

# Pet therapy

Conference wrap up

New autism services

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THROUGH KNOWLEDGE AND EXPERIENCE

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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.

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# Conference wrap up



## KIA ORA KOUTOU.

Ngā mihi nui kia kouotu katoa.

A big thank you to everyone who attended our biennial conference, Transitions #Breakthrough2017 in Auckland in July. Two hundred and five delegates joined us for the event and 100 of you completed the evaluation form and rated this event very highly.

We have a pretty good idea of the things you appreciated most and tips for ways to do things better.

Our planning team is meeting soon to consider the feedback and think about future learning events. Is one big national event the best way to go? Would smaller regional events be better? Is it ideal to have autistics, families and professionals all at one event and if so, would it be better to stream the presentations with each audience in mind?

If you have some suggestions to help us consider these questions and you have not already shared these ideas via the #Breakthrough2017 evaluation survey, please send an email clearly and briefly outlining your recommendations. Go to our website and use the Contact us – other enquiry tab to email us.



**CONFERENCE WORKSHOP:** Participants in the “Redesigning the website on a shoestring budget” get to work.

In September I attended the fifth Asia Pacific Autism Conference (#APAC17) in Sydney. This was a conference on a much larger scale, with an excellent range of keynotes and presenters. For those who weren't able to attend these events, we have tried to share the love in this Journal with summaries of various presentations. APAC19 will be held in Singapore, which is a timely reminder that that this is not the Australian but the Asia Pacific Autism Conference.

I also visited a client site in Melbourne with Specialisterne Australia and met the seven new employees working in records management at the Victorian Government's Department of Health and Human Services. It was very encouraging to see how positive these recruits are about their new roles and how well Specialisterne's Dandelion programme has worked for them. We are working hard to get Specialisterne into New Zealand. Go to the new Employment pages on our website for updates.

Explore Behaviour Support Services and the Ministry of Health held a roadshow throughout New Zealand to outline Explore's new model of autism services after picking up the contract from IDEA Services. Sean Versteegh, specialist advisor for Explore, has given us a summary of this new model and the relevant pathways on page 17 of the Journal.

The next round of our network meetings is underway. The key topics of interest we are covering with these regional meetings are education, behaviour and sensory sensitivities. Look out for the dates and venues of these meetings on our website and through social media. These are free to attend and open to anyone in New Zealand.

By the time you read this we will hopefully have a new government and Altogether Autism will continue to advocate for improved services and support for our autism community nationwide. We welcome hearing from you by phone, email, Facebook, Instagram or Twitter – or even kanohi ki te kanohi / face to face.

Noho ora mai.

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





**THRIVING:** Dr Michelle Garnett and Professor Tony Attwood.

## Changing culture to appreciate autistic talent

**THE THRIVING** at Work programme, developed in Australia, is a comprehensive package that includes materials for employers/leaders, managers, team members and employees with Asperger's Syndrome.

Professor Tony Attwood and Dr Michelle Garnett designed it to support new employees with AS (Asperger's Syndrome/ ASD level 1) within numerous settings.

In New Zealand this employment process is commonly known as induction and it is also known as onboarding.

It assists the employing organisation to create a culture of inclusiveness, i.e. changing the culture of the organisation to include, enjoy and appreciate autistic employees.

Michelle and Tony refined the programme with Jay Hobbs from Specialisterne Australia over a 12-month period and the content has evolved with suggestions from individuals with AS who participated in Thriving at Work.



**JAY HOBBS**

The packages include resources to de-mystify and de-bunk myths about autism, understand both the strengths and the challenges in employing, managing and working with people with AS, and provide both general ideas and strategies that work, as well as strategies individualised to each employee.

Both the management and employee components include the follow-up support that we know from both research and clinical experience is so important to creating success.

The process can be individualised, but initially the leader/ employer could learn about how to support people with AS at work via the leader/employer modules.

The process from there could be adapted to need, but within a large organisation involves educating a human resources person/psychologist to become accredited in the Thriving programme, and to lead the onboarding and maintenance process with management, staff and the employees with autism.

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He or she would provide initial assessment for each autistic employee, take them through the five sessions, resulting in an individualised plan for each.

He or she would also train the managers and assist managers to train staff.

Key support people would be identified within the team and skilled up in the individual profile of an employee with AS, including ideas and strategies about how to accommodate and assist.

Plans are made for trouble-shooting and ongoing support for both autistic employees and their team members and managers.

Tony, Michelle and Jay have run the Thriving at Work programme in a variety of workplaces to support employers to better understand AS and help individuals on the spectrum to transition to their new work environment.

- Professor Tony Attwood is an internationally recognised clinical psychologist, educator and author. His book *Asperger's Syndrome: A Guide for Parents and Professionals*, is an international best seller and seminal in the field.
- Dr Michelle Garnett is a clinical psychologist and founder and director of Minds & Hearts, a clinic specialising in Autism Spectrum Disorders. She trains clinical registrars across four universities and has co-authored three books with Tony on autism.
- Jay Hobbs is the Assessment and Support Manager based in Brisbane at the Cooperative Research Centre for Living with Autism. Jay has worked with people on the autism spectrum and their families for over 15 years in both Australia and the UK.
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## WIN! BOOK GIVEAWAY

Jeanette Purkis and Emma Goodall have a new publication on resilience due for release on 21st November, called **The Parents' Practical Guide to Resilience for Children aged 2-10 on the Autism Spectrum**. We are so excited about this we have not one but THREE copies to give away!

To enter the draw for this much-needed new book send your name and address to [info@altogetherautism.org.nz](mailto:info@altogetherautism.org.nz) by 21st November.



**CONGRATULATIONS TO JANE HENSON OF PUKERUA BAY** who won a copy of *Autism Spectrum Disorder in Aotearoa New Zealand: Promising practices and interesting issues*. Thanks to all those entered.

# \$160,000 for child autism and sleep disruption research

**SLEEP DISRUPTIONS** such as delayed sleep onset and frequent and prolonged night-time awakenings, can have an enormous impact on how children function during the day and within their families.

Such sleep problems are associated with poorer physical and mental health and wellbeing (for example: obesity, diabetes, mood disorders, and substance abuse), quality of life, cognitive functioning, learning, and academic performance.



**DR LAURIE MCLAY**

University of Canterbury researcher Dr Laurie McLay has received an emerging researcher first grant from the Health Research Council of New Zealand (HRC) valued at \$160,825 over three years. Dr McLay will use the grant to continue her research on developing effective treatments for sleep problems that affect the growing number of New Zealand children and young people with autism spectrum disorder (ASD).

A senior lecturer in Health Sciences in the College of Education, Health and Human Development, Dr McLay will work with a team of psychologists, including Associate Professor Karyn France and Professor Neville Blampied also from the University of Canterbury, on her research titled: Functional behavioural sandman: Treating sleep disturbance in children with Autism Spectrum Disorder (ASD).

Dr McLay says that up to 83 per cent of children with ASD experience sleep disturbances, and that these are unlikely to abate over time in these children without effective treatment.

"Sleep disruption or deprivation has adverse effects on the daytime functioning of children with ASD. This includes problems with social reciprocity, rates of stereotypic and ritualistic behaviour, health related quality of life, and adaptive behaviour. Sleep problems also have negative secondary effects on family functioning and parental wellbeing, including maternal mental health, and parent relationships," she says.

Although these sleep problems have complex origins, she says evidence suggests there is a learned component that requires behavioural solutions.

"There are poorly understood biochemical differences in children with autism, such as irregular melatonin production and secretion, however, pharmacological strategies like melatonin and sedative medications only offer partial solutions," Dr McLay says.

"There is a large, treatable behavioural component to the sleep problem that becomes entwined with the parental behaviours that can unintentionally exacerbate it. We are recruiting families nationally to take part in the study."

The study has four primary objectives:

1. a translational science objective of enhancing the connection between assessment and treatment by developing science-based, parent-implemented, individualised, comprehensive and socially valid interventions predicated on the results of Functional Behavioural Assessment;
2. to measure the durability of treatment effects over time;
3. to assess the secondary effects of improved sleep outcomes on parent, child and family well-being, and daytime functioning of children with ASD; and
4. to better understand parents' perspectives of the treatment process.

Dr McLay says the study outcomes will inform the translation of these assessment and treatment processes into a model of service delivery that is able to be used by clinicians working in the field.

Dr McLay is one of 13 researchers to receive emerging researcher first grants valued at a combined total of \$3.03 million in the HRC's 2017 funding round, up from \$1.45 million in 2016.



**ALL TOGETHER:** Altogether Autism national manager Catherine Trezona enjoying the new sensory garden at Life Unlimited, Hamilton with researchers Rebecca Armstrong, Tegan Andrews and Liliya John. The garden complements the existing multi-sensory room Whare-O-Rongo and allows people with physical or intellectual disabilities to enjoy a wide range of experiences for therapy, learning, relaxation and fun in a safe and inviting outdoor space. Look out for our new readership survey coming soon on our website. Anyone who completes the survey will have their names entered in to a draw to win a prize.





**GAINING CONFIDENCE:** Bethany Gray, left, at the Altogether Autism conference with Karen Sluter from Enrich+.

# Transitioning from conference to university

*Bethany Gray always felt she was different from people around her and wondered why. When she was 17 she was diagnosed as being autistic. This is her journey.*

**THE AUTISM** diagnosis I received at 17 explained my difficulty in reading body language, understanding behaviours and communicating with others.

With the help of Enrich+ I have been able to explore, understand and begin to try new strategies to help me cope with my stress levels and manage new situations that I find myself in.

I had begun going to Youth+ every week where I found I didn't have to watch everything I said and worry whether it was acceptable or not. It was here that I met Tanwen Ward who began to help me develop the strategies to cope with everyday life, creating my CV and helping me to apply for jobs. She was also vital in being my support person when finding information about Otago University for next year.

It was through the changes I was trying to make, for example going horse riding, beginning part time work at Columbus Café, gaining in confidence to speak to people I didn't know, that Karen Sluter asked if I would talk at the Altogether Autism Conference, as it was on transitioning, which is what I was going through. Even though I wasn't sure about it at first, it was suggested it would be a great experience and that my own story could help others like me, plus someone said it would look good on my CV for university!

The conference did turn out to be a great experience and I felt that I had achieved something at the end of it. Some of the highlights were meeting lots of interesting people who understood some of the difficulties that I experience every day. I enjoyed meeting the assistance dogs and talking to people who help train them. The food was good too! For the

first time I enjoyed talking to people I didn't know as I still had people around me that I knew and supported me. Overall it was a very positive experience and helped me gain more confidence in myself.

Since the conference I have enrolled in an adult gym class and have been accepted for Health Science at Otago University for 2018. This I hope to complete and go on to study medicine. My final goal is to become a surgeon. For the immediate future I am still working with Tanwen from Enrich+ to build on skills which will help me cope next year whilst at university.

The conference helped me to meet new people. For example, I met with John Vogenthaler from Te Pou to talk about the study he is presently undertaking. I also met Selwyn Cook,

Workbridge Employment ambassador, who could help me get some employment when I go down to Otago. It gave me the confidence to continue to go out of my comfort zone and try new things.

The main thing I would want people to know who didn't attend the conference is that even though transitioning from school to adult life is extremely hard, and being autistic makes me feel I have a different operating system to normal people as I tend to see and experience things differently than what they do, I am not letting this stop me from letting me do what I want to do with my life.

I have gone through many changes and transitions through the last few years, and have learned to push myself out of my comfort zone. I know if I am going to succeed in life I need to work past feeling uncomfortable and wanting to be always on my own and learn how to handle everyday situations and life!

**"Overall it was a very positive experience and helped me gain more confidence in myself."**

## Speaker highlights from the conference



*The Altogether Autism team was out and about during the July conference in Auckland. Here **Rebecca Armstrong**, Altogether Autism researcher writes about two speakers, Tanea Paterson and Caroline Hearst.*

**One of the key characteristics of people with autism are difficulties with socialising but this does not mean there is no desire.**

### Tanea Paterson – Psychological Health, Substance Use and Autism

**TANEA PATERSON** is an autistic woman who is a qualified addiction practitioner and has her own personal journey with substance use and chronic pain.

Tanea's presentation at the Altogether Autism conference was very engaging and focused on autism and substance use. Little is known about the relationship between autism and substance use. I have summarised my take home messages from Tanea's presentation.

Some research indicates substance use may be rare among autistic individuals due to a lack of socialising, fewer interactions with substance using peers and less novelty seeking behaviours (Santosh & Mijovic, 2006 as cited in De Alwis et al., 2013). However, robust research has just come out of Sweden titled "Increased risk for substance use-related problems in autism spectrum disorders: A population-based cohort study" (Butwicka et al., 2017). This research included 26,986 individuals diagnosed with autism during 1973 – 2009 and 96,557 non-autistic relatives. The results indicated that having a diagnosis of autism alone doubles the risk of addiction particularly amongst those with an IQ of 100 or above. Having a diagnosis of intellectual disability, and attention deficit hyperactivity disorder in addition to autism multiplies this risk fourfold. Additionally, having a diagnosis of autism with an average IQ or above and co-occurring ADHD increases the risk of addiction eightfold.

Tanea looked at key concepts as to why people with autism may be a particularly vulnerable group when it comes to addiction. These included the concept of "social lubrication" – a term used for the effects of alcohol in alleviating the discomfort and feelings of unease in social interactions when people are communicating with others. One of the key characteristics of people with autism are difficulties with socialising but this does not mean there is no desire. This concept of social lubrication is directly related to people's desires for acceptance and to fit in. Seeking comfort and predictability may also be a motivator for substance use. The common experience of executive functioning difficulties may also impact on substance use behaviours e.g. impulsivity and autistic inertia ("can't start, can't stop"). Sensory seeking or avoiding may also impact on people's substance use and relate to their substance of choice (e.g. sensory seeking may result in the use of stimulating substances while sensory avoiding may result in the use of sedative like substances). Co-occurring issues such as anxiety and/or depression and the need to self-medicate may also contribute to substance use. Tanea experiences chronic pain and highlighted this as a motivator in her own personal journey.

I particularly liked that Tanea provided an abundance of information and followed it up with not only an example of a safety plan but also practical suggestions for clinicians working in the field. She also gave an example of what a safety plan might look like when someone is triggered to use drugs or alcohol. It included a visual for the person to take

### The opposite of addiction is connection

(Johann Hari; Chasing the Scream)



**TANEA PATERSON**

home detailing what might happen, what potential triggers may be, early warning signs, what works, what doesn't work and who to call or contact. She also indicated that the use of the Autism Spectrum Quotient (AQ-10) can be incorporated

into the original assessment. This provides a quick screening tool for adults with suspected autism who do not have learning disabilities. Research shows that this is a group that usually gets labelled as difficult, inconsistent, and over all treatment resistant and

unfortunately the framework for treatment often does not fit a neurodiverse perspective.

This presentation highlighted the acute disconnect between mental health and disability services. The tendency for disability services to exclude clients with addiction difficulties and addiction services to exclude autistic clients means that people with autism experiencing issues with substance use (and mental health in general) are not getting their needs met. This has massive implications for these sectors to create more awareness, to provide professional development for staff and to create/include autism friendly and focused interventions.

#### References:

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- Butwicka, A., Langstrom, N., Larsson, H., Lundstrom, S., Serlachius, E., Almqvist, C., Frison, L., & Lichtenstein, P. (2017). Increased risk for substance use related problems in autism spectrum disorders: a population based cohort study. *Journal of Autism Development Disorder*, 47, 80-89

Tanea Paterson gave a poster presentation on autism and addiction at the Cutting Edge conference held in Wellington from 6-9 September 2017. Cutting Edge is an annual conference on addiction. Tanea also presented at the 2011 Cutting Edge addictions conference and received an award for the best contribution to clinical practice for her poster (see back page).



**SALE TIME:** Key-note speaker Sue Kinnear buys a Uccello kettle for her mother from Sue Davies, left, and Liliya John of Life Unlimited.





**TIME TO RELAX:** Julianna, Josh and Maria Man with Altogether Autism national manager Catherine Trezona and key-note speaker Sue Kinnear on smooth transitions

## Caroline Hearst – *Transition to identify positively as autistic*

**CAROLINE HEARST** is a “late diagnosed autistic woman”, a consultant for therapists and autistic adults, an autism educator offering continuing professional development and a facilitator of peer support programmes for autistic adults.

Her presentation at the Altogether Autism conference was on “*Transition to identify positively as autistic*”. She is also the founder of AutAngel, a community interest company in the United Kingdom run by and for autistic people and she serves as a member on the forum of the National Autistic Society.

With Caroline having both personal and professional experience with autism she offered a wonderful perspective for working with both autistic individuals and professionals. Her sessions were initially developed for therapists and counsellors as they were not identifying autism in their clients or were finding it challenging to support them. However, this particular presentation focused on the development and implementation of a new service “*Exploring Identifying as Autistic*” (see below). This is an autistic devised and led programme for people who were diagnosed as, identified as or wondered if they may be autistic. As someone with a particular passion for research, autism and peer support I thoroughly enjoyed this presentation and was impressed with the information that Caroline provided the audience including the outline of the new programme they used.



### The 10 week programme *Exploring Identifying as Autistic*

This programme consisted of 10 two hour weekly sessions. This group aimed to provide a safe place where people could learn about autism, discover their many strengths and talents and process their identification as autistic. The aim was to provide them with tools and strategies to capitalise on their strengths and face their challenges. The peer support structure also provided a socialising aspect where people could discuss their experiences, their strength and their hope with like-minded people.

Outcomes included gaining a good understanding of what autism meant in their life and identifying their path forward, to experience connection with a peer group and decreased anxiety, to be better able to build on autistic strengths and mitigate autistic challenges and to be better able to explain their condition to others and both request appropriate accommodations and adapt some of their own behaviours where need be. The content was structured (but flexible) and presented through information, open discussion and role plays. The 10 sessions covered:

1. Introducing and establishing ground rules
2. Social communication
3. Theory of mind
4. Emotions and empathy
5. Sensory issues
6. Executive dysfunction
7. Social impacts of autistic traits
8. Anxiety, depression and mental health
9. Diagnosis and identification of autism – what does it mean for you now?
10. Where to from here?

There was a great emphasis on the autistic led nature of the programme and how this was central to its success. There was also an emphasis on how the peer support element acted to increase self-esteem of the participants. I am looking forward to receiving the independent research on this program which is a collaboration between Dr Laura Crane of Goldsmiths University and the Centre for Research in Autism in Education.

It would be great to see this research replicated in New Zealand!

If you want to know more about Caroline and the services she has in the UK please visit [www.autismmatters.org.uk](http://www.autismmatters.org.uk) and [www.autangel.org.uk](http://www.autangel.org.uk). For our PRISM professional development workshops in New Zealand contact Altogether Autism or enquire online at [altogetherautism.org.nz/enquiries/](http://altogetherautism.org.nz/enquiries/)

# Parents' intervention choices



Parents are often tasked with a series of important decisions soon after a child is diagnosed with autism – including assessing which interventions are effective, safe and worth the time and effort in implementing in order to benefit their child and their family. Altogether Autism researcher **Tegan Andrews** empathises with them.

**Paradoxically, interventions which have very little evidence-base were being promoted by paediatricians.**

**SIFTING THROUGH** copious amounts of conflicting information regarding what interventions are available, accessible, affordable, effective, and safe can be very complex.

Recently I attended a presentation at our Altogether Autism conference, on how parents choose which interventions to implement and why, presented by Daniel Shepherd\* and his colleagues from Auckland University of Technology (AUT).

They recently conducted a study aiming to understand why parents choose interventions for their child, why they reject interventions for their child, and why they may discontinue an intervention.

More than 500 parents completed an online survey asking about five specific types of interventions – speech and language therapy (SLT), behaviour therapy, applied behaviour analysis (ABA), occupational therapy (OT) and dietary interventions.

The distinction between behavioural therapy and ABA was that while both used behavioural techniques (and many other interventions include behavioural elements too), ABA was a more intensive programme designed for the individual.

## Why parents chose an intervention:

About 80 per cent of parents sought out interventions from more than one type of intervention.

Information on SLT, occupational therapy and behavioural therapy came from teachers, paediatricians and Ministry of Education staff.

Psychologists also were heavily credited in providing information on behavioural therapy. Information on diets came from paediatricians and from the internet whereas information on ABA largely came from the internet and other parents. Dietary interventions and ABA were not as widely accessed by parents and were more likely to be self-funded rather than government-funded like SLT, behaviour therapy and OT.

**"Interventions with a strong evidence-base were not the ones being promoted by health and education staff, or made easily accessible through government funding."**

## Why parents didn't select an intervention:

The top reasons parents did not access SLT were because they felt it was irrelevant to their child's symptoms and the availability of SLT.

For behaviour therapy, it was unawareness and unavailability.

For ABA, unawareness and expense were the top two reasons.

For OT, availability was the main reason why parents were not accessing these services and for dietary interventions, skepticism was highest, followed by lack of awareness.

## Why parents stopped an intervention:

When parents chose to discontinue with an intervention, one of the most common reasons were goals realised (no longer needed), particularly for SLT and behaviour therapy.

ABA became too expensive to continue for many families, and the availability of OT was the key reason as to why parents ceased the intervention. For dietary interventions, the main reason was that the interventions simply seemed ineffective.

I found there were a few interesting points to this study. Interventions with a strong evidence-base were not the ones being promoted by health and education staff, or made easily accessible through government funding.

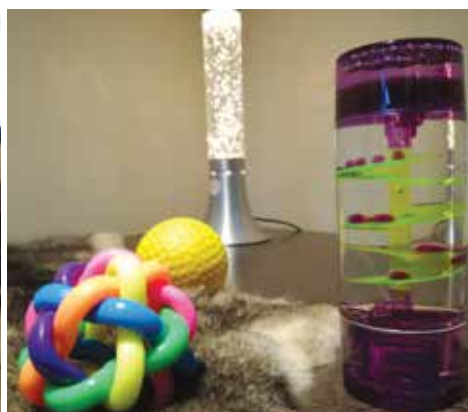
Paradoxically, interventions which have very little evidence-base were being promoted by paediatricians. These professionals have a duty of care to their patients and families in order to provide quality information to assist parents in making these tough choices for their children.

It was positive to see parents reporting a healthy dose of skepticism around dietary interventions – where evidence for their efficacy is lacking. In conclusion, it is very important that parents have access to information which is unbiased, up-to-date and accurate.

*\*Daniel Shepherd's presentation is on the Altogether Autism website.*



**SHATTERING CAGE:** Key-note speaker Jason Edgecombe



**STIM TOOLS:** A popular item in the Quiet Room while outside Erin Geaney and Sue Davies process registrations.







**OLD FRIENDS:** Charlotte West and Jenny Gibbs.



**ALL EARS:** Altogether Autism national manager Catherine Trezona and conference participants Min Khanthee and Joanne Dacombe.



**BOOK SIGNING:** Author Emma Goodall with Louise Stickle-Ryan.



**ENRICH+:** Karen Sluter.



**CONFERENCE CUTIES:** I-r DOGabled NZ's Jo Limmer and Mo and Heather Laanbroek and Django were present at the Altogether Autism conference. The information stand was a constant buzz of activity over both days, from those wanting to take some time out with canine therapy from the visiting dogs, to those seeking new and innovative therapies for our children with Autism. As a new organisation in the field of special therapies, DOGabled was both welcomed and celebrated by the attendees, presenters and organisers alike.

Conference photos by Mary Anne Gill and Pip Stephenson.

# Research offers fresh clues as to why girls evade detection



*Catherine Trezona attended the fifth Asia Pacific Autism Conference (APAC17) in Sydney in September and shares the latest research into gender differences in the assessment of autism.*

**Girls fake it through to adolescence but then... they throw it all away.**

## **ARE AUTISM** assessment tools gender neutral?

Autistics and professionals have been discussing this for several years and APAC17 offered delegates a range of presentations on this topic.

Dr Felicity Chandler from Autism Spectrum Australia (Aspect) outlined a range of hypotheses that have been suggested to explain the lower rates of autism diagnoses in females compared with males. The ratio is currently thought to be 3:1, that is, there are three males with an autism diagnosis for every one female (Loomes, Hull & Mandy, 2017).

Why is autism more commonly diagnosed in males than females? Is it a matter of timing? Are girls better at faking it, masking their incomprehension of the social world by imitations? Do autistic girls share a strength in expressive skills with neurotypical girls? Rigid and repetitive behaviours are less predictive of autism in girls so does this mean special interests are viewed by others as pretend play?

Does the skill of autistic girls in mimicking neurotypical girls lead them to develop a parody of ways to behave during a diagnosis?

Dr Chandler investigated hypotheses such as these by reviewing the autism assessment data of 246 people aged between 16 months to 48 years, who were all given an autism diagnosis at a tertiary referral service.

The clinicians were all experienced in autism assessments and were aware that autistic females might look different from autistic males. Of the 246 people, 189 were male and 57 were female.

The researchers asked a range of questions such as:

- What was the age of the first concern?
- What was the age when seen by the consulting professional?
- What was the outcome of the first professional consultation?

No significant difference was noted across these three questions in this group of 246 people.

Two gender differences in timing were identified. A longer gap between the first professional consultation to diagnosis was seen in the females compared with the males.

A longer gap between the parents' first concern and the first consultation was also found in the older girls, but not found in the younger group. Overall, girls under 13 years were diagnosed around one year later than boys, but it was unclear why.

In a separate presentation, Tony Attwood shared an update on a pilot study of a new diagnostic tool for assessing autism in girls, called the Girls Questionnaire for Autism Spectrum Conditions (GQ-ASC).

Attwood, Garnett and Rynkiewicz have developed this questionnaire to address the perceived limitations of standard instruments currently used to diagnose autism,

such as the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Observation Schedule-2 (ADOS-2).

These two tools have been considered the gold standard for diagnosing autism. (For a summary of recent research on the ADOS and ADOS-2 and gender sensitivity, see page 11).

Attwood reviewed an earlier attempt to improve the way girls are assessed for autism. In 2011, Kopp and Gillberg added 18 items for girls between 6-16 years to the Autism Spectrum Screening Questionnaire (ASSQ). This revised tool identified that autistic girls were more likely than autistic boys to avoid demands, be very determined, be careless with their physical appearance and dress, and interact mostly with younger children.

The assessment tool for girls developed by Attwood and colleagues has been tested on a sample of 236 children and adolescents (138 boys and 98 girls) who were aged between 5 years and 13 years and had a diagnosis of autism spectrum disorder – level 1 (without intellectual or language impairment).

Parents were asked to complete the GQ-ASC which was then analysed by the researchers using Principal Component Analysis. Eight key components of the tool were identified:

- Gender identity
- Sensory
- Compliance
- Friendships (girls are more likely to have best friends, enjoy socialising and this higher social interest may provide more motivation for coping mechanisms)
- Social Masking (girls have a greater ability, are more creative, employ coping mechanisms)
- Imagination (girls tend to have more imagination)
- Imitation
- Talents and Interests

The results also showed significant differences in the presentation of autism in males and females with females reporting greater levels of difficulty in behavioural characteristics associated with gender identity, sensory sensitivity, social masking, imagination, imitation, and talents.

The significance of research into gender difference was brought home by Attwood when he described a typical scenario. Girls fake it through to adolescence but then when it ultimately doesn't work and they are not accepted into teenage girls groups, they throw it all away.

Without an accurate autism diagnosis and appropriate support, girls at this stage may turn to promiscuity, drugs and self-harm as a balm to a damaged sense of self-worth and acceptance.

The pilot study of the GQ-ASC is due to be published in the Journal of Autism and Developmental Disorders in late 2017.

The questionnaire will be freely available with the article.





## Girls mask autism symptoms using social skills



*The research on why fewer girls get diagnosed with autism than boys continues to pile up. Altogether Autism researcher Liliya John checks out the latest findings.*

**Girls with autism have the ability to camouflage their autistic features.**

**TWO RECENT STUDIES** from Poland add to the growing body of research indicating girls are less likely to be diagnosed with autism than boys due to their skill at social masking and gesture.

Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Observation Schedule–2 (ADOS-2) are considered the gold standard instruments for diagnosing autism.

Recent research on gender differences in autism shows that currently used diagnostic screening tools for autism such as ADOS and ADOS-2 may fail to capture the unique presentation of autism in females.

ADOS is a semi-structured, standardised diagnostic instrument which assesses communication, social interaction, and play. ADOS can be used to diagnose autism in all age groups and in those with and without language impairment.

In a 2016 Polish study, researchers used the ADOS and ADOS-2 in a sample of 15 adolescent girls and 16 adolescent boys with a diagnosis of autism or Asperger's (Rynkiewicz, & Lucka, 2016).

Girls with autism showed statistically significant differences in the communication section of ADOS and ADOS-2 algorithms compared to boys with autism.

Girls with autism also showed fewer behavioural features associated with autism under the communication section in both ADOS and ADOS-2 algorithms, however, they scored high on autistic features on self-reported questionnaires and clinical interviews.

Also, girls with autism were found to be less or not autistic in comparison to boys on non-verbal communication, i.e., items on gestures and visual communication in both ADOS and ADOS-2 algorithms.

These results supplement existing research evidence that girls with autism have the ability to camouflage their autistic features especially social communication challenges.

The findings indicate that girls with autism are at risk of missing an autism diagnosis in ADOS or ADOS-2 despite having a developmental history and clinical presentation that confirms their autism.

As a follow up to the study, researchers from Poland conducted another study where they used a computerised ADOS-2 test to investigate the 'female camouflage effect' in autism (Rynkiewicz, et al., 2016).

The sample consisted of 16 girls and 17 boys with a diagnosis of high functioning autism/Asperger's and were aged between five to 10.

The researchers used a computer technique which automatically coded children's non-verbal mode of communication (gestures) while they performed two demonstration tasks of ADOS-2.

The computer technique generated a 'Gesture Index' and researchers then compared the 'Gesture Index' for both girls and boys. The findings showed that girls with high functioning autism have better non-verbal communication skills (gestures) compared to boys with high functioning autism.

Deficits in gestural communication are a feature of autism and it is scored under the communication section of ADOS-2.

The better a child performs the gestures, the lower the score they get on this item. As found in this study, girls with autism have a higher 'Gesture Index' compared to boys with autism and as a result, they stand at risk of being underdiagnosed or not receiving a diagnosis.

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# The fight for my culture, my Autistic identity



*Attending the fifth annual Asia Pacific Autism Conference (#APAC17) autism conference in Sydney recently was a 'Jeanette holiday' for Australian autism author Jeanette Purkis because she got to meet up with friends she rarely sees, had incredible conversations, met new people and learned new things.*

**I AM HAPPY** and proud to be me and all that means.

In my mind everyone has the right to feel comfortable and happy to be them, unless they are a serial killer or something of course.

Sadly being proud and happy to be ourselves is often incredibly hard or impossible to achieve. For those of us who belong to one or more 'intersectional' groups – groups of people who face disadvantage – self-respect, love and pride can be a very hard ask. I had to fight hard for my own autistic identity and often the enemy seemed to come from within.

When I discovered I was autistic, I actually refused to accept it. I stopped myself from entertaining the very idea I was autistic or different or disabled or anything else. My denial of my autism was a conscious thing, I could have changed at any time and deep down I knew I was autistic but consciously I saw it as validation of what the bullies told me all through school.

My limited understanding of autism combined with my self-hatred and shame meant there was no way I could accept it. I kept thinking back to a music concert I attended a few years prior to my diagnosis where these girls were about to bully me and then one of them suggested I had some kind of intellectual disability and they left me alone. It was bad enough being bullied but then receiving pity from the bullies? I felt like I was too strange to even be bullied! It was just too much, I already hated myself. I didn't need a diagnosis which confirmed that!

How did I get from self-loathing to self-respect? I would love to tell a tale of a light bulb moment where I realised I was okay as me and then I found some autistic friends and life did some fairytale thing and everyone was happy and throw in a couple of rainbows and kittens playing and schmaltzy music. Of course life doesn't really work like that and in fact it took me many years to value and respect myself.

Even when I started to apply 'Autism' to myself, I did not do it very enthusiastically. It was like a guilty secret. I found it easier to discuss some genuinely shameful things I had done in the past than my diagnosis. I only told a select few – those who I thought wouldn't bully me or ridicule me. Even when I spoke of my autism it was in hushed tones, as if I were afraid someone else might hear. I know, not much of an advocate!!

The change, like so many changes, was supported by a friend and mentor. Somehow I ended up doing a course for autistic adults to enable us to do a public speaking job in schools. A woman was at that course who I was instantly drawn to. She said she was Donna (Williams) and told me about her many books. She was energetic and dynamic and evidently owned and valued her autistic identity. We became friends – and

**When I discovered I was autistic, I actually refused to accept it.**

had the most amazing mentoring relationship. I learned my autistic identity in her house, in conversations with her and other autistic women she knew. Donna (who preferred Polly (Samuel) but was Donna when I knew her) supported me to write my story. When that was published I got thrown in the deep end of public speaking and media interviews and a public as well as personal identity as an autistic woman. It was very challenging but ultimately a great thing.

My transformation from ashamed to advocacy was not complete at that point but it looked a lot healthier. I have written of this many times before but Donna's mentorship and friendship changed my life, and changed my 'me' on a fundamental level. I think that to support people to become proud of themselves and accept and understand their identity better is a precious gift. I will certainly always be grateful.

**"I think that to support people to become proud of themselves and accept and understand their identity better is a precious gift."**

As an aside, mentoring which produces more mentors and / or leaders is amazing.

A number of my friends who I don't often see had dinner together tonight. I wore my red curly wig and my gold sequin shoes. My friends and I had one of those discussions where you feel like you might have changed the world a little by having

it. We reflected that things are changing, mostly for the better, at these sorts of events and hopefully flowing on from that into support services and other important things.

The world is different. My world is different. I don't think these events happened within the same timeframe but I do know I am incredibly proud of my autistic identity and of the great friends I know.

I actually have a culture where I belong and am so grateful to have this and be accepted. To have positive identity and connections with others in your culture is a great gift and a wonderful thing. I want to see a world where this is the norm.

Everyone needs their culture, their 'tribe', their identity.

Jeanette Purkis has a Master's degree in Fine Arts from RMIT University and works for the Australian Public Service as a policy adviser. Jeanette recently received an Excellence Award from the CEO of her department for promoting inclusion and advocating for disability.

She is a frequent speaker at autism conferences and she facilitates a support group for women on the autism spectrum. She has received the ACT Volunteer of the Year award for her work in Autism advocacy and in particular in facilitating a women's group for Autistic women in Canberra. Jeanette has a diagnosis of Asperger syndrome. She lives in Canberra, Australia.





**CATCHING UP:** Altogether Autism national manager Catherine Trezona with Jeanette Purkis at APAC17 in Sydney.

# Focus on strategies for understanding mental health and autism



*Altogether Autism national manager Catherine Trezona attended the fifth annual Asia Pacific Autism Conference (APAC) in Sydney in early September 2017. There she heard keynote speaker Jeanette Purkis talk on Mental Health and Autism: Strategies and Self-care.*

**DO YOU HEAR** voices? Yes, voices are meant to be heard.  
Do you see things? Yes, things are meant to be seen.

Such answers may lead a psychiatrist to give a client a diagnosis of schizophrenia, when the accurate diagnosis should have been autism.

Jeanette Purkis, in her keynote presentation at APAC2017 in Sydney, put it another way: "If you're a person with a hammer, everything looks like a nail."

Jeanette knows first-hand the damage an incorrect diagnosis can cause, and her experience as both patient and professional, combined with her love of writing and presenting, brings wisdom and insight to the autism community: "Misdiagnosis is common and terrible on identity," she says.

In addition to some clinicians not getting the diagnosis right, crisis teams seldom 'get' autism which can lead to 'terrible invalidation' when a person is at their most vulnerable.

Meltdowns, which are very common in autism often due to sensory overload and stress, can be seen through a mental health lens as poor behaviour and this misunderstanding by clinicians can keep autistic people in the mental health cycle for years.

## Jeanette's tips for clinicians are:

- You can't fix autism so forget cures and focus on strategies
- Learn to 'speak autistic' (e.g. autistics are not 'puzzling', just different)
- Understand intersectional disadvantage when multi-factors coincide, such as autism + intellectual disability + poverty + racism.

## Jeanette's tips for autistics

- Be informed – keep involved with decisions that affect you
- Positive Enablers – find one, be one

**Jeanette credits Mr Kitty with being the best therapist she has ever had!**

- In crisis – remember that this too will pass
- Use thinking skills
  - Opposite action (doing the opposite of what you feel like doing, such as when you don't feel like getting out of bed, but you do it anyway – it will 'trick' your mood to improving)
  - Distraction (Jeanette's gold standard thought strategy and includes anything you find engaging and that captures your whole attention such as television, playing with your pet, or talking a walk)
  - Acceptance (Jeanette finds this can be the hardest and you may benefit from support from professionals who offer strategies such as mindfulness, acceptance and commitment therapy or cognitive behaviour therapy)
  - Happy Box (create this before you need it, to remind yourself of happy times and that sad times are temporary. Fill your box with things that make you happy such as photos, chocolate, poems, books, art, and fidget tools).

Jeanette also recommends making use of a range of healthy habits such as asking for help when you need it, keeping involved in decisions that affect you, taking medication as prescribed, building your confidence and self-worth and taking care of your physical wellbeing through right eating and exercise. More healthy habits include rewarding yourself for your achievements and helping others. And perhaps most importantly of all, at least for animal lovers, get a pet. Jeanette credits Mr Kitty with being the best therapist she has ever had!

Jeanette has co-authored an excellent book about mental wellbeing and autism with Emma Goodall and Dr Jane Nugent, called *The Guide to Good Mental Health on the Autism Spectrum*. You can read about it on our website, along with an interview with Emma Goodall on the background to writing it.

# Hiring autistic employees – a smart choice

*People with autism often have difficulty getting or keeping a job. Liliya John, Rebecca Flower, Catherine Trezona and Jason White discuss neurodiversity in the workforce and the benefits of hiring autistic employees.*

**PEOPLE WITH** autism may have many invaluable skills that are sought after by today's employers – like attention to detail, diligence, perseverance and an ability to think outside the square – but they are often disadvantaged when it comes to getting and keeping a job because of differences in social communication and interaction, and because of other people's lack of understanding.

When Specialisterne Australia's John Craven visited New Zealand earlier this year to speak at the Altogether Autism conference, he told story after story of people with autism who had excelled in the workplace when "inclusive employers" saw through their social and non-verbal communication difficulties and took a punt on hiring them. Despite this, fewer than 20 per cent of autistic adults with typical intelligence are fully employed and many others are not fully utilising their talents.

## What's in a name?

In this article, the authors refer to people diagnosed with an autism spectrum disorder in a range of ways, reflecting the preferences of members of this community. Many adults prefer identify-first language i.e. 'autistic people', while others prefer to be described using person-first language i.e. 'people with autism'. Many are comfortable with the descriptor 'on the autism spectrum'. Most prefer not to refer to autism as a 'disability', as autism is a different way of thinking with its own strengths and characteristics, coined by the phrase 'neurodiverse'. Those without autism are often described by autistic people as 'neurotypical' or 'NT' for short.

## What's in a number?

We don't know how many autistic people live in New Zealand as the numbers of autism diagnoses are not currently collected by any national agency. Best estimates range between 45,000 and 70,000, i.e. 1 in 100 and 1 in 68. These estimates are based on international statistics.

The New Zealand Autism Spectrum Disorder Guideline (2008, updated 2016) estimates 1 in 100 New Zealanders are on the autism spectrum. More recent findings from a study by Minds for Minds, a New Zealand based research network, suggest the prevalence of autism in New Zealand is similar to European populations, believed to be 1 in 68, or nearly 70,000 people (Virues-Ortega et al., 2017). Without knowing how many people in New Zealand are on the autism spectrum, our best estimate on the number of autistic people who are unemployed is also hard to pinpoint. What we do know is that getting and keeping a job is particularly challenging when you are autistic. There are several reasons for this.

In June 2017, Altogether Autism and Specialisterne Australia partnered to develop a survey to identify autistic talent in New Zealand. Altogether Autism provides evidenced information and advice to anyone in New Zealand living or working with autism. Specialisterne Australia is a non-profit social enterprise that helps employers understand, value, and include in their organisation the unique perspective and capabilities of individuals on the autism spectrum.

In little over one month, 125 people completed the online survey. Of these, 57% had tertiary qualifications but only 6% were in full time employment, despite their readiness and willingness to work. The three key barriers to getting a job identified by the survey were unclear employer expectations, difficulty with job interviews, and no opportunity to demonstrate skills.

The three key barriers to keeping a job were lack of awareness and acceptance of autism, poor recognition of support needs, and poor social attitudes in the workplace.

Three key changes needed for autistic talent to thrive at work were identified as the recognition of special talents and skills, working with people who believe in their autistic workmates, and matching skills to tasks.

An excellent example of an individual who found it difficult to remain in employment was provided by one of the participants in our surveys. This individual had a position that involved reporting errors, and each of these errors would require fixing. He/she did a diligent job, however found that the supervisor was making "odd" comments that they didn't quite understand. After multiple discussions with the supervisor, the individual, confused, resigned. On their last day, the supervisor explained that the individual had been finding too many errors, and the company couldn't keep up with the work. Ultimately, this was making the company look bad. Unbeknownst to the individual, what the supervisor was doing in these "odd" conversations was hinting that the individual "miss" some of the errors. Individuals on the spectrum are known to follow rules to the letter, which is one of the reasons for making such great employees (Dakin & Frith, 2005; Keita, Guy, Berthiaume, Mottron, & Bertone, 2014). Unfortunately, when an employer doesn't want the rules to be followed, this can cause issue.



## What impact can employment have on an individual's life?

An additional survey run alongside the autistic talent search asked people with autism to share their employment experiences. Sixty two percent of the 47 respondents were currently unemployed. The main characteristics of a positive work environment were a good fit between personal interest and the current job, and positive attitudes and support from colleagues at the workplace. Disclosing their autism in the workplace had gone badly for some, leading to a gradual reduction in working hours, being passed over for promotions, removal of decision making powers and under recognition of capabilities.

## Why autistic individuals can make great employees

When given the chance, people on the spectrum can make fantastic employees. Not only are they thought to be reliable, honest, and persistent (Howlin, 1997), but there are a number of skills that autistic individuals excel in over and above neurotypicals. Compared to the general population, autistic people are thought to be better at processing local, or detailed, information (e.g., Dakin et al., 2005; Keita et al., 2014). Autistic individuals have been found to perform better in the abstract reasoning and spatial processing tasks (Stevenson & Gernsbacher, 2013). Further, individuals on the spectrum are often able to concentrate on one thing for long periods of time, may perform well in repetitive tasks, and have low rates of absenteeism (Scott et al., 2017). Another area where autistic employees are likely to excel is in their area of interest. A part of the diagnostic criteria is having a strong and intense interest (APA, 2013), autistic people are often very knowledgeable in this area, and may get a lot of enjoyment from spending time on this interest (e.g., Mercier, Mottron, & Belleville, 2000). If a position is a good fit for an individual they are likely to have more success in the workplace (Muller, Schuler, Burton, & Yates, 2003; Olney, 2000), as are they when the position is related to their specific interest (Keel, Mesibov, & Woods, 1997; Koenig & Williams, 2017).

## How can HR leaders help to seek autistic talent and support autistic employees?

The survey respondents were also asked to report on the challenging experiences they had faced in seeking employment and staying in employment. For many, the interview process is the most challenging experience. Adapting the interview process was frequently suggested as an autism friendly organisational practice. For instance, instead of asking the job applicants to describe what they know about the particular job or their experience in doing it, why not offer opportunities to showcase knowledge, experience and expertise in the actual work environment.

Social skills have been reported as one of the most common features examined by an employer during an interview (Huffcutt, Conway, Ross, & Stone, 2001). Yet by definition, a key feature of autism is differences in communication. As defined in the diagnostic criteria for autism, individuals on the autism spectrum experience, to varying degrees, have difficulties with social communication and social interaction. Therefore, in an inherently social and unscripted process such as a job interview, challenges for autistic individuals are not surprising.

Challenges or differences with social communication and interaction may present in an interview in behaviour such as misinterpretation of a question. For example, Wehman et al. (2017) reported that during an interview for an internship program, one participant on the spectrum responded that the best they liked about working for the company was "lunch!" (p.287). Not only did this individual interpret the question literally, but he/she (presumably) showed little understanding of how an employer would perceive such an answer. Autistic individuals may have difficulty recognising and correctly interpreting what other people are thinking or feeling. This can include non-literal language (e.g., sarcasm) and

non-verbal behaviour (e.g., facial expressions), each of which may provide important information to a candidate during an interview. In the case of the above-mentioned individual who reported enjoying 'lunch', had only an interview taken place, he/she may not have been offered a position. However, as the employer had the opportunity to assess the individual's work ethic and skills during an internship program, he/she was subsequently employed, and remained employed for at least 5 years post-internship (Wehman et al., 2017).

Survey respondents also emphasised the need for employers and colleagues to have more understanding, awareness and acceptance of autism. The special skills, strengths and talents, e.g., attention to detail, creative 'out of the box' thinking that the autistic people contribute to the workplace should be given due recognition and appreciation. Respondents also suggested that organisations should provide autism

awareness training for the staff as improved understanding and awareness can foster a non-judgemental and supportive attitude towards the autistic employees. Autism awareness training would also help the managers and supervisors to communicate effectively with the autistic employees as they

prefer clear and direct instructions, preferably written instead of verbal. Providing workplace accommodations is another key organisational strategy that can be of great support to autistic employees. Providing compact and private office space, flexible working hours, a safe place for time out etc., would help to improve comfort as well as productivity. Additionally, strategies to manage lighting, and noise would be helpful for those with sensory sensitivities.

## Author bios

- **Catherine Trezona** is the National Manager for Altogether Autism. She is committed to bringing the successful Specialisterne model to New Zealand.
- **Liliya John** is a researcher for Altogether Autism. She is responsible for coordinating research projects between Altogether Autism and Specialisterne Australia.
- **Jason White** is the Employment Services Manager at Specialisterne Australia, where he looks after business development, programme delivery and client relations. He has worked exclusively with the autism community in employment services and transition support since 2009.
- **Dr Rebecca Flower** is the Research and Innovation Manager at Specialisterne Australia, where she is responsible for research, development of tools, intellectual property and quality control. Dr Flower has an undergraduate degree in Psychology, a PhD which focused on autism, and has published research in organisational psychology.

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## Study finds exercise improves children's brain power

**A NEW STUDY** has found that short bursts of intensive exercise boosts children's brain power and has benefits for children with learning difficulties or conditions such as autism.

Scientists have long known that exercise is good for the brain. Previous research has found that long, sustained workouts lasting for around 30 to 40 minutes improve memory and learning in both adults and children. But the latest research looked at the effect of short bursts of high-intensity training (HIT) lasting just 10 minutes each day on children aged 7-13 years.



DAVID MOREAU

University of Auckland researcher David Moreau from the School of Psychology and his team established baseline data by testing the 305 participants on six tasks involving memory, information processing and behaviour prior to the study commencing.

They then randomly assigned participants to either a placebo group involving activities such as games and quizzes, or to an HIT group that involved an intense ten-minute workout every weekday over a six week period. Participants in the HIT group showed larger improvements in tasks involving memory and tasks involving information processing and behaviour, including the ability to focus on a task to completion without getting distracted. The latter has been shown to be a key indicator of professional and academic success in adults.

"These findings reinforce previous research which has found that exercise is one of the most effective non-invasive ways to improve memory and cognitive understanding," Dr Moreau says.

"The significance of the study is that it shows exercise does not have to be time-consuming and that a range of children, some with learning difficulties, get real benefits from short periods of fairly intensive physical activity."

The study 'High-intensity Training Enhances Executive Function in Children in a Randomized, Placebo-Controlled Trial' was published in *eLife* which publishes research across the life sciences and biomedicine and is supported by the Howard Hughes Medical Institute, the Max Planck Society and the Wellcome Trust.

## In an MMMbop you're alone



**Claire van Oirschot\*** of Whakatane is 32 and identifies as having Asperger's Syndrome. She publishes a semi-regular blog called *clairesblog424* in which she talks about, among other things, being a Hanson fan, her family's move from Holland when she was 3, complex emotions, having a bike accident and getting a cat. Here she explains what being an Aspie is like.

**A LOT OF** the time I feel so isolated and alone. As though no one understands me at all.

I would not be too surprised if no one understood me. I mean... I barely understand myself half the time. Like... my mind is just this mystery – like a maze or something. Keeps getting more confusing and mysterious the further I go along. The more I try understanding myself the more confusing things feel.

Life is hard. I know that it is hard for everyone because everyone has his or her 'trials and tribulations'. I feel that for people with disabilities – regardless of what they are – it is just harder. I think it is not necessarily because of the disability itself. Personally, I think it is because of prejudice and intolerance of others. I know from experience how hard it can be to handle things that are different. Whether it is a different situation or food or environment or a disability. Is easier in some ways to just stay inside your 'comfort zone' and not try 'expanding your horizons'.

It is also much easier to only see things from your perspective and not try looking at things from anywhere else. Then – it is hard to grow as a person or to become a more rounded person. The world would be boring if everyone was the same. I truly believe that it is important for everyone just to be himself or herself and not try changing to impress anyone else. If everyone could just be themselves with all their quirks and eccentricities – and yet be caring and compassionate – then the world would be a much easier place to live.

A lot of the time, I feel like people are judging me. Whenever I am out in town, I wonder what people who look at me are thinking. That I am fat or that I have terrible fashion sense or worst of all that I am handicapped. I know it is a horrible word to use. Especially these days. Before I was diagnosed with Asperger's when I was 16, I was definitely judged. Mainly by fellow school peers on the bus and at school. Was horrible and it still stings sometimes. There is that old saying, "sticks and stones may break my bones but words will never hurt me". I know from extensive experience that words do hurt. Sometimes they hurt more than many injuries ever could because eventually most wounds heal but the pain caused by mean words can take a lifetime to heal. If ever.

Thankfully, I was never physically bullied at school. Have heard horrible accounts of girls beating up on other girls. In some cases, severely injuring them and in others, death. So – you could say my bullying experiences were not half as terrible. Somehow words can have a way of getting into one's psyche and just mess their head up. Still does that to me sometimes and have trouble just dealing with it. Hence, why I get so emotional sometimes and have all the issues I do. Wish there was an easy 'fix it' but there isn't. Is just something one should find their own ways of dealing with and maybe living with.

Acceptance is super important. Accepting that not everyone will be accepting of you and to try not let others' harsh opinions of you reflect what you think of yourself. Most of the time I accept myself and love myself even. I love my crazy sense of humour and my enthusiasm for life. I love how invested I get into things. How much I love my family and friends – how important I realise they are to me and how lost I'd be without them. I also love how creative I am and how I try to see the world.

It is important to try accepting differences in others and not judge things you do not understand.

\*Claire van Oirschot. Picture courtesy: Whakatane Beacon.



# National Autism Spectrum Disorder Support – what services are available?



*Sean Versteegh is a specialist advisor and clinical psychologist for Explore Specialist Advice NZ*

Explore prides itself on providing quality, flexible services and educational programmes that are based on positive support frameworks and evidence-based best practice.

**EXPLORE SPECIALIST** Advice (Explore) took over the national contract for education services for families of children and young people who have Autism Spectrum Disorder (ASD) earlier this year.

As well as providing ASD services, Explore is the national provider of behaviour support services for people with disabilities who experience challenging behaviour.

Explore prides itself on providing quality, flexible services and educational programmes that are based on positive support frameworks and evidence-based best practice.

Its services and programmes are delivered by registered health professionals, including psychologists, occupational therapists, speech language therapists, social workers and other behaviour specialists with experience in the sector.

## EXPLORE'S ASD PROGRAMMES

Programmes are arranged into three levels to suit the specific needs of a family / caregiver who has a child with ASD. The levels provide a clear needs-based pathway, from Parent Education and Support to intense Behaviour Support services.

All programmes are flexible to meet the specific needs of each family, are based on best practice and on New Zealand's ASD guidelines, and are provided free of charge throughout New Zealand, including in rural and remote locations.

### Level 1: Parent Education and Support:

- ASD+ programme (under 7 years)
- The ASD+ programme is for parents and caregivers who have children recently diagnosed with autism.
- It is designed to increase parent/caregiver knowledge about common challenges children with ASD face such as communication, behaviour, stress and learning styles.
- The programme helps parents/caregivers identify ways of supporting a child with these challenges. ASD+ includes seven modules that can be delivered in a group session or individually. You can also access the ASD+ programme remotely.

Parents can refer themselves to this programme by contacting Explore to make a direct referral (0800 000 421), or by contacting your ASD Coordinator, Health Professional within Child Development

Services, Early Childhood Education Services or your NASC Coordinator.

### Level 2: Targeted Parent Support

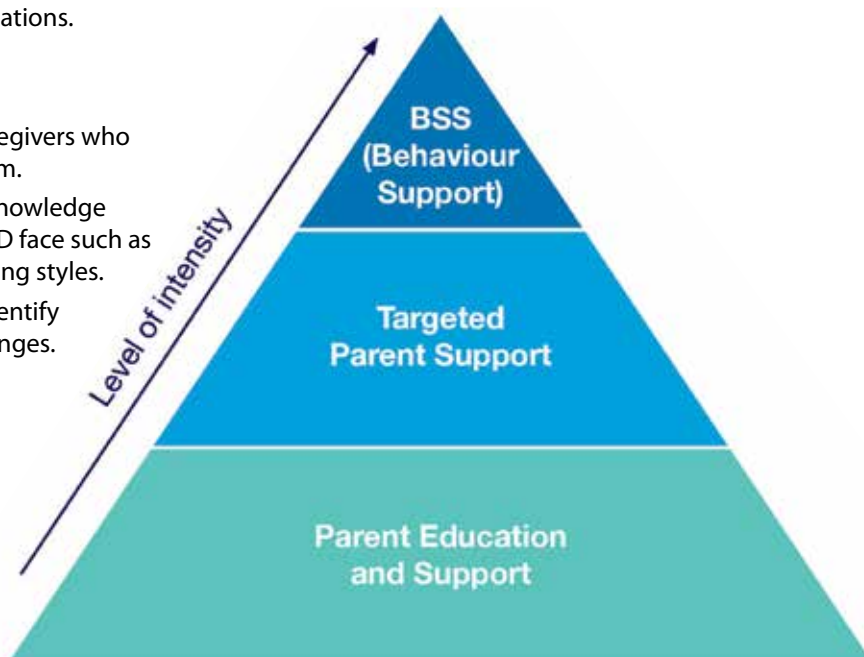
The Targeted Parent Support programme aims to strengthen parents/caregivers' skills to manage specific difficulties their child may be experiencing as a result of autism. Working with an Explore specialist, parents/caregivers learn skills to manage their child's particular challenges such as social communication, understanding relationships, understanding strong emotions, coping with change, managing sensory sensitivities, everyday activities and routines like mealtimes, sleep and toileting.

For a referral to this programme contact your ASD Coordinator, Paediatrician within Child Health Service, a qualified professional (psychologist, psychiatrist with ASD experience and expertise) or your NASC Coordinator.

### Level 3: Behaviour Support Services

Behaviour Support services are tailored to a child/young person's individual needs where their challenging behavior has a significant impact on their life.

Working with an Explore specialist, parents/caregivers will learn skills to help reduce the impact of the challenging behaviour.



- For a referral to the Behaviour Support Service please contact your local NASC.
- For more information you can also contact Explore on **0800 000 421** or visit **[www.explore.org.nz](http://www.explore.org.nz)**
- Explore is part of HealthCare NZ, one of New Zealand's most experienced providers of community-based health, disability and rehabilitation support services.



**SELF PORTRAIT:** Deshan Walallavita with his self-portrait with medals.

## Deshan's award-winning art journey

**PROOF HAMILTON'S** Deshan Walallavita is rapidly exploring his full potential as an artist came in August when he was named a top 10 finalist in the IHC Art awards.

The first people he and his family thanked were the teams at Life Unlimited Community Services and Enabling Good Lives.

Deshan, 22, who has high-functioning autism attended Patricia Avenue School and late last year was ready to put his school days behind him and work towards adulthood and being independent.

Life Unlimited community support manager Honey Hireme said when Deshan started on the Transition programme, the team worked on goal planning and connected him with a number of community activities and programmes.

One of those was the Sandz Art Gallery where Deshan's talent became obvious.

"Deshan is a great young man who gives 100 per cent in everything he does. He enjoys art, sports and being with his family," said Hireme.

"We are so proud of what he's done."

It was Sandz Art Gallery who entered one of Deshan's art works in the competition which attracted nearly 400 entries.

He was highly commended and IHC flew him and support persons to Wellington for the awards at Shed 6 on the Wellington Waterfront. His art sold for \$535.

Wellington-based artist Emma Lou won the awards and with it \$5000 with her finely detailed pastel drawing, self-titled Emma Lou. Second prize of \$2000 went to Wellington

artist and 2016 winner, Jo-Anne Tapiki for her tapestry work Kiwiana, and third prize of \$1000 was won by Cherie Mellsopp of Hamilton for her drawing Jade on Black.

Hamilton artist Julian Godfery won the People's Choice award for his work Invisible Magic.

**"Deshan is a great young man who gives 100 per cent in everything he does."**

Entries included sculptures, installations and textile art, painting and drawing. The IHC Art Awards are open to all New Zealanders with an intellectual disability, age 13 or over, whether or not they use IHC services.

The finalists' work was auctioned at the event with all proceeds from the sales going solely to the artists.

- Life Unlimited's Transition programme is a process that occurs for young people who are in their last years of high school and preparing to move on. The aim is to move students smoothly into post-school education, employment and/or community services and activities.
- Students preparing to leave school between 16-21 years old with a disability who receive Ministry of Education Ongoing and Reviewable Resourcing Scheme funding and need support to achieve a successful transition into post school activities can access Life Unlimited's Transition programme.
- Life Unlimited staff meet with the student, their family and the school and agree a Memorandum of Understanding.
- The work is one-on-one.



# DO YOU WORK WITH PEOPLE ON THE AUTISM SPECTRUM?

## PROFESSIONAL DEVELOPMENT WORKSHOPS COMING UP!

Prism Professional Development Series is for professionals working with people on the autism spectrum including educators, health professionals and support workers. Developed by Altogether Autism, it is based on theoretical, academic and clinical knowledge, and delivered by specialist facilitators.

All workshops are interactive and present information in ways to appeal to different people, including role-plays, videos, group exercises and discussion. Participants are provided with a comprehensive workbook and ongoing access to tailor-made information.

## SUPPORTING PEOPLE ON THE AUTISM SPECTRUM

### WORKSHOPS OPEN TO ALL PROFESSIONALS

#### WELLINGTON

Tuesday 28 and Wednesday 29 November 9am - 4pm

Venue: Angus Inn

Corner of Cornwall Street and Waterloo Road

Lower Hutt, Wellington

The workshops will offer a safe and supportive environment for people to ask questions about autism. The facilitators will provide best practice skills and strategies to interact in positive ways with people on the spectrum and their families.

**\$460 incl GST per person includes morning/afternoon tea and lunch.**



*"Tutors were fantastic, engaging, friendly and incredibly well educated."*

*"Love the booklet with the powerpoint, this made a very easy to follow workshop."*

*"Great course, very helpful, all information I will use in my work."*

*"Awesome training, feeling empowered and looking forward to implementing new strategies for our people."*

# Autism & Addiction – Whose business is it?

**Tanea Paterson, Autism Advocate** *Dip.App.Addiction Practitioner*

## What is Autism?

- Strong Genetic Basis
- Covers a spectrum of 'neurodiversity'
- Decreased life span of ~ 18 years
- Autistic adults (formerly Asperger's) are 9x more likely to die by suicide
- Neurological, biophysiological, communication & sensory differences
- 'Thinking in Pictures'



Neurodiversity Symbol

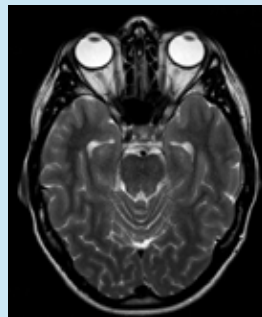
## Why Autistics use Drugs

- Social Interactions and Communication
- Anxiety 'social lubrication'
- Executive Functioning – Impulsivity, repetition
- Avoiding or Seeking Sensory Input
- Sensory processing problems
- Co-Occurring Problems – Self Medication
- Community – A desire to 'fit in' or to 'drop out'
- Relationships – Seeking Comfort and Predictability
- Pain – Ehlers Danlos, Fibromyalgia



Stephanie Tihanyi  
"Neurodiverse Tree of Life"

- Autism DOUBLES the risk of addiction. Elevated risk with an IQ above 100. Co-Occurring ADHD multiplies risk (Butwicka, 2017)
- Nearly 7% of people assessed upon admission to addiction tx, were diagnosed with Autism, as compared with 1% in the general population. (Wijngaarden-Cremers 2014)



## Barriers to treatment

- unidentified – Autistic Traits not seen
- not Co-Existing Autism specific prepared
- access to Autism courses
- labelled as difficult, inconsistent, unreliable....'treatment resistant'
- frameworks of tx do not fit
- if diagnosed, services may claim to have no skills to work with Autistic people and pass back to disability
- disability may discharge the person from their service due to substance use, leaving them on their own

## REFERENCES

- Butwicka, A., et al (2017). Increased Risk for Substance Use-Related Problems in Autism Spectrum Disorders: A Population-Based Cohort Study. *Journal of Autism and Developmental Disorders*, 47(1), 80–89.
- Wijngaarden-Cremers PJM, Brink WV, Gaag RJ (2014) Addiction and Autism: A Remarkable Comorbidity?. *J Alcohol Drug Depend* 2:170. doi:10.4172/2329-6488.1000170
- Autism Workforce Development  
[www.tepou.co.nz/disability-workforce/autism-workforce-development-/156](http://www.tepou.co.nz/disability-workforce/autism-workforce-development-/156)
- Altogether Autism Prism Professional Development  
[altogetherautism.org.nz/prism](http://altogetherautism.org.nz/prism)

## What works ?

- Identify Autistic Traits AQ-10
- Access specialist diagnostic assessment, include genogram
- Assess sensory profile including interoception and proprioception
- Focus on self understanding & Identity – Literature, Autism Groups – local or online Facebook, Reddit etc
- Therapeutic plan between Tangata Whaiora and Key Worker
- Collaboration Between Services
- Develop and strengthen therapeutic alliance

## Brief Autism Assessment

**AQ-10**  
Autism Spectrum Quotient (AQ)

A quick informal guide for adults with suspected autism who do not have a learning disability.

Please tick one option per question only:

	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
1 I often notice small sounds when others do not				
2 I usually concentrate more on the whole picture, rather than the small details				
3 I find it easy to do more than one thing at once				
4 If there is an interruption, I can switch back to what I was doing very quickly				
5 I find it easy to read between the lines when someone is talking to me				
6 I know how to tell if someone listening to me is getting bored				
7 When I'm reading a story I find it difficult to work out the characters' intentions				
8 I like to collect information about categories of things (e.g. types of car, types of bird, types of flower, types of plant etc.)				
9 I find it easy to work out what someone is thinking or feeling just by looking at their face				
10 I find it difficult to work out people's intentions				

**SCORING:** Only 1 point can be scored for each question. Score 1 point for Definitely or Slightly Agree on each of items 1, 7, 8, and 10. Score 1 point for Definitely or Slightly Disagree on each of items 2, 3, 4, 5, 6, and 9. If the individual scores more than 6 out of 10, consider referring them for a specialist diagnostic assessment.

This test is recommended in Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (NICE clinical guideline CG142) [www.nice.org.uk/CG142](http://www.nice.org.uk/CG142)

Key references: Allison C, Auyeung B, and Baron-Cohen S, (2012). *Journal of the American Academy of Child and Adolescent Psychiatry* 51(2):203-12.

## The Future

- Including the AQ-10 in assessment
- Develop Autism specific addiction therapies
- Extend Te Pou – Autism Professional Development Framework to Addiction Sector
- Services access professional development such as PRISM through Altogether Autism

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