paid tribute to former Life Unlimited chief executive Mark Brown who retired in October after nine years in the role to pursue other interests in what he sees as the start of his "active retirement".

"Mark has been a great supporter of Altogether Autism and was very instrumental in establishing PRISM Professional Development Series and our employment initiatives. We wish him well and look forward to working closely with Megan."

Altogether Autism also works in partnership with Parent to Parent New Zealand.



**GETTING TO KNOW YOU:** Life Unlimited chief executive Megan Thomas, left, was joined by K'aute Pasifika Trust chief executive Rachel Karalus.





**PARTNERS:** Carole and Maria from The Warehouse, Anglesea St, Hamilton with Altogether Autism national manager Catherine Trezona.

# Accessible autism friendly shopping experiences at The Warehouse

**THE WAREHOUSE GROUP** and Altogether Autism have partnered to better understand the needs of neuro-diverse customers and parents.

Tanya Colvin, head of team member wellbeing at The Warehouse and Altogether Autism national manager Catherine Trezona recently visited several Warehouse stores to look at ways to create a more accessible shopping experience for New Zealand's 80,000 strong autism community.

"We are excited to be working with Altogether Autism to help us improve our customer experience for the autism community. In early 2020 we will start by trialling

a low-sensory autism friendly shopping hour in selected Warehouse stores and our goal is to roll it out across all stores after the six week trial," said Tanya.

"The response from the autism community about this new initiative has been really positive and appreciative", said Catherine.

"Shopping for people with access needs can be a nightmare, and relatively small accommodations can make all the difference. Autistic people and families have given me an ambitious wish-list for changes, and I know Tanya and her team at The Warehouse are committed to doing all they can to respond to these ideas."



**ALTOGETHER AUTISM**

**BY AUTISTICS, FOR AUTISTICS:** Tanea Paterson (second right) presented a powerful message at the By Autistics, For Autistics network meeting in Dunedin on 27 November. Among those attending were I-r Nicola Edwards, Emily Garraway and local artist, Tom Fox.

# Need free help, advice and information in real time?

LIVE  
CHAT



Since we launched Live Chat in September 2018, we've had hundreds of conversations in real time via the Altogether Autism website with people from around New Zealand on a variety of topics. Get in touch with us today.



[www.altogetherautism.org.nz](http://www.altogetherautism.org.nz)