

ALTOGETHER AUTISM
JOURNAL
ISSUE 1 2019



**ALTOGETHER
AUTISM**
Takiwātanga

Autism acceptance

INFORMING · EMPOWERING · CONNECTING

ALTOGETHER AUTISM

THROUGH KNOWLEDGE AND EXPERIENCE

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

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

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

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

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



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Cover illustration: Tamara Miles. Te Tau Titoki honours the spirit of takiwātanga, as the name is derived from the whakataukī, Ā te tau titoki which means, "when the titoki fruits."

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Autism professional development demand grows



AS THIS JOURNAL hits subscriber mailboxes, we have started delivering Strengthening Early Learning Opportunities (SELO) programmes for early childhood educators with funding provided by the Ministry of Education. They include one-day workshops and centre visits.

Within hours of us advertising these programmes in Auckland, they were full which gives you an indication of how much demand there is in the

education sector for autism professional development.

We have also been approached by primary and secondary school teachers to run programmes with them which we do through our PRISM training. Details are on our website or you can contact Amanda on 0800 008 011 or 07 903 7028.

We are excited about Te Tau Titoki, the new workforce development resource just launched by Te Pou o te Whakaaro Nui, (Te Pou). Te Tau Titoki has been informed by autistic people and professionals, and continues our uniquely New Zealand understanding of autism as takiwātanga, learning in my/his/her own time and space. Johh Vogenthaler, Programme Lead / Principal Advisor Disability at Te Pou, shares more about this resource and the significance of the titoki tree on page 22.

April was Autism Awareness Month and we worked alongside autistic adults and the team at Chartwell Library in Hamilton for a New Zealand first – an Autistic Human Library*.

The autistic adults volunteered themselves as 'books', on loan to people visiting the library for one-on-one conversations about their lives. As far as we know, this is the first time such an event has happened in New Zealand, and I know the opportunity for parents to talk with autistic adults about their experiences was very encouraging. Read more about this on page 20 of this Journal and let us know if you are interested in volunteering as a 'book' for future events in your local library.

We have been travelling around the country meeting up with many of you at our Connecting with Community network meetings, hosted in collaboration with Parent to Parent. Jane Bawden, CEO of Parent to Parent, has generously shared her family's story in this edition of the Journal, and we are grateful for the continued collaboration with Parent to Parent.

In addition to our Connecting with Community network meetings, we are also hosting By Autistics, For Autistics network meetings. Details are on our website under Events. The primary goal of these meetings is to create a safe place for autistics to come together and learn and share experiences that matter to them. Paula Jessop, autistic advocate, and I are co-hosting these.

A big shout out to Sarah Blythe for a very successful Ride for Autism. Sarah is a mum and a powerhouse of action, who raised over \$8300 at the ride with 140 bikes. This will sponsor 40 educators to attend our PRISM autism training in the Manawatu.

Talk With Me is a brand-new app, soon to be launched, and fully endorsed by Altogether Autism. Swati Gupta is the creator of this exciting new technology and she shares her journey in developing this app on page 11. Check out this article to learn how to subscribe to updates and be the first to download Talk With Me for free for a limited time when it goes live.

Me te mihi nui / In appreciation,

Catherine Trezona – National Manager, Altogether Autism

*Since this event, we have learned the Human Library is a trademarked concept, so we apologise to the Human Library founders and we won't use this term again but will run similar events.



Autism no puzzle, nothing wrong with us



Many autistic people strongly dislike the puzzle piece as a symbol for autism, writes Paula Jessop, Altogether Autism's autistic advisor.

THE PUZZLE piece as a symbol for autism was originally used by the National Autism Society in UK in 1963. Time went by and it was used to represent autism by an organisation in America, Autism Speaks.

Autism Speaks then went on to use the puzzle piece in very big Autism Awareness campaigns in America, leading to the puzzle piece being adopted as 'the symbol' for autism.

But the problem for many autistic people, is that Autism Speaks campaigns were particularly negative and problematic to autistic people.

Autism awareness campaigns historically have been modelled on campaigns to raise awareness of diseases, illnesses like cancer.

Early autism awareness promotion was based on organisations and parents' belief that autism is a disease. A tragic and terrible one.

Autism Speaks was the biggest organisation to approach autism awareness from this perspective that autism is a disease requiring fixing, curing. Therefore, their campaigns were the most hurtful, upsetting and offensive to autistic people.

In 2006, as part of Autism Speaks campaigning for Autism Awareness, the organisation ran a range of advertisements on television and created a short film about autism that featured the organisation's leader at the time talking about her desire to kill herself and her autistic daughter, via driving off a bridge.

She spoke of these urges in the film, while her daughter was in the room and could hear what she was saying. Autistic people continue to be horrified there was ever a time it was seemingly socially acceptable for people to discuss killing us while we listened.

Another advertisement featured comments that autism ruined families and was almost a curse to families.

Their campaigning held a lot of very negative ideas about autism, that autistic people found very offensive and unfair.

"Autistic people on a whole, desire a shift in perspective of what autism awareness is about."

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So, due to this, and a whole range of other issues with Autism Speaks, autistic people find the puzzle piece a reminder of an organisation that spent years running very public campaigns in America that framed autism as a tragic disease. To autistic people, the puzzle piece represents negativity about autism, not a positive perspective of autism.

A second issue for autistic people, is the puzzle piece also represents viewing us as 'puzzling' or a 'mystery'. Often terms used in the past referring to autism.

For autistic people this is problematic, as we don't wish to be viewed as akin to a puzzle that can't be worked out.

Autistic people tend to use a rainbow infinity symbol, as connected to the neurodiversity perspective. For autistic

people, if they see an organisation or parents using the puzzle piece, and they know the history of the puzzle piece, they will assume an organisation does not consult with actual autistic people and may find that problematic. Or they may assume an organisation disregards their feelings towards the symbol and find that very disrespectful.

Autistic people on the whole, desire a shift in perspective of what autism awareness is about.

For many years adults have openly, publicly discussed their desires for autism awareness to shift to an approach aimed at creating acceptance for us in society. Continuing to ignore our wishes, to use symbols which may remind us of our discrimination in society or that people sometimes do kill us because of our autism, IS disrespectful.

Words and symbols might not seem to mean much, but they represent a perspective which increases discrimination against us in society. It's time to shift to autism awareness, as well as throwing away symbols from an era gone by that was not kind to autistic people.

Paula Jessop is an autistic woman who advocates for 'radical acceptance' of autism as a valid type of neurological difference and supporting autistic people through strengths-based methods.

NEURODIVERSITY is ÂSOME!

Autism Acceptance or Autism Awareness?



What is 'Autism Acceptance', as opposed to the usual 'Autism Awareness', asks Penni Winter?

Autism Acceptance means simply that – acceptance, even embracing, of autistics and autism, making us welcome in the world.

AUTISM AWARENESS grew out of an earlier era, when few people knew what autism was, and so parents of autistics began public education campaigns.

But from the beginning autism was cast as a 'problem', with a focus on getting help with coping with autistic children – and the images were always of children – while words like disorder, illness, and disease were used to describe us. Cure talk was rampant. Videos and billboards implied we were a sort of modern plague.

This has led to today's situation, where most people now know that autistics exist. But we're still mostly portrayed in very negative terms, particularly in the mainstream media, books by parents of autistics and in a lot of parent groups online.

We're described as an epidemic, a tragedy, a burden, and the cause of family breakdown. The increase in diagnosis of autism is cast as an increase in the occurrence of it, and dire predictions made of a future groaning under our weight.

The public image of autism is almost entirely negative too.

When most people think of autism, they imagine the non-verbal kid flapping and rocking in the corner, or the nerdy computer-genius-cum-hacker. Both stereotypes, of course, being male and young, and usually white too.

We're thought to be lacking in emotions, empathy, and the ability to love others. Not really even human – and hence a

frequent target for rejection, bullying, abuse, assault and even sometimes murder – with our killing called an 'act of mercy', and our murderers getting the sympathy, not us.

Meanwhile, an entire 'autism industry' does its best to milk panicking parents of their last dollar in vain attempts to 'cure' us, through sometimes dangerous therapies designed to force 'normal' on us.

Professionals talk solemnly of our many deficits, and we're often assumed to be lacking in intelligence, especially those of us who can't use oral speech to communicate our needs. And despite decades of raising awareness, the system isn't really that much better at understanding us or providing for our needs than it ever was.

"Despite decades of raising awareness, the system isn't really that much better at understanding us or providing for our needs than it ever was."

That's what 'autism awareness' has brought us to.

To digress a little – since the recent terrorist attack in Christchurch, an amazing thing has happened. The average Kiwi has begun to see their Muslim neighbours as human, as fellow Kiwis, not some alien, semi-sinister 'other'. I've often longed for a similar transformation – without

the tragedy! – of how autistics are viewed. Instead I've been waiting for someone to suggest the killer was autistic, because that's happened all too many times before with mass shootings. The counterpart to Islamophobia is what I call neurophobia. It's real, it's out there, and it's killing us as surely as bullets.

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Our suicide rates are far higher than the general population, as are our rates of unemployment and homelessness.

Autism acceptance

Many of us on the spectrum, naturally enough, along with our growing number of non-autistic allies, don't much like 'awareness' campaigns. So, from small beginnings several years ago, we began a campaign and day/month of celebration instead – Autism Acceptance, which has now spread worldwide.

Autism Acceptance means simply that – acceptance, even embracing, of autistics and autism, making us welcome in the world. It's about recognising that we are members of the human community, and just as deserving of basic human rights, even while acknowledging that our humanness is expressed differently.

It involves centering autistic voices, understanding that we are the real experts on autism, rather than marginalising and ignoring us, as awareness campaigns usually do. It includes understanding that our autism is not separate from us, but intrinsic to our very nature, hence our preference for 'identity-first' rather than 'person-first' language – 'autistic', not 'with autism'. It also involves the support of our non-autistic allies, such as those at Altogether Autism, who are open to understanding what it's really like to be autistic, and to see us as real people, not stereotypes.

Because when you look beyond those stereotypes, you'll find we're of all races, religions, nationalities, social classes, genders, sexualities, ages and talents. Of those of us who do work, we're certainly not all computer geeks. We're also academics, actors, teachers, office workers, truck drivers, photographers, vets, firefighters, chefs, posties, musicians and much more. Many of us are also parents, and/or have partners. But we all have areas of life we struggle with, even those who manage to present as 'normal'. This is actually called 'masking' – we've learned how society views us, so we try to conceal our autism, even at great personal cost.

The so-called low functioning

I want to emphasise here, that when I talk about acceptance, I am most definitely including those deemed 'low-functioning'. Most autistics actually loathe the functioning labels. They are misleading and even dangerous. Misleading, because we're all a mix of capabilities, it's more helpful to talk of individual needs rather than trying to pigeonhole us. Some of us have higher needs than others, but all autistics have more in common with each other than they do non-autistics, no matter our outward appearance.

And dangerous, because these labels can be, and often are, used against us. There's a saying amongst autistics – "if you're deemed high-functioning, your struggles are ignored. If you're deemed low-functioning, your strengths are ignored." This is a frustrating reality for many.

The labels are also used to try and divide us – so often, if we challenge a parent of an autistic child online on how they talk about or treat their child, they respond with some variation of 'you're-not-like-my-kid', or 'you're-too-high-functioning-to-understand'. As if there are two

types of autistic, and it's okay to treat one sort badly, while the other sort should just shut up and let it happen. Even when we point out that we were once 'like your kid', and that you can't tell online what a person's capabilities are anyway.

Autism acceptance is the goal

Autism acceptance, therefore, is about acknowledging autistics as part of the community, changing the public image of autism and autistics, and shifting the dialogue about autism from a negative stance to a positive one, centering autistics in that dialogue. We both want and need acceptance, not mere 'awareness', because the quality of our lives, and sometimes even whether or not we'll have one, is at stake. And though much has been achieved, there is still a long way to go.

We're here. We've always been here. We're human. Accept us. Embrace us. Include us. You might be surprised at what happens.



Penni Winter is an autistic person in her 60s. A Kiwi writer and artist, her blog can be found at strangeringodzone.blogspot.com



ALTOGETHER AUTISM HIGHLIGHTS

AUTISM AWARENESS: Sarah Blythe, with her sons Neko, 7, Mataeo, 4, and mother Deb Costello at the recent Ride for Autism awareness in Feilding which raised funds for specialist autism teacher training in the Manawatu.



All Abuzz for Jaime



Jaime Rowlands is 33, autistic, has bipolar two disorder and needs 24-hour care, reports Mary Anne Gill.

It's not perfect but it's better than the other options available ... Come and have a look at what's possible.

JULIE ROWLANDS describes her daughter Jaime like a “bee in a bottle” when she was a child – all over the place, buzz, buzz, buzz.”

For the past four years Jaime has lived on her own in a self-contained flat next to her parents’ place in Hastings which seems odd given the level of care she needs.

Jaime has eight support workers funded by the package she receives from the Ministry of Health following a Needs Assessment and Service Coordination appraisal.

“She needed to be in a place on her own. It was the only way life was going to be liveable for her and us,” explains Julie.

It was a bold decision given Jaime’s history of unpredictability but the flat is fully fenced, the doors are locked “even the cat door,” says Julie.

“I know she’s safe. She’s very rule-based and she knows she’s not allowed to go out at night and she doesn’t.”

The journey to Jaime’s life today is one of pitfalls and hurdles, a mother who would not accept the usual for her daughter and a supportive family unit.

She was born in Melbourne in 1986 to Julie and her engineer husband Paul.

Her development in those first three years seemed to Julie, a registered nurse, to be behind other children. It was when their son Michael was born that the couple were able to see his developmental progress compared to Jaime’s and the comparison was stark.

By then they were living in Hastings.

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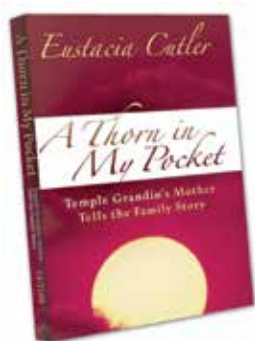


ALTOGETHER AUTISM HIGHLIGHTS

ON THE MOVE WITH PRISM: A presentation at the Hamilton event in February, left, and at right specialist facilitator Martyn Matthews (in blindfold) with Jude Nepomuceno.

The only person who would listen to Julie's assertions was local Plunket nurse Joan.

"She was amazing and so supportive."



At kindergarten and then at school, it was clear Jaime needed lots of support.

"We used to go for occupational therapy, but nobody seemed able to pin down what was wrong."

Then Julie read "A Thorn in My Pocket" by Eustacia Cutler, the mother of American Autism Advocate – Temple Grandin.

"I knew then that Jaime had autism."

When she was six, the family were able to secure a referral to a paediatrician in Auckland who confirmed Jaime was autistic.

It resulted in her getting a full-time teacher aide throughout her schooling.

"People overestimate what she's capable of because she is verbal. But she had no idea of danger and we desperately needed that level of care to keep her safe.

"Wherever Jaime has been throughout her schooling, she's always been able to teach the teachers!" says Julie.

At 19, Jaime left school and Julie, who had been working part time as a practice nurse with a local GP, had to start thinking "what now?"

It was about the time individualised funding came in from the Ministry of Health. It is a mechanism that enables people with disabilities to directly manage their disability supports.

"We grabbed that."

It gave the family 20 hours funded care which Julie used to employ one support worker.

"It was too much for one support worker, that's the lesson I learned," says Julie who had also started her own coaching business working from home.

Meanwhile Paul was working overseas a lot, first in Egypt and then in Laos. Julie and Jaime spent nine months living with him in Egypt. It was a hard life away from the supports so they returned to Hastings.

Julie and Jaime had the support of a neuropsychiatrist for a number of years first with her autism, and the diagnosis

of bipolar type two that came later. This finally explained the mood swings she so often experienced. Medication has stabilised those as has the decision to move her into a self-contained flat.

"She has settled so well into 'her house'. She learned to do things we would never have thought she could. She makes her own breakfast every day. She makes porridge in the microwave, sometimes it's lumpy but she still eats it. She also makes her own toast but because she can't judge quantities very well, we give her butter and jam sachets."

The first of the eight support workers come into the flat at 9.30am.

"They are a very stable group of caring people, who help Jaime to be as independent as possible"

The days tend to be full. Jaime goes regularly to the gym, she has a voluntary job grooming two horses and makes visits in the community.

"If (her mood) isn't working on a particular day, she can stay at home. Some days she's 5-6 years old, other days she's 13 years old and like any teenager."

She likes to wear the same clothes and eat the same things.

At night she loves listening to music and plays DVDs of her favourite programmes – Barney and The Wiggles.

She's learning how to txt.

Recently Altogether Autism provided professional training for the support workers with national manager Catherine Trezona and autism and developmental consultant Martyn Matthews.

"They needed that extra support to understand Jaime better," says Julie, who still runs her coaching and now has a DoTERRA essential oils' business.

But looming ever large in her consciousness is her upcoming 60th birthday.

"I know that without me, the supports for Jaime would be difficult. I've got to set it up so it's more sustainable.

"I try not to focus on it too much because it does my head in. I have set things up as best I can."

For now, it's working.

"It's not perfect but it's better than the other options available. I say to people who question me: 'come and have a look at what's possible'. Jaime has a very nice life and she's happy most of the time," says Julie.



BIKER CHICKS: The Altogether Autism team of I-r Catherine Trezona, Amanda Phillips and Jamie-Leigh Timoti at the Riding for Autism Awareness rally in Feilding on March 3.



TEAMWORK: The Altogether Autism team – I-r Laetitia McKenzie, Joanne Lawless, Jamie-Leigh Timoti, Sanam Bagherian, Amanda Phillips and Catherine Trezona offering PRISM and Selo programmes around the country.



Be an ally, not an advocate

*Augmentative and alternative communication methods which replace speech or writing has given Sophia a voice, says her mother **Rebekah Corlett**.*

Seek out, listen to and amplify the voices of autistic people where possible – over parents, and over people who refer to themselves as experts.

MY DAUGHTER Sophia, who is 10 and autistic, uses verbal communication sparingly, and is learning to use an augmentative and alternative communication (AAC) device.

I do not speak for Sophia. I am not her voice, she has her own. I am her ally, not her advocate.

Seek out, listen to and amplify the voices of autistic people where possible - over parents, and over people who refer to themselves as experts.

Our journey starts in 2011 when Sophia was diagnosed with autism shortly before she turned 3.

She was our first born so my husband and I initially hung on the words of the experts who told us she would eventually talk. I don't ever remember being particularly fearful that she wouldn't talk as she was perfectly good at making her own needs known.

People who know and love Sophia know she is strong willed, mischievous and clever in all the best ways.

Our interaction with speech language therapists in early childhood education was problematic – we experienced a succession of therapists who worked with Sophia for a few months before leaving for new jobs – which meant breaks in between, and then having to build a rapport with the new person and effectively going back to square one.

Years 1-3 at school focussed on low tech communication options. Sophia started requesting favourite items like apples, toys and iPad via core boards and pecs cards at school and home.

At age 8 our school speech and language therapist applied for funding for an AAC device through The Talklink Trust.

We waited 18 months to reach the top of the list for an assessment. It felt a very cruel, drawn out process - but one thing I can say for sure about being on this journey is you get used to sitting on waiting lists.

We had a six-week trial of different talkers and apps to decide which suited her communication needs best, settling on an iPad mini with TouchChat communication app.

The impact was instant. Sophia was calmer as she was able to request items independently. She didn't have to rely on me to guess what she wanted or how she was feeling. Sophia branched out from requesting just her favourite items - and used a bit of creative flair in the process. With no assigned visual for hot chocolate, she came to me one day asking for a 'Hot Coffee Chocolate Milk.'

Sophia was able to choose between two activities which had previously been chosen for her – park or beach, walk or bike.

Sophia was able to describe her pain when she fell off her trike and broke her wrist. She was able to express her feelings of anxiety and frustration in many doctors' visits over a six-week period and was remarkably calmer as a result.

Which is my main point. AAC gives Sophia a voice. It gives her

independence of thought and action. So, we need not put words in her mouth or talk on her behalf any longer.

As a community we need to recognise AAC as an official form of communication. This will take education, understanding and funding.

Our government needs to better fund AAC – not because it's a nice thing to do – because it's a fundamental human right to communicate.

"At a time in our country when we are being encouraged to acknowledge diversity in our communities, I ask you to celebrate neurodiversity in the same way we celebrate diversity in race, gender and faith."

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Because the UN Convention on the Rights of Persons with Disabilities as well as Convention on the Rights of the Child state it in plain English.

And at a time in our country when we are being encouraged to acknowledge diversity in our communities, I ask you to celebrate neurodiversity in the same way we celebrate diversity in race, gender and faith.

Make AAC affordable and accessible to all wherever they are on their journey with autism. The earlier the better.

When you go out into your communities, especially into schools. Don't just praise the high achievers. Search out the students with neurodiverse needs and ask how the education system is treating them.

Be an ally, not an advocate for autistic people. Amplify the voices of autistic people. Because it's time to pass the mic and turn up the volume.

- Rebekah Corlett is a parent, occasional blogger and most importantly Sophia's ally. www.facebook.com/iamrebekahcorlett
- Rebekah spoke at a parliamentary breakfast hosted by Autism New Zealand and Hon Carmel Sepuloni, Minister for Disability Issues for World Autism Day, which this year focussed on Assistive Technology, Active Participation.
- Augmentative and alternative communication (AAC) is an umbrella term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.



Asperger's: A Teenage Perspective

*Speaking at a recent network meeting in Invercargill **Bethany Hughes**, who was diagnosed with Asperger's Syndrome when she was five, spoke of how learning and growing with autism was by no means an easy experience.*

I'VE HAD MY fair share of social and emotional challenges. At the same time, autism has also given me a unique insight for detail, a bold, questioning nature, and a passion for causes I care about.

Despite my early diagnosis, it wasn't until I was 10 and a book titled 'All Cats have Asperger's Syndrome' was handed to me, and I wondered 'what on Earth is this all about?'

Upon reading this book, it felt as if my brain had undergone a reboot.

Everything that has happened made sense. The difficulty with fitting in, an unusually vivid imagination, excessive curiosity, and passionate interest in nature-- it all clicked together.

I felt a lot of relief in finding out why I thought the way I do after these years, but I also was very frightened about my future following this discovery. I worried that I would never find any true friends I could rely on, or that I wouldn't be able to achieve my dreams of a career with nature because of my condition.



It is normal to feel scared, confused, or overwhelmed following a diagnosis. Issues with picking up social cues, anxiety, finding friends, sensory sensitivity, and discrimination were and still common for me today. I hate being forced to participate in activities typical of my age group that I find exhausting and pointless.

People on the spectrum have a wide range of unique abilities, and although they face different problems from the neurotypical population, they can live with great joy and fulfilment if allowed the opportunities and guidance to do so.

Society needs to stop looking at autism as a lack of ability. Instead, recognise for the abundance of ability it really is.

- The full transcript of Bethany's speech is on the Altogether Autism website

Autism acceptance at point of diagnosis



Jenny Gibbs is a clinical psychologist who has spent the last 25 years working in a child development centre with an increasing proportion of her role being diagnostic assessments of children and adolescents who may have autism. She reflects on what Autism Acceptance month meant for her.

AUTISM ACCEPTANCE month has meant I have been reflecting on what autism acceptance means to me both as an individual and as a clinician.

It has not always been comfortable. One of the privileges of my role as clinical psychologist with Altogether Autism is that I have spent time with autistic adults, including autistic advocates. That has meant being part of some interesting and at times confronting conversations about what acceptance is.

I have found myself feeling uncomfortable and at times defensive when those of us who work in health and disability are challenged about what it is like for autistic people to work in these settings.

People who work in health and disability are typically people who care about others and we do not want to think that we, and the organisations we are part of, do not genuinely accept or include autistic people and others who are different to the dominant neurotypical culture.

As someone who remembers the 1970s and 1980s well this discomfort is familiar; debate around feminism, indigenous rights, homosexual law reform all created discomfort that provided the impetus for change.

Some questions I have been asking myself considering these difficult conversations include:

- What is my attitude to autism?
- Do I genuinely value autistic people?
- Do I have friendships with autistic people? (aside from my quirky family – sorry guys you don't count because you can't choose your family!)
- How much am I prepared to adapt to make it comfortable and safe for an autistic person to be themselves with me?
- How tolerant am I about making these adaptations in my workplace?
- How would I feel if my child or grandchild had autism?
- Do I see autism as something that needs to be treated/cured?

I want to talk briefly about what autism acceptance might mean for a clinician at the point of diagnosis which might also answer some of these questions.

Autism acceptance requires an early conversation about terminology and the medical model.

We need to talk about the differences between how the terms autism and Asperger's are used in the public domain versus how the diagnostic term Autism Spectrum Disorder (ASD) is used by clinicians. We need to say what we mean by terms such as autism and autism spectrum and then what it means to meet diagnostic criteria for ASD and how it is possible to be "on the spectrum" but not have ASD.

We need to talk about the problems inherent in the language used in our current diagnostic criteria. ASD as described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) is all about deficit and impairment.

We should actively avoid language that implies that autism should be lessened or eliminated and instead ensure we talk only about strategies for managing the challenges that person has.

We can acknowledge that it is difficult to convey a positive message about autism when both the label ("Disorder") and the descriptors of it are so negative, but we can explain that for now we are stuck with the term ASD with its deficit and impairment focus as currently this diagnosis enables access to health-funded disability services.

We can then move on to using positive language. We can talk about the autism spectrum as a neurodevelopmental difference with some common features, but for each person a unique mix of strengths and challenges.

Intervention can then be promoted as being to make life easier for the person by, for example, enhancing their ability to communicate, reducing their frustration, assisting with planning and organising, reducing sensory overload.

We should actively avoid language that implies that autism should be lessened or eliminated and instead ensure we talk only about strategies for managing the challenges that person has.

When talking about strategies we need to consider how we can make environments (physical and social) more accommodating rather than automatically trying to make the person fit.

Tony Attwood, a well-known Brisbane-based psychologist, is known for saying at diagnosis "Congratulations, you have Asperger's Syndrome". This certainly promotes acceptance but is not necessarily appropriate for a parent or individual who is devastated by this news.

How do I acknowledge, allow and understand the grief a new diagnosis of autism may bring while continuing to use positive language about autism? I believe it is about separating out autism from the challenges that may arise because of the autism or because of the other conditions that often occur in tandem with autism (e.g. learning difficulties, anxiety, ADHD).

In the case of parents, no one wants their child to have something that they know will make life harder for them. It is understandable to worry that life in a neurotypical and disability unfriendly world will be harder for their child and to feel sad that their own dreams for this child may not be realised.

However, from those first conversations the grief can be acknowledged but the seed can be planted that autism is not in itself something to be feared and that many of the qualities that are typically described as a negative can be viewed positively.

For example, when talking about problems arising from a child's sensory sensitivity we can add that this same sensitivity means they can see and hear things in a unique way. Instead of talking about a child's special interest as an obsession, we can describe it as a passion. Making inappropriate comments can be described as direct communication. Instead of saying that they lack empathy, we can say they may have difficulty expressing empathy in ways that others expect or understand.

Using positive language is important for modelling autism acceptance and it also makes people feel better.

■ Continued on page 11

My sister in law Catherine, whose youngest daughter is severely disabled, made a comment very early in my career as a psychologist that hugely influenced my practice. She said she hated psychologists and refused to have them as part of her daughter's treatment team because their focus was her daughter's limitations not her strengths.

I have worked hard not to be that psychologist.

The recent conversations about autism acceptance have prompted further reflections and another shift in my

thinking. I expect these conversations and reflections will continue to inform my understandings and practice as a psychologist.

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

Reflection following coming of age



This is a special year for Jane Bawden's family starting with her twin children who turned 21 in March. She writes about their journey to adulthood.

MY CHILDREN'S lives started with drama in March 1998 – they were born 11 weeks early.

Now, they are well and truly launched into adult life.

My daughter Laura is away studying at university, my son Hugh continues to live with my husband Royden and me at home in Auckland, and both are enjoying all that adult life is offering them.

Their birthday was an opportunity for reflection on those 21 years; our hope and dreams for our children, our role as their parents over that time and going forward and our hopes and dreams for ourselves too. It was also an opportunity to acknowledge the people who have played such a role in supporting our son's development and our family as a whole.

Our son had an initial diagnosis of "failure to thrive". In time that diagnosis turned into diagnoses of a rare chromosomal disorder and non-verbal autism.

But 21 years later we no longer think in terms of diagnosis; we celebrate a thriving young man who contributes to his local community, who managed without spoken language to communicate to us that he wanted to attend his local high school and did not want to attend activities congregated on the basis of disability. He told us he was ready to leave school at the same age as his peers and wanted to stretch his wings with a variety of roles and activities which for years I would not have thought possible.

In between times there have of course been many, many challenges, at the top of which I would put extreme sleep disturbances and a stress response of running away to reduce anxiety. These are largely behind us now as we understand more of what makes our son tick and he understands more about how to communicate effectively with us. His life is planned around his interests and needs and includes a support team of excellent staff whose personal values and aspirations for our son, match our own.

When I reflect on the biggest influences in our son's life, it is the family support organisations that have truly changed the trajectory of our thinking and so the path that our son has taken.

In the early days Standards and Monitoring Services (SAMS), Standards Plus (now Imagine Better) and Parent to Parent created opportunities to meet other families and space to learn about the machinery of government and how we might influence policy or the application of policy, how to identify the talents and interests of our children, how to create and



TWIN BOND: Hugh and Laura Bawden-Hindle recently celebrated their 21st birthdays.

hold a vision for our child and for our whole family, and how to plan to achieve that vision.

We learnt how to stay strong, about self-care, and we had the chance to off-load to families who "got" us.

In later years I have been hugely influenced by Janet Klees and Michael Kendrick, both of whom visit and teach in New Zealand regularly. I developed a set of bed-rock Enabling Good Lives principles as the foundation for the life we continue to work for with our son – everything for us rests on the concept of "right".

The right people, the right relationships, the right roles, all supported by the rights enshrined in the United Nations Convention on the Rights of Persons with Disabilities and reflected in the Enabling Good Lives principles.

And now my main influence is autistic adults who generously give back to the wider community through social media and publications such as this journal, creating space for families to learn from them how best to support their autistic family member.

One of our support team is autistic and she is my first port of call when I am trying to work out what my son's behaviour might be communicating and how we could respond. We are very lucky to have her input.

It is a genuine privilege to be part of Parent to Parent and Altogether Autism, knowing that families and individuals will continue to be supported as my family has been supported, for many years to come.

- Jane Bawden is chief executive of Parent to Parent NZ, a barrister, trustee of Spectrum Care and a company director
- Parent to Parent supports families/whānau in the disability community and provide expert autism information through the Altogether Autism service with Life Unlimited.

Autism-friendly tips for

MANY AUTISTIC people of all ages can, and do find using public transport stressful.

Planning and carrying out a successful journey requires a complex series of steps and this can be challenging for people on the spectrum, especially for those who are extremely sensitive to sound, light and smells.

Anxiety around social interaction and communication adds to the stress, particularly when there are unexpected changes to the transport timetables. This can lead to people with autism trying to avoid public transport and may greatly reduce excitement or enthusiasm for travelling away from home.

For people with autism, adequate transportation can offer freedom and independence by increasing mobility.

Initiatives such as the recent Have a Go Days in Hamilton

and Wellington are an excellent example of transport providers considering the mobility challenges facing a range of people with different needs.

The aim of each Have A Go Day was to make travel comfortable and easy for everyone in the community, by providing a relaxed, free opportunity to experience a range of transport options.

The Wellington initiative was the idea of My Life My Way, a collaboration of disabled people, their families, organisations and community members in the Hutt Valley.

The event, supported by the Greater Wellington Regional Council, Transdev, NZ Bus and Hutt City Council, aimed to help remove some of the barriers to using public transport.

There are also several autism-friendly strategies that people can learn to use for themselves.

Write a Script, or use a Sketch or Sign

Often using visual aids can help people with autism. This could take the form of a script in words or pictures detailing every step needed to use public transport, and – what to do if the bus is late. Scripts can also – teach how to offer a seat to elderly/pregnant woman/other passengers, and teach coping strategies if their favourite seat or driver is not there., Scripts and visuals are useful for coping with missing the bus or other unexpected events.

Things such as planning alternative routes, and instructions on how to check time tables can also be represented as Signs or Scripts or Sketches.

Block out noise

Wear headphones to reduce background noise and play soothing music through them. Some autistic travellers use headphones as a socially acceptable way of signalling they prefer not to engage in conversation.

Carry a familiar object

This can be a book, phone, toy or even piece of cloth; something with a familiar smell, or feel. Favourite smells on a handkerchief can help with avoiding unpleasant smells. This can help to comfort and distract, reduce stress, and avoid a sensory overload.



or public transport use

Travel at quiet times if you can

It might not always be possible, but avoiding rush hour can reduce the stress of public transport. If the train or bus is very full, have strategies to cope with waiting for the next one, which may be less crowded.



Select a seat

Sitting next to an exit may be preferred, but ensure there are strategies such as a script or visual support for choosing a different seat if this seat is not available.



Plan and practice

Plan and practice making the trip and learn strategies to cope with change. Options for different routes will help reduce anxiety. Always have a back-up plan for all the possible unexpected changes including different drivers, different routes, road blocks and breakdowns.



Importance of learning key to strategy



Wellbeing is a word that has been thrown around a lot lately, writes Children's Commissioner Andrew Becroft, especially in politics.

PART OF THE Government's 'Wellbeing Budget' will play a huge role in the implementation of the Child and Youth Wellbeing Strategy.

The strategy is a key requirement of the Child Poverty Reduction legislation, which passed into law in December 2018. The requirement to have such a strategy is a first for New Zealand.

Another critical part of the legislation is the requirement to gather the views of children and young people – another first-time requirement. These views will help ensure the strategy is in tune with what children and young people think and want, rather than merely what policy makers believe they should have.

Too often, adults talk about 'wellbeing' as the absence of negatives. Children and young people often flip that on its head. They see 'wellbeing' as the presence of positives.

Our office worked in collaboration with Oranga Tamariki to gather the voices of over 6000 children and young people late last year, specifically for the Child and Youth Wellbeing Strategy.

We spoke directly with children and young people, and we heard their opinions through a survey, to find out what they think a "good life" is, and what they need to have a good life in Aotearoa New Zealand.

A lot of the children and young people spoke about how they need to be supported in order to live a good life, and how their whānau need to be supported too.

Young people with disabilities spoke about the effect of their disability having a significant impact on their families' finances.

Some families struggled to cover the costs of extra support. As a result, they weren't able to afford things they otherwise might. This extra support is needed in order for these children to live the best lives they can.

"I feel like the best life for young people is to have the opportunity to do what you love and to follow the things that inspire you and interest you."

19 year old young person with a disability from Wellington, What Makes a Good Life? (2019)

Children and young people told us over and over again about the importance of learning. They know that education can help to set them up for success in life and help them achieve their aspirations. But the education system as it stands is not currently serving all of them well.

Government, educators, boards, the health sector, communities, and parents all need to turn their focus to ensuring each and every one of our tamariki are valued, respected and have the opportunity for a life fully realised.

A child with a disability spoke to us about how it is really important that kids get to go to a school they like and are supported to stay in a mainstream school.

These are just some of the invaluable insights gained from a diverse group of children and young people that will directly feed into the development of the government's Strategy.

We hope they will contribute to a strategy that puts the needs of children and young people first.

Last year, I wrote about some ways each of us can contribute to a genuinely inclusive education. We can do our best to:

- Develop an accepting culture
- Give teachers the tools they need
- Advocate for funding for eligible students
- Be creative about sourcing community support
- Make sure board decisions are child-centred

Screenings are important for identifying diversity in abilities. So it's promising to hear that the Disability and Learning Support Action Plan intends to screen all children before and after they enter school.

The plan will screen for dyslexia, dyspraxia and autism spectrum disorder in order to identify all children's needs more quickly. That should enable support to be given earlier.

As we all know, the education system plays a crucial role in a child's life and wellbeing. Helping children stay in school by providing them with the right support, regardless of their abilities, contributes significantly to the overall wellbeing a child experiences

Having positive experiences in school and being supported to reach their full potential contributes markedly to avoiding poor life outcomes. For this to happen, we all need to play a role.

Government, educators, boards, the health sector, communities, and parents all need to turn their focus to ensuring each and every one of our tamariki are valued, respected and have the opportunity for a life fully realised.

During another one of our engagements with young people about education, this is what one student said when asked what she would change about school:

"Make sure every student is accepted and knows that they are accepted by every teacher. Respected."

16 year old Māori/Pākehā female, Education Matters to Me (2018)

Judge Andrew Becroft was appointed a District Court Judge in 1996. In 2001, he became the Principal Youth Court Judge of New Zealand; a role that he held until 2016 when he was appointed the Children's Commissioner.

Talk With Me app: helps children with autism experience the joy of social interaction



Swati Gupta, Founder of Inklusys and former principal research scientist at Callaghan Innovation, talks about her journey of developing the Talk With Me app and the team behind it.

- Available for iPad and Android in mid-July
- Promotional free trial at launch
- Subscribe to our mailing list at talkwithmeapp.com to stay informed

TALK WITH ME is a collaborative learning tool where children with autism sit alongside and share the app with people in their lives and have social conversations. It comes with a variety of topics for children to practice. Talk With Me is fully customisable. Educators and parents can personalise the content according to the child's needs.

All our content is crafted with care by our passionate and committed speech and language therapists, and there is a wide variety of content to choose from for your child. We'll keep creating new and timely content for you to try, so that you never run out of options as your child progresses through the material.



Helps children learn how to interact socially



TALK about a variety of topics

- Make weekend plans
- Have fun discussing cartoons
- Plan doctor and hairdresser visits
- Share what you like and dislike
- Discuss your favourite animals



LEARN how to interact socially

- Rules and flow of conversation
- Collaboration and cooperation
- Eye contact and joint attention
- Turn-taking and sharing

CONTROL all content

- Adults work with the kids
- Separate lockable interface for adults
- Download new conversations
- Remove existing conversation



CONNECT and build relationships

- Find common interests
- Share your thoughts
- Connect deeper with family & friends
- Make new friends

Therapists, parents, educators, caregivers work with the kids



CUSTOMISE everything

- Edit existing conversations
- Change voice, text, images
- Use your own photos
- Change colour theme



CREATE new conversations

- Easy to use interface to create new conversations for your child
- Vast library to search images
- AI powered algorithm to help you create effective conversations

Key Results

- over 20 minutes of continuous and independent conversation
- minimal therapist intervention
- excellent joint attention and cooperation
- attempts to verbalise
- expressions of joy
- understanding of turn taking
- minimal training and good memory retention of the tool's use.

Several special-needs teachers and therapists commented that these are astounding results for children who normally have attention spans of up to three minutes at best, and very limited social interaction.

They usually require high intervention and persuasion for any activity.

They rarely work together independently and, previously, if left alone, they wouldn't communicate at all.

■ Continued page 16

Trials

In 2016, Callaghan Innovation, University of Otago, and Upland Unit conducted a feasibility study, which showed that the level of children's social interaction and engagement was superior with Talk With Me, as compared to their personal AAC device, and physical symbol-based vocabulary cards they use regularly.

A Callaghan Innovation student project with Worcester Polytechnic Institute, USA, conducted interviews with the autism community members in New Zealand and abroad, to analyse the need for applications that improve social skills in children with autism.

We found that a tablet-based app for developing communication skills, that is customisable, collaborative, and culturally appropriate could meet the needs of the community.

Later that year, with support from Norman Barry Foundation and Kiwinet, we conducted multiple informal intervention trials in New Zealand and India. They enabled Talk With Me to

be used in people's natural environments and according to their own time and preference. This provided valuable insight into how people would use Talk With Me if they downloaded it from the app store, without any strict guidelines about

when and how to use it. Our key results were replicated with most children.

In 2017, Callaghan Innovation and University of Otago, with support from Autism NZ, conducted a study to investigate Talk With Me at home with parents.

Most families perceived their child to have gained increased confidence and participation at school, and improved turn-taking in conversations.

But we also found that children's engagement decreased over time; this

was primarily due to the small number of conversations on the app, that were either too hard, too easy or uninteresting for some children. We incorporated this feedback into our development process.

"Skills learned while using the app transferred to everyday life"

– a therapist

"Children have started greeting each other in class"

– a teacher

"My daughter said for the first time, 'Dad I want to play, let's go out and play'"

– a father

Backstory

My interest in neurodiversity and autism started around 2010 when I was living in Singapore. I was intrigued by the question of how the brain processes information. The quest to find an answer led me to the literature in psychology, neurosciences and cognitive sciences, which, in turn, led me to neurodiversity. I was fascinated that there are other ways of being human.

The story of Talk With Me started in 2015, soon after I moved to New Zealand to work as a scientist at Callaghan Innovation; our team collaborated with the special-needs Upland Unit of Hillmorton High School, and we started experimenting with various ideas around using computer games to enable social interaction among children with autism.

The ideas we were testing were good, but nothing like a breakthrough. Until one day, while talking to the Upland Unit's speech and language therapist, the idea of enabling conversation through symbols and pictures started to emerge.

Several iterations and trials later, we got what we call the Talk With Me app today. Interestingly, an initial version of this app was built by someone on the spectrum; Shane Mazlin, programmer at Callaghan, has Asperger's Syndrome.

We never want to be complacent about being on the right track to build something that people actually need, so we make sure that we constantly reach out to parents and professionals and get their feedback on our development process.

During 2015-16, we conducted multiple rounds of end-user testing with support from Callaghan Innovation, Kiwinet, and several other organisations, that provided proof-of-concept for the technology. Thereafter I founded Inclusys to develop Talk With Me as a valuable resource for parents and educators to help children with autism learn social interaction skills.

"Two girls at our school developed an enduring friendship"

– a teacher



SWATI GUPTA

It has been an immensely rewarding journey, notwithstanding the endless challenges and roadblocks along the way.

I could not have done this without all the help and support I got from so many amazing people I met at various stages of my journey. We're now a small team who are all in it for the right reasons.

On these pages you also hear from Amy Taylor, our very passionate and committed Speech and Language therapist, who takes input from people in the community and crafts

amazing content for our app; and from Abhishek Singh, our technology lead, who is a maverick at all things computing and talks about programming languages like a poet might talk about the rising sun!

How I got involved?

I got involved with Talk With Me because I happened to know the right dog!

When I was doing my Masters in Speech and Language Pathology, I would often dog-sit for an awesome couple, one of whom is an academic in autism research. She knew my interest area was communication, especially in autism.

One day she asked me if I would be interested in going into schools and doing research for a new app designed to help children with autism interact socially. Of course, I said, and the rest is history!

What I like about Talk With Me?

My absolute highlight moments, in the last one year that I've been working on Talk With Me, are when we trial the app with adults and children with autism.

Seeing their faces light-up as they interact with it for the first time, is very exciting and makes me feel like we are on to something great here. It is a wonderful tool to foster important and enjoyable communication.

I love the script format of the app which either prompts specific questions to be asked or offers a variety of answers to choose from. This is great as it means the user can choose what they wish to say, and with ease. I believe it is what makes the app so enjoyable and motivating for young people.

Writing conversations for Talk With Me is a fun and exciting endeavour. There is always so much more to write about. On completing one set of conversations, so many more exciting ideas come to mind. I love thinking about the ways different content could be enjoyed by a child, or found useful by a parent, teacher or a therapist.

We all want to be able to communicate. The motivation to communicate varies from person to person, but for the most part, people want their needs heard, they want to understand the information coming at them, and they want to be able to connect with others. Difficulty in verbalising, comprehending language, expressing oneself accurately, or understanding social cues can all be barriers in one's ability to communicate effectively. Talk With Me is a tool that can support communication in such situations; and even better, it can do this in a way that one feels compelled to continue using it.

How I chose my career?

My choice of career as a Speech and Language therapist has its root in my childhood desire to help people reach their full potential. After my schooling, I took some time off to travel and explore various options. As I learnt more about the world and about myself, I realised that education was the right sector for me and decided to Major in Education.

My experience in both work and study grew, and I came to see the valuable role communication plays in everything. From enabling learning, expressing one's concerns and needs, to connecting with others, people reach their full potential when they are given an opportunity to communicate. I believe that through supporting communication in all settings, we can enable people to be the best they can be and live the best lives they can live. So, after my Undergrad, I decided to pursue a Masters in Speech Language Pathology.



AMY TAYLOR: Speech and Language Therapist



ABHISHEK SINGH: Technology Lead

"I will read you from a book and you will be my friend"; true bonds are formed when we travel distances and unravel the unexplored.

We have a world within us that waits to be discovered, and deep inside, we have that itch to go for it.

Talk With Me touches the itch that fuels us to make bonds with others, the bonds that lead us to dream, to take the journey and to make the discoveries.

One day a college friend shot an email to recruit for Swati Gupta and that's how I first heard about Talk With Me.

I was instantly intrigued by how this app would help those on the autism spectrum. I got a meeting with Swati, and here we are!



Cook Strait dream a team effort for Sam



Something as simple as eating a banana could have spelled the end to Sam Muir-James' dream of swimming Cook Strait, writes Mary Anne Gill.

SAM MUIR-JAMES is believed to be the first autistic person to complete the 26-kilometre swim between New Zealand's north and south islands.

The 33-year-old finished in the dark at nine hours 14 minutes.

But because of the strong currents and three metre swells prevalent on 3 March 2019, Sam swam a little further, 30.1 kms.

Pool coach Jane Logan, who has a Queen's Service Medal for services to swimming, accompanied Sam and his father Wally down to Wellington while his mother Jayne stayed behind to monitor progress online from home in Otaua.

"He had a great mindset going into the swim. He wanted to do the first 10kms quickly and focus on the finish," says Jayne.

He didn't have it easy though because of the three metre swells and the strong currents and rips.

Four hours into the swim he took a bite from a banana and was dragged 500m back in the water!

His support crew made the decision to limit Sam's intake to fluids and soft jube lollies only from that point otherwise. Phil Rush, the pilot for his Cook Strait swim and a world-renowned long-distance swimmer himself, along with his team on the launch, make the crucial decisions about any swimmer. They would never have let Sam swim through the night.

As the sun was sinking behind the hills in the South Island, the choppy seas became like a washing machine and the struggle a tough one.

Jane Logan says Sam was still warm, still determined, his right arm going through the mechanics of stroking – but with no power at all.

"His left arm was still pulling, we had eye contact every stroke he breathed. He had followed the boat all afternoon and

now as dusk set in I needed to add my effort to help him," she says.

When he had his next drink and gel the team added a small pale blue glow stick at water level and the two pink ones on the rope of the inflatable rescue boat which they assumed he was following.

Sam told Jane later he had followed her eyes. The last hour, when he only swam one kilometre, was hard work as Sam's arms became powerless and his energy sapped after labouring all afternoon in the water.

There was no moon, it was dark with the only light a couple of glow sticks. Sam was tiring, his shoulders ached from fighting the currents. Then he spotted land and touched Penaro Point at 9.14pm.

Jayne was ecstatic at the end.

"I had so many emotions during the time Sam was in the water. He really did do something very special," she says.

"I was never anxious, during the swim or scared swimming in the dark," says Sam.

"I felt like the king of the sea, swimming on top of the swells looking down on the launch and rescue boat bouncing around under me."

The water temperature ranged between 13 and 15 degrees Celsius.

Sam had worn singlets and shorts in winter and took regular cold showers to climatise for the swim.

"Sam was strong. He had trained for a long time for this to happen, longer than most, and once Sam

starts something, he will not give up unless he's pulled out," says Jayne.

Sam had his supporters who had watched him from all around the world on social media via live tracker.

Messages of support came from complete strangers.



SAM MUIR-JAMES

"I felt like the king of the sea, swimming on top of the swells looking down on the launch and rescue boat bouncing around under me."

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How it all began

Sam and his 41-year-old brother Daniel both have autism.

Jayne and Wally James are professional clowns who have always believed in inclusion in all aspects of their lives. The family live in Otaua, one hour south of Auckland at the northern bank of the lower reaches of the Waikato River and part of the Waikato District.

Sam also does clowning. He started juggling when he was 12 and he sometimes performs with his mother at children's and Christmas parties.

It was water that always interested Sam though and so they got him into water sports. He joined a canoe club and excelled in river racing, competing in the New Zealand junior kayak sprint champs as a 20-year-old and earning two silver medals.

He was a natural sportsman able to try his hand at anything through school and his boundless amount of energy made ultra-marathon swimming a natural fit.

Sam has swum for Counties Special Olympics since he was 22 and when he turned 25, he became eligible for the Manukau Masters Group.

His dream was to swim Cook Strait, so he trained hard, 10kms in the pool up and back three times a week. At weekends

Wally would take him to the sea or to a river and would paddle in a kayak alongside Sam as he averaged 15-20kms each time.

During that time, he accumulated medals at swim series and open water events.

Twice he swum the Taupo Epic 17km race.

Two years ago, Phil put Sam to the test in Lake Taupo.

He wanted to see if Sam was capable of swimming beside a rescue boat for a long time.

Nearly 15 hours later, Sam had proven his point.

"We don't even think about his autism when he's swimming," says Jayne.

"We just want to support him to be the best he can be and we're so lucky he has so many dedicated and encouraging people who get behind him."

The next challenge? Foveaux Strait possibly in February 2020 and Apolima Strait in Samoa in March 2020.

"There's no stopping him now!!!"

"What I say is 'never give up on our special people, believe in them and they will believe in themselves.'"



CLOWNING AROUND: Jayne Muir-James with son Sam in action preparing for a clown gig.



Being a book for the day was fun



*Autistic volunteers became real people on loan to the reader for one on one conversations about their experiences with autism in what is believed to be a New Zealand first at Chartwell Library in Hamilton to celebrate World Autism Awareness Day. One Unique Minds director **Jason Edgecombe** was one of them and writes about his experience.*

People change, they grow and evolve over their life. Never listen to a person who says what your kid can or can't do.

THE HUMAN LIBRARY gave me the opportunity to talk to a few people including a support worker, the chief executive of Life unlimited, and a father whose young son had recently been diagnosed with autism.

My favourite question on the day though was this: "what tips would you give to parents of a neurodiverse child? Three tips?"

Wow... I had to think hard about that one for a minute... but this is what I said:

1. **It's never bad behaviour.**
2. **The teachers are never right.**
3. **Don't hide what you do.**

It's never bad behaviour

Kids communicate in lots of different ways, only some of which professionals and parents understand, and we tend to "label" some of that communication as negative.

Let's take crying for instance, babies don't cry for no reason, they cry when they are hungry, tired, lonely, feeling bloated, or a host of other things.

Kids act out when they feel they aren't being listened to, so when we see a kid displaying "Bad Behaviour", what we are actually seeing is a kid who is trying to communicate something and we (adults) aren't listening.

The longer we go without listening, or making the child feel heard, the "worse" the behaviour gets. So if a kid is doing something "naughty" look around and listen.

The teachers are never right

I'm not saying this to get back at all those teachers that said I would never amount to anything (just making sure that's clear).

Teachers have a lot of restrictions placed on them, and a lot of demands on their time and expertise, and they are not given (anywhere near) enough support or training (like not even close, plus very little training on neurodiversity).

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GREEN BEAN: Helen Smith Waikato regional coordinator, Parent to Parent.

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Teachers do their best, but they are trained to teach a curriculum that is out of touch with the real world, and teachers only see kids in a school environment which is stressful, controlled, ugly, and very scary for a lot of neurodiverse kids. In effect teachers only see our neurodiverse kids at their worst.

People change, they grow and evolve over their life. Never listen to a person who says what your kid can or can't do.

Don't hide what you do

As I grew up I got into a lot of trouble, I was bullied, got into fights, was in trouble with teachers nearly every week (or more in some periods).

I spent six months of grade three being beaten up every recess by a group of boys over an eraser (rubber).

It sucked and as I grew up I Hated (with a capital H) that my dad never protected me, never looked out for me or supported me or fought the school for me.

It's one of the reasons I left Canada, it's why I stopped talking to my dad for ages, it broke our relationship.

Except none of that was true, well the bullying and trouble with teachers is, every single time I was bullied my dad was in the school after talking to the teachers, the principal, the vice principals everyone and anyone who he felt had let his son down (which was basically everyone).

He stopped me getting suspended when a kid beat me up, he argued when the school put my primary bully (the one who hounded me and physically hurt me more times than I can count) in the same class (at the same table) as me, he practically lived at the school when I was being daily physically beaten. But he never let me see any of that, he hid all of that from me till I was 25 and asked him straight out why he did nothing. Turns out he Hated (with a capital H) that his son never appreciated all he did for him.

Let your kids know that you fight for them, even if it's hard, even if you think they can't understand, tell them you try, let them see you angry at the injustice and the discrimination, share that with them otherwise they might end up bitter that you didn't do what you actually did do.

In the end being a book was something I will certainly put my hand up for again.

Thanks to Altogether Autism for organising the event and for the Chartwell Library for hosting it.



Footnote: The Human Library is a trademarked concept, so we apologise to the Human Library founders and we won't use this term again, but will run similar events.

Jason Edgecombe is a husband, father of two, business owner, speaker and expert in neurodiversity. He is the founder of Breaking the Label and the main developer of its personal development programme. He writes a regular blog on Facebook as ASpieDadnz.



ON LOAN: Autistic volunteers who were real people on loan to the reader for one on one conversations about autism. l-r Daniel Smith, Jason Edgecombe, Paula Jessop, Barbara Choat, Karleigh-Jayne Jones, Tessa Clews, Elroy Liddington.

Medicinal Cannabis; still not a recommended treatment for children with autism



The use of medicinal cannabis and cannabidiol (CBD) in children with autism is receiving an increasing amount of attention in the current media, writes researcher Emily Acraman.

The research is only in the very early stages and as such, there are still many questions that remain unanswered.

THERE ARE A growing number of articles and parental reports that discuss the success of **cannabidiol (CBD)** as a treatment for children and individuals on the autism spectrum (Gee, 2019).

However, the clinical research to support these findings remains nearly nonexistent. As it stands today, the existing evidence does not support that CBD and similar products should be recommended as a treatment for autism (Salgado & Castellanos 2018).

What is medicinal cannabis?

Medicinal cannabis encompasses a huge range of products, from those which have undergone clinical testing and have been determined to meet medical standards, through to the non-pharmaceutical grade products (commonly associated with recreational use). It is important to understand the various terms associated with medicinal cannabis products that are currently being used by the public, as well as paediatric researchers in the autism field. **Cannabis** is a general term that refers to the three species of hemp plants (*Cannabis sativa*, *Cannabis indica*, *Cannabis ruderalis*). **Marijuana** is a term that refers to the dried leaves, flowers and stems which are often smoked for medical and recreational purposes.

Marijuana contains more than 100 different chemicals, however the two main chemicals used in the medical application of cannabis are:

- **Tetrahydrocannabinol (THC)** – this is the psychoactive component in marijuana (the chemical that produces the 'high')
- **Cannabidiol (CBD)** – this is a substance found in cannabis that is seen to have potential therapeutic value, with little or no psychoactive properties.

Cannabidiol (CBD) products are most commonly what is referred to when talking about medical cannabis, especially in the studies and reports involving children with autism. CBD products have very little to zero of the THC component, so when taking it you don't feel the 'high' that is generally associated with its recreational counterpart (Campbell, Phillips, & Manasco, 2017).

The World Health Organization notes that CBD 'could have' therapeutic value, does not carry any addiction risks and is generally well tolerated with a good safety profile (World Health Organization, 2018).

Since 2018 doctors in New Zealand have been able to prescribe CBD products as prescription medicine after a bill saw cannabidiol removed from the list of controlled drugs. A person with a prescription is now able to import CBD products for personal use. This law change brought New Zealand into line with other countries, such as Australia who passed a similar bill in 2015 (Misuse of Drugs (Medicinal Cannabis) Amendment Bill 2018).

What does the research say?

Although the use of medical cannabis to treat children on the autism spectrum is gaining popularity, there is still a significant lack of clinical research which proves CBD and similar products to be a safe and effective treatment for children with autism.

A 2019 Israeli study looking at the safety and efficacy of cannabis oil (containing 30% CBD and 1.5% THC) showed that 80% of parents reported a moderate to significant improvement in their autistic child's behaviour following a six-month treatment period using cannabis oil (Schleider, Mechoulam, Saban, Meiri, & Novak, 2019).

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Own time and space

TE POU O TE WHAKAARO NUI launched a new resource aimed at improving the quality of disability support services and the workforce supporting people on the autism spectrum. Te Tau Titoki honours the spirit of takiwātanga, as the name is derived from the whakataukī, *Ā te tau tītoki* which means, "when the tītoki fruits." The tītoki tree does not fruit regularly but does in its own time, an allusion to autistic people blooming in their own time and space.

ALTOGETHER AUTISM HIGHLIGHTS

LAUNCHING: Altogether Autism's Catherine Trezona and Jamie-Leigh Timoti catch up with Te Pou o te Whakaaro Nui Māori strategic lead Keri Opai.

However, the results of this are based on parental reports and no control group was used in the study so the findings should be interpreted with caution. There is also currently another Israeli study underway looking at cannabinoids for behavioural problems in children with autism which will carry more scientific weight. However, no results of this study are available yet and it is unknown when they will be available (Aran, 2018).

There are also concerns within the current research due to the differences in strains and strengths of the active chemical components in cannabis being used. This refers to the concentration and ratios of the THC and CBD within a product. These inconsistencies make it difficult to make safe dosing recommendations especially for use with children.

This has been a subject of interest not only for medical professionals, but also for government legislators (Madras, 2015). Also, there is also very little known about the long-term hazards of regular cannabis use especially in the child population and this remains a critical area for future study (Hadland, Knight, & Harris 2015).

Summary

While there are anecdotal reports to suggest CBD and similar medicinal cannabis products may be a promising intervention for children with autism, it currently remains an unproven treatment. The research is only in the very early stages and as such, there are still many questions that remain unanswered. The safety profile and recommended dosing levels of the use of CBD for autistic children – is still

not properly understood. It is also not clear – what specific symptoms are most likely to improve under cannabis treatment (Salgado & Castellanos 2018). – There is a lot of interest in this topic both nationally and internationally, and more research will increase our knowledge in this area over the next few years.

However, given the lack of evidence-based research medicinal cannabis cannot be safely recommended for the treatment of autism at this time.

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Emily Acraman is a researcher at Altogether Autism.

Fresh topics at autism training

CREATIVE ABILITIES is a dedicated team who work alongside people who have physical and/or intellectual impairments. The team works in partnership with individuals to create a friendly, stimulating, happy and safe environment by providing a holistic service.

Clinical training and development officer Ronald Rey says the team assists people to live a quality lifestyle, providing support in all aspects of daily living, including opportunities to meet with others and participate in the local community.

"We learned new things from the PRISM training that enables us to understand more about our clients with autism.

"Consequently, we are able to assist them effectively with empathy because of the knowledge we learned from the learning activity.

"The topics are fresh and not the usual information that we get in an autism training," he said.



ALTOGETHER AUTISM HIGHLIGHTS

PRISM TRAINING: L-r Olena Timofeieva, Celso Agosto, Robbie Beluso, Jaqueline Civil, Sheila Agosto Catherine Trezona, Sanam Bagherian, Nerren Barola, Cecilia Duenas, Rochelle Manulat, Mary Jo Matullano. Telita Brahne (sitting).

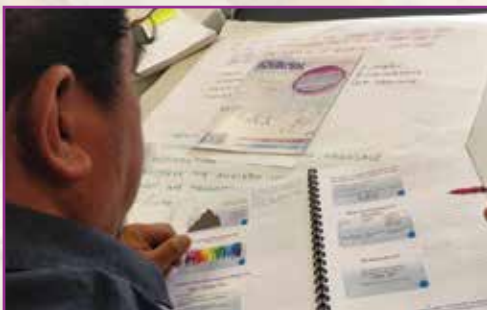
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