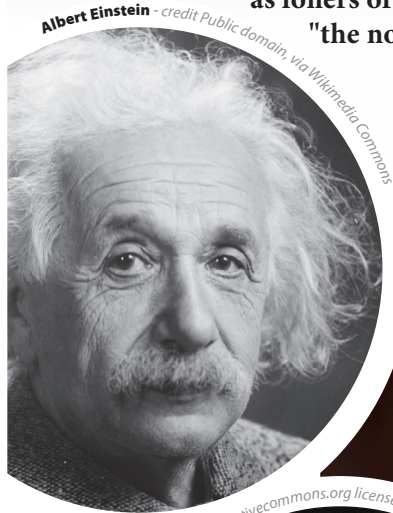


# NeuroDiversity

Celebrating strengths, acknowledging challenges, embracing different

by Lizzie Brandon

Throughout history, there have always been mavericks: trailblazers, artists, inventors, and scientists whose amazing brains led them to make extraordinary breakthroughs. On the flip side, these people may have struggled because they didn't quite fit in with society's expectations. They were regarded as loners or odd as they didn't conform to "the norm".



Albert Einstein - credit Public domain, via Wikimedia Commons

Animal welfare activist Temple Grandin at her 2010 TEDTalk. Temple was diagnosed with autism at age three. In 2010, Time magazine included her in its 100 Most Influential People in the World, 'Heroes' category.



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With the benefits of 21st Century insights, we can speculate with some certainty that Mozart, Sir Isaac Newton, Albert Einstein, Charles Darwin, and Hans Christian Andersen were all neurodivergent.

The term "neurodiversity" was first coined in 1998 by Australian sociologist Judy Singer to acknowledge that every single person's brain works in a unique way. Over the past 25 years, it has typically referred to the likes of autism, dyslexia, dyspraxia, and ADHD. Now, as diversity, equity, and inclusion (DE&I) flourish beyond buzzwords, it's taking centre stage.

*"Neurodiversity is more than a concept or a debate," says Massey University's Maximiliano Pierret. "We all think and experience the world differently. You can argue that neurodiversity, which encompasses being 'neurotypical', applies to the whole of humanity. And what is 'neurotypical' anyway?" he adds. "That in itself is probably a misconception!"*



▲ Maximiliano Pierret is a lecturer in Neurodiversity, Autism and Inclusive Education in the Specialist Teaching Programme and the Masters of Inclusive Education at Massey University.

## Ditch disorder – D is for different

What can we do collectively and as individuals to better understand and support neurodiverse members of our community? Perhaps it should begin with our own ways of thinking, shifting the paradigm from a purely medical perspective to more of a sociological view.

The DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) has long been regarded as a medical bible in this field. "When it gives criteria for autism, it talks about having a deficit in social communication,

◀ Award-winning musician Billie Eilish has spoken candidly about living with Tourette's syndrome.

ShoreLines



and restrictive and repetitive behaviour. All of those characteristics are about what's lacking.

"If someone asked you to define yourself, would you list the three things you couldn't do? And yet, that's how we've been conditioned to perceive autistic people." There's exasperation in Max's voice.

"Using only a medical model means there's a normality, and anything outside of that is wrong. Hence, terms like ASD (autism spectrum *disorder*), ADHD (attention *deficit* hyperactivity *disorder*), and dyspraxia or ODD (oppositional defiant *disorder*)."



Photo by Tim Mossholder on Unsplash

An estimated 20% of Aotearoa's young people are neurodivergent.

Max feels some empathy, therefore, for parents who don't immediately seek support. "Sometimes parents can be the first resistance to early intervention because that means accepting the unwelcome thought that their child is somehow *disordered*."

"In my opinion, it's time to stop thinking of D standing for disorder or deficit. D is for different."

***"If someone reacts or behaves differently, it doesn't mean it's wrong. It just means different."***

Max reasons that comparisons can be drawn between racism, sexism, or ageism – viewing someone as less worthy based on the colour of their skin, gender or when they were born. "But now we know that diversity and inclusion enriches all aspects of our lives."

For sure, in business, research suggests that teams with neurodiverse members can be up to 30 per cent more productive, and that their integration can boost team morale.

Software giant SAP reported that a neurodivergent employee helped develop a technical fix worth an estimated US\$40 million in savings!

"These are not people we are just obliged to accommodate. We should positively integrate and desire them in our society," urges Max. "They're going to come with problem-solving skills that we haven't considered. Right now, with humanity on the brink of so many disasters, we definitely need people who are thinking in a different way."

***Max says it's time we learned to embrace someone's strengths and not crush their spirit. "Everyone should be given the opportunity to feel proud of who they are."***

"We need to be aware of our preconceived ideas. Unconscious bias makes us act a certain way towards someone without analysing why we're doing that."

"Anyone is more likely to feel a sense of belonging to society if they feel included and genuinely valued for who they are and what they can do. Enabling the appreciation of neurodiversity should be a collective responsibility."

In the course of his research and personal development, Max has heard many neurodivergent people's experiences. These often highlight others' assumptions and use of demeaning language. For example, defining an autistic person as "high-functioning" or "low-functioning". "When you call someone high-functioning, you are not seeing their challenges. Likewise, when you call someone low-functioning, you are not recognising their strengths."

One autistic non-verbal teenager wrote that, when he didn't start speaking at an early age, people simply assumed he was intellectually slow. "In fact, from the age of five, he'd taught himself to read by looking at subtitles. Not being able to tell anyone this must have been so frustrating!"

### **Embracing neurodiversity from an early age**

Based in Albany, Acorn Charitable Trust provides specialist services for neurodiverse children and young people.

In Aotearoa, one in ten children are neurodivergent



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"We know that every child can learn. Sometimes they just need to be given the right tools," explains the charity's CEO, Tami Harris. "We strive to recognise each child's strengths and understand what is important to them and their family. We help them develop the resources that will empower them to advocate for themselves, lead a meaningful life, and thrive in their community."

***Autistic children are three times more likely to be stood down, suspended, or excluded from New Zealand state schools.***

Of the various support services provided by Acorn, early intervention /psychology is the most in demand, closely followed by speech therapy. "We get a lot of referrals for tamariki who are having challenging behaviour, and we work with many children who have been excluded from school or who are only allowed to attend for a couple of hours each day."

She observes that neurodiverse children don't deliberately "misbehave" for the sake of it. "Behaviour is a form of communication; they are communicating an unmet need.

"Our team of specialist psychologists look at the child's learning and break it down into tiny micro steps, so they don't need to use that concerning behaviour. What are

the underlying issues or lagging skills, and how do we address those to support that child?

"It doesn't mean that there are no consequences or that any behaviour is okay," she clarifies. "And it's not about being good or bad. It's about helping the child know themselves, what environments work for them, and making those adaptations for them."

The team also helps reveal the child's gifts. "With that kind of brain, there are also a lot of positives. They're probably creative; they're usually good lateral thinkers. They'll take risks – which can go either way – and often drive innovation."

Acorn's early intervention programme is a comprehensive developmental plan, and most families enrolled in it have children with high support needs.

They tend to be non-verbal, struggling with self-help and toileting, and have some behaviours that prevent them from participating at kindergarten. Most participate in between six to 20 hours of therapy every week, with the



▲ Tami Harris

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primary goal of learning to communicate. "With intensive support, and sometimes using an AAC (augmentative and alternative communication) device, they learn how to interact. "Some learn how to speak, too. You can imagine how the trajectory of their life changes!"

**Showing respect and avoiding assumptions**

"As they get older, I think the most challenging thing for neurodiverse people generally is trying to fit into a world that is designed for so-called neurotypical people. This can affect their mental health, with feelings of alienation or not being accepted for who they really are. Sometimes, they feel the need to hide their true selves, which can take a toll," reflects Tami.

Identity is a crucial aspect of this, which is why a section of Acorn's website is dedicated to the importance of pronouns, pronunciations, and inclusive language. It features links to the Rainbow Inclusive Language Guide and an autism terminology guide developed by Aotearoa's autistic community supported by Autism New Zealand.

"Whether chosen for us or by us, names are essential to our identities. Having your name mispronounced can make you feel like you're not valued or that you don't belong. If you're unsure how to pronounce someone's name, ask them!



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Transgender and non-binary people are up to six times more likely to be autistic

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"Moreover, when we share the pronunciation of our own names, we signal that others are welcome to share theirs – and that we're committed to putting in the effort to learn them."

Tami continues. "Sometimes we might make assumptions about a person's gender identity based on what we think we see (their clothes, hair, or mannerisms). When we create space to share pronouns, we let others know we are interested in who they really are – not just what they look like."

**Is New Zealand lagging behind?**

As the name suggests, Acorn Charitable Trust is not publicly funded. Tami maintains that this puts New Zealand at a disadvantage. "In my mind, Acorn is providing essential services, which are government-funded in many other countries, such as Australia, the UK, India, and Romania."

Acorn regularly works with young people in the care of Oranga Tamariki. "These are often teenagers in rather dire straits because they didn't get that early intervention," Tami says.

*"I feel that New Zealand is quite behind when it comes to recognising those needs and supporting children when they're young. Of course, this has a huge economic cost to the country because resources have to be allocated to things like adult residential care and welfare support."*





"If we could shift that funding towards supporting neurodiverse children, the benefits for individuals and society could be far-reaching."

**How early intervention can transform a life**

When he was 18 months old, Mike's son started behaving differently. His verbal language regressed; he stopped looking at his parents and became obsessed with small spinning hoops. Mike and his wife were shocked to realise that their son was autistic.



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*"We had no idea...if our boy would ever have a "normal" life.*

*The public system had a six-month waiting list just to assess him and nothing otherwise to help him. We understood that if we acted quickly while his brain was still developing, we had the best chance of helping him learn to communicate and relate to others.*

*This alone would make a tremendous difference to his future prospects. When Acorn came to assess him, they could see the issues without any formal assessment and arranged for a therapy programme to begin when he was 20 months old.*

*Since this time, he has had about 20-22 hours of therapy per week...Our boy has gone from making four sounds (and we had to work for those) to asking us questions and playing with others at daycare. It has been a tough journey for him, basically learning to talk like I would learn a foreign language. But just last week he arrived at his age level of speech at 4.25 years old. He also learned to read along the way!*

*I want to say that Acorn has made it possible for our boy to live a good life. Whereas 50 years ago he might have been institutionalised for all his life as 'retarded', he is now going to live a productive and happy life, and be no burden at all on society. This is an amazing outcome for him, for us, for our country."*



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