

ALTOGETHER AUTISM JOURNAL

2021



ALTOGETHER
AUTISM
TAKIWATANGA

Yeah!



ALTOGETHER AUTISM TAKIWĀTANGA

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 Advisory Group, autistics and family members.

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

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



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Covid brings mixed blessings



Tēnā koutou katoa

This is our first Journal since 2019, with Covid providing all manner of interruptions and disruptions. But as we are all discovering, Covid has also brought opportunities. So, we are doing some new things here at Altogether Autism. The first is our Autistics 4 Autistics (A4A) Zoom meetups.

We are also offering autistic-led network meetings as we travel around the country. Our autistic advisors are sharing the latest on autistic language preferences and hosting an autistic-only meet-up. Check out the events page on our website for details on when we are coming to your region.

We have formed a relationship with Hidden Disabilities to supply the sunflower lanyards and related products. Our parent not-for-profit Life Unlimited, has been approved as the New Zealand distributor through our Mobility Centre stores.

We offer free training to businesses wanting to welcome wearers of the sunflower lanyards. Check out the full range of products on the Mobility Centre website.



April was Autism Acceptance month, and we thank everyone who shared videos, stories and insights across our various social media. Check out our Facebook and Instagram pages if you missed these stories.

There have been some changes in the members of our advisory groups. We are sad to farewell Betty Pulefolau from the Consumer Advisory Group. Betty has been one of our advisors for many years and is stepping down to focus on her graduate diploma. Thank you Betty for all you, Brian and Roman have contributed to our community and we know Altogether Autism will continue to stay connected to the Pasifika Autism Support Group.

We have also farewelled Dr Kevin Appleton, psychiatrist, from our Professional Advisory Group. Dr Kev has given us wonderful support and resources. You can read some of his articles on his website, such as Quirky Girls and Autism in Adults. Thank you for all you have contributed to our work, Dr Kev.

Joining us as professional advisors are Catherine Swan, developmental paediatrician at Canterbury District Health Board and Jane Hughes, also from Christchurch. Over the last decade, Catherine's focus has been diagnosis and support for autistic children and their

whānau. She is also a clinical lecturer at the University of Otago and has five children, so we are fortunate that she has agreed to share her knowledge and experience with us. Jane Hughes from Canterbury, is our most recent new professional advisor, as a consultant psychiatrist within a specialist mental health service for adults with an intellectual disability. This expertise in both autism and mental health is highly valued and one of the most requested topics from our information service.



JANE HUGHES



CATHERINE SWAN

Ngā manaakitanga (with best wishes),

Catherine Trezona – National Manager, Altogether Autism

In this issue

- 3 Complex information requests service
- 4 On being authentically autistic
- 6 Mothering autistic children creates joy and challenges
- 8 Stimming: a movement towards acceptance!
- 10 Lockdown impact on autistic teenager
- 12 Unmasking in the workplace – the late diagnosed autistic dilemma
- 13 Autistic and transgender: the intersection of two minority identities
- 16 The importance of authentic autistic representation in the media

- 18 Disability and the law – supporting people and their families
- 19 Journey of wellness after troubled decade
- 20 How lockdown became the new norm
- 21 Learning to be ourselves
- 22 Burning out as part of undiagnosed autism
- 24 Spotlight on core boards
- 26 More than one neurotype
- 27 A year on from life in a pandemic

Complex information requests service



Our complex information requests service uses the combined expertise of our researchers, published research, professional experts and autistic lived experience to provide a rich response writes consultant clinical psychologist Jenny Gibbs.

ALTOGETHER AUTISM provides a national autism information service contracted by the Ministry of Health. The objective of the service is to provide a comprehensive range of advice and information to autistic people, their families, professionals and to other interested people. When information requests are complex, we have a team of people available to help.

When Altogether Autism's researchers receive a complex information request, they initially get to work to find out what the professional literature is saying about the topic. The researchers may then approach some or all of Altogether Autism's advisory group members for their thoughts, ideas and opinions on the information request.

Altogether Autism has two expert advisory groups, the Consumer Advisory Group and the Professional Advisory Group.

Our consumer group provides expertise and input in an advisory capacity to the work of Altogether Autism to ensure the service remains useful and relevant to autistics. It has appointed members with lived experience of autism and consists of autistic people and parents of autistic children. A minimum of 60 per cent of the group identify as autistic in recognition of the importance of the autistic voice.

Our professional group provides a multidisciplinary perspective and up to date information and opinion regarding best practice in the diagnosis, intervention and provision of services for autistic people.

The group has appointed members from a range of disciplines who have a regular and active role in the group on account of their expertise, knowledge and experience in the field of autism.

After consultation with the advisory groups the researcher integrates all the information into a single report. This provides a rich response which considers the published research, local clinical knowledge of best practice and systems and lived experience.

Autistic voices lead our work

Altogether Autism's first strategic goal for this year was that autistic voices lead our work.

Our Consumer Advisory Group members are part of a strategy group which set goals for Altogether Autism considered important to the autistic community. Representatives of the strategy group attend the management group meetings to ensure the autistic and parent voice are actively represented at the highest level.

In Altogether Autism's day to day operations, our consumer members provide regular input. In addition to their contributions to information requests, they present at network meetings and workshops, write articles for the journal and website, advise of issues that are important to the autistic community, and host our Autistic 4 Autistic zoom meetings.

There can be different perspectives and at times tensions within a group of neurodivergent and neurotypical people and in being a service that tries to meet the needs of autistics, parents and professionals, I personally feel privileged to be working with all our advisory group members as we navigate this space.

Jenny Gibbs is a clinical psychologist at Waikato DHB's Child Development Centre and is Altogether Autism's consultant psychologist



On being authentically autistic



The theme of this journal is 'authentically autistic'. **Rachael Wiltshire** explains what the phrase 'authentically autistic' means to her, and why it is important.

We all deserve to live in a world in which we don't have to hide parts of ourselves to be accepted.

I STUMBLED into the phrase 'authentically autistic' quite by accident.

Altogether Autism was seeking advice from the Consumer Advisory Group on a workshop we were developing for parents in Feilding, and we were asked what we, as autistic adults, would like parents of autistic kids to know. I said this:

'I guess the key thing I would like parents to know is that they shouldn't be raising their child to appear neurotypical – because masking all the time is exhausting and leads to breakdowns. They should be aiming to equip their child with strategies that enable them to function in the world, whilst still being authentically autistic. The best way to do this is to make sure they listen to what autistic adults have to say – there are plenty of people to follow online.'

I had never heard the phrase 'authentically autistic' before – that combination of words just seemed to sum up the concept I was trying to express. Serendipitously, however, it turns out that it is a concept that other autistic people have been talking about online.

Here, I'm going to explain what being authentically autistic means to me, and why I think it is so important.

It may seem counterintuitive, but I think the idea of being authentically autistic is most important for the neurotypical people who support an autistic person (i.e., parents and professionals), rather than the autistic person themselves. I certainly don't want autistic people to read this and worry that they are being 'inauthentically autistic', or that there is a 'wrong way to be autistic'. If you're autistic, then however you do you is authentic!

Rather, I'd like to see parents and professionals examine the way they relate to autistic people through the lens of supporting us to be authentically autistic; any supports offered should help us to function in the world whilst still maintaining our autistic identity, rather than seeking to make us appear more neurotypical.

Of course, most people don't set out with the goal of forcing a person to be more neurotypical: I know that parents and professionals do generally have our best interests at heart. But the weight of societal pressure can mean that even if your goal is not to make someone appear more neurotypical, that can still be the inadvertent outcome.

The 'authentically autistic' lens can help combat some of this unseen pressure. For example, I felt that when I was growing up my parents were always saying, 'well, you've got to compromise to fit it' – and yet it seemed to me that I was always the one having to make changes to compromise, when to my mind it should have been about meeting each other halfway.

Now, Mum and Dad if you're reading this – that is no shade on you. I know that you love me, that you want what's best for me, and I am incredibly grateful for all the support you gave me growing up and continue to give me. At face value, giving your child strategies to compromise so they can fit in with the world better seems like a helpful thing to do.

But if we examine this through the 'authentically autistic' lens, we can then ask why it is so important that the autistic person fits in with the world. Instead, why can't the world sometimes bend to fit them a bit better?

■ Continued on page 5

■ Continued from page 4

Encouraging the world to make more space for autistic people, and neurodivergent people more generally, is so important for our wellbeing. The idea of 'authentically autistic' in part came about from me reflecting on the fact that I tend to manage to be quite successful (or pass as neurotypical!) for a year or two, but I have a pattern of having bouts of major anxiety/depression, which I think is probably related to the stress of spending so much time acting neurotypical.

Therefore, to me being authentically autistic is about being confident in my autistic identity and living in a way that ensures my needs as an autistic person are met, so that I don't get those periods of burnout. For me personally, I think a lot of that is about being comfortable with disclosing the fact that I'm autistic because it's much easier to be yourself if people around you know why you might sometimes seem a little 'weird'/different.

Attending autism conferences is one of the most freeing experiences I've had because I don't have to worry that people will think I'm strange for standing in the corner and not talking to anyone – it would be nice if I could feel that free all the time.

Of course, that's just what it looks like for me – it might look different for other people.

But for parents and professionals, I ask that you try to support your child or client to be a confident autistic person, not a person who is damaged from trying to pass as neurotypical all the time.

I recognise that this is not an easy task, because we live in a society that is constantly sending both subtle and overt message that the way we relate to the world is weird or wrong. That is why I have contributed articles to this journal about media representations of autism and about advocacy online – because the better society understands neurodiversity, the more freedom we will all have to be our authentic selves.

We all deserve to live in a world in which we don't have to hide parts of ourselves to be accepted.

“But for parents and professionals, I ask that you try to support your child or client to be a confident autistic person, not a person who is damaged from trying to pass as neurotypical all the time.”



To me, being authentically autistic is about having both the confidence and the freedom to be myself and it is a

journey that I am on, as I learn to be more open about being autistic in the hope that by doing so, I will help create a more accepting world for other neurodivergent people. My hope is that the articles in this journal will help us all to take a small step towards that world.

Rachael Wiltshire is an autistic member of Altogether Autism's Consumer Advisory Group. Outside of her autism advocacy work, she studies and teaches dance and tutors high school students





Mothering autistic children creates joy and challenges



Allowing her authentically autistic twin boys to be themselves is important for writer Angela Cuming.

TOMMY AND HENRY are diagnosed just shy of their third birthday and for a while everything stops.

Then late one night you are watching them fall asleep and they look just as perfect as the day they were born and you realise that while everything has changed, the most important things are still the same.

Their speech and language therapist visits and you get a bit wobbly asking if they will ever speak because all you want to hear are the words "I love you." I bet they tell you all the time, she says.

A day later Tommy strokes my hair and whispers, "so cute" and Henry presses his face into the back of my neck, and you now understand completely.

It's photo day at kindy. You get a little neurotypical niggles about wanting a 'nice' picture of the boys, but it doesn't work out. And then you take them about to the beach, the place where they love to run wild and happy and free, and you pull out your phone and capture smiles so big and wonderfully

happy and they will be the photos that are framed on the wall.

Now the beach is their playground and part-time classroom and they spend hours throwing rocks into the water and sit in the water, so the waves splash over them and grab shells and

write their letters and numbers in the sand and suddenly you stop feeling like they are missing out on things other kids do.

You see another headline declaring screen time the enemy and you wince a little, because in Tommy and Henry's home there's unrestricted screen time.

You find yourself second guessing if it's the Right Thing To Do, and then they start singing the Greek alphabet they have taught themselves via YouTube and watch videos of themselves running along the beach and giggle as they replay a clip of the Teletubbies with dirty knees over and over again and you stop reading those headlines.

"Then late one night you are watching them fall asleep and they look just as perfect as the day they were born and you realise that while everything has changed, the most important things are still the same."

■ Continued on page 7

■ Continued from page 6

Then there's another celebrity chef popping their head over the parapet to tell you children need to Grow Their Own Vegetables and they won't be 'picky eaters' and this once would have bothered you but you are now too busy making your happy and healthy boys their fifth helping of buttered toast for dinner.

"What time do they go to sleep?" people ask and it's literally how long is a piece of string because you are learning their brains are wired to just sleep when they need to. You buy a big mattress and put in on the floor and learn to love that morning cup of coffee just that little bit more.

You start to see how unfair the world can be. The city school you were thinking of sending them to that declined to provide a mobility parking space, the comedienne that jokes about vaccines and autism, the organisations that use a puzzle piece to represent autistic brains and lives.

But there is the good stuff, too. The kindy teachers who love them as fiercely as you do and spend months patiently guiding through how to wash hands and put on gumboots, the neighbour who drops off a second-hand typewriter for them to play with, the local primary school principal that asks what she can do to get her school ready for their enrolment.

Your village of occupational and speech and language therapists gives way to a village of autistic adults, who show incredible grace and kindness and patience with you and other allistic (non-autistic) parents of autistic children.

You watch Tommy and Henry fall asleep again. Tommy strokes your hair and Henry presses his face into your neck.

I love you too, you tell them.

Angela Cuming is a New Zealand-based writer, journalist and blogger. She is Mum to three boys, including 5-year-old autistic identical twins. She and partner Paul moved to Dunedin three years ago and live near the beach.



Stimming: a movement towards acceptance!



Stimming is often thought of as one of the hallmark features of autism, writes researcher Emily Acraman.

Navigating the neurotypical and sensory world can be hugely overwhelming, and stimming provides a practical and reliable means to calm and self-regulate.

WITH A LONG HISTORY of misunderstanding and negative social stigma, growing evidence confirms these behaviours are hugely important for the neurodiverse community.

The term stimming comes from the clinical phrase 'self-stimulatory behaviour', also known as stereotyped behaviour. The neurodiverse community have reclaimed these technical terms, and the wider autism community now refers to this behaviour as stimming.

For an autistic person, stimming usually refers to repetitive or rhythmic behaviour that is commonly expressed through body movements (e.g. hand flapping, finger flicking, hair pulling or pinching, feet flexing, spinning, necklace playing etc) but also vocalisations (e.g. muttering, grunting, stuttering, whistling, singing) (Kapp et al, 2019).

The autistic community advocates that stimming behaviour is a self-regulatory coping mechanism, and efforts to control this behaviour could have negative effects for autistic people (Lilley, 2018).

Research exploring stimming from the autistic perspective supports this position and suggests these behaviours are beneficial.

There is a long history in both research and clinical practice, of efforts to reduce, minimise or eliminate stimming behaviour in autistic people. Unfortunately, interventions which aim to control this behaviour remain popular (Jaswal & Akhtar, 2018).

What is the benefit of stimming?

Most of the recent theories around why autistic people stim suggest that stimming provides reliable and self-regulated feedback as a response to an overwhelming, unfamiliar or unpredictable environment (Kapp et al, 2019). This includes seeking hyposensitivity (sensory seeking) satisfaction in a sensory lacking environment and hypersensitivity (sensory avoiding) relief from both excessive sensory input, and emotional overload (such as anxiety).

While there isn't a lot of research to support this, autistic adults tell us that stimming has a far greater function than just self-stimulation (Kapp et al, 2019; Steward, 2015).

A 2015 study by Steward, which involved an online survey of 100 autistic adults highlighted a wide range of reasons why autistics stim. The most common of these being, a coping mechanism to reduce anxiety (72%), to calm down (69%) and overstimulation from sensory input (57%). Additionally, 80 percent of the study participants reported that they enjoyed stimming, nine percent reported they did not like to stim and 11 percent said it depended on the stim. Interestingly, 72 percent of participants involved in the study had been told not to stim (Steward, 2015).

A 2019 study published by Kapp et al, explored the views of 32 autistic adults regarding stimming. Researchers asked the study participants why they stim, what the value of stimming is for them, and what they feel about other people's perceptions and reactions to their stims. One of the key findings of this study was that although participants

said their stims were automatic and uncontrollable, no one reported consistently disliking them. Further, most people described their stims as pleasant and calming.

When asked why they stim, study participants reported their stims were either a response to sensory overload, or overpowering thoughts. The autistic people in this study reported they were often overwhelmed by sensations, new information or their own thoughts. Stimming acted as a self-regulatory coping mechanism which helped them to feel calm and in control. While the study participants reported beneficial and meaningful purposes for their stims, the majority also described encountering negative social judgements from people which made them feel rejected and self-conscious about stimming around others (Kapp et al, 2019).

"While many children of the same age can struggle to find the words to capably express their inner thoughts and feelings, stimming for an autistic person prevails where words fall short."

■ Continued on page 9

Conversations around stimming...

It is clear through conversations with parents of autistic children and autistic adults, that stimming serves a necessary and meaningful purpose for the autistic individual.

I spoke to a parent of a 10-year-old non-verbal autistic boy. She talks about her son's stimming as his own unique way of communicating his emotions. While many children of the same age can struggle to find the words to capably express their inner thoughts and feelings, stimming for an autistic person prevails where words fall short. This parent celebrates her autistic son's stims, as it gives her and those close to him a visible and definitive understanding of how he is feeling in a particular moment. His family, friends and teachers have learnt to recognise his stims, what they mean and what he is trying to communicate. His stims are a combination of hand flapping and vocal stims whether he is happy or upset. The difference is the intensity in which he stims. When he is happy, he flaps his hands with hands open and arms out and vocalises joyful, excited noises. When he is experiencing strong negative emotions, he flaps his hands more rigorously, keeping them closer towards himself and vocalises more distressed sounding noises. His family say they like that his stimming is his way of communicating with the world around him, he just expresses himself through his body rather than his words. Another parent talks of her 11-year-old autistic daughter's verbal stims. While some people refer to them as tics, she believes that from an outside perspective they seem to serve a different purpose. Tics are sudden involuntary behaviours or mannerisms. They do not serve a purpose, are usually disliked by the person displaying them and often associated with stress (Lilley, 2017). On the other hand, a stim is a behaviour that serves a direct purpose for the individual. To this parent, her daughter's verbal stims look like an extension of her physical stims and serve as a regulator of her surrounding environment. They express happiness, excitement, nervousness, stress etc when a hand flap doesn't suffice.

One autistic adult speaks of his stims in relation to energy input/output. He sees stimming as a healthy transferal of excess energy often brought about externally (e.g. through sensory bombardment) or internally (e.g. through a flood of thoughts). He explains that suppressing stimming techniques will inevitably lead to unhealthy releases, such as anger or physical outbursts.

Moving towards acceptance

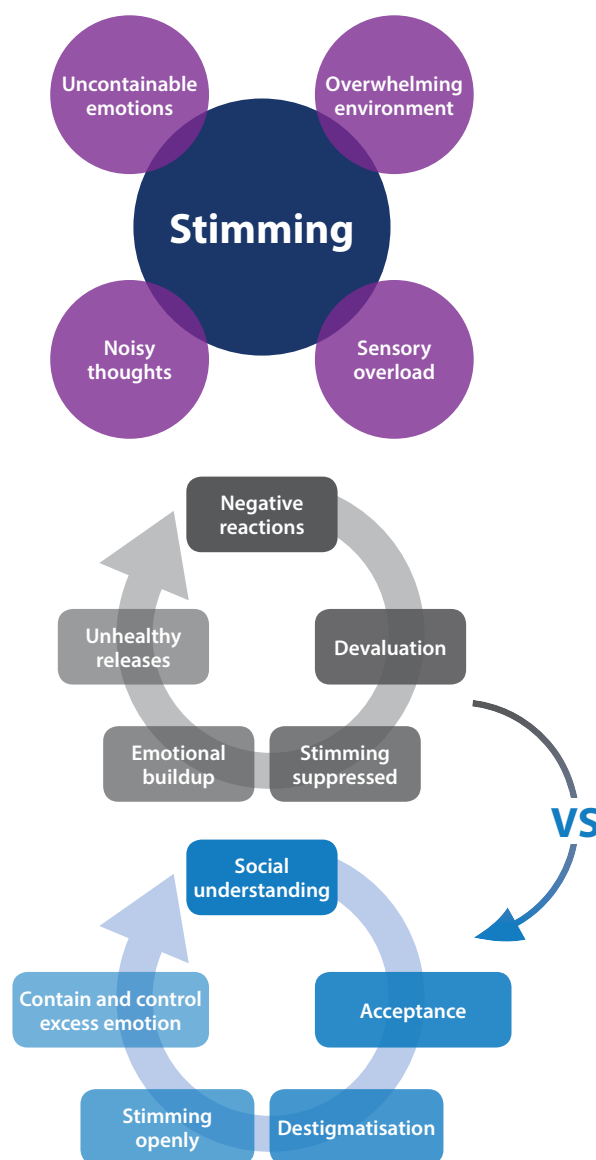
While there is clear evidence of the benefits of stimming for autistic people, many autistics still report experiencing negative social stigma and judgement surrounding their stims. Potentially this may also be why treatments and interventions to control or reduce stimming remain popular. Autistic adults and researchers in this field, however, highlight that this approach is misguided as "it strips people of a key means of coping" (Kapp, 2019).

When stimming involves self-injury, then intervention is often necessary. However, in most cases rather than focusing on interventions to reduce or control an autistic person's stims, the focus should be on increasing non-autistics' understanding and awareness. It is important anyone supporting an autistic person finds and understands the balance between acceptance and change.

Autistic people tell us that rather than discouraging or trying to control their stimming, families and professionals could instead look at why the autistic person might be stimming in the first place. For example, is the person having difficulty processing sensory input? Are they feeling anxious or overwhelmed in certain situations? Is the person using their stims to communicate excitement and joy?

Navigating the neurotypical and sensory world can be hugely overwhelming, and stimming provides a practical and reliable means to calm and self-regulate.

Overall, society's understanding holds a real key to the social acceptance of stimming. It is important we take the autistic person's lead by accepting these behaviours and understanding the fundamental benefits they have for the individual (Kapp, 2019). Hopefully greater awareness of autistic people's experiences with stimming may help to transform social stigmas and lead to a greater understanding and acceptance.



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Emily Acraman is a researcher for Altogether Autism.



PHOTOS: Alan Gibson © Life Unlimited Charitable Trust, Life in a Pandemic

Lockdown impact on autistic teenager



The impact of several lockdowns in Auckland on autistic children and their parents is captured by Julie Veli who says she and her son had Covid fatigue.

THE SECOND LOCKDOWN was TERRIBLE.

We definitely had "Covid fatigue".

We butted heads badly.

Harper did not want to do anything, I knew he understood it was Covid but at the same time he was confused, frustrated and sad – and he had no one to take it out on but me. That is how it felt.

We did not talk much during that time and we spent our time on different floors of the house.

Afterwards when we went back to school and work, we just went back to normal. I think it is because we were happy to be out of the house and away from one another.

The three- and seven-day lockdown this year we handled that move much better.

We did some baking, we baked cookies. The first lockdown we did not bake because our oven was broken. He enjoyed

Harper did not want to do anything, I knew he understood it was Covid but at the same time he was confused, frustrated and sad – and he had no one to take it out on but me.

eating what we baked. We were both more relaxed, no pressure no expectations other than to just stay home. Probably because this is the third time going through it.

There was a lot more TV, TikToks, Netflix, PlayStation, Nintendo, YouTube this lockdown, and not much going outside. I could not fault it because we were happy, well happier than the second lockdown, we liked each other.

IMPACT OF LIFE IN A PANDEMIC BOOK

This will seem vain or selfish.

The picture of myself I found confronting, because I looked ugly. My confidence took a hit. I know it showed how I felt.

My outside showed how I was feeling inside. I think it is because I try not to show that. I understand the picture went with the story that I told. I saw defeat. I look defeated. It is a true reflection of my thoughts and emotions of me trying and being tired. It showed me vulnerable and I felt that single-parent title.

■ Continued on page 11

Continued from page 10

Harper was very handsome, he looked happy. I take some solace looking at that picture of him in that I am a good parent. I am doing good parenting with him.

Our family and friends loved the book and have been supportive after reading it. Some of my family found the magazine article (Seasons Magazine) so that was cool. It opened their eyes to the reality for Harper. His everyday life and what his future may look like.

Our PASG (Pasifika Autism Support Group) Fanau – I know they were proud of us for sharing our story and showed us love for it.

I showed a copy of the book to some of my work colleagues who thought it was cool and who really enjoyed the other stories.

Harper loved it – seeing his face when he saw himself in the book was awesome, I wish I recorded it.

He kept our frame picture front and centre in the lounge for quite a while. (Now he has put it face down on top of the fridge)

Harper is taller than when we were in the book.

When we hug, all I see is his chest. He gives good hugs.

He is becoming more independent – making his breakfast, showering, choosing his clothes and dressing all unassisted. Still struggles to do any chores.

He still needs to know ahead of time what he is doing, where we are going, what we are eating, who is going to be there – routine is still key.

He still talks about Covid most days. Talks about seeing our family in Australia, especially with the news of the travel bubble.

"Harper was very handsome, he looked happy. I take some solace looking at that picture of him in that I am a good parent. I am doing good parenting with him."



Recently we have gone back on the Clonidine, a small dose at lunchtime to help regulate his emotions because in the afternoons he had developed a pattern of meltdowns most days. I do not see it as a setback. It is me trying to help him, so he is not suffering.

Our goal is to get him into the satellite class at Green Bay High.

He wants it too. He talks about the school, about the school uniform, about his friend Jackson who goes there, he really wants it.

He is 14 now, and autism or not – he wants friends, to go to the mall and even go shopping for clothes at Farmers and Cotton On.

He wants to be a teenager.

Julie and Harper Veli appeared in the *Life in a Pandemic* book produced in September 2020 by Life Unlimited Charitable Trust. The article appears in www.lifeunlimited.net.nz/lifeinapandemic



Unmasking in the workplace – the late diagnosed autistic dilemma



Autistic people are great employees, writes Dianne McLean, a recently diagnosed autistic woman who says it's amazing how many things now make sense in her life.

It is never easy to open up and declare you are autistic to an employer, doing so may just make the difference between being able to stay in that employment or having to leave.

AUTISTIC PEOPLE MAKE EXCELLENT EMPLOYEES. We often have unique skill sets that make us ideally suited to many jobs and our focus and attention to detail can be great assets in any workplace. We are loyal and very hardworking, attributes all employers value highly.

However, sometimes we may experience unique challenges that can make coping in the workplace difficult at times. Most of my working life has been as an undiagnosed autistic woman and although I coped for the most part, there were two jobs that left an everlasting impression on me and now I am diagnosed have led me to reflect on what I do need and want in a workplace.

The first example was the worst job ever – for me. On the face of it, it should have been my dream job. Sole charge (for the most part) with routine jobs typical of an office, working for a shuttle bus company taking people to and from the airports in Hamilton and Auckland.

Unfortunately, I failed to recognise in myself the lack of executive functioning skills I needed to successfully perform a vital part of the job description and this led to much angst and stress for me and huge amount of frustration on the part of my bosses. Terrible things happened – like people being stranded at the airport because I had failed to note down their return date.

I did learn something very important from this after I finally handed in my resignation and that was that I needed to find a job that utilised my strengths instead of me always having to compensate for my weaknesses. This decision was one of the best I've made for myself because it led me to working in rest homes organising the activities.

Rest home work suited me very well for many years, mainly because the environment was quiet and the way the day was structured gave me plenty of time between activities to 'decompress' and organise for the next. There were some things I struggled with – visiting residents in their rooms, for example – but overall, I did very well in that role and my ability to hyper focus meant I often went above and beyond my given duties.

I managed to do this job successfully until by chance I found myself in the best job I have ever had, as a tertiary level tutor for a private training provider. Strangely enough on the face of it, it should have set all my autistic nerves jangling. But it didn't. I have often wondered what made the difference. Tutoring wasn't like the office job and I didn't need to use the same skills, but it should have presented enough challenges to make my working day miserable, but it didn't.

Some of the reasons for this were because there were certain supports built into the job already, such as an assistant tutor to deal with the administration tasks and the fact the course I was teaching ran from a remote location rather than

on a busy campus. It helped, too, that I loved the course I was teaching. But I think the reason I did so well came down to the level of support offered to me and all the other employees by the management. This support was offered in various ways to all of us in the company, not just to me. At that stage I was still undiagnosed, so no one knew I was autistic, even myself. I'm confident had my diagnosis been known even more support would have been offered to me, because that was the company kaupapa.

What I learned from this job was the value of being supported in the right way at work. It makes such a difference and although it is never easy to open up and declare you are autistic to an employer, doing so may just make the difference between being able to stay in that employment or having to leave.

When I received my diagnosis, I asked my psychologist if it was important to tell people about it. His advice was – it is always better to be honest. And of course, it is. It opens the possibilities for better understanding and acceptance between colleagues and concessions from management that can facilitate a better working day. Especially if some of our challenges are more hidden. For example, I often struggle with unexpected changes in the routine, or I get stuck on a detail and can't move on from it, which can frustrate my work colleagues at times.

I don't think any amount of support would have helped me in my first example, to be honest, because I lacked certain skills due to my autism and that's a lesson. But for those of us who have skills and talents but just need to work a little differently or even remotely, disclosing may mean all the difference. And, if an employer isn't willing to make accommodations to be supportive of our differences, we must ask if they are an organisation that deserves our talent and resources in the first place.



Dianne McLean is a late diagnosed autistic author who lives in Thames where she happily indulges in her love of all things 'steampunk'.



Autistic and transgender: the intersection of two minority identities



Over the past decade there has been a noticeable increase in transgender visibility in the media writes researcher **Ashe Yee**.

A NUMBER of high-profile celebrities have come out which for many people was their first exposure to what it means to be transgender. There has also been an increase in transgender research. One interesting finding of this research is that autistic people are much more likely to experience gender dysphoria and to identify as transgender than their neurotypical peers.

"Your experience of the world is really different so it's always in conflict. I was seen as being in the wrong, but it was like 'I can't be in the wrong'; it was really debilitating! Add to that seeing gender differently and WHOA! Autistic people can end up with mental illnesses because they're being told their truth doesn't exist and that's really scary" – Zain

Strang, Powers Knauss, & Sibarium (2018) estimated that between 6.3% -13.3% of youth referred to clinics for gender identity purposes were autistic, which is approximately 10 times higher than rates of gender dysphoria in neurotypical youth. Furthermore, the Counting Ourselves study (Veale et al., 2019); the first comprehensive national survey into the health and wellbeing of trans and non-binary people conducted in Aotearoa New Zealand, reported that one-in-five of the 1178 participants (22%) described themselves as neurodiverse. The question was not specifically about autism but goes a long way in highlighting the neurodiversity within the Kiwi trans community.

Being both trans and autistic is a very unique experience. It is no secret that transgender people face a lot of prejudice and discrimination as they move through the world, from misgendering and denial of their identity, transphobic hate speech, physical and sexual violence, and even discrimination in employment and healthcare. Autistic people can also face similar forms of social, workplace, and healthcare discrimination and prejudice. People who are both trans AND autistic can therefore face a kind of "double

Much like with autism, gender is a spectrum, and no two people are exactly alike. You are valid, you are not alone, and you are loved.

discrimination" that results from existing in the intersection of two marginalised identities.

Here's a quick little primer of some of the terms used in this article.

Sex generally refers to a person's biology, e.g., what body parts they were born with, what their chromosome combination is, and what their general pattern of hormones are. Of course, this is not an exact science either, as there are people born with XXY chromosomes, there are people born with a mix of sex characteristics, and some people naturally have hormone levels way outside of the average range for their sex.

Gender on the other hand is a social construct that is often discussed in terms of masculinity and femininity. When you think of gender, think of the ways we perceive ourselves and others, how we dress, how we express ourselves, and the behaviours and roles we consider 'girly' or 'manly'. That is gender in action.

In other words, sex is physical, gender is a feeling, identity, or manner of expression. When someone's sex and gender match up, e.g., they are assigned male at birth, and they identify as a man, they are cisgender. When someone's sex and gender do not align, e.g., they are assigned male at birth, but they identify as a woman, they are transgender. For some people, their gender identity lies somewhere between feeling mostly masculine or mostly feminine. A person who feels this way may describe their identity as non-binary, e.g., not entirely male or female, but a mixture of both or neither. Trans people may experience gender dysphoria which refers to feelings of discomfort and distress at their body or their presentation not matching their gender identity. Dysphoria is common; however, it is not a requirement for being trans.

■ Continued on page 14



Conflict

Coleman-Smith, Smith, Milne, & Thompson (2020) interviewed 10 autistic trans people to find out more about this nuanced experience. The participants ranged from age 18 to age 65 and included a mix of trans men, trans women, and non-binary people. The following quotes are from this study.

Most people who participated in the study shared a common story. Initially they described feeling at conflict with their bodies and their inner sense of self. Puberty was a rough time for everyone as their bodies began to change in ways they did not want or expect and the pressure to conform to normative gender presentations increased, even for the trans men who were initially allowed to dress like 'tomboys'.

"I never felt I was a girl and I never...wanted to wear girly clothes or things like that, I always saw myself as being a man... [I thought] everyone else was strange 'cause they saw me as being a girl." – Sam

Most people described hating their bodies and feeling like they belonged to someone else. This led to feelings of isolation and many began to struggle with their mental health. This was in large part due to feeling invalidated, mistreated, or discriminated against by others, but also intense feelings of self-hate and anger at themselves for not being able to be or act neurotypical or like their gender at birth.

"More than once I attacked it...one time when I was particularly feeling down, I scratched and scratched. I skinned my arm, mum caught me and sent me to the doctors". – Rihanna

Realisation

This progressed to a gradual development and understanding of their gender identity which manifested as 'feeling different' for a lot of people, followed by learning what being transgender was at a pivotal point of their lives. For some it was relieving, in much a similar way to initially getting an autism diagnosis. It finally gave them a term to describe how they were feeling, as well as hope that there were potential pathways forward with their gender identity.

"Autism became a coat hanger I hung everything on...it wasn't until a long time later, when I saw about transitioning I realised these things were clearly about my gender like my breasts...I couldn't abide them, knowing about them, touching them, that wasn't sensory sensitivity...it was very specifically gender." – Walter

For others it was a bit more distressing when hit with the realisation of how marginalised trans people are within society and that living as their authentic selves could prove challenging. This occasionally resulted in concealing or suppressing their gendered feelings due to lack of knowledge around gender transition services and out of fear of discrimination and rejection from their families, peers, and broader society.

"There's big conflicts between how you feel and what other people are saying and how you deal with that...you hide

who you really are...you mentally push it away...because it's not good for your mental health to keep banging your head against a brick wall." – Felix

For those who suppressed these feelings, they eventually reached a precipice where they could no longer go on living as their inauthentic selves which spurred their decision to begin transitioning.

"I reached that point...everything went completely to hell, my mental and physical health fell to pieces...I'd nothing to lose anymore and...it gave me the courage to say 'to hell with trying to fit, I'm gonna decide who I am.'" – Felix

Social transition

All participants began with a social transition which consisted of choosing new pronouns and a new name, wearing different clothes, etc. Participants talked broadly about all the ways their life improved after they started transitioning, like improved self-confidence and wellbeing, as well as better management of their gender dysphoria.

"Since I've been like this, I've been happier...The more happy I am, the more engaged I am and the more I want to engage...the more I do and aren't misread, the happier I am!" – Alana

For some people, being autistic has acted as a protective factor against fears of the negative perceptions of other people during their gender journey. In other words, being autistic allowed some people to live authentically according to their gender identity, and not feel pressured to conform to societal expectations of how men and women "should" look or act.

"...there's us that are oblivious to what other people think of us and there's those who worry about what everybody's thinking...I fit into the category of 'I'm not bothered' which is a blessing, so I've not had any negative experiences. I'm quite happy with my shield of "this is who I am", if I don't actually do the 'right' social male thing, tough, I'm used to not fitting in anyway." – Zain

Others found social transition more difficult and talked about their negative experiences since coming out, like physical abuse, verbal abuse, and predominantly transphobic comments which could be devastating.

"At first your confidence is through the roof...then it wouldn't take much for it to just crumble...at first I found it a lot easier to make friends, so I had more friends. Then after a while it went away...a few random comments can really get to me; I get really paranoid about it...I don't go out as much". – Alex

A lot of participants felt that socially transitioning while autistic was harder compared to neurotypical trans people because they had less of an intuitive understanding of gender presentation.

"I don't feel like I'm fully socially transitioned because I am experiencing more autism barriers than I was as a woman...I had thirty odd years to learn how to pretend to be female and I'm still trying to come up with new strategies to be

consistently read as male because expectations are different. Autism makes this slow. I'm also being read more as autistic because I've not learned the disguises for someone now read as male...My confidence is affected...so more autistic behaviour like stimming creeps out." – Felix

Gender-affirming healthcare

Everybody that was interviewed also eventually followed their social transition with a physical transition, i.e., accessing hormone replacement therapy or having gender-affirming surgeries. N.B. although pursuing a physical transition is common for a lot of trans people, not everybody wants to and that's okay!

Unfortunately, some trans people have also reported that their autism can sometimes act as a barrier to accessing gender-affirming healthcare. It is not uncommon for families, doctors, and other health professionals to focus on an autism diagnosis while ignoring gender dysphoria and exploration, or even writing it off as a 'symptom' of autism and not a true facet of someone's identity, aka, "are you really trans or just autistic and this is a special interest of yours?"

"I've always enjoyed collecting toys; [my father] said 'if you're still playing with toys...you're not mature enough to make these decisions...he thinks because of my interest I couldn't know about my gender...when your gender is wrong, it's pretty clear!" – Sam

Some participants also reported anxiety when trying to access gender affirming care for the first time, citing fears that the health providers would not be experienced enough with autism to adapt the assessment process to their needs. Fears of not being able to give the responses they thought the providers 'wanted' were also high due to communication difficulties and not experiencing or expressing their gender in a neurotypical way.

Community connection

It is common after coming out as trans to seek out other members of the LGBT community to connect with, however some participants had trouble with doing this despite having the desire to. Due to the face-to-face nature of a lot of LGBT community spaces and get-togethers, e.g., noisy bars, loud Pride parades, etc, these spaces could be overwhelming and a sensory overload.

"Everyone is talking over drinks and it's a positive atmosphere and welcoming...but I felt that I couldn't engage with it...I get really uncomfortable in that sort of situation...with lots of people having a conversation it's like 'Argh!'." – Kate

However, online chatrooms and social media can provide an alternate avenue to connect with others in the community. Despite the initial difficulties, being able to meet and interact with other trans people facilitated the change of information and advice and it provided a sense of belonging.

"I made some friends who were very into being openly feminine, and open about dress and stuff, so that helped me to experiment with dress and presentation...so accepting friend groups help a lot...through them I was able to be the person I wanted to be." – Kate

Final thoughts for parents/families?

Autistic trans people face a lot of challenges that neurotypical trans people and autistic people who aren't trans do not have to. Some of these are structural and not

easy to change quickly, but others, like family support, start in the home. Family and social support are associated with higher self-esteem, life satisfaction, and improved psychological wellbeing. It is very important to be supportive of your trans autistic children, to give them space to explore their identity, and to not be dismissive.

A lot of trans people, autistic or otherwise, can have strained relationships with their family members. How they are treated when living under their parent's roof can directly affect the quality and willingness to maintain that relationship once they move out (if they have the means or capability to). It is not uncommon for trans people to cut off most if not all contact from their families once they are able to leave due to the mistreatment they experienced when they were living together. Dismissing your child's identity, preventing any attempts at social or medical transition, and refusing to call them by their correct pronouns and chosen

name are some of the fastest ways to destroy your child's trust in you.

If this is a confusing or difficult thing for you to come to terms with, it has probably been even more difficult and confusing for your child to

explore and come to terms with, and they need your love and support during this time more than ever.

Final thoughts for autistic people questioning their gender

Figuring out your gender is a journey, not a sprint, and it is okay to have periods of uncertainty. Trying out different identity labels, names, pronouns, and clothes can be helpful to see how you feel about them. You may want to do this with a few close friends, with your family if you feel like you can trust them with this information, or in online spaces, chat groups, or video games.

There is also no one-size-fits-all approach to gender and there is no way to do gender 'wrong'. You might feel like a girl and identify as a girl, but not like wearing dresses. You might feel like a boy and identify as a boy, but still enjoy wearing skirts because they are comfortable or because you like them. You might not fit neatly into either stereotyped box or instead have an identity that is more fluid.

Some people may try and police your identity and claim there is a 'right' and 'wrong' way to be trans, but there isn't. Often, when people are first figuring out their identity, they discount themselves from the community for not being 'trans enough' because their dysphoria isn't overwhelming, or because they didn't know they were trans from a young age. Much like with autism, gender is a spectrum, and no two people are exactly alike.

You are valid, you are not alone, and you are loved.

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The importance of authentic autistic representation in the media



In this article, Rachael Wiltshire examines recent controversies around autistic representation in the media and discusses why accurate media representation is so important in supporting autistic people to be safe leading authentically autistic lives.

The more this diversity is represented in mainstream media, the more likely it is that an autistic person will recognise themselves and be able to learn about autism, or even seek a diagnosis.

RECENTLY CONTROVERSIES around how neurotypical people portray autistic people have made the media.

First there was Australian singer-songwriter Sia's feature film 'Music', released in New Zealand cinemas on January 28. Problems first arose when the trailer dropped in November last year and autistic people pointed out that Sia should probably have cast an autistic person in the lead role of autistic character Music, rather than the neurotypical actor Maddie Ziegler. Sia took offence at this and things got nasty online. More recently, it has emerged that the film shows Music being held in prone restraint during a meltdown, which autistic people have pointed out is both terrifying and dangerous. Then, as part of Autism Awareness Month in April, YouTuber Mark Rober decided to organise a livestream to raise money for an autism charity, with a number of big-name celebrities being involved. The problem? No autistic people were involved in the creation of this livestream, and the charity it is supporting, Next for Autism, also has no autistic people in its leadership team and funds research that seeks to prevent autism. When autistic people rightly raised their concerns about this, Next for Autism simply removed any references to preventing or curing autism from their website.

The purpose of this article isn't to rehash all the reasons why this movie and livestream are harmful; that has already been covered extensively by the autistic community online.

Instead, I want to talk about why authentic representation of autistic people in the media is so important.

Authentic autistic representation is important for autistic people

Like many autistic children, I knew I was different long before I got my autism diagnosis. When I was 9 or 10, I used to sneak into my parents' room and read their parenting books, trying to understand why other children behaved the way they did and where I fitted in. So, when I finally got my diagnosis when I was 12, I felt a sense of relief. 'Finally, I'll be able to read books about me!' I thought.

Except, I couldn't.

This was 2006. There was not a lot of mainstream literature about autistic girls. The main books I had available to me were Luke Jackson's autobiographical 'Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence' and Mark Haddon's 'The Curious Incident of the Dog in the Night-Time'. I couldn't relate my own experiences to either of those autistic boys, and so for a long time I questioned whether my autism diagnosis was the correct one. Maybe I really was just weird.

It wasn't until I read Jennifer Cook O'Toole's 'Sisterhood of the Spectrum', when I was 21, that I finally found an autistic person whose experiences I could relate to. It took me that long to truly believe that the label 'autistic' was the right one.

It is comforting to see yourself represented in the books you read or the stories you watch on screen. It's a reminder that you're not alone, that others experience the world in a similar way to you. Autistic people are unlikely to accidentally stumble upon others like them in real life, so stories are the perfect way to find that sort of connection.

Seeing themselves in the media is important for people who know they are autistic. But it's even more important for those who don't yet know about their autism. The autism spectrum is incredibly diverse and people experience autism in many ways. The more this diversity is represented in mainstream media, the more likely it is that an autistic person will recognise themselves and be able to learn about autism, or even seek a diagnosis. And as I will discuss later, I believe being able to confidently identify as autistic is key to flourishing.

Authentic autistic representation is important for neurotypical people

The controversy around 'Music' and Mark Rober's livestream has illustrated just how uninformed many neurotypical people are about autism, which is hardly surprising given that most autistic characters in mainstream media still fall into the 'socially inept white man with areas of brilliance' stereotype. This helps explain why 'Music' is so disappointing – as a girl and an Augmentative and Alternative Communication (AAC) user, handled properly this character could have done so much to address some of those stereotypes. Instead, the film appears to be reinforcing another stereotype: that autistic people are too impaired to be able to participate in society. When the trailer dropped, I saw many comments from neurotypical people claiming that of course an autistic person couldn't have acted in the film, as a film set was way too stressful an environment for any autistic person to cope. This was news to me, an autistic person who had spent eight hours dancing in a student film the previous week!

Such stereotyped views of autism in the wider community are harmful to autistic people. Many autistic people spend their lives 'masking' – hiding our autistic traits to appear neurotypical and fit in with the world. That can work for a time, but it's not sustainable – I have had bouts of severe anxiety and depression every 2-3 years since I was 12, and

■ Continued on page 17

I'm sure that is at least in part due to the cumulative stress of masking. When I've tried to work an office job, I've only lasted about eight weeks before the stress of trying to function 'normally' in that environment has gotten the better of me. I believe that the best 'treatment' for autism is to just let autistic people be autistic. Sometimes that might involve the autistic person using strategies to help them cope with the world, like wearing headphones or sunglasses, asking for flexible working conditions, or stimming. But it also involves the wider world accepting that people experience the world in different ways, that not everyone is going to conform to the neurotypical norm, and that that is okay. Accurate and diverse portrayals of autism in the media have a key role to play in building that wider acceptance.

For me, living an authentically autistic life also requires that I'm comfortable being out about being autistic. I can't expect people to not hold me to neurotypical norms unless I'm willing to first explain why those norms are inappropriate. But in a world where most people's understanding of autism comes from stereotyped media representations, coming out as autistic is potentially risky and stressful. If I tell someone I'm autistic, the response I am likely to get is 'oh, but you don't look autistic', 'but you're not obsessed with trains' or 'you must be very high functioning, though'. Another possible outcome, as illustrated by some of those comments by neurotypical people about Sia's choice not to cast an autistic actor, is that people will view you as less capable because of your autism. Coming out autistic currently requires you to be prepared to have an in-depth conversation with everyone you come out to about what autism actually is and why their assumptions about it are probably wrong.

If we have diverse portrayals of autism in the media, a lot of that educational work is done for you before you come out. Even if people still have questions, you can at least point them towards different characters that might help them develop a more nuanced view of autism. Put simply, having a diversity of autistic characters in mainstream media means autism will be better understood in society at large. A better understanding of autism means it is safer for autistic people to come out. And when autistic people can live authentically autistic lives, they can flourish.

Improving autistic representation in media

You may be wondering what we can do to diversify autistic representations in the media. The easiest step we can all take is to make sure we are getting our information about autism from autistic people, by following them on social media.

However, that is not a complete solution; if you're following autistic people on social media, you have probably got at least a passing interest in autism already. The mainstream media is still incredibly important for increasing understanding amongst people who otherwise would have no interest in autism.

So, if you are in a position of influence within the media industry, invite autistic people to the table. If you're writing a story about autism, autistic people need to be involved



every step of the way; preferably include an autistic writer on your team, or at the very least have some autistic people read the story and provide feedback before it is published or produced. Be willing to interrogate your own biases about autism, to accept that autistic people are the experts

on autism, and to change what you're creating if autistic people express concern.

Most importantly, create space for autistic people to tell their own stories. From my own experience, I know that confusion about social rules and anxiety can both get in the way of me writing the stories about autism that I want to write. Putting yourself out there creatively is scary but becomes easier when you have friends and mentors to

support you on that journey. I struggle with opening up to friends though, so would need more explicit mentoring if I were ever to write a novel or create a show about autism. So, check in with the autistic people in your life. If they have a story they want to tell, support them to do that.

My hope is that one day autism – both in media and in life – will be unremarkable: just another way of being. To get there though, we must put significant effort into centring autistic voices in the media conversation about autism. Acceptance can only come through understanding.

Rachael Wiltshire is an autistic member of Altogether Autism's Consumer Advisory Group. Outside of her autism advocacy work, she studies and teaches dance and tutors high school students.

Disability and the law – supporting people and their families



*Practising law in the disability space is something **Nan Jensen** excels at but her decision to go into it was through what she describes as “selfish” reasons. She writes on why she practices law.*

Some areas of law are more relevant than others, but really it is about servicing a community, understanding their needs, and understanding the disability framework in New Zealand.

OUR AUTISTIC SON was struggling at school, and we took the Ministry of Education to arbitration to get him the help he needed. I was not a lawyer at the time and had no clue what I was doing, but I wrote the submissions and presented them, and we were successful. It is the most stressful thing I have ever done, but it changed my son's life – and mine!

Not long after that, I found myself at Waikato University studying law. By the time I finished, I knew I would practise Disability Law to help others like my son and our family.

While in law school I met a lawyer called Tony Banks who was running a workshop on disability-related topics. The audience was families of disabled people. When Tony retired, I took over. I now run a variety of workshops and speak at conferences and symposiums, am on a professional expert panel for Altogether Autism and have also been asked to work with schools and residential services to ensure they are complying with the law.

I have broken down my workshops into smaller topics and have made videos available on YouTube and Facebook. Ironically Covid-19 has helped more people get access to the workshops as these are now often run online.

Disability law – what is it?

There appears to be no official category of Disability Law according to New Zealand Law Society or Auckland District Law Society. So, what is it? Of course, some areas of law are more relevant than others, but really it is about servicing a community, understanding their needs, and understanding the disability framework in New Zealand.

There are many different types of disability, so the needs of the community are diverse. People in wheelchairs with physical difficulties but perfectly functioning brains do not want to be infantilised and understandably demand their rights to self-determination and support, such as accommodations in the workplace and accessible homes. But those with intellectual or other developmental disabilities may be incredibly vulnerable to ‘fake friends’ and salespeople (the people I call predators). This group must have their rights respected and their decision making and autonomy supported, but it is my view that we are being negligent if we allow them to be abused and taken advantage of in the guise of protecting their rights.

Not everyone learns from their mistakes – some autistic people struggle to generalise from one situation to another.

So, if they are abused or taken advantage of by a predator, it may happen repeatedly with different people. They may not recognise the common characteristics of the abusers or situations. Achieving the proper balance between protection and rights is an ongoing challenge. Blind and hearing-impaired people share a variety of challenges and have their own separate and unique issues.

I practise in most areas of private law – because disabled people have the same issues as everyone else. The difference is that most matters are complicated because disabled people's lives, and their families' lives are complicated. Families are exhausted from always advocating. Where a specialty that I do not have is needed, I refer to other lawyers and work with them if they are willing.

Last year I got my own diagnosis of autism. I believe I can contribute advice and ideas to clients which it seems many

other lawyers cannot. I understand because of my own family and experience.

The ultimate problem facing most families is: what happens to the disabled person when their parents are gone? This is the greatest concern and fear – I know this from my own life!

"I would love to find other lawyers who share my passion, want to learn what I know, and who might want to collaborate in this area."

I accommodate clients where possible, so I travel to meet them in their homes, or workplaces or wherever is most convenient for them. I work from home and do evenings or weekends – whatever works best. I would like to learn sign language.

The future

I am continuously compiling a list of issues and problems that arise either because of legislation or lack thereof, but also because of attitudes and interpretation, and sometimes simply because of no experience of disability or a specific kind of disability in the legal system. In the first half of 2021, I hope to be able to engage some of our politicians about this to help in the search for solutions on how our legal system can help, and not inflict more harm.

I would love to find other lawyers who share my passion, want to learn what I know, and who might want to collaborate in this area. All too often I have clients coming to me with legal work which might be suitable for the non-disabled, but which just will not work for my family situation. I would like to start slowing down but I feel that I cannot until I find others who will carry on this work.

Nan Jensen is a lawyer specialising in disability law. She is a consultant with Quinlaw in New Plymouth. Nan is a fitness instructor and the classes she runs are very appropriately on trampolines. This article first appeared in Law Talk Issue 945, the magazine of the New Zealand Law Society.



Gabrielle Hogg, Disabilities Minister Hon Carmel Sepuloni and Joshua Sime at the 2021 Parliamentary Breakfast.

Journey of wellness after troubled decade



Changing the online world for the better. That's Joshua Sime's goal. This is his story.

I may have struggled a lot throughout my teenage years, but things will get better and I am now trying my best to behave, obey the law, be kind, and all the other things that make someone a good human being.

MY JOURNEY as a 20-year-old autistic man has not been easy. For the last 10 years, there have been several suspensions from schools, violent behaviour at home and trouble socialising.

I've had stints in Oranga Tamariki care, mental care hospitals, care and protection facilities, youth prison and even prison.

My parents in Oamaru love me dearly but their understanding of autism is limited.

This is an example of the lack of support given to parents with autistic children.

There were some personal successes like the time in Wellington last year when I helped pull together a petition for autism and disability friendly hours in supermarkets.

I joined forces with the then Hutt South MP Chris Bishop and we succeeded in getting Countdown to announce that all its stores across New Zealand would offer a low sensory 'quiet hour' from 2.30 to 3.30pm every Wednesday. That felt good.

But I struggled in Wellington and returned to Oamaru where I thought things would improve.

I ended up not taking my medication, had trouble sleeping and then had drastic mood changes which left me mentally unwell.

I moved to Dunedin, but life was no better there. I doused myself in flammable oil; the police were called and I was sent to Wakari Hospital for inpatient mental health treatment. I was slowly getting better being back on medication and sleeping but I still had some anger issues and threatened a staff member.

After that, I was moved to a more secure ward. I wanted them to think I was psychotic so I could stay longer so I left the ward as I was sort of independent and could be let out and I brought in some Dettol, which is flammable, and a lighter and I lit my shirt on fire and waved it around in the hallway.

Police charged me with arson and I was remanded to prison for four months in the suicide unit. It was tough being in a cell for 22 hours a day for four months. I had a television, but it was muffled as it was behind a wall.

It was mentally tough.

On my release, I went into patient aligned care (PACT) through a disability trust and I'm discovering myself, becoming stronger mentally, emotionally and spiritually.

I have support workers that help me with doing daily tasks like grocery shopping. I was going to move to Invercargill to study at the Southern Institute of Technology in Invercargill but decided to just aim at getting a job here in Dunedin.

I have a support worker contracted by Oranga Tamariki to help me and a probation officer to support me. It's a tough journey and it is not going to be easy.

I may have struggled a lot throughout my teenage years, but things will get better and I am now trying my best to behave, obey the law, be kind, and all the other things that make someone a good human being.

To help other autistic children and teenagers going through similar issues, it would be helpful if people like me could tell other parents, teachers, police, ambulance and other services how they would have liked to have been treated when they were young.

As much as psychologists have a good understanding of autism, autistics themselves have more advanced understanding of autism than anyone else.

Joshua Sime is 20, was born in Auckland raised in Oamaru and is the oldest of four. His dream goal is to have a career in cyber security. He gives lived experience presentations at Altogether Autism's professional development for mental health and forensic clinicians.

How lockdown became the new norm



Before lockdown Tyrone Cook was going out, going to the gym, going shopping, meeting up with his mother once or twice a week and his support worker would take him on shopping. Then Covid-19 happened. This is his story.

AT THE TIME there were five of us living here, then Steve died. He had Huntington's and it was in the last stages. He came home and we hoped he could hold on until level 2, but I think he decided 'I'm home, I'm comfortable, I'm out of here'. He wouldn't have wanted to die up there in the hospital, he was home and with his flatmates.

Every time they put those ads on TV, the alerts sound would be no good for me – it would make me anxious. I tried to mute the ads when they came on. But the good thing was I had my phone on vibrate so when they sent out the emergency alert from Civil Defence, it came in as a vibrate, it didn't make that horrible noise. I turned off all the noises in my phone during lockdown.

We did try to get online shopping. I signed up for the priority shopping at Countdown but when we first went to do it, it was all booked out. And the closest we could have got was a week later. We thought 'yeah we aren't waiting a week for food'. We managed to find some slots but one of our staff members went in for us.

I'm hoping if something happens like that again they'll have more thought to things like that.

I handled lockdown well.

During lockdown social distancing is important, everyone must do it. Autistics everywhere 'We've been telling you that for some time!'

Here's everyone else freaking out and here's me saying 'Dude, this is nothing new to me.'

For once everyone is doing what I try to do daily.

The thing I liked about lockdown was that people were suddenly thrown into my world. Finally, they're learning why we do certain things.

Now that we're down to level 1, I don't think anyone learned anything. Everyone is now thinking 'we can go back to normal now'.

After this lockdown people may say 'now I understand why this person acts like that, or why that person doesn't like crowds.' Whether people want to be educated, is a whole different story.

We only had the level 2 masks and we finally got the gowns for the staff in level 2. Not long after going into level 1, we turned up home one day from an outing and there's a big box with some more masks. It was kind of a bit late.

We were told that if any of us got sick, even a cold, we would be quarantined into our room and have meals brought to us. It didn't happen to anyone. Luckily, nobody got sick. Except Steve died.

The thing I liked about the Lockdown too was every time Jacinda went on TV, she had an interpreter, and you don't normally see that. There were some complaints about the

The thing I liked about lockdown was that people were suddenly thrown into my world. Finally, they're learning why we do certain things.



interpreter being too animated and I would say 'that's our language'. I was impressed she always made sure there was an interpreter on the corner of the screen.

I would go into lockdown again. I've done it already before; I think it would be a lot easier this time because I know what to expect.

Although my dairy remained open, they executed a one in, one out policy and the streets were safer for me to cross.

I would like these things to remain.

One year later

We are in level 1 (not level zero people, so PLEASE keep washing your hands, scanning QR codes or signing in!) and I am back to the gym, going to the movies and out with Mum.

I have a new flatmate and a new staff member and finally I got assessed for a communication device (I was told nine months, then COVID happened), I have been on a road trip to Mount Maunganui and planning a trip to Dunedin to stay with my best friend.

I ordered some products from a company called Stimtastic, one being a cat chewable (any name suggestions for him and the hedgehog one welcome). The cat comes with me everywhere so far and is a regular at church where he has had many questions.

I am writing blogs not only personal ones but also for Invacare Australia and New Zealand, both are getting me recognised globally and I plan to start a YouTube channel.

Now I hope we can stay in level 1, or better yet ... become Covid free altogether.

Tyrone Cook lives in Hamilton. He appeared in the *Life in a Pandemic* book published by Life Unlimited Charitable Trust in September 2020. Read the article www.lifeunlimited.net.nz/lifeinapandemic

Learning to be ourselves



Adult autistics arrive late to the authentically autistic party, writes Jolene Stockman and not because they typically avoid parties.

AFTER A LIFETIME of training ourselves to fit in, pretending the world doesn't hurt, and generally camouflaging as normal, how do we learn to be ourselves?

For the last year, I have been co-hosting the Autistics 4 Autistics (A4A) group for Altogether Autism. For people known for their social awkwardness, there's something decidedly cool about this group. It's the little things. It's people who laugh at your jokes. Who nod. Who get it. People who hold space for you with kind eyes before they even know you.

In my regular life, I have people who get me. I'm publicly autistic, so don't have to mask as much as some. I'm married, self-employed, with a home and a formal diagnosis; privileged in so many ways. But that's the thing: if you've never had a community, how can you know what you're missing?

Many of us don't know what it's like to be authentically autistic because it is not something we have been allowed to be. We may not have been given therapies or attempts to force us to fit in – but perhaps even more insidiously, we have learned to do it to ourselves.

So, we have to find each other. We have to see other autistics in the wild, successful, happy, thriving. Autistics can struggle in the neurotypical world, but often we light up around each other. We get to be ourselves and to know, really know, that we are not broken normal people, rather, we are perfect autistic people. Autistics have a shared sense of self that reaches across genders, ages, skills, and personalities. To be autistic is to be part of a culture. A rich and vibrant culture that shines with distinctive language, food, art, traditions, routines, and rituals. When we spend time with other autistics, our weirdness is suddenly normal, our awkwardness is confidence. Autistics speak autistic, neurotypicals speak neurotypical. These are two different cultures, two communication styles, two languages that need to be translated and understood. The autistic culture features a unique way of being; and now, thanks to an online world that no longer depends on physical contact or sensory anything, autistics are finding community with other autistics.

"The same way that autistics know we're different – in the playground, in the office, in the streets, is the way that when we are together, we know we are the same."



We are connecting, joining forces. Autistics are sharing experiences, advice, jokes. And it turns out, our social skills are not non-existent, they are autistic. Research^{1,2} backs this up: autistics have social skills with other autistics.

Meanwhile back at the Autistics 4 Autistics Zoom Group, conversations bounce from the practical to the absurd, the sombre to the hilarious – and everywhere in between. In fact, I think the only thing we don't do is small talk. (Classic autistic communication!) The same way that autistics know we're different – in the playground, in the office, in the streets, is the way that when we are together, we know we are the same.

And no, it's not perfect. Like any community, we are made up of individuals – we have different experiences, ideas, opinions. We rub each other the wrong way (not literally), we have different strengths and weaknesses, different

preferences and personalities, plenty of opportunities to disagree, and you know what that means? That means we're human. Surprise! Human. Not perfect, but not wrong. We're individuals, but we are the same where it counts and we know it. Respect and equality doesn't require a neurotype.

For autistics, spending time with other autistics can mean seeing our authentic selves, and the possibilities for our authentic selves, reflected back to us. It means feeling free to speak, behave, and think in ways we've been told, and believed, aren't okay. So, how do we learn to be ourselves? By knowing there's nothing to learn at all.

Autistics 4 Autistics Zoom Group: Fridays 1pm-2pm and the last Sunday of every month 1pm-2pm. Register at Altogether Autism.

And for the neurotypicals keen to come along? Sorry, it is autistics only. But do not worry, you still have the rest of the world. For now.

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Jolene Stockman (Te Ātiawa) is a Distinguished Toastmaster with a Bachelor of Broadcasting Communications. She is also tangata whaitakiwātanga (an autistic person). Jolene is a member of the Altogether Autism Strategy Group and Consumer Advisory Group. Since her adult diagnosis and TEDx Talk, Jolene has presented at the Asia Pacific Autism Conference (APAC) in Singapore, and the 2nd European Autism Congress in Budapest. She is a trustee for not-for-profit Autism Connex and works with corporates and community groups to raise understanding and optimism around autism. For more about Jolene and her work, visit www.jolenestockman.com



PHOTO: Kelley Tantau © Valley Profile

Burning out as part of undiagnosed autism



*Autistic burnout is a hot topic in the autistic community, writes **Dianne McLean**.*

JOKES ASIDE, for many of us burnout is very real and may have led to us receiving our formal diagnosis. Although, we may be grateful that going through burnout had a positive outcome, it is without doubt distressing and disruptive and not something we want to go through if we can avoid it.

The fact that burnout keeps coming up in blog posts, memes and articles tells me that this is an important topic for us. It would be difficult to find an autistic person who has not experienced this phenomenon at some stage of their life and some of us experience it regularly.

Personally, I have experienced episodes of burnout throughout my life. Roughly one serious event for every decade of my life. For most of that time, I had no idea the likely cause was trying to manage life as an undiagnosed autistic.

For me, the amount of energy needed to navigate the allistic* world and to keep up the appearance of fitting in was (and still is) overwhelming. I just wore myself out on a regular basis, making myself so sick in the process, I needed extended time off life to recuperate.

During one episode my parents had to come and look after my house and my children because I was too sick to manage the everyday tasks of running the household.

One of the frustrating things for me was often there was no medical reason to be found, not one that could be quantified in a blood test, anyway. One doctor said to me as he handed me a medical certificate giving me indefinite time off work, 'you're obviously very unwell and something is going on with you, but I can't find a medical reason so I'm giving you time

It is very important to practice self-care, to ask for accommodations at work and to be honest and open about our support needs.

to go home and rest and hopefully you'll begin to feel better.'

That was a reasonably positive interaction with a medical professional. Mostly I was misdiagnosed as depressed and given medication which made no difference to my overall wellbeing.

There are different reasons why someone may experience a period of burnout, not all of them related to autism, such as working too hard for too long, going through stressful life events with inadequate support.

Autistic burnout is related specifically to exhaustion brought about by the difficulties arising from autism itself.



And that is the trouble with autistic burnout, not only is it experienced differently by each individual going through it – much like autism itself – but the things that are overwhelming to an autistic person are not things the allistic community are likely to see as problems.

An excellent example would be the everyday chore of the weekly supermarket shop. Most people (the ones I know, anyway) detest supermarket shopping but for many autistic people – myself included – the supermarket is the special kind of hell reserved for those who eat potato chips in bed.

The level of anxiety and overwhelm brought on by negotiating the aisles is something an allistic person can have no idea of. Even though they may not enjoy doing it, it doesn't use up all their energy in the same way it does for an autistic person.

■ Continued on page 23

Doing all we can to conserve our energy resources, such as shopping online, for example, is one thing. It is very important to practice self-care, to ask for accommodations at work and to be honest and open about our support needs – not always easy to do, I know, but I have found living a more authentic autistic life to be tremendously helpful in mitigating the stress of navigating the allistic culture around me. Not everyone understands, but I have found enough empathetic people who actively listen and choose to step inside my world to make being open and honest worthwhile.

But this is only part of the picture. While it is useful and valuable to be proactive in safeguarding our precious energy reserves, the other part of the story is the need for greater understanding amongst medical professionals and others in the autism community.

We may only be now putting a name to it, but autistic burnout is not new. It will have been around as long as there have been autistic people, especially among the so called 'high functioning' individuals adept at masking, and it won't be going away any time soon. And yet, it is only recently that researchers have begun to study this phenomenon to try and define it and to understand its effects on autistic people.

This is a very positive step in the right direction.

Hopefully, this research will answer important questions about how autistic burnout differs from other causes of burnout, how it impacts the lives of those who experience it and what markers doctors could use to diagnose it. Greater understanding about how it presents will lead to improved

support for those who are suffering a burnout and much improvement in targeting interventions that really work instead of sending a patient home with a prescription for anti-depressants and failing to address the underlying causes.

Personally, I'm pleased to see resources being channelled into research that could be of actual benefit to autistic people instead of the futile search for causes and 'cures'. I see this as a moment in time that could be marking a shift in the attitudes of the scientific community, that till now have seemed indifferent to the wishes of the #ActuallyAutistic community. Now is the right time to reopen honest conversations with our doctors and others who support us.

Not everyone will be comfortable talking to groups, large or small, of professional people but now is the time for the everyday, garden variety autistic to begin sharing about our real lived experiences. A large fire can begin from a small spark and we shouldn't underestimate the power of each person talking about autism to one or two others.

Talking about burnout and how it has impacted our lives will foster understanding and interest in this as a topic for further research and interventions that will lead to greater understanding and inclusion.

** Allistic means non-autistic.*

Dianne McLean is a late diagnosed autistic author who lives in Thames where she happily indulges in her love of all things 'steampunk'.



Spotlight on core boards



Speech language therapists **Sam Brydon** (left) and **Estelle Pretorius** (right) write about an overview of core boards from a research and practice perspective.

Core boards can make an excellent, low-tech, starter communication system, but they have limitations. The vocabulary is limited by space and portability.

THE NEW ZEALAND Autism Spectrum Guideline (2016) recommend the use of Augmentative and Alternative Communication (AAC) to support young children's use and understanding of language.

Introducing AAC systems within naturalistic contexts, involving familiar communication partners, may enable children to develop meaningful, functional, and successful interactions further in life.

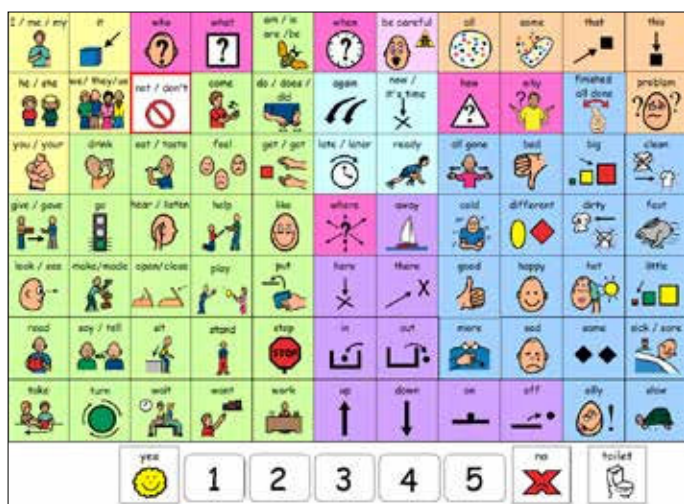
The past 10 years has seen a rapid increase in the use of core boards as a communication tool for autistic children. This is part of a wider movement within the field of AAC to provide communication systems that have a large symbol vocabulary from the outset, allowing children who cannot communicate verbally to still express a wide range of ideas. Prior to this, AAC systems tended to be more limited, with small vocabularies that represented common or preferred objects.

Children were often required to show that they could recognise individual symbols before being introduced to more vocabulary, which limited their freedom of communication.

What is a core board?

There are a few different versions of core boards currently used across New Zealand. Essentially, a core board is a colourful board with symbols that are fixed in place. This is known as the 'core vocabulary'. In addition, there are several strips attached at the top, containing specific vocabulary, usually organised into categories such as food, toys, places, and people. This is known as fringe vocabulary.

The core board pictured here is probably the one most widely used in New Zealand, which is provided by The TalkLink Trust to their clients. It has 77 cells on the main board and includes yes/no symbols as well as numbers positioned at the bottom of the board. Fringe strips can be personalised to the child and their environment.



Core words versus fringe words

Core words are the highest frequency words in any language. Around 80% of what we say when we are talking is made up of around just 250-500 words. These words are highly flexible and are the building blocks of sentences. They can be used across a range of different activities and contexts. For example, a child can use the word "more" to request more hugs, more drink, more lollies or more computer time. On a typical core board, these words are colour-coded to represent the different parts of speech. They are usually organised with sentence starters on the left-hand side, verbs in the middle, and adjectives on the right to support the basic rules of literacy. There are also symbols that represent more than one word for the sake of space-saving. The increasing inclusion of core vocabulary in most AAC systems is an exciting and recent development that offers anyone who needs to use AAC, more autonomy and access to a full language.

Fringe words cover all the content words in our vocabulary. Although these words give additional information, they only make up 20% of what we say when we talk. Fringe words tend to be personalised and context specific. They are mainly nouns, but also common verbs and adjectives (van Tilborg & Deckers, 2016).

Using a core board

One of the biggest changes that has occurred with the introduction of core boards and other core-based AAC systems, is the way in which children are supported to use them to communicate. More commonly, AAC systems for autistic children are introduced through highly structured and systematic teaching approaches that are often initially applied in clinical settings by trained professionals. However, more recent research recommends a more naturalistic approach that mirrors how typically developing children learn language (Gevarter & Zamora, 2018). When an AAC system such as the core board is introduced to a child in this way, adults take responsibility for ensuring the core board is always available, use the core board when they are communicating with the child, and provide opportunities for the child to use it. This means that the child can see the potential of the communication system. The adult can also model a range of key words by pointing to the symbols as they speak; this is known as aided language modelling (Biggs, Carter, & Gilson, 2018). Some teachers have an enlarged core board at the front of their classroom, so they can model symbols to a whole group of children.

Some communication partners who are new to core boards express concern about the number of symbols and remembering where they are located. It certainly takes lots of practice to find your way around a 77-cell core board! It is important to remember that there is no expectation that the child will learn and remember every symbol.

Continued on page 25

At first, they may learn the general position of a symbol and point to that area of the board, and over time, the adult can model and reinforce the exact position of the symbol. Because the symbols are fixed in place, and never change position, there is a strong element of motor planning involved. With continued practice, motor memory helps both adults and children to find symbols that they have used many times before. It is as much about the placement of the symbol, as the actual icon that helps with finding it. If there is a strong concern that a child will be overwhelmed by the amount of visual information, it is possible to mask the board down to a few key symbols, and then add more symbols as the child increases their fluency.



Support for communication partners

As with all AAC systems, core boards can often be seen as unsuccessful, therefore quickly abandoned by frustrated families or education staff. The strategies needed to support a child to use any AAC system, including core boards, are not intuitive, and the key adults around the child need training and ongoing support to put these skills into practice (Light, McNaughton, & Caron, 2019).

These strategies include aided language modelling, skilful use of prompting, and responding to all communication attempts in a timely and reinforcing manner (Biggs et al., 2018). Specifically, for children on the autism spectrum, adults will need to set up and provide irresistible communication opportunities such as people games, toys that need help or other highly preferred activities. It cannot be overstated how difficult it can be to provide all these supportive strategies, and all too frequently, families and education staff are not given the support needed to embed these skills and use them confidently.



Limitations of core boards

Core boards can make an excellent, low-tech, starter communication system, but they have limitations. The vocabulary is limited by space and portability. The fringe vocabulary can become unwieldy and difficult to access if it grows past a certain limit. It is not suitable for children with cognitive visual impairment. Also, good fine motor skills are needed to access the fringe vocabulary independently. For some autistic children, intentionally gaining the attention of an adult and sending a clear message, is not established. This can lead to them pointing to symbols on the core board, but not being observed or responded to. Some children on the autism spectrum find it difficult to direct their attention when the adult is modelling on the board, so the strategy of aided language modelling can be of limited use for them. One of the most significant limitations of the core board is the lack of voice output, which is increasingly being recognised as an important feature of communication systems for autistic children. New software packages such as Language Acquisition through Motor Planning, (LAMP), incorporate features such as a large core vocabulary, learned motor plans, and predictable voice output. Combined with a semi-structured therapy programme purpose-developed for children on the autism spectrum, LAMP offers another exciting option for children who need to use AAC to communicate.

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Sam Brydon is a British-trained speech language therapist who works with children and young people with complex communication needs. She is currently undertaking doctoral research to explore the effectiveness of core boards as a communication tool, as well as exploring the support needed by families to implement core boards with their children.

Estelle Pretorius, speech language therapist, is a member of the Altogether Autism Professional Advisory Group, and doctoral student at Massey University.

More than one neurotype



Autistic advocates are increasingly making their voices heard on social media. **Rachael Wiltshire** interviews neurodiversity advocate Kahukura Sinvold of 'More Than One Neurotype' to find out more about her experiences online.

The more this diversity is represented in mainstream media, the more likely it is that an autistic person will recognise themselves and be able to learn about autism, or even seek a diagnosis.

THE RISE OF SOCIAL MEDIA has made it much easier for autistic advocates to make their voices heard. Their accounts educate the general public about autistic people's experiences, doing much to counter the stereotypes perpetuated by media portrayals of autistic people. They help parents and professionals to better understand how their child or client views the world. Finally, they validate the experiences of autistic people, making us feel less alone and helping us to learn more about how our own brains work.

Can you start by giving me a brief introduction to yourself and your account?

My name is Kahukura (Ngāi Tahu, Te Ātiawa) (she/her pronouns) and I am an autistic and attention deficit hyperactivity disorder (ADHD) neurodiversity advocate who was 'late diagnosed' in my thirties. I created the Facebook page "More Than One Neurotype" as a place to create educational graphics aimed at helping people understand and accept different brains, often with a focus on children. I follow the identity perspective of autism, which means I see it as a natural variation rather than a medical condition. That doesn't mean being autistic and ADHD doesn't have its challenges; it can be very disabling and challenging! But this isn't because we are 'wrong'; it's largely because our ways of being aren't accepted or accommodated.

Why did you get involved in autism advocacy online?

I'm an avid user of Facebook and I needed a space to infodump my thoughts and graphics. I get very frustrated with the lack of understanding around neurodivergency so I try to help people understand based off my own experiences. Neurodiversity is a special interest so I enjoy talking about it.

What do you enjoy most about being an autistic advocate online?

Connecting with other autistics and ADHDers and learning from all the other amazing advocates. I also enjoy having my thoughts valued.

What is the most challenging part of being an autistic advocate online?

Dealing with lots of comments and opinions, it can be quite unregulating! Especially when a post goes semi-viral and especially when things being said contribute to ableism and the stigma around being autistic.



How do you cope with negative comments?

(Personally, whenever I read a negative comment on anyone's post, it makes me so viscerally angry and upset – so I'm in awe that you manage to cope with that every day!)

I have boundaries around what comments I'm ok with staying; those that cross that boundary are deleted and I ban people. If I don't do this I can end up wasting energy with someone in an unproductive way. It's a form of self-care to create a space I like to be in.

What does 'authentically autistic' mean to you?

It means being who I am. It means not having to change my communication styles, my conversation patterns, my excitement... It means I don't have to cut off parts of myself to fit in. Hopefully one day I'll be able to do that without retribution from those who don't understand what it means to be autistic.

Thank you so much to Kahukura for agreeing to be interviewed, and for all the work that you do! Make sure to follow her on  Facebook or on  Instagram @morethanoneneurotype



Autistic advocates to follow online

If you're looking for more autistic advocates to follow online, these are some of my favourite Instagram accounts.

Many of these people also have accounts elsewhere (for example, on Twitter, YouTube or TikTok), and those details will be in their Instagram bios:

@morethanoneneurotype

@chloeshayden

@the.autisticats

@neurodifferent

@fidgets.and.fries

@neurodivergentrebel

@justkeepstimming

@kidish_bambino

@autienelle

@lafilledani

@autistic.academic



PHOTO: Alan Gibson © Life Unlimited Charitable Trust, Life in a Pandemic

A year on from life in a pandemic

Being in lockdown made Jessica Hita and Tuhoro Paki realise they have the necessary skills, knowledge and experience to help their autistic son Te Aurere Hita-Paki on his takiwātanga journey. This is their story, one year on.

WE WOULD NOT HAVE IMAGINED how things would pan out for us.

Though one thing remains the same, lockdown for us was a huge blessing. All that we had achieved, all that we learnt and the time we got to spend with Te Aurere, we've realised not to take those precious moments for granted.

As we settle in to 2021, no longer with Nana, Koro, Uncle and Big Cousin by our side (well not physically at least, as we are no longer under the same roof), we return to work full time and Te Aurere and his sister Te Ata Hāpara back at kōhanga, time just seems to be passing by. It all seems so chaotic at times, though we constantly remind ourselves that despite the rat race, despite the challenges and hustle and bustle of work we must remain committed to the time and effort we put in to spending time with Te Aurere, Te Ata Hāpara and with each other. We know all that we can achieve when we are giving each other time and so that remains constant.

After lockdown we made the decision to purchase our first whānau home, I guess you could say it was a celebration gift of making it through level 4 lockdown, that partnered with a dream that we had been working towards for quite some time. It proved challenging at first, we had just spent a large part of our lives living under one roof with all Te Aurere's favourite people, now here we were moving into our own home as just our little whānau of four.

We had some concerns on how Te Aurere might manage with the change, with a new home, new environment, new neighbourhood and no longer having Nana and Koro by his side, though he has managed it well, we all have. It's a place Te Aurere knows is his home, a place he is extremely comfortable and very familiar with, bonus is its only two minutes from his kōhanga and Nana and Koro are not too far away either, so we are over at their house weekly. Again, he has surprised us with his ability to adapt to change and a reminder that he is capable of several things that we worry about.

We know all that we can achieve when we are giving each other time and so that remains constant.

Te Aurere turns five this year in July and we often get nervous of the thought that he will be off to a new kura and that he will no longer be our little baby anymore, so we are currently in the process of visiting kura and trying to find one that fits for him. We admire his kaiako, his kōhanga and especially his whaea marahia, who since returning from lockdown has been with him every day supporting us as a whānau and guiding Te Aurere through his day-to-day tasks. Lockdown helped us appreciate the importance of routine, time and effort when it comes to Te Aurere and his development. He has his days, but we've been fortunate as a whānau and with the support of kōhanga to establish routines and working weekly to achieve some huge milestones especially with Te Aurere's vocabulary. He has continued to grow and surprise us, he loves dancing to music at home, at kōhanga and at McKenzie Centre which we are still visiting weekly with our key support worker Suzanne. We are now working with her to organise school visits for Te Aurere. It's very daunting, the prospect that he will be off to big boy school, but at the same time we know that the support we have received from whānau, kōhanga, kaiako, Suzanne and the McKenzie Centre, Te Aurere will be more than ready when the day comes. We truly are empowered to take on this new adventure as daunting as it does seem.

A lot has changed but still plenty has remained the same, a new home and new job for Māmā working at a new law firm which has taken up a lot of time and energy, however change is exciting for our whānau. As Te Aurere and Te Ata Hāpara grow older we are reminded how precious time is, time spent with each other, time spent with whānau and friends and were reminded to never to take a day for granted, that's certainly something we learnt during the COVID-19 pandemic.

Jessica Hita is a lawyer with Tukau Law. Tuhoro Paki is a settlement and claims advisor at Waikato-Tainui. Te Aurere Hita-Paki, is 5 in July and was diagnosed in 2019.

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