

ALTOGETHER AUTISM
JOURNAL
ISSUE 2 2017



Untap autistic potential

INFORMING • EMPOWERING • CONNECTING
**ALTOGETHER
AUTISM**
THROUGH KNOWLEDGE AND EXPERIENCE

Why do girls go undiagnosed?
Conference activity heats up

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, people on the spectrum and family members of people with autism.

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

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

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Making the transition



TRANSITIONS #Breakthrough2017 is our biennial learning event, held in Auckland on Wednesday July 19 and Thursday July 20. Thanks to Te Pou's Consumer Leadership Development Grant, over 50 consumers – that is, autistic people and their family/whānau – are able to attend. Several of these people are also speakers, bringing a rich range of topics. People with lived experience of autism will present two of our four streams of workshops. Transitions

#Breakthrough2017 will be an extraordinary opportunity for immersion in autistic culture. We feature several of the speakers in this Journal and all the abstracts are on our website. Check out the full programme on pages 8 and 9 and go to our website to register.

"Te Reo Hāpai – The Language of Enrichment"

Keri Opai, Paeārahi- Strategic Lead, Te Pou o te Whakaaro Nui, met with me recently, to discuss his newly created glossary of Maori language use in the Mental Health, Addiction and Disability sectors. This new creation project is called "Te Reo Hāpai – The Language of Enrichment". I am really excited about the possibilities Keri's work brings to new language for autism and other 'disability' terms. I believe language is powerful and the words we use shape attitudes and identity – as we see when we use words not favoured by those we are talking about! Takiwātanga – in my own time/space - is such a fresh way of looking at autism and emphasises difference rather than disability.



Keri Opai

Specialist employment programme



John Craven

Altogether Autism and Enrich+ hosted John Craven, Specialisterne Australia, for a week in May to share the Dandelion Programme with businesses and government. This is a very successful model used throughout the world to connect employers with autistic talent. We are very keen to bring this programme to New Zealand and as a first step, we are developing two surveys to learn more about autistic employment in New Zealand. If you have a story to tell, either as an autistic employee or an employer of an autistic person, we want to hear from you.

System Transformation

Paula Jessop, our autistic advocate, attended a Ministry of Health funded meeting in Wellington with me to discuss the System Transformation project with Sacha O'Dea, programme lead, Ministry of Health, and Esther Woodbury, national policy and relationships manager, Disabled Persons Assembly. Gabby Hogg and Joanne Dacombe, two other autistic advocates, also attended this meeting. Sacha invited us to meet with her to discuss ways to include an autistic perspective in the system transformation project of disability support services. We identified some of the issues specific for the autism community. We then discussed why an autistic perspective was important, options for including this perspective and agreed upon some actions.



Paula Jessop

Keeping in touch

We know there are issues bubbling away between issues of the Journal and we like to keep readers informed via our website and our social media platforms. In recent months, your engagement with us through these channels in ever-increasing numbers has been helpful and we thank you for that. Your feedback, for example, resulted in us creating a search button on our website's front page and each article, which appears in the Journal, also goes up separately on the website along with any references to other websites. Keep an eye out on our channels for updates during the conference.

Catherine Trezona
National Manager, Altogether Autism

Final keynote speakers

ALTOGETHER AUTISM is delighted to announce the final two keynote presentations for the 2017 learning event at the Holiday Inn Auckland Airport on July 19 and 20.

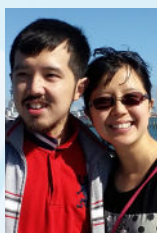


Peter Dowrick joins the line-up and will speak on the theory of feedforward as a cognitive-behavioural principle of learning with advantages for autism.

Dowrick is a registered psychologist. His hands-on consultation extends from Aotearoa New Zealand, Great Britain, Canada, many states across the USA, plus Micronesia and American Samoa, to Liberia (for United Nations worldwide literacy), and Indonesia, with consultation-from-a-distance to another 17 countries. His faculty appointments include universities in New Zealand, London, Alaska, Pennsylvania, and Hawai'i, and he has consulted with more than 100 agencies in different countries. He is also a current member of the Altogether Autism Professional Expert Group.

Dowrick is an expert in observational learning theory, and is internationally recognised as the 'father of self-modelling'. He originated the concepts 'feedforward' and 'creating futures' in behavioural science. His keynote presentation will explore how feedback on the past becomes useful only when converted to feedforward for the future. He will give video examples to illustrate feedforward as a visual self-image of future success, playing into the strengths of autism.

Also presenting at this year's event is Josh and Maria Man – an Asian/Kiwi/Australian sibling duo – who will offer their unique insight and reflections on what it has been like dealing with life's transitions, growing up with each other and ultimately living apart in different countries.



They hope that their experiences will help professionals work with families more effectively, remind families to care for each other and encourage people with autism (and their siblings) to have their voices heard.

Josh Man (known as the Bold One-Eyed Pirate in Australia) is a young man with autism peering into the complicated world of bustling humans and autism. He describes himself as a 'fingertypers' (as he communicates through his iPad) and a passionate advocate for people who communicate differently. Josh Man is a seasoned presenter and consultant in Australia, appearing at numerous disability conferences and universities including as keynote at the Queensland Disability Conference (Cairns, 2014); speaker at AGOSCI (Australian Group on Severe Communication Impairment) Conference (Adelaide, 2015); and at the Think-Prepare-Plan Conference (Brisbane/Townsville, 2016).

Maria Man is Josh's older sister who works as a speech and language therapist in Hamilton, New Zealand with children and young people with autism. She previously worked for five years with families of children with complex needs at Disability Services Queensland in Brisbane.

Bridging the cultural and language barriers between her Chinese parents and service providers, Maria Man has had a long personal experience of being a strong advocate and caregiver for Josh and her family.



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Education Amendment Bill applauded

NEW ZEALAND'S leading provider of research-based autism information acknowledged the historic passing of the third and final reading of the Education (Update) Amendment Bill, which prohibits the use of seclusion in schools and early childhood services, and creates a legislative framework for the appropriate use of physical restraint in schools.



Altogether Autism national manager Catherine Trezona says she agrees with Education Minister Nikki Kaye's comment in Parliament on May 11 that: "there is no situation where it is acceptable for children and young people to be secluded."

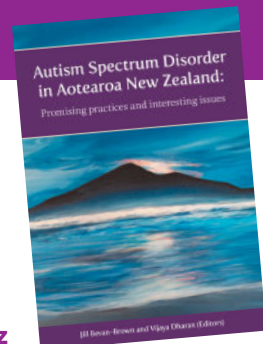
"We made our position very clear late last year on seclusion," said Ms Trezona. "Altogether Autism does not support the use of seclusion, where a person is placed in isolation in a room or area from where they cannot voluntarily exit. Seclusion is a violation of human rights and may result in damage to a person's wellbeing."

Altogether Autism supports the planned use of respite. "Respite is the removal of a person to a safe place with minimal sensory stimulation (such as loud noise and bright lights) for a specific short period of time," said Ms Trezona who developed Altogether Autism's position on seclusion in November last year in consultation with clinical psychologist Jenny Gibbs, Paula Jessop, Consumer Reference Group member and autism advocate, and Nan Jensen, Professional Expert Group member and solicitor.

WIN!

Go in the draw to win a copy of **Autism Spectrum Disorder in Aotearoa New Zealand: Promising practices and interesting issues.**

Send your name and address to editor@altogetherautism.org.nz before **20 July 2017** for your chance to win.



Gender differences in autism



There is limited information regarding autism in the female population and what we know about autism is mostly about autism in males. Liliya John writes that since the beginning, our understandings of autism have always been from a male perspective and this knowledge gap in terms of gender may have contributed to many females 'flying under the radar'. Research clearly indicates the possibility of a diagnostic gender bias, meaning females who meet the criteria for autism are at disproportionate risk of not receiving a clinical diagnosis.

ONE OF THE most consistent characteristics of autism is the inconsistency with which it affects men and women.

Autism is approximately four times more common among males than females and the frequently stated sex ratio is 4:1 (Halladay et al., 2015). However, according to a latest study by researchers at the University College, London, the true male-to-female ratio of children meeting the criteria for autism is not 4:1, as is often assumed; rather, it is closer to 3:1 (Loomes et al., 2017). In addition to prevalence rates, research also indicates that males and females may have different autism profiles, i.e., they may differ in the ways in which they exhibit both the strengths and difficulties of autism (Lai et al., 2015).

Why does this gender difference in diagnosis occur? Why do many girls and women go undiagnosed? Are women less vulnerable to autism? Does autism look different in girls, making it harder to detect or diagnose? What are the differences between girls and boys with autism? Even though autism and gender difference is widely researched, we do not have clear cut answers for these questions yet.

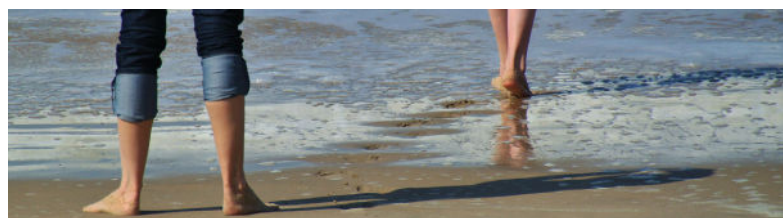
One of the strong arguments for why autism might be missed in females has been linked to diagnostic criteria itself. Historically speaking, ever since the first published descriptions of autism by Leo Kanner and Hans Asperger in the 1940s, it was primarily conceptualised as affecting only males. All four of the participants from Hans Asperger's study were boys and eight of the 11 cases described by Kanner were boys (Werling et al., 2013). Asperger even believed that autism was specific to boys even though clinical evidence made him change his assumption later. Asperger (1944/1991) commented: "It may be only chance that there are no autistic girls among our cases or it could be that the autistic traits in females only become evident after puberty. We just do not know" (p. 85).

Also, there is far more research on males with autism than females with autism. Studies either tend to recruit four male participants for every one female participant or they completely exclude female participants (Lai et al., 2015). Since the diagnostic criteria for autism is developed based on research and considering that females are underrepresented in most clinical samples, the diagnostic criteria itself is biased. This in turn reinforces the male bias in diagnostic tools and instruments, perpetuating the exclusion of females in the way autism is both defined and diagnosed (Haney, 2016).

Research findings on gender differences in autism

- Females show less restricted and repetitive behaviours and interests compared to boys (Frazier et al., 2014; Zwaigenbaum et al., 2012; Van Wjingaarden-Cremers et al., 2014). The presence of repetitive behaviour and special interests is a key diagnostic criterion and clinicians often look for examples around stereotypically "male" interests, such as train timetables and numbers during the diagnostic process (Supekar et al., 2015). However, girls with autism do not necessarily have the same kinds of special interests as typical autistic boys, and their interests are similar to those in typically developing girls, such as fascination with dolls, horses, pop stars and celebrities, Disney films etc. which are socially accepted. These differences in special interests and behaviours could be one reason why many females slip through the net when it comes to diagnosis.

- Females require more severe autistic symptoms and more complex behavioural and cognitive symptoms to be diagnosed with autism (Frazier et al., 2014; Bargiela et al., 2016). One study found that if boys and girls had a similar level of autistic traits, the girls needed to have either more behavioural problems or significant intellectual disability, or both, to be diagnosed (Dworzynski et al., 2012). Hence, females with a higher IQ or less severe symptoms stand at a risk of missing a diagnosis (Van Wjingaarden-Cremers et al., 2014).
- Girls tend to have internalising symptoms such as depression, anxiety and eating disorders whereas boys tend to have more externalising symptoms such as aggression, and hyperactivity (Altman et al., 2016). When girls with internalising symptoms are referred to professionals, the symptoms often get misinterpreted and misdiagnosed as those of anxiety, avoidant personality disorder and eating disorders.
- Many autistic women miss diagnoses due to their ability to camouflage or mask their social difficulties by mimicking socially appropriate behaviour. They also may have higher social motivation and a greater capacity for traditional friendships than males with autism (Bargiela et al., 2016).



What are the benefits of improved understanding of autism in girls?

Research on gender differences could help in the development of non-biased diagnostic criteria and diagnostic instruments in future.

- It will raise awareness among health professionals who are involved in early identification and diagnosis of autism. It would help diagnose women those who would otherwise be undiagnosed.
- Understanding of how autism presents differently in females will also help in understanding their different needs and providing them with the right supports and interventions.
- It could also help to understand whether transitions differ in both sexes and if yes, how do we help girls to have successful transitions?

References:

- Altman, L., & Turk, J. (2016). Comparison of autistic profiles in young females and males with autism spectrum disorder: A review of the literature. *Journal of the American Academy of Child and Adolescent Psychiatry*, 1(55).
- Asperger, H. (1991). *Autistic Psychopathy in Childhood* (U. Frith, Trans.). In U. Frith (Ed.), *Asperger and his syndrome* (pp. 37–92). Cambridge, UK: Cambridge University Press. (Original work published 1944).
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with Autism Spectrum Conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281–3294.
- Dworzynski, K., Ronald, A., Bolton, P., & Happe, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(8), 788–797.
- Frazier, T.W., Georgiades, S., Bishop, S.L., & Hardan, A.Y. (2014). Behavioral and cognitive characteristics of females and males with autism. *Journal of American Academy of Child and Adolescent Psychiatry*, 53(3), 329–40.
- Halladay, A. K., Singer, A. T., Bishop, S. N., Constantino, J. M., Daniels, A. J., Koenig, K. L., ... Szatmari, P. (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism*, 6(1), 36.
- Haney, J.L. (2016) Autism, females, and the DSM-5: Gender bias in autism diagnosis. *Social Work in Mental Health*, 14(4), 396–407.
- Lai, M.C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: Setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(1), 11–24.
- Loomes, R., Hull, L., & Mandy, W.P.L. (2017). What is the male-to-female ratio in autism spectrum disorder? a systematic review and meta-analysis. *Journal of the American Academy of Child and Adolescent Psychiatry*. doi.org/10.1016/j.jaac.2017.03.013
- Supekar, K., & Menon, V. (2015). Sex differences in structural organization of motor systems and their dissociable links with repetitive/restricted behaviours in children with autism. *Molecular Autism*, 6(1), 50.
- Van Wjingaarden-Cremers, P. J., van Eeten, E., Groen, W. B., van Deuren, P. A., Oosterling, I. J., & van der Gaag, R. J. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44(3), 627–635.
- Werling, D. M., & Geschwind, D. H. (2013). Sex differences in autism spectrum disorders. *Current Opinion in Neurology*, 26(2), 146–153.
- Zwaigenbaum, L., Bryson, S. E., Szatmari, P., Brian, J., Smith, I.M., & Roberts, W. (2012). Sex differences in children with autism spectrum disorder identified within a high-risk infant cohort. *Journal of Autism and Developmental Disorders*, 42, 2585–96.

Empower the system, a parent's take on transition



*It can be challenging transitioning children from early childhood education into school. **Mary Anne Gill** finds out how a Northland family achieved it.*

WHEN PETER and Suzanne Casey get time to think about what lies ahead for their three daughters Charlize, Raven and Piper, their scariest thoughts are about how to transition them into secondary school.

There are still five years before the Northland couple have to make those decisions about the girls, aged 7, 5 and 4, who are all on the autism spectrum.

However, their experience of finding good pre and primary school options have them both on high alert.

They are a blended family of nine children, five from Suzanne's previous marriage, and one from Peter's and now three together.

Four of the nine have some form of autism.

Some would say they are unlucky; Peter considers they are blessed. There are challenges though.

"The hardest thing we find is we don't get our one on one time together as often as we would like but hey we've got unique and special kids who come out with things that make them really funny and interesting."

Charlize first came in contact with Morningside School deputy principal and special needs coordinator David van de Klundert (see pages 6 and 7) back in 2014.

Prior to that, she had gone through her assessments at Whangarei Hospital and by the time she was 4, experts had diagnosed her as being on the spectrum.

The search for a primary school seemed simple.

The Caseys lived in Whangarei and were in zone for their local school. They had visited the school but felt a little uneasy about it for Charlize.

Continued page 6



CHALLENGES AROUND: Peter Casey with his daughters (left to right) Charlize, 7, Piper, 4 and Raven, 5. Photo: Liz Inch, Northland District Health Board.

Continued from page 5

"Charlize was a runner and would disappear just like that. For example once I got up to go to work at 6am and there was someone knocking at the door at 6.30am with Charlize. She'd heard me go, I hadn't shut the gate properly and Charlize was out. We had four or five episodes like that," says Peter.

Their local school is on a busy road. Peter and Suzanne were worried. David lived across the road and he suggested the quieter Morningside School would suit Charlize better. It was well fenced and securely gated.

She started there in February 2015.

"I cannot say a bad word about what David did for us. The communication was good. He was involved particularly in the early days, he came along and he coordinated things. He lay down the hard words when he needed to and liaised well with the teachers."

"Charlize has never once said she didn't want to go to school. For example before the last holidays she was in tears because she wanted to go to school."

Raven has different issues. "She was a screamer, it was her way of vocalising, her answer to frustration was to scream and our neighbours didn't like that."

The Caseys moved to the country, to Mount Tiger, about 10kms northeast of Whangarei and enrolled the two girls in Glenbervie School, a semi-rural school with a roll of about 250. Both are doing well there. Charlize is doing better academically this year.

"She is being made to step up and challenge herself, she is getting more stimulation. She just loves school," says Peter.

The couple have their frustrating times. "Things like the girls going to bed. That was a big struggle but we got there. We've got a good routine at the moment but we'll wait for the next wave."

In the meanwhile, they are both thinking of those milestones they need to hit for a successful transition. The journey through primary school seems under control but then there is high school.

"That's the real scary one for Suzanne and me. How are we going to handle that transition? We don't know how they are going to develop. Charlize gets on with people but high school is going to be a major step for her."

The Whangarei community makes it easier for the family to cope.

"In Whangarei you've got a chance for better understanding because it's smaller.

"For example at Morningside, the kids see other kids in wheelchairs, with disabilities or behaving differently, so it's normal for them.

"We don't know if high school will have the same mix," says Peter.

So what is his take-home message to the "system" to those making the decisions, which affect families like the Caseys and children like Charlize and Raven?

"Be empowered be understanding and allow these special children to grow within the system. Empower them to be part of the day-to-day life and education programme. This will give them their best chance of coexisting in the mainstream world after their school lives."



POINT OF CONTACT: Morningside School's David van de Klundert.
Photo: Liz Inch, Northland District Health Board

Team-work needed to guide children on their journey



*Transitioning children from one teacher or from one setting can be a period of uncertainty. Whangarei-based special needs coordinator **David van de Klundert** relies on many people to help him through the transition process.*

IT IS VITAL the transition process, especially between early childhood education and school, is as inclusive and as positive as it can be. In my experience as a Special Education needs coordinator, I acknowledge that transitions can be a period of uncertainty and stress.

The New Zealand Autism Spectrum Disorder Guideline (2016) states that for children with ASD: "Times of transition (from one teacher to another, as well as from one setting to another) are stressful for all children and young people and their parents" (p. 129). In order to allay these pressures, I am reliant on information and advice from many people.

There are three ways I do my first point of contact with a prospective family.

Firstly, through the initial enrolment process with a family that may come into my school to enrol their child. I will meet with family and the child to explain our school, our culture and our strengths and to listen to family about their child's needs.

The second way involves our own contact with our local early childhood education providers whom we are in regular contact with. They will bring to our attention potential enrolments in our school and will alert us to any children who may have special needs.

Thirdly, contact with our early interventionist is crucial. This person works for Group Special Education and links me to the child, to their family and whānau, to the centre and to resourcing.

The more information that these sources of information give me, the better understanding I will have of the child, the family, the resourcing, the interventions, the period of transition needed and what type of teacher and classroom placement will best meet the needs of the child.

From all of these sources I then set about building a transition team that usually involves the family and whānau, the early intervention specialist if one is involved, an early childhood centre member, a teacher and myself. If I can, I bring in my Special Education advisor.

I also rely on the knowledge that I have of my school setting in meeting and managing need. I identify barriers to inclusive practice. In essence the information that I receive about a child is balanced with the information that I have about my own setting.

The New Zealand ASD Guideline (2016) states that, "...the most suitable setting will be one:

- That provides adequate structure and gives the child or young person opportunities for contact with typically developing peers.
- Where staff are well trained and have a positive attitude, expertise, understanding and willingness to work in a team with the family/whānau
- That has the ability to be flexible in meeting the child's needs over time." (p. 127)

Therefore communication is vital. The more I have the better I am able to address needs and supports.

There is another factor that is just as important - that factor is time. Time is crucial on so many different levels.

Everyone involved in the process needs time to:

- Build relationships with the child, the family, the centre, and with and between teaching staff. This is key to a successful transition.
- Meet with other professionals that may have been involved with the child.
- Read all documentation.
- Transition a child into the new school setting to observe behaviours, identify areas of need and to strengthen communication ties.
- Transition a family and whānau into the new school to assist them with their concerns, to celebrate successes, to learn from them about their child's needs and to support a gradual introduction into the school day if required.
- Visit the centre to start a relationship with the child and their family, to observe, and ask questions.
- Support any intervention or resourcing processes that either may exist or are in the process of being applied for.

In reviewing this area of transition, there is still a general need to address the following:

- Better data gathering tools to be shared with schools. Much of what is discussed is based on anecdotal and qualitative data that doesn't always capture such things as the frequency of and triggers of behaviours.
- Better profiling tools that can describe in better detail the specific behaviours across the spectrum and what supports these.
- A better understanding and explanation of the interventions that have been used - why they were successful and the contexts that they are the most successful in, as well as those interventions that have not been as successful, the reasons why and the contexts that this happened in.
- A better understanding by schools of Te Whāriki to better understand areas of focus in both social and education domains so that there can be a better approach to programme continuity.
- For all professionals involved in the transition to have a better understanding of ASD so that shared understandings with such things as evidenced based interventions can be better understood.
- To continue during the transition period, the support that the early childhood centre has in place and the conversations with the early childhood centre once the child starts school.

- To have better built in "check in" times after school has begun after two, four and six weeks as an example by all members of the transition team to better able manage the transition and identify any barriers and to celebrate successes.

As a final word, every child transitions between at least three to four education settings before they complete their schooling.

However, within this they may transition into and out of at least 13-15 classrooms.

Along the way, we in education gather a large amount of information and involve many individuals.

Much of this information becomes lost or deemed obsolete.

This is a shame as this data contains valuable information about each child's growth, their challenges and successes.

Children with ASD and their families and whānau can sometimes become frustrated in repeating their child's story, and advocating for their child's needs.

We need to do a better job, at times, to archive and communicate between settings the information required to ensure that we use transitions as a building block to support continuing growth and positive outcomes.

David van de Klundert is the Deputy Principal and Special Needs coordinator at Morningside School in Whangarei. He is currently completing his Postgraduate Diploma in Specialist Teaching with an endorsement in ASD through Massey University.

New provider for autism services

ASSOCIATE HEALTH Minister Nicky Wagner recently welcomed a new provider for Autism Spectrum Disorder (ASD) programmes, previously run by IDEA Services.



Nicky Wagner

"People with ASD are often vulnerable to sudden change or loss of routine so IDEA's decision to cancel its autism services caused a great deal of unnecessary stress for hundreds of disabled people and their families," Ms Wagner says.

"Within days the Ministry of Health has secured a new provider, meaning there will be no interruption to services."

Explore Services Ltd took over the provision of autism education, communication and behaviour support programmes at the end of April.

"I'm extremely pleased to have a new provider in place so quickly, giving reassurance and security to this vulnerable cohort and their families," Ms Wagner says.

The Ministry will be working with Explore and IDEA Services to ensure a smooth transition. Those referred for specialist autism services will automatically be transferred to Explore.

"Explore already provides specialist behaviour support services across New Zealand and has experience transferring large numbers of clients. Its first move will be to write to anyone affected by this change, including those on the waiting list, and provide more detailed information," Ms Wagner says.

"The Government is committed to ensuring people with ASD and their families have access to the best possible services."

Explore is contracted to provide autism services for two years, ending 31 March 2019.

Transitions #Breakthrough2017

Wednesday 19 July

8am	Registrations		
9am	Whakatau		
9.15am	Opening Address	Paula Jessop	
9.30am	Keynote Speaker	Rita Jordan	Current understanding of the autism spectrum and the implications for education and support
10.30am	Morning Tea		
11am	Presentation Session 1		
	Stream 1	Paula Jessop	Peer support: What is it and how could it help young autistic adults transition to independent living
	Stream 2	Maureen & Tor Poulter	A journey of empowerment
		Rachael Wiltshire	The C word: Personal experiences of coping with change and growing up as an Aspie
	Stream 3	Peter Dowrick	Learning from the future: Autism leading the way
		Karen Sluter	Transitions: Moving forward and overcoming challenges
	Stream 4	Surrey Jackson	Developing our Autism workforce - A collaboration to develop effective autism training
		Jan Hastie	Vicarious Futurity: Identifying strengths in adolescents with Autism from a parent's perspective
Midday	Lunch		
1pm	Keynote Speaker	Maria & Josh Man	Growing up with the bold one-eyed pirate - A brother-sister perspective on living with autism
2pm	Presentation Session 2		
	Stream 1	Emma Goodall	Transitioning from disconnected to connected - Interoception
		Antony Thomas	Severely autistic, yet profoundly artistic
	Stream 2	Sue Kinnear	Smooth transitions
	Stream 3	Michael Mathews & Barbara Choat	Life after mum and dad - A major transition challenge for a person with Asperger's syndrome/high functioning autism
	Stream 4	Neil Burton & Robin Barnaby	Change the story and you change the life: Post diagnosis transitioning through the power of words
3pm	Afternoon Tea		
3.30pm	Presentation Session 3		
	Stream 1 & 2	Mind Over Manner Susan Haldane	Applied theatre workshop designed to teach professionals, caregivers and families effective strategies to support autistic youth through transitions
	Stream 3	Nan Jensen	Legal arrangements for transitions
	Stream 4	Karman (Kar) Vega	Creative stimming: Art as a therapy for our unquiet minds
5.30pm	Sessions Finish		
6pm	Drinks		
6.30pm	Dinner		

*programme is provisional and subject to change

Conference Programme*

Thursday 20 July

8am	Registrations		
8.30am	Keynote Speaker	Sue Kinnear	Smooth Transitions
9.30am	Presentation Session 4		
	Stream 1	Caroline Hearst	Transition to identifying positively as Autistic: The facilitator of a successful peer support programme in the UK discusses the findings of the independent evaluation of the programme
	Stream 2	Emma Goodall	Safety and relationships - Transitioning to adulthood positively
	Stream 3	Keri Opai	What is the Maori word for Autism? Is there such a term?
		Abi Raymond	Transitioning to a place of knowing - Case examples of using a visual and action based therapy approach to support emotional intelligence in young people with Autism
	Stream 4	Rita Jordan	Addressing self injurious behaviour across the autism spectrum: Issues in support and prevention
10.30am	Morning Tea		
11am	Presentation Session 5		
	Stream 1	Tanea Paterson	Psychological health, substance abuse and autism
	Stream 2	Tanya Breen	What I did in my holidays: The critical Autism studies conference and Autism CRC training on participant research in autism
	Stream 3	Rochelle Nafatali	A Pasifika parent's perspective on life after ASD diagnosis: 'The squeaky wheel gets the oil' and fighting the war against low expectations
		Hilary Stace	A life for Ashley and the role of Allies
	Stream 4	Sharon Crooks	High functioning Autists in New Zealand's mainstream inclusive schools: Exploring stories and examining tensions
		Cat Noakes-Duncan & Louise Stickle-Ryan	He kai kei aku ringa ('there is food at the end of my hands'): The story of spectrum playgroup
Midday	Lunch		
1pm	Keynote Speaker	Jason Edgecombe	Shattering your cage
1.45pm	Presentation Session 6		
	Stream 1	Beth Noble	Autism and sensory processing in the built environment - "Lived experience and the research project to find more"
		Matt Frost	The ASD Action Plan - An update
	Stream 2	Ian Ward	It's all about the family
		Madison Ward	What about me - I am normal too
	Stream 3	John Craven	Specialisterne: Seizing the opportunity of autism - a global shift
	Stream 4	Estelle Pretorius	Transitions in the early years
2.45pm	Afternoon Tea		
3.15pm	Keynote Speaker	Pete Dowrick	Learning easily: It all comes back to feedforward
4pm	Closing Address Catherine Trezona		
4.10pm	Poroporoaki / Karakia		

Critical autism studies: Making a positive difference



*Listening to the opinions of autistic people has taken on a new life prompting Waikato consultant clinical psychologist **Tanya Breen** to ask and answer: what are critical autism studies?*

CRITICAL AUTISM STUDIES is a relatively new field of scholarly thought that originated in 2010 (O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow, & Orsini, 2016).

Proponents of critical autism studies are concerned with making a positive difference in the life experiences of autistic people.

The three main components of this interdisciplinary approach are:

1. Scrutiny of the power relationships within the autism research and practice.
2. The promotion of positive accounts of autism that confront the prevailing negative views that influence how autism is considered by the public, addressed by government, and represented by the media.
3. The development of research methods and theoretical approaches to autism study that are inclusive and valuing (Davidson & Orsini, 2013).

Critical autism studies is not the sole preserve of the academic community. The values of critical autism scholars are shared by many autism advocacy and self-advocacy networks (O'Dell et al., 2016).

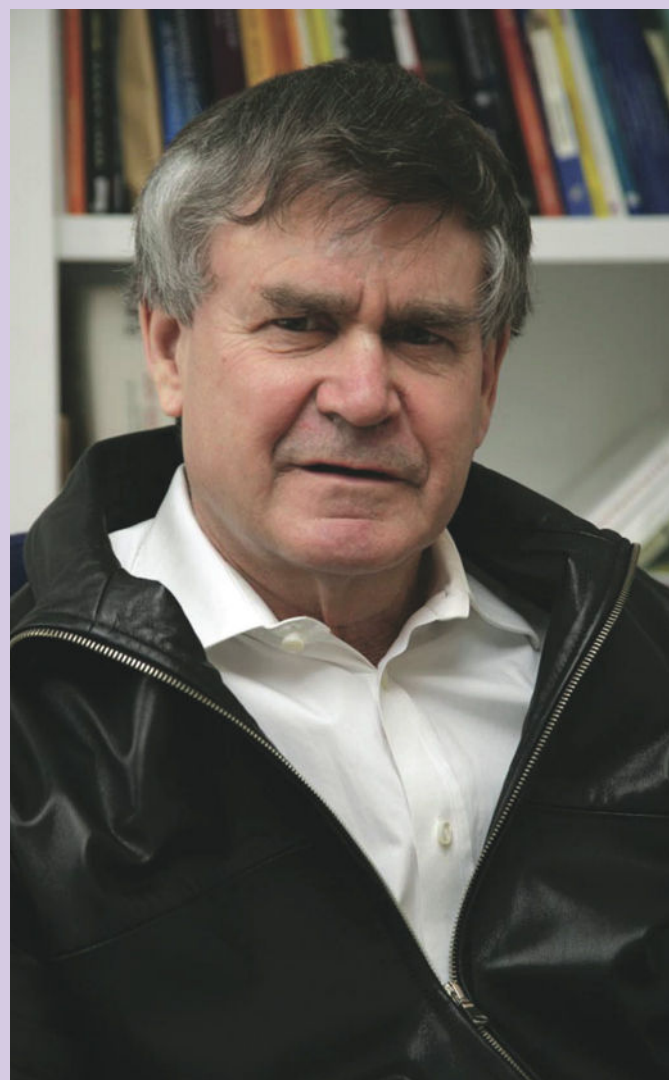
Philosopher Ian Hacking and Looping

Central to critical autism studies is the work of Canadian philosopher Ian Hacking. When considering the classification and categorisation that happens to people who are different, Hacking formulated the notion of 'looping', a process that transforms both the classifications/categories, and the people defined by them (O'Dell et al., 2016).

Hacking described 10 looping stages:

- Counting, when the focus is on identifying how many people fit into the category
- Quantifying, which focuses on developing or changing diagnostic criteria
- Norming, against which categorised people are measured
- Correlating, when even unrelated factors are correlated with the category
- Medicalising, when the labelled people are defined as ill or disordered
- Biologising, the search for biological causes
- Geneticising, the search for genetic explanations

- Normalisation, implementing treatments and interventions designed to make the categories people as normal as possible
- Bureaucratising, consisting of state implemented systematic strategies of diagnostic surveillance and intervention
- The final stage of resisting, when the people who are classified reclaim control back from the experts and institutions, and in doing so sometimes create new experts and institutions (Hacking, 2002, 2006).



CANADIAN PHILOSOPHER: Ian Hacking

Hacking has also considered autism specifically (Hacking, 2009a, 2009b, 2009c, 2010). Of relevance is Hacking (2009b), which emphasised the value and importance of listening to the opinions of autistic people. Hacking (2009b) suggested that through autobiography, autistic people were challenging what non-autistic people think they know about autism, and were developing language to "describe experiences for which there is little pre-existing language" (p. 1467).

An Example of Looping Using the New Zealand Context

There are numerous examples of looping in autism in New Zealand, but to illustrate, I will mention one: the counting-quantifying-realising loop. As many people know, formal classifications of autism by the American Psychiatric Association and the World Health Organization (the DSM and ICD diagnostic systems respectively) have changed significantly since autism was first described, and New Zealand is unique in that we have another definition, that used in the New Zealand Autism Spectrum Disorder Guideline (Ministries of Health and Education, 2016). With each change of diagnostic criteria, what is and is not the 'official' version of autism changes. These changes can be experienced as very threatening to previously diagnosed people (and their families), not the least because diagnosis impacts on self-identity, place in the autistic community, and eligibility for support. Contributing to the problem, to plan services, the Ministry of Health and other organisations need to estimate demand (requiring them to "count").

However, it is difficult to do this when the definition of what is to be counted changes. Furthermore, whilst diagnosis was initially driven by medical professionals wanting to quantify autism, changes in how autism is defined are also now driven by the lived and reported experience of autistic people (i.e., the inclusion of sensory issues in the DSM-5 diagnostic criteria is a case in point). This has also changed the counting and the quantification.

In addition to complicating service provision, the changing understanding of what autism is, caused by looping, underlies a source of tension in autism in New Zealand - namely the debate about who is autistic, and who has the right to speak on behalf of non-verbal autistics.

Interesting Research

Some research and articles using the critical autism approach that I have found interesting include:

- In Sweden, humour and joking were investigated by a researcher who joined a class of 10 students with Asperger syndrome, aged between 20 to 50 (Bertilsson Rosqvist, 2012). Probably not surprising to the autistic community, the researcher found that joking and humour was common. However, this finding seriously challenges the neurotypical and medical view that autistic people don't understand and use humour.
- In Canada, applied behaviour analysis (ABA), an intervention commonly used with autistic children, was investigated (Gruson-Wood, 2016). The focus was on the experience of being trained to be an applied behaviour analyst. The researchers summarised some of the controversy about ABA that occurs within the autistic community, including the concern that autistic children are subjected to intensive surveillance and repetitive demands. They found that trainee applied behaviour analysts were subjected to very similar (even the same) processes, with positive and negative effects. Interestingly, the researchers described good therapists as those who became "docile", and who demonstrated masculine objectivity.

Self-diagnosis of autism was considered by one US researcher (Sarrett, 2016), in particular, the controversy about self-diagnosis that exists within the online autism community, Wrong Planet. The researcher engaged in online conversations with autistic people, and discovered that whilst the autistic community promote the notion of autists as autism experts, there was heated debate about whether full membership of the autistic community required formal diagnosis by a medical or psychiatric professional. This was further complicated by the lack of confidence that many autistic people had in the diagnostic skills of the medical and psychiatric professionals.

Thoughts on Critical Autism Studies and the 2017 Conference

I believe that through critical autism studies, findings will emerge that shape policy and processes for autistic people, improving their life experiences. I am excited by inclusive research, where the knowledge and skills of autistic people are valued and used to identify research topics, and shape methods, producing autism research that is interesting, meaningful, and challenges neurotypical ways of thinking about autism.

The third critical autism studies conference takes place in London in June 2017. The theme is "Travelling Through Autistic Worlds in Policy, Practice and Identities".

Judging by conference proceedings from the previous meetings, presentations will be made by autistic people, academics, researchers, and family members, and cover topics as wide ranging as the analysis of first person and parental narratives of autism, to neurodiversity, and autism as a social movement. Somewhat nervously, I will be presenting some early work undertaken as part of my current doctoral studies into autism and legal proceedings. I hope to share information about what I hear and learn when we gather in Auckland for the Altogether Autism conference on 19 – 20 July 2017.

About Tanya Breen

As a consultant clinical psychologist in private practice in New Zealand, Tanya Breen often appears as an expert witness in criminal cases where autistic people are charged with criminal acts. She also undertakes autism diagnosis, assessment and intervention/support with individuals and their families, and provides professionals with autism training. Tanya is well known for her work on the New Zealand Autism Spectrum Disorder Guideline, her role in the development of Altogether Autism and work as our first clinical consultant, and her work with the Ministry of Health on a range of other autism related topics. Tanya is currently working towards the degree of Doctor of Health Science, where she is researching autism and legal proceedings.

References

- Bertilsson Rosqvist, H. (2012). The politics of joking: narratives of humour and joking among adults with Asperger's syndrome. *Disability & Society*, 27(2), 235-247.
- Davidson, J., & Orsini, M. (2013). Critical autism studies: Notes on an emerging field. In J. Davidson & M. Orsini (Eds.), *Worlds of Autism: Across the Spectrum of Neurological Difference*. Minneapolis, MN: University of Minnesota Press.
- Gruson-Wood, J. F. (2016). Autism, expert discourses, and subjectification: A critical examination of applied behavioural therapies. *Studies in Social Justice*, 10(1), 38-58.
- Hacking, I. (2002). *Historical Ontology*. London, England: Harper University Press.
- Hacking, I. (2006). Making up people. *London Review of Books*, 28(16), 23-26.
- Hacking, I. (2009a). Autism and talent. *Philosophical Transactions: Biological Sciences*, 364(1522), 1467-1473.
- Hacking, I. (2009b). Autistic autobiography. *Philosophical Transactions: Biological Sciences*, 364(1522), 1467-1473.
- Hacking, I. (2009c). How have we been learning to talk about autism: A role for stories. *Metaphilosophy*, 40(3-4), 499-516.
- Hacking, I. (2010). Autism fiction: a mirror of an internet decade? *University of Toronto Quarterly*, 79(2), 632-655.
- Ministries of Health and Education. (2016). *New Zealand Autism Spectrum Disorder Guideline* (2nd ed.). Wellington, New Zealand: Ministry of Health.
- O'Dell, L., Bertilsson Rosqvist, H., Ortega, F., Brownlow, C., & Orsini, M. (2016). Critical autism studies: Exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability & Society*, 31(2), 166-179.
- Sarrett, J. C. (2016). Biocertification and neurodiversity: the role and implications of self-diagnosis in autistic communities. *Neuroethics*, 9(1), 23-36.

Historic settlement will benefit autism clients too



*New Zealand's 50,000 care and support workers accepted a \$2 billion negotiated equal pay settlement from the Government in April. **Karen Gregory-Hunt** of the E tū union explains the difference it will make in one woman's life.*

THREE YEARS ago, Moana Witehira began working with intellectual disability provider, IDEA Services in Whangarei – and quickly realised she had found her niche.

Moana works one on one with a woman with autism as part of her role as a senior vocational support worker. She helps develop the skills of the people she works with and ensures they lead meaningful lives in the community.

"I get to do different things every day which I know has an awesome impact on the people we support," says Moana.

"It's tough – it's one of the hardest jobs that I've ever had. But I love my job. I love the people I support with a passion.

"They make me smile going to work and that's why I've been going to work on such a low wage because their smiles just brighten up my day and I feel like I'm doing something good for the community."

Until recently, Moana who has a Level 3 qualification, earned less than \$18 an hour. Her promotion to a senior vocational worker bumped her pay to \$19.28 an hour. The Equal Pay settlement will lift her wage to \$23.50 an hour – which she says will transform her life and that of many of her workmates.

"I won't have to stress so much to pay my bills, because I'll have the extra income. Things will be less of a struggle. I'll be able to afford to go on holiday. It will mean a lot for my workmates too.



Moana Witehira

I don't do overtime but my workmates do, if they don't have kids and they want to make more money, it means they won't have to work 100 plus hours a fortnight. People do that all the time. They always have to pick up extra hours."

Moana is adamant the settlement will also be hugely beneficial for her autism clients, by reducing staff turnover and providing more stability and routine, which people with autism, like her female client, need.

"She's highly anxious, especially when it comes to changes in her routine, and that includes staffing," says Moana.

"She can have behaviours where she hurts others when she has staff changes. So the equal pay settlement will have lots of benefits for people with autism. At the moment, we go through a lot of staff and I think that's due to pay," she says.

Moana says people with autism are also very quick to pick up on issues like stress.

"I believe the equal pay settlement will target the right people for the right job, because at the moment we're offering minimum wage pretty much. And because we're going to have a better pay rate very shortly, we'll see a lot of good going back to the people we support - because obviously, we'll be getting paid what we deserve and that will cause a lot less stress in our lives and we're going to better support our people.

"I think people with autism can feel that; that's a part of how they are. They know the people's vibes that they're working with. That's how they kind of feel and react to people and read their body language. If the people caring for them are stressed, it's my experience they can pick up on that and that can cause them to have anxieties and behaviours.

"Happy staff, happy clients," says Moana.

"People with autism really rely on routine to cope with everyday things and I really do believe that this will target the right people for the right job."



CELEBRATING: Moana Witehira (bottom left) celebrates with other IDEA delegates following the historic equal pay settlement.

Tēnā koutou katoa e te hunga pānui
Ko Taranaki te tupuna maunga, Parininihi ki Waitōtara, Waitōtara ki Taipakē.

A time and space for Takiwātanga



Racism filled schooling for Keri Opai but there was discrimination against anyone who was different, including those with autism. Today he has come up with a Māori word for 'autism'. He explains the interpretation and the journey taken in creating it.

WHAT IS the Māori word for 'autism'?

Is there one?

As of yet, no. But I'd like to hope that I've come up with an appropriate interpretation for a glossary I'm producing for Māori language use in the Mental Health, Addiction and Disability sectors that will be launched at Matariki/Puanga time (the Māori New Year) this month (June).

The resource creation project is called 'Te Reo Hāpai – The Language of Enrichment'.

The word I have coined in te reo Māori for autism is 'Takiwātanga'. It is a derivation of my phrase for autism: "tōku/tōna anō takiwā" – "my/his/her own time and space".

I am sure many people have harrowing war stories about difficult times at school.

All throughout my schooling from a little boy, racism was a constant, pervasive aspect of student life but going hand in hand with the racism was the umbrella discrimination against anyone that was different.

Different from the Pākehā, privileged, multigenerational farming families.

That included a group of secondary school students cruelly jeered at and demeaned who had any disability. From kids having cerebral palsy to being in a wheelchair to stuttering, these underprivileged were ostracised, criticised and berated at any given time.

They were cast aside and sometimes beaten up for no real rhyme or reason except to make the bullies feel better about themselves and their own inadequacies.

Feeling some sort of connection with other young people who were different and shunned, I would sometimes play games and socialise with members of the group. I especially liked a guy called Peter who happened to have autism. He was funny and musically talented and we got on well.

Unfortunately, most of the rest of the school didn't feel the same way and poor Peter was bullied no end. If I saw it going on I would stand in the way and tell the bullies they had to come through me first. Of course, they never would take me up on the offer because they were cowards and afraid of getting a hiding.

This was my introduction to autism and the misunderstanding surrounding it. So, when I took on the privilege and burden of creating a Māori word and concept to describe it, my first thought was that I wanted to honour my life-long friend, Peter.

Peter is still a good friend of mine and other than honouring him, and the struggle that people with autism like him can go through, I needed to talk with others who had knowledge and experience that could help me with a Māori interpretation.

I talked with a couple of clinicians but their perspective was always, not unsurprisingly, clinical. Lots of jargon and terminology that was always rather removed and sterile and polysyllabic words that would threaten to squash an elephant with their weight.

I talked with John Vogenthaler, the resident expert at my



THUMBS UP: Keri Opai (right) with Peter.

organisation Te Pou o te Whakaaro Nui, which was really helpful and he put me in touch with Matt Frost, a really neat person with autism who was also a researcher and policy analyst. We arranged to meet at Matt's favourite café and we spent a good couple of hours just chatting and sometimes talking specifically about how he experienced his autism.

Sitting there and talking for hours it reminded me very much of when I would spend time with kaumātua (Māori elders) and their style of teaching/informing/sharing. The conversation would meander and sometimes become tangential but if you leaned in, really listened, got into the same timing and rhythm, there were pearls of profound wisdom aplenty.

This is what I based my interpretation on; that people with autism tend to have their own timing, spacing, pacing and life-rhythm. I recalled times with my mate Peter doing things like going to the movies where he would laugh loudly at some parts that weren't intentionally humorous and my time with Matt and other people with autism I've known in my lifetime and this seemed to be the best way to describe the experience. As well, it seemed quite a positive way of explaining it and that is very important to me and essential for the Te Reo Hāpai resource in creating clear, correct and appropriate Māori language for now and the future. Hence, 'Takiwātanga'.

As my kaumātua says: "He mana tō te kupu" – "Words have great power."

I hope my interpretation pays adequate respect to caregivers and people, friends and whānau with autism.

Tēnā tātou katoa

Keri Opai is Paeārahi – Māori strategic lead at Te Pou o te Whakaaro Nui where he guides responsiveness to, and engagement with, Māori people, organisations and iwi. His experience is predominately in education and he has taught te reo Māori and tikanga Māori since he was a teenager. He is a licensed interpreter and has a Master's Degree in Mātauranga Māori (Māori Knowledge).

Autism-friendly practices for gatherings

1. TOILETS:

Autistics often need to know where the disability toilet is even though they may have no apparent or obvious physical disability. Other toilets are often scary social environments they find difficult to navigate.



7. ATMOSPHERE:

Autistics prefer that any breakout groups meet in separate rooms. Some find it hard to 'tune out' noise or conversation from other groups due to auditory processing issues and an intense desire to focus.



2. PARKING:

Autistics often need parking pre-organised - whether paid or free. If they are reclusive they don't want to walk long distances in public; if they are bewildered by cities they don't want to immerse themselves in them before an important meeting; and if they are anxious they will want to be on time and prepared - not late and rattled.



8. ACCOMMODATION:

Autistics who need to travel long distance to attend gatherings may prefer to be accommodated the night before or after the meeting. Travel can be very stressful and involve much unsettling processing, which can compromise social and personal safety, as well as their sense of wellbeing.



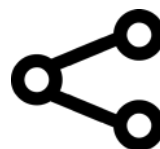
3. LIGHTING:

Autistics often prefer no overhead fluorescent tubes or sufficient natural lighting to limit its effects. Many autistics see at a higher rate of frames per second because of the absence of typical neurological visual filters and flickering light may disturb them, while bright lights can be overwhelming.



9. RETENTION:

Autistics often prefer not to see group work discarded whether it's large format paper sheets or whiteboards, or even pages on a group note taker's pad. Either destroy the material after they have left, or - better still - offer each individual a copy as contributors to the material.



4. SPACING:

Autistics often need increased personal space. Many autistics are very uncomfortable with close proximities, especially in clammy, perfumed, hostile and drawn-out gatherings.



10. TIMELINESS:

Autistics often prefer that schedules are adhered to as planned. Keep them informed if there are any schedule changes and the reasons why changes have been made.



5. RETREAT:

Autistics often need a place to retreat. Many experience anxiety and emotional challenges that are only resolved through finding refuge in a low sensitivity environment (preferably marked 'Reserved' and 'Quiet Please!')



11. WELCOMING:

Autistics often prefer a friendly face or someone they know from a picture or website. If requested, ensure a greeter is available at the right time and where necessary have autistic attendees send through a picture of themselves ahead of time.



6. SEATING:

Autistics often prefer to have nothing between them and the wall behind them, and prefer to sit near the exit. Many experience low-level unconscious discomfort and are more likely to need to quietly exit a room than typical folk.



12. RELEVANCY:

Autistics sometimes need to be reminded when they are speaking too long or when their contribution is off topic. Use forthright but gentle reminders to let speakers know if they are running over time rather than humour, subterfuge or subtle hints.



These are some of the needs many people with autism may have when attending gatherings, meetings or conventions.

Please consider each one when organising a meeting, especially if more than one autistic is there.

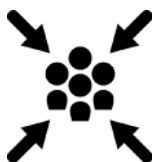
13. MATERIALS:

Autistics are often word-based or visual learners and prefer written or pictorial materials. Ensure you use appropriate visuals for key concepts and circulate full documentation well ahead of time as autistics are unable to 'parallel process' information during meetings and need to think about things beforehand. Be aware that some autistics may prefer to be 'away with their thoughts' chewing over material at tea breaks and lunchtime...alone.



14. EMERGENCIES:

Autistics can become confused or anxious during an emergency or venue evacuation. Ensure one staffer is ready to guide all autistics to the correct assembly point.



15. VOCALISATION:

Autistics often have difficulty hearing consonantal sounds. Ensure microphones are functioning correctly and not hissing. And make sure those who rely on consonantal lip-reading can see the speakers' faces clearly.



16. SOUNDS:

Autistics are often unsettled by repetitive sounds such as clicking, hissing and ticking. Check the environment to see if any devices such as air-conditioning units or clocks could cause distress. Be aware the some autistics are very sensitive to sound - even small or faint sounds - when trying to focus.



17. ENVIRONMENT:

Autistics often find it challenging to cope with some everyday things like strong perfumes, bright colours, food smells and draughts. These things should be assessed during the planning process. Wherever possible ask participants to tone down perfumes and deodorants, mask bright walls and seat autistics away from the lunch areas and open windows or air-conditioning outlets.



18. VENUE MANAGEMENT:

Autistics expect venue staff to have an understanding of autism. This will ensure unusual requests or behaviours are handled sensitively and professionally.



19. ASSISTANCE:

Autistics may not always know when to take matters literally, or when it's their turn to speak or to offer an opinion. Don't hesitate to ask them individually "Do you have anything to add?" and to warn them that it is the last opportunity to speak before moving on to the next topic. If participants are expected to complete tasks, such as feedback surveys or expense claim forms, you should be specific and proactively offer assistance.



20. REFERENCE:

Use language as preferred by the individual. Most autistic people like to be called autistic while some prefer 'person with autism'. Some may refer to themselves as 'autistics' or 'auties'. Check with individuals of their preference and use appropriate language accordingly.



21. IDENTIFICATION:

Autistics who are advocates may prefer that other attendees are aware of their condition. They may choose to mention it when they introduce themselves to others, but also consider offering them identification.



Adapted from information provided by Asperger's Syndrome New Zealand.

Donna Williams: A tribute



PASSED AWAY: Polly Samuel, also known as Donna Williams, passed away in April.



*Chris Samuel informed Facebook followers of the death of Polly Samuel aka Donna Williams on Saturday 22 April 2017. **Paula Jessop** writes this tribute about the Australian woman who inspired many, including her.*

USUALLY I love to write and words flow easily onto the page. In writing a tribute to Donna, I have no idea where to begin. As tributes to Donna circulate social media and autistic people come forward to speak of the profound effect she had on their lives, I wonder how any of us can capture the person she was.

My first encounter with Donna was through her book "Somebody Somewhere". I picked it up at a bookstore thinking it looked interesting. What I read stunned me as I related strongly to her descriptions of her thoughts, feelings and experience of the world. Later I was to discover it was her second bestselling autobiography and her first book "Nobody Nowhere" was in fact, the first autobiography written by an autistic person published in mainstream publishing and became an international best seller spending 15 weeks on the New York Times bestselling list.

Donna's documented life was at times a harrowing read. Her journey had held homelessness, abuse and every type of life experience most would seek to avoid. But she was not bitter.

Reading Donna's book led me to wonder if I too was autistic and seek assessment for diagnosis. Like many, her first impact on my life was helping me discover I was autistic.

Donna went on to write four autobiographies and four informative autism textbooks along with many poetry books. She became one of the first autistic people to speak at autism conferences and she travelled around the world giving keynote presentations. She was an outstanding, engaging, funny, deeply informative presenter. I saw her speak in 2010 and like most of the audience I sat captivated by every word, spellbound by her charisma and intellectually prodded by her very original theories about autism.

She was stunning and then she humbly came to hang out in the retreat room with other 'everyday' autistics as if she was just one of us.

She wore many hats in life and achieved goals with gutsy whirlwind passion. Donna wrote frequently. She hypothesised about autism, the world, spirituality, living and what might make a better humanity. She was herself a humanitarian who quietly gave of herself to causes and people in need. She churned out poetry into books and challenged other autistics on social media to poetry sessions for fun.

Art seemed easy to her and she painted original pieces with her usual speed. She was also a musician and lover of being silly, dancing, laughing and not taking life too seriously. The only thing she seemed to really take seriously was to promote the power of love and the need to love.

The second impact Donna had on my life was through online consultations. Like many others now speaking of how deeply helpful Donna's consults were, I found the same.

After a lifetime of trying to manage serious bouts of mental illness, recover from deeply traumatic life experiences and find a way to move forward in life, Donna gave me a sense of peace and hope. Her style of mentoring was not to tell us what to do, but tell us what we could do. What we were capable of and empower us to be ourselves, unashamedly in the world.

Like many others, I continued to keep in contact with Donna for many years, via email, social media. She became a friend of sorts although I'd never profess to be in her inner circle. But we chatted via social media semi regularly and both seemed to enjoy doing so. As famous as Donna actually was, she seemed to enjoy just feeling a part of autism communities as herself, another autistic person, not as famous Donna.

Yet the fact is, she was famous and she did have a huge impact on shifting ideas about what autism is and influencing many an autism professional. She also reached many parents and these parents report her knowledge fundamentally useful in understanding autism.

Many of us who had some contact with Donna loved her lack of ego whilst also respecting her many years of autism advocacy, which did help enhance understanding of autism.

It needs to be said, Donna was one of the founding members of Autism Network International, which was the first international community of autistic people. She was also one of the pioneers of the neurodiversity movement. Many of us are forever thankful for Donna's part in the pro autistic social movement.

For me, I'm deeply saddened by the loss of my long distance friend. For the autism communities, we lose an amazing advocate, a mentor, a teacher. We thank her for her dedication and endeavour to honour her work. We send our condolences to Chris, her soul mate and husband. Goodbye and rest in peace Donna.

PS. Donna did change her name to Polly and although she liked us to shift from calling her Donna to Polly I never did. It's ok, one of the things she liked about me was a stubbornness in doing as I was told.

Paula Jessop is a member of the Altogether Autism Consumer Reference Group and an Aspie presenter known for giving thought provoking speeches relating to 'lived experience' of Autism.

Appreciation and integration in the workforce



Experts say the rate of diagnosed autism is approaching two per cent of the population and that less than 20 per cent of higher functioning adults with autism are fully employed. **Mary Anne Gill** spoke to an Australian consultant who says that means there are probably 80,000 people in New Zealand who could be working and are either not working at all or are not fully utilising their talents.

JOHN CRAVEN loves telling success stories, like the one about the woman on the spectrum given two years to complete a project and she did it in three months.

"They wanted to give her an award and she said 'no, just give me another project to do.'"

During his week in New Zealand, John produces story after story about people with autism excelling in the workforce and getting jobs after brave employers saw through their social and non-verbal communication difficulties and took a punt on hiring them.



John Craven

In fact, he says, it is "brave" for an employer not to hire someone with autism given his or her strengths. People with autism have skills that can be invaluable in many areas including well-recognised areas like information technology (IT), cyber security, data analytics, fraud management and records management as well as other roles in the creative and animal husbandry areas.

It is in the area of IT – the low-hanging fruit as John calls it – where people with autism could provide an immediate solution to New Zealand's current chronic shortage of talent.

"A high proportion of people with autism are good at IT including data analytics and cyber security. The autistic person is often able to think outside the box, outside the square.

Continued page 18



NINE TO NOON: Altogether Autism national manager Catherine Trezona with Specialisterne Australia chair John Craven in the RNZ studio during an interview with Kathryn Ryan on Nine to Noon.

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They are visual. They look at the problem and can pick the patterns. We have clients all around the world, particularly banks, who use them successfully to manage security and detect fraud."

John graduated from Melbourne University in 1972 with a Bachelor of Science majoring in mathematics and statistics. He joined Arthur Andersen, a leading global professional services company, which today is Accenture. Fifteen years ago, he set up his own consulting firm which he sold in 2014 and in May 2015 established Specialisterne Australia as its inaugural chair.

Founded in 2004 in Denmark, Specialisterne (the Specialists) aims to prove that people with autism can be valuable members of the workforce so long as employers understand their talents and they receive the support they need to excel.

Individuals with autism often have the critical skills needed by companies such as attention to detail, high diligence, perseverance and a low tolerance for mistakes. That makes them an untapped resource, says John.



Thorkil Sonne

"I've been inspired by Specialisterne, the founder, Thorkil Sonne, is very charismatic and very passionate and sincere about reaching Specialisterne's goal of 1 million jobs globally by 2025. We're just trying to help and do something positive.

It's very good for business and government. Business is always looking for good talent and in fact they're sitting right under our noses."

Since Specialisterne's expansion into Australia, 80 people with autism now have careers in IT, engineering and farming.

In fact, the farming success has John producing yet another story of success.

In a pilot programme with SunPork, Australia's largest producer of pork, five percent of their farm-based workforce are people on the spectrum.

"We had one guy who loved the job, loved the pigs, but couldn't stand the smell of the pigs. We tried everything, peg on nose, mask, putting perfume on a handkerchief but he just couldn't do it.

"So we found him a job in the workshop instead. He is the most brilliant equipment repairer/manager. He repairs motors, tractors, cars, they needed someone, they got the best. He still hangs out with the other guys in the workroom who are working with the pigs."

There is a danger that putting a person with autism into the wrong job can result in long-term damage.

John is careful to guide employers into placing people into jobs that suit their individual talents.

Noisy environments can often provide problems because of sensory overload, flashing lights and many conversations can rattle them.



"Just as a generalisation, but pretty accurate, autistics are not good at surprises so customer service is probably an area they're not best suited to."

That no surprises attribute can often floor them out at interviews too.

"The interviewer is trying to catch them out and because they don't think on their feet that well they get caught out. And they tell the truth."

John mentions a computer programmer on the spectrum who knows 30 computer languages. He applied for a job in Canberra in cyber security and he went through their normal process. When it came to the interview, he failed.

"They asked him 'are you an expert programmer?' and he said 'no'. He didn't think on his feet. He was being honest because in his eyes he was not an expert."

Then there is a danger of pigeon holing people with autism.

"We had a lady who looked good at IT, she was super smart so good at anything.

"We got her into our assessment programme and she was two weeks into it and she didn't seem to be tuned in. Our consultants got talking to her and she said she really didn't want to do IT. She could do it but she loved design. She wanted to draw things so she became a designer and is successful at that."

While there are some with outstanding talent, there are other who are not geeks, as John puts it, but are still worth employing.

"If your focus is opportunity and reward then look at the autistic talent as part of your secret weapon."

There have been some autistic people who are lazy and use their autism to cover it up, he says.

SPECIALISTERNE

Passion for details





CATCHING UP: Specialisterne chair John Craven reads the Altogether Autism journal watched by (left to right) Altogether Autism national manager Catherine Trezona and researchers Rebecca Armstrong and Liliya John.

"Usually it's about motivation and support. Too many of the bad stories we hear are about the people who are bored in their jobs."

John has plenty of theories about people with autism.

The codebreakers in World War II, for example, are "absolute straight A autism".

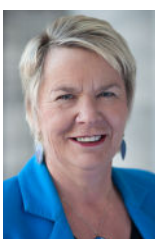
The authors on Wikipedia are also probably mostly autistic, he says.

"They want to do something that's important and useful."

Autistics make good modern-day spies in cyber security and detecting fraud.

"One of the things they'll do is they detect patterns and they have patience. They'll do something for a long time because they want to solve it. We had a company who wanted people reviewing logs. The autistic person will go down the list for hours; a neurotypical person wants half an hour on, half an hour off."

John found the trip to New Zealand inspiring. He met Disabilities Minister Nicky Wagner at the Beehive in Wellington.



Nicky Wagner

She wants Altogether Autism to provide a profile of 40-60 autistic people who have the potential to work in the government sector.

"I'm very interested in Specialisterne Australia's work and the possible applications for New Zealand," she says.

"John outlined some of the organisation's successes supporting people with autism spectrum disorders into jobs that match their unique talents."

"People with ASD are a fantastic source of talent for employers and can really bring a competitive edge to businesses."

Altogether Autism national manager Catherine Trezona says the next step is to develop a survey for people with IT skills and an interest in working in the state sector.

"This is not an offer of work but more of a scoping exercise to help us get an idea of who and how many potential autistic IT employees are out there."

John and Catherine met with 13 organisations during the week.

"We have a model we're showing to employers. We think the community needs to move from being perhaps a little apprehensive about autism to being appreciative of the unique talents," says John.

Altogether Autism will conduct a survey on autistic employment experiences from both employees and employers as a lead up to the Transitions #Breakthrough17 conference in July where John is a speaker.

"It's important because there are some fantastic people at the heart of this and their families and the people they live with and grow up with who are impacted.

"Here we have a group who could be contributing to the community, to business and be fulfilled and they just are not.

"The figures are embarrassing. Only 20 per cent are working to their capacity."

That has to change, says John.

Mary Anne Gill is communications and marketing advisor for Life Unlimited Charitable Trust and a former award-winning journalist.

Putting children's needs first



*Parents of special needs children get used to having doors slammed in their way so **Rebekah Corlett's** experiences with her son made for a welcome change. Here she explains how that attitude change made a big impact.*

THIS MORNING, as I was helping my 5 year old son Ryan hang up his schoolbag and coat in his classroom, he turned around and said quite bluntly "Bye mum, go to your house."

There it was. A glorious kick in the guts that made me gasp, smile and get teary all at the same time. He was telling me, in his unique way, that after a few weeks at school he was okay with his new environment, he did not need me holding his hand any more - and most importantly that the transition from kindergarten to school was now complete.

Ryan has Global Development Delay, which for him means that he has cognitive and communication delays, poor motor skills and some anxiety around any change of routine. His early childhood education teachers, therapists and aides all agreed that Ryan was a charming little boy, who loved running with his friends, but struggled when it was time to focus on a single activity.

In his last year at kindergarten I lost count of the number of nights I lay awake worrying how I could possibly send a child to school who only spoke 2-3 word sentences and couldn't hold a pencil!

Despite all Ryan's challenges, I had to really push our lead worker to submit an ongoing resourcing scheme application. They were concerned that he would not meet the narrow criteria for funding, yet I persisted.

When the application was approved, it gave me the confidence I needed to oversee Ryan's transition myself. I did not want to step on anyone's toes, but I knew the potential for failure if his needs were not put first. I did not want to encourage any anxiety around making school a part of his daily routine just for the sake of following some ministry guidelines.

I wanted Ryan's temperament to set the pace and length of the transition. If I did not think he was in the right mood for a school visit, we would reschedule. If he was happy to stay for an extended visit, the school were very accommodating. We visited at different times of the day so he got a taste of all the perks and challenges of a full day of school. Whether he was taking part in a group activity, or happily sitting observing what the other kids were doing, it was all relevant preparation for school.

I also made sure that I was present for the visits, rather than his support worker. Ryan loved his education support worker dearly, but ministry rules meant that she could only stay for part of the visit, which I thought was too confusing for Ryan, and unnecessary. On the first visit, I sat with him, and as he got more comfortable, I stepped back. By the last visit, I was able to leave the room completely.

My daughter Sophia, 8, attends the same school in the specialist satellite class. She has Autism Spectrum Disorder, and is non-verbal. Specialist school was a perfect fit for her social and learning needs. At times I wondered if we as a family had made the right choice sending Ryan to a mainstream class. Specialist school seemed so much more straightforward than being an Ongoing Resourcing Scheme -funded student in a mainstream school!

A teacher friend of mine commented that we should base our decision on where he fit in best socially. I noticed during one of our school visits that Ryan was more on par socially with the kids there than when we visited Sophia's class. He was being included as an equal, and that silenced every one of my concerns about our school choice right then.

Even the small things made a big difference in Ryan's transition. Every morning as we dropped Sophia off at her class we would walk past his room, stopping to look in the window and point out his room number. At home we would refer to school as 'room 1' which worked really well to remove any of his anxiety around the mention of the word 'school' and leaving his kindy friends behind.

Most importantly, the school opened their doors to our whole family. The principal and teaching staff have made sure that we knew that we could come and ask any questions that arose. Parents of children with special needs seem to be much more akin to doors being slammed in our faces, than opened to us, so that was another small gesture with a big impact.

Now that Ryan is well settled into school life, I can look back at the transition process with some pride. We took our time, followed his lead and it all went quite smoothly. Obviously, I know that it will not always be like this - we will take it all in our stride, day by day.

The great thing about finding the right school is that the child-parent-teacher relationship can evolve as the child grows. It is a truly collaborative arrangement, where we all take turns at talking, listening and leading, and where Ryan is always at the centre of our decisions. So the transition from early childhood education to school may be complete, but the learning journey continues.





TRACTOR MAN: Richard Genet with his father Anton in the workshop at their Tauranga property. Photo: Bill Hedges, Rotorua.

Valuing team work in a unique situation



*As children on the spectrum age, it can make it difficult for their parents. **Mary Anne Gill** talks to a Tauranga woman about how her 41-year-old son is still transitioning.*

PEOPLE CALL Julia Genet a “champion for change” and her son Richard the “tractor man”.

The 69-year-old mother of two makes no apology for her description and is about to take that even further by offering her innovative company concept to other families in the Bay of Plenty.

The rationale behind her and daughter Caroline establishing New Breeze Ltd in 2004 was a frustration with the system that provided funding and support for Richard who in 1994, at age 18, finally got an official diagnosis of autism and intellectual disability, which in 1999 via a needs assessment, brought with it funding from the Government.

The family, husband Anton, Julia and Caroline, were living on a Hawke's Bay farm when Richard was born in April 1976.

“Richard was very challenging. He clearly had an intellectual disability, cause unknown,” says Julia.

“When he was 7, he was spinning, screaming, rocking – all the very strong autistic things.”

Julia took him to see Australian-based psychologist and author Dr Tony Attwood who was in New Zealand for a speaking engagement.

“He gave us some basic things to do with Rich which involved a balance between using his fine motor skills and gross motor skills.”

Back then, school was not compulsory for children with a disability.

“Nobody bothered with him much.”

They enrolled him into Hohepa in Clive, a community for children and adults who have intellectual disabilities. There they practiced the curative education principles of Rudolf Steiner.

Richard was in a class of seven and initially thrived in the community but his parents struggled when he was home for the 12-week holiday breaks.

“Rich was having major meltdowns for so many days. We tried to put in place everything we knew about autism but we didn't have an official diagnosis and couldn't get one so we struggled and there was no funding then.”

Julia was on the Hohepa Council of Management, the Disabled Persons Assembly and Autism NZ national committees.

“It was a fairly vibrant time for disability then. People were talking out for themselves. It was the most amazing training ground for me.”

As they became more aware of disability issues, Julia and Anton realised Richard felt cloistered in the Hohepa environment.

“We wondered if it was the right place for him. We thought there were more opportunities opening up.”



Richard Genet

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In July 1999, they shifted him into Supported Individual Lifestyle Choices (SILC) in Tauranga.

"We'd been going up to Tauranga quite regularly visiting my sisters. We loved it here. We saw a house and land in Oropi with 550 mandarin trees and a bed and breakfast which we thought would be ideal."

They missed it at auction but soon afterwards, it came up for sale again about the time Anton had an accident, which resulted in a severe brain injury. He now requires 24-hour support.

Julia, using skills she picked up when studying real estate, sold the Hawke's Bay farm and bought the 6000 sq m Oropi property, about 10kms south of Tauranga, and moved there in November 2000.

Richard's job, when he visited, was to mow the lawns on the tractor. Since he was a baby, his special interest had always been tractors – hence the 'tractor man' nickname.

He was struggling at SILC though and there is some debate over whether it was he or Julia who was eased out. Julia maintains she was the problem, not her son.

Lorna Sullivan of Standards-Plus in Tauranga, a long-time advocate for disabled New Zealanders, advised Julia to set up her own company to receive Richard's individualised funding package.

"It really set a precedent. What we were doing was something quite different."

There was no way Anton, Julia and Richard, at this time in his life, could live on the Oropi property. "We just wouldn't have been able to make it work," says Julia.

She found a piece of land in Maketu that was flat but on the top of a hill and it could house Richard's beloved tractor.

There was a home there and they built a little cottage for Richard and a big workshop at the back for Anton. It was a breezy site hence the name for the company New Breeze Ltd. It was also a new way of supporting a person with a disability who required 24 hours support.

The cottage was custom built, lined with medium density fibreboard and had everything bolted down.

"Rich didn't want us (his family members) looking after him. Through the company, we managed Richard's funding. Then we had to learn how to employ staff. Originally, we went through many staff. We are lucky though, we do get high quality staff despite the pay."

Julia and Caroline maintain the system could work for many people.

"I don't think families are always the best person to look after their son and daughter with a disability for ever. I don't do his everyday care; the support people manage it and the environment so he's the best he can be."

She is a great supporter of the Social Role Valorisation programme, a name given to an analysis of human relationships and services, formulated in 1983 by Wolf Wolfensberger.

The theory is that society tends to identify groups of people as fundamentally different and of less value than everyone else.

"This is the key to getting things right for people with differences," says Julia.

Richard's nieces Isabella, 10, and Charlize, nearly 5, live in Pyes Pa south of Tauranga.

"Rich loves them to bits. They're really good with him, they manage amazingly well. Sometimes Rich has some interesting behaviours. For example some of the social skills he learned from acting at Hohepa, he still does today, like bowing dramatically and kissing their hands. To them though he's just Uncle Rich."



TEAM AFFAIR: (left to right) Isabelle, Caroline, Charlize, Richard and his carer Dhanya Jose with Julia Genet. Photo: Bill Hedges, Rotorua.



LEGO COLLECTION: Richard Genet's collection includes several tractors. Photo: Bill Hedges, Rotorua.

The Oropi property came on the market again and Julia decided a move back would benefit everyone and be a step towards sustainability for the family, so she put Maketu up for sale.

"It was interesting to see how Rich managed while people were looking at the property. He offered them cups of tea and took them tiki touring."

They moved back to Oropi in January this year. Richard lives in the main home and Julia and Anton are staying with Caroline and the girls.

They want to build a cottage for Richard but council red tape and Tauranga's booming building market has thwarted their plans so things are moving very slowly.

"Meanwhile Richard lives in the main home happily lording it up there," says Julia.

The workshop has been fixed up so Anton and Rich spend a lot of time in there.

The plan is still to build a cottage as while they could renovate the flat in the workshop they would still need all the red tape.

"A lot of the mandarin trees are gone so we've got some avocados which means we can have a micro business."

Julia's granddaughters are looking forward to living on the property with extended family.

"Anton needs 24-hour support. He chokes sometimes. So they have Opa (grandad) choking and Rich yelling. It's great fun here. I've shifted them so many times."

Julia says she marvels at how well Richard transitioned from Maketu back to Oropi.

"People need to realise how well autistic people can manage change with the right support."

The next challenge is to establish a collective based on the Australian Homes West model. It is a family-governed service, which supports people living in their own or rented homes.

Julia sees about five families involved and it would enable them all to employ an administrative and support coordinator across each individual family who would have their own support people.

A key strength of the model is to allow for succession planning.

A family member can be on the board so when that member resigns, or wants to take leave, another member of the family or friend with the same vision, can take their place.

"For older parents with older children living at home, this is a real solution. The older children can have their own home and support people and a degree of independence. It's a win-win."

So does she ever get frustrated or downhearted?

"I sometimes feel sorry for myself when I'm caught up with red tape more than anything. I get frustrated by some of the bureaucratic nonsense."

In her down times, Julia loves surfing the net, she enjoys reading and spending time with the grandchildren.

"Rich loves celebrations so we have plenty of those."

She pays tribute to Richard's carers who she says work so well with Richard and the family and as a team.

There are regular meetings between them all but it is the team who support Richard, not her.

That is why he lives a charmed life.

Any families interested in forming a collective in the Bay of Plenty area, contact Julia juliag@eol.co.nz

Award-winning autism book

CALMING SENSORY rooms or gardens are preferable for a distressed autistic child compared to seclusion rooms – the use of which reveal a lack of teacher education, says a contributor to an award-winning book on strategies for teachers of autistic children.

Autism Spectrum Disorder in Aotearoa New Zealand: Promising practices and interesting issues (NZCER Press), won the Best Resource in Higher Education award in the New Zealand Content Counts Education Awards last week. Judges commented that the book was strongly tailored for a New Zealand audience, and “a timely publication given the growing awareness of autism.”

Edited by Dr Jill Bevan-Brown, an Adjunct Professor at Massey's Institute of Education and respected for her expertise in the field of autism, and her colleague Dr Vijaya Dharan, the book aims to inform and inspire teachers who have children diagnosed with Autistic Spectrum Disorder (ASD) in their classrooms.

Contributing writer Julianne Swanepoel's chapter is one of several in the book addressing the controversial use of seclusion rooms to manage behavioural difficulties in autistic children. In her chapter – Sensory therapies and interventions for individuals with autism spectrum disorder – she says seclusion rooms are used, “because the teachers have not been supported, informed or been given sufficient education as to how to deal with these children. If teachers know what triggers the meltdowns and total frustration the children experience, they can avoid ever using a seclusion room.”

“A sensory room or garden where children can voluntarily take themselves off to calm down is far more productive and effective,” she says, although these are costly to create.

Approximately one in every hundred children in New Zealand is diagnosed with ASD, and the number is expected to increase. However, few teachers have training in this area, say Dr Bevan-Brown and Dr Dharan.

Their book is a “smorgasbord” of 15 chapters of evidence-based approaches that have been trialled and written by teachers and other education professionals with special education expertise. All contributors have graduated from Massey's Post Graduate Diploma in Specialist Education with an endorsement in Autism Spectrum Disorder – a unique qualification in New Zealand.

“Autism Spectrum Disorder is a complex and increasingly prevalent condition which most educators will encounter during their career,” the editors say.



Importance of peers

Contributing writer Fran Dowson says seclusion rooms represent an out-dated approach to autism that does not reflect current practice or understanding about children with autism. Her chapter examines how using a toolkit of social skills interventions could help a student with autism in developing the skills they need to modify targeted behaviour. “Every behaviour has a purpose for the individual [with autism],” she says. “If we shut a person away when they display an undesired behaviour then we lose an opportunity to learn why they are acting in that way in the first place and what they can teach us about their needs in that moment.”

A case study of a technique she describes in the book focuses on the involvement of a student's peers in an intervention, allowing the student to develop new social skills. The student, she says, “did not like being singled out for attention, and by making this a group project – and later a whole class activity – he felt he had a leadership role rather than being the target of the intervention.”

Punishment adds to anxiety of autism

Another contributor to the book and special education expert Jenny Tippet, says the goal of an effective teaching programme for autistic students is, “not only to teach but to prevent obstacles to learning such as anxiety and negative behaviour. Research has shown that punishment does not bring about positive change, rather it escalates anxiety and exacerbates negative behaviours such as self-harm and aggression.”

She says teachers need more training for a better understanding of specific autism characteristics. “Successful inclusion in regular education settings can only be achieved if teachers understand what these specific characteristics are and how they impact student learning and teaching.”

She outlines in her chapter the approach of the Ziggurat Intervention Model, which addresses the core characteristics of autism, such as social and communication differences, inflexible thinking and restricted patterns of behaviour, as well as sensory, cognitive, motor and emotional differences. It offers a comprehensive intervention process to guide teachers including such things as: addressing individual sensory and biological needs; providing structural and visual supports in addition to verbal instructions; and identifying skill deficits and teaching skills particular to the student.

“In New Zealand schools all teachers are required to teach students with Autistic Spectrum Disorder,” Ms Tippet says. “It's essential they are taught not only what makes these students different, but also what strategies and interventions they need to employ to allow them to learn.”

Dr Dharan says every child with autism is different, so standardised approaches are not applicable. The approaches and techniques covered in the book can be tailored and adapted to meet the particular needs and personality of the individual child, she says.

Massey University offers Master's in Specialist Teaching in the ASD endorsement and short courses in ASD from time to time.

All staff of the Specialist Teaching are Ministry of Education accredited professional development providers and can offer targeted professional development support to a cluster of staff across all sectors – early childhood, primary and secondary.

About the authors:

Vijaya Dharan (left) is a senior lecturer at Massey University and present co-ordinator of the postgraduate ASD endorsement. Her research interests are focused on issues related to equity and diversity, particularly in the field of ASD.

Jill Bevan-Brown (right) is an adjunct professor at Massey University, and former co-ordinator of the ASD endorsement of the post graduate diploma in specialist teaching. She has a particular interest in culturally responsive provision for Māori children and their whānau.

Much-needed autism skills framework in development



A recent report identified barriers that prevent the uptake of learning and development as well as implementation of knowledge into practice. **John Vogenthaler** writes on how these issues have a significant impact on autistic people and their whānau.

WENDY AND GABBY are members of the reference group collaborating on the much-needed development of an autism skills framework for the disability workforce. Both women have experience of autism.

Wendy is the mother of a 23-year-old autistic man who currently receives support in a residential setting. Previously, Wendy and her son received individualised funding (IF) which gave them choice and control to choose who provided support for her son and how.

As Wendy's son grew up, they went through several support workers and struggled to find someone that understood her son and Autism Spectrum Disorder (ASD).

Wendy has chosen psychology students as support workers in the past. "I thought, this is great – this person has an interest in autism," she says. But without much knowledge of ASD, they were unable to connect with her son. "He can tell when people don't understand him and that's when he has started hitting them."



Wendy Duff

"It's stressful being a mum," she says. "I don't have time to teach people about my son and his autism. But having a framework that outlines the needs of autistic people would be a huge help." Wendy explains, "I would still have to find my own staff if we were using IF, but being able to send them to training and feeling like they have a basic understanding would be amazing."

Gabby is an autistic woman. "Imagine being able to prevent an autistic crisis," she says. "That's why I think a framework is needed. It could reduce the number of people with autism that go into crisis and help people to know the warning signs and where to go for help."

The autism framework reference group, chaired by Te Pou's John Vogenthaler, is made up of organisations and individuals – both autistic and non-autistic.

"I have liked being treated as equal to the non-autistics," Gabby says. "John has adapted the reference group to our needs too. He attempted to make a visual aide for me and gave the options to everyone so I was never singled out." Gabby noted that he did forget the visuals once. "I joked with him about it, 'you know the saying with autistics: three steps forwards, two steps back! We had a chuckle about that.'"

"The group surprised me," says Wendy. "The success has been in working with people with ASD and parents of people with ASD. It's one of the best groups I've been part of."

The framework outlines the knowledge and skills expected by people with autism, families, support providers, specialists and IF employers. It will help employers identify where their workforce needs training, and training providers to develop the training the sector needs. People with autism and their whānau and caregivers will also be able to use the framework to increase their own knowledge and skills.

The resource is expected to be available at the end of 2017. "I know my IF host can't wait for the launch of it," says Gabby.

Altogether Autism Autistic Advocate, Paula Jessop, and regular Journal contributor, Tanea Paterson, are also members of the reference group contributing to the Te Pou autism framework reference group.



FAMILY SUPPORT: Gabrielle Hogg with nephew Nathaniel and niece Mercede.

John Vogenthaler is a project manager on Te Pou's Disability Workforce Development team, focussing mainly on improving the capabilities of the workforce to support individuals with Autism Spectrum Disorder.

Whirlwind of emotions and challenges



Recreate NZ is a not-for-profit organisation that delivers youth development programmes. Amy Mauer shares a story about how their programmes have affected the ongoing transition of a young woman with autism.

TRANSITIONING INTO different stages in life for people with autism may as well be a bungy jump off the Auckland Harbour Bridge.

A steep climb to the unknown, support cables that you have to trust will catch you and then there is that step ... that one tiny, little, step.

The one step that will send you plummeting over the edge, experiencing a sensation that you have never before felt in your life, and it is scary, very scary.

We understand that experiencing new things, transitioning through life and growing, as a person can be a raw whirlwind of emotions and challenges.

Our team helps individuals overcome their challenges, using social and adventure platforms to help youth with disability achieve great things.

We design programmes that let individuals start in their comfort zone and expand into the unknown, whether it is a day programme in Auckland, a weekend getaway, visiting the Gold Coast, climbing Mt Ruapehu or a movie at Sylvia Park.

The programmes allow us to work with the individual and the family, slowly introducing new challenges and goals.

This approach affords our participants the confidence to try new things, attempt harder programmes and to work towards new goals.

An example of an incredible transition from a shy little girl to a strong and confident 24-year-old young lady is Taylor Brown.

Taylor has achieved so many unbelievable feats, through trusting the strong relationships she has formed with Recreate NZ.

Taylor has been part of the Recreate NZ family for more than 10 years and in this time we have watched Taylor grow, learning to trust herself and to have confidence in her ability.

We have been privileged to assist Taylor in trying many new things over the years, from her first night away from home, to a life skills course that gave her the confidence and skills she needed to sign up to Unitec; to achieving kitchen skills that have transferred into her home life.

Gaining independence and confidence to deal with life and any changes that may come about is not often an easy feat for members of the autism community. Fostering positive attributes takes time, understanding and an un-wavering support system. If you were to meet Taylor 10 years ago, you would not recognise the amazing young woman she is today.

Taylor is one of many inspirational individuals in the autism and Recreate community who has experienced a great deal of change in her life with poise and grace.

Transition is not easy and there is no one-way to achieve it. Every story is different and no two people have the same path. At Recreate NZ, we value the journey towards independence and self-confidence and make it our goal to create an environment full of love and positivity, making the transition easier when the time comes.

We cannot change the sensation of a bungy jump but we can add more ropes, hold your hand when you take the step and supply the chase boat to catch you at the bottom.



TRYING NEW THINGS: The Recreate Lifeskills cooking module was a success for Taylor Brown.

Programme Coordinator, Amy Mauer (BSC MSc psych) has been a part of the Recreate family for the last 10 years, first as a youth volunteer, then working for Recreate to create meaningful opportunities for young people who experience disability, including those with autism.

Lifeskills course sees dramatic improvements



*The Brown family have been a part of the Recreate community ever since daughter, Taylor was 14 and was participating in an afterschool dance programme. Taylor has gone through many stages of transition with the support of the Recreate team, says mother **Jane Brown**.*

OUR 24 YEAR OLD daughter was fortunate enough to take part in the Recreate Lifeskills cooking module last year.

Taylor has autism, and in the last few years has also suffered from chronic depression and anxiety. While attending the Lifeskills course, we noticed a dramatic improvement in several areas of her life.

An increasing confidence in the kitchen was apparent after just a few weeks, as Taylor started actively participating in food preparation at home instead of watching, which was her normal position.

She surprised me on more than one occasion by peeling and chopping vegetables without being asked to, and I was genuinely surprised to see her handling a sharp knife with far greater self-assurance.

This has extended to stirring and cooking on the stovetop- something she would never have previously participated in for fear of burning herself or spilling hot food.

Taylor is now aware of healthy eating. She is now actively discussing healthy eating options, and will snack on a carrot or piece of fruit when hungry, whereas previously she would search the pantry for less healthy choices.

As a parent of a very dependent child, it is uplifting and encouraging to observe these seemingly simple occurrences taking place in our own home. She is also now making her own breakfast each morning.

Once again, this is an example of a task she just would not have bothered with previously.

Another area Taylor always struggled with at home was hand washing. We have tried unsuccessfully for many years to teach her correct hand washing protocol.

After a few weeks on the Recreate course I saw a marked improvement in this area of her personal hygiene, much to my delight!

The Lifeskills cooking module has had a much greater impact on Taylor than I imagined.

Within this course, the superbly skilled staff at Recreate have designed a programme that covers a multitude of skills apart from cooking- including but not limited to food hygiene, budgeting, grocery shopping, planning, reading, writing and personal analysis.

The small class size means every student gets hands on experience and individualised help- this is most pertinent for our special needs children to be able to thrive and learn.

We have been thoroughly delighted with the programme and the very tangible outcomes we have witnessed with Taylor; not only the practical skills of cooking and food preparation, but a developing sense of self-assurance and confidence.



STRONG AND CONFIDENT: Taylor Brown joined the Recreate family 10 years ago.

Autism Spectrum Disorder Study Award from Ministry of Education

This study award will support you to study Massey University's **Postgraduate Diploma in Specialist Teaching: Autism Spectrum Disorder**.

The study is two years' part-time by long-distance (with block course work twice a year).

You will receive:

- Tuition fees
- Travel contribution towards your travel to the block courses
- Study leave (50 days maximum)*

Apply Now

For more information go to www.education.govt.nz or email specialiedworkforce@education.govt.nz

Applications close 30 September

* You will receive 50 days if you are employed full-time, otherwise this will be pro-rated based on your FTE status

