ALTOGETHER AUTISM
JOURNAL
ISSUE 3 2018

BY AUTISTICS FOR AUTISTICS

INFORMING·EMPOWERING·CONNECTING
ALTOGETHER AUTISM
THROUGH KNOWLEDGE AND EXPERIENCE

Mental health and autism

From meltdowns to a job

INFORMING›EMPOWERING›CONNECTING

ALTOGETHER AUTISM

THROUGH KNOWLEDGE AND EXPERIENCE

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

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

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

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

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

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By autistics, for autistics

IN OUR LAST readership survey, 85 per cent of you told us the articles you most liked to read in our Journal were personal perspectives. In this edition, you will find many such articles, by autistics, for autistics.

Those who have contributed their stories have bravely shared inspiring and at times harrowing accounts of their journeys.

Many thanks to all the writers and artists who are featured in this Journal. A big shout out to two of our youngest contributors, Jonathon Squirrell for the artwork on the front cover, and also to Sebastien Rappley for the excellent infographic explaining how he experiences meltdowns. If you or someone you know would like to see their artwork in future editions of the Journal, please send us a sample of your work.

We're delighted to share some of the creations that were exhibited at iNDx Exhibition in Dunedin recently. Congratulations to Tanea Paterson and her team who organised this display of autistic talent.

We recently worked with Brian, Betty and Roman Pulefolau, to establish the Pasifika Autism Support Group (PASG) in the greater Wellington region. The intention is to base it on the very successful South Auckland group, founded by Brian and Betty. We've met with several Pasifika leaders in the Porirua region and appreciate their contributions made to advance this goal. More about this will follow.

NETWORKING: Sharyn Heathcote, Parent to Parent administrator, Wellington, Trisha Lealiifano-Mariota, community advisor, Victoria University, Siaosi Anamani, Vaka Tautua, Wellington Disability Information and Advisory Services (DIAS) team, Faye Seumanutafa, Vaka Tautua, Wellington DIAS team, Rosie Macleod, Sue Trueman, Parent to Parent regional coordinator, Wellington, Betty Kolose-Pulefolau, co-founder Pasifika Autism Support Group.

Have you explored our new website? We are very grateful to those who helped us redesign it and please give us feedback so we can continually improve. Remember all our Journal articles are available to read and print from our website, so check them out there and share with your people.

You can now contact us for trusted information in real time by our new Live Chat. Go to any page on our website and look for the orange icon on the bottom left of each page. When you click on this orange icon and post a message, this is read by one of our live chat agents. Your chat is anonymous. You can ask us anything you like and if we can't answer you straight away, we will find out the information and get back to you. So now if you have an information request, you can contact us by live chat, email, our website or by phone.

I am delighted to introduce you to Jane Bawden, the new chief executive at Parent to Parent, our sister organisation. Jane started in her new role in September and is a lawyer by background, with over 20 years' experience in the disability community and the health sector, in a range of advisory and governance roles including the boards of Standards and Monitoring Service (SAMS) and Spectrum Care. Her son Hugh was diagnosed when he was three with autism and a chromosomal disorder. Hugh has recently finished five very happy years at his local high school and has embarked on a good life. Jane and our governance team are already working closely on the future vision and strategic goals for Altogether Autism, and I greatly appreciate the experience she brings.

Although this is our last Journal for 2018, we are now sharing regular updates and news by email. If you are not on our mailing list, please go to our website and subscribe.

Me te mihi nui / In appreciation,
Catherine Trezona – National Manager, Altogether Autism

NETWORKING: Paula Jessop presents at a recent Altogether Autism network meeting.

A desire to be part of the solution

*Ten years ago **Paula Jessop** entered the world of autistic communities and autism self-advocacy to promote the disability concept of 'nothing about us, without us'.*

To my fellow autistic people, these stories are just the beginning.

We will do more. We will do better.

IN OUR MINDS, as autistic advocates, it felt that frequently we were the objects spoken about, not with.

Advocates work in many ways to promote our 'lived experience' as autistic people, the true experts in autism due to our experience living in the world as autistic people. One of my goals as an advocate, was to help change a dynamic where organisations that support autistic people and their families seemed to be failing to positively connect or consult with autistic people. We felt excluded.

I'm not sure we've solved this problem yet, but it is true much has changed in the last 10 years. Autistic people are increasingly seen, heard and involved in the autism sector.

At Altogether Autism we are on a continued journey together, as passionate autistic people, professionals, and parents who care deeply about the lives of autistic people. We see this as a journey. We desire to be a part of the solution of a past of where autistic people frequently were unseen, and unheard within the autism sector. We make mistakes, we don't get it right all of the time. We have challenging conversations. We sometimes fail in our attempts at inclusion of autistic people. We endeavour to confront challenges and conflicts in our journey to truly put the concept of 'nothing about us, without us' into practice.

We began by having autistic people speak at our conferences. By putting together a consumer reference group that contained myself and John Greally, to represent the views of autistic people. But along the way, I noted a problem. Autistic people's lives and stories from their perspective, were being shaped to a non-autistic audience. Showing our stories was being done is a way that would enhance the understanding of people who were not autistic, but was potentially providing little assistance to actual autistic people.

The idea of 'By autistics, for autistics' was born.

With this journal we hope to begin a new journey. A journey where we bring stories from those who have autism, to others who have autism. Stories that are not shaped to help those with autistic people in their lives understand autism, but to help those who have autism. This is beginning, to find ways to help actual autistic people learn about their own autism, from other autistics.

In our journey to forming greater connections with actual autistic people, to making our organisation one that truly includes autistic people in every way possible, we are inspired by Ta Himi Henare who said:

"Kua tawhiti kē to haerenga mai, kia kore e haere tonu. He nui rawa o mahi, kia kore e mahi tonu".

"You have come too far not to go further, you have done too much not to do more".

- Ta Himi Henare (Sir James Henare) Ngati Hine elder and leader.

To my fellow autistic people, these stories are just the beginning. We will do more. We will do better.

Note on language: Paula is an advocate who chooses identity first language, as a way to represent autism as an identity, not just a part of a person. Some use person first language, 'person with autism'. We recognise that it is the choice of individuals to use whatever language they personally prefer.

Paula Jessop is an autistic woman who works with Altogether Autism as an autistic adviser and advocate. As an experienced advocate, Paula argues the need for a 'radical acceptance' of autistics as neurodiverse people with the right to be accepted, understood, supported, and accommodated in society. Paula hopes to create greater connections with actual autistic people in the autism sector through promoting understanding of 'lived experience' by giving presentations, helping connect autistic people with each other and representing autistic people's experiences to leaders in the sector. She also works to support autistic people to having a 'good life' as a disability community facilitator for Enrich+.

Autistic adults create a unique social environment

*Almost a decade ago, writes **Barbara Choat**, a small group of young autistic adults in Hamilton got together to form a social group that was an autistic friendly place to make friends and have fun together.*

"Voices from the Spectrum Trust"

THE STORY OF the 'Voices From The Spectrum' Trust is one of autistic adults creating a place for themselves run by themselves.

Our autistic adults are capable, intelligent people who are ready to make changes to better the lives of our people but we need a structure in which to organise things. Big things can grow from small beginnings.

They had tried the existing social groups set up for autistic people at the time but had found that, because they were independent and capable individuals, they often found themselves acting as helpers to other autistic people who had supervisory and/or other support needs at these groups. This often resulted in their own social needs not actually being met.

So they got together and formed a group for autistic adults who did not need supervisory support or care but who wanted a place to form like-minded friends. It is this group of autistic adults who never received extra support growing up and who fall through the gaps in service provision because their needs go unrecognised.

But their needs are very real and their struggles to fit into a world that is structured by, and for, non-autistic people are very real. They may look very capable but life can be very tough sometimes. It is very common to find our autistic adults isolated and living with depression and anxiety conditions. Housing problems and homelessness are issues for many too. The vast majority are unemployed, or grossly underemployed, even though so many have quite accomplished academic portfolios. Employment can be difficult if you are seen as different by employers and your learning style does not easily fit into the traditional type training or working models. Many also have co-morbid conditions or age related problems to deal with which complicates things even more for them.

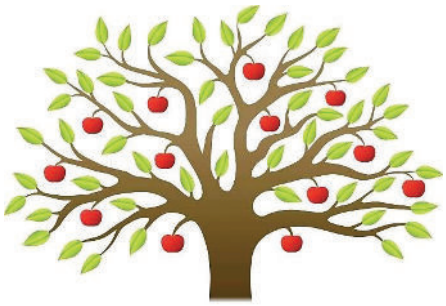
Life can be tough for our autistic population but things can be done. When people get together, they share stories, they share problems and they start seeking solutions to them. This is why groups like ours are so important.

Autistic people often struggle with social communication and some can have sensory difficulties with some social environments so it was originally planned that we should meet up on the quieter Monday nights at the various pubs, restaurants and activity venues around Hamilton. Hence the 'Monday Mates Group' was started. Lots of activities were planned and happened: quiz nights, go-carting, snooker, bowling, mini-golf, meals out etc, with some good, long term friendships formed.

We never actively advertised the Monday Mates Group as it was initially seen as just a group of mates getting together but it soon became so much more. As people heard about it, our numbers grew as more autistics joined us, until it got to the point where the group was really too big to continue as it was.

We have a very strong base philosophy that if the need is there then we need to try and fill it. We also began to recognise that many adults who 'fitted' into our group did not have an 'official' diagnosis of being on the (Autism) Spectrum but 'just knew' and were very much 'peer recognised' as being 'one of us'. Sometimes this is an age thing too as older people never got a diagnosis when they were younger. Our group caters for 18 year olds right up to a few people approaching their retirement years.

Often we will find a parent or sibling actually attending as well because they recognise that they 'fit' here too. There have been lots of discussions around the use of terminology such as being seen as 'neurodiverse' and where this fits comfortably under the spectrum's umbrella. We also have interesting discussions around how autism and terminology is used under different models of thinking such the medical model vs. the social/cultural model and others. Our group recognises, respects and celebrates neurodiversity in relation to the Autism Spectrum.



Big things can grow from small beginnings.

Want to help 'Voices from the Spectrum Trust' get established?

Visit: givealittle.co.nz/cause/better-lives-for-autistic-people

We need, and would appreciate, your support.

Thus, the original structure of this group was forced to change. The base philosophy of those using the group should dictate what the group did still held firm but was being compromised because the larger numbers meant a reduction of the variety of group activities being done. It had become a consistent night out at a restaurant, pub or bar instead.

We needed more structure around our social group network to ensure they could continue and have the resources they needed with more coordinators to ensure a variety of activities and social situations were made available to our people.

We also needed a base where we could meet up regularly which was user friendly to us and catered for the spatial and sensory needs we had. With this comes increased costs of course and we are very aware of the fact that the majority of our people live on benefits and restricted budgets so the need for a charitable trust that would help raise the money needed for our activities was mooted.

Thus, the 'The Voices from The Spectrum Trust' developed naturally out of this growth. We stay true to the group of people we serve and state clearly that our group is for adults who identify with the spectrum who are independent enough not to need supervisory support or care. We do not provide support staff. There are other existing networks that we can refer people to if they need this level of support or care. This trust is therefore being run by the people it is there to serve. It has been structured carefully to ensure that people who use the social groups etc are heard and that what is needed is provided.

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Now we have a structure where our group can get together as a whole as well as in smaller topic based groups such as film groups, an Anime group, a couple of games groups, a quiz group, a women's only group, an adventurers' group or just small groups to chat in – we form groups to match whatever is wanted.

We are now finding that, with their increased confidence, our people are starting to plan further. We have organised a self-advocacy course specifically tailored to the issues pertinent to our group and using a presentation format more akin to autistic learning styles in an environment that is autistic friendly.

When people get together they start talking and common interests, talents, strengths, issues and problems are raised and shared. Solutions to common problems get discussed and ideas and plans start formulating.

We are proactive and want to explore solutions to common problems for our people that may include in the future exploring different employment and accommodation models. Although we are a local group, we are aware of the use of the wider internet and social media and how we can use this also.

Everyone has times of difficulty and crisis in their lives but where does one turn if you need an ear that understands what you are going through as an autistic adult? Peer support networks are important in so many ways. Many of us are lucky to also have family support but as we age things may change. So many people often find themselves feeling alone or misunderstood and struggling. Isolation makes all of this worse. We all need help at times – having a place to go to find an understanding person to listen and help you seek solutions is important.

The 'Voices From The Spectrum' Trust aims to provide a local peer support network for our Waikato people. There are also things we can do to help support our wider autistic community – like sharing information on what other groups and services are around and are doing – where to find things, linking people together, or simple things like providing opportunities for parents of newly diagnosed children to talk to autistic adults about some of their concerns. We have a role to play in our community but we are also aware of our boundaries and that we are very much a part of the wider network of groups and organisations that are for autistic people and their families. As we say..."all these people matter to us too – they are part of our extended tribe".

Barbara Choat is from Hamilton.
For more information www.vfts.org.nz

Just the average kiwi family

*They describe themselves as the "stereotypical kiwi family". But at home they're certainly not the average family. The **author** prefers to remain anonymous*

But what we do really well is accept each other, and our kids, for who they are.

I HAVE A good job, my wife runs a not-for-profit and is a qualified social worker.

We have two of our three kids still at home. There's the house in the suburbs, car that's only a few years old, and we're lucky enough to have three small dogs. From the outside-in, we tick all of the white-middle-class-average-family boxes.

Except we're not.

For the people that know us well, it's obvious that we're certainly not the average family. Both my wife and myself have a dual diagnosis of Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) - me more ASD, my wife more ADHD.

And because we are who we are, we're not the average parents either. So it was always a given that our kids were going to be a little different. Not what society calls 'normal'.

That's because, in our family (and probably most others) normal is subjective. Our family works around mutual understanding and acceptance. Sometimes as parents we do well, sometimes we fail dismally. Most of the time we're somewhere in between.

We have great days. We have not-so-great days. We have days when our own hyperfocus or special interest means the rest of the world is a blur, and things do get missed. But what we do really well is accept each other, and our kids, for who they are. Yes, it can be frustrating. It can be awkward. It can be ridiculous. There are laughter and tears. But mostly, it just is. And usually it works for us okay.

But it's taken a while to get to where we are now. As autistics, appreciating someone else's point of view is hard at the best of times. Spouses don't come with instruction manuals, and neither do kids.

And just because it was a certain way for us when growing up, doesn't mean that it's the same today. As a parent dealing with an emotional teenager, who is full of hormones and doesn't know themselves why they're upset, it can feel impossible. Our youngest often has to be encouraged away from his room and computer into daylight, so we can remind him that there is a world outside a computer screen.

"In a lot of ways, being who we are makes us better parents to our quirky kids. In our family, it's okay (and expected) that we'll be our authentic selves"

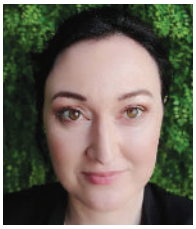
For me particularly, my own sense of black-and-white is often a problem for the rest of the family.

My wife's spontaneity and noise throws our youngest son completely, and I struggle with it myself even on good days. We've had to learn as a couple the art of compromise and negotiation. And as parents, to pick our battles even when we know we're right. It can be tough.

In a lot of ways, being who we are makes us better parents to our quirky kids. In our family, it's okay (and expected) that we'll be our authentic selves.

Stuff that would throw some parents completely we can take in our stride. But in some ways it's harder. Some days we have to keep reminding each other that there are no perfect parents out there. And all we can do is be the best we can be.

Coming Out provides a sense of peace



*When **Jolene Stockman** got the autism diagnosis, it all made sense to her, finally.*

If I self-identify, if I come out, I tell the world that being wired-up differently is okay, it's maybe even amazing! And more than that; I tell myself.

DIAGNOSIS: AUTISTIC! Congratulations! Here's a label, a t-shirt, a blueprint, and a special car park.

Welcome to the new world – the one where your quirks are high-fived, your other is same, and where your existence rewrites normal.

After an unprecedented shutdown (a shopping centre, school holidays; need I say more?) I got worried and found answers. Honestly? I was hoping for a tumour. A clot. A physical something that I (or ideally, a medical professional) could remove and be done with. An answer to the problem that was me. "Ahhh, yes - it was this the whole time: an extra doodad, a missing piece, a loose screw."

And then the diagnosis came in: autistic.

"Hey guys, I'm autistic. And it's cool - check out the movie! Bye now, I'm off to live under my weighted blanket!"

A Choice

When I was diagnosed as autistic the world shifted. My world, anyway. I was an adult, but suddenly so much made sense. I made sense. And as I worked through the shock, the denial, the confusion, and the mountains of myths, facts, and stats, I had a decision to make: do I tell?

There are plenty of reasons to keep it quiet: denial, fear, prejudice, judgement, rejection (and that was just in my own head!) Why rock the waka? I've made it this far; I'm a grown up (ish!), I'm married, I work, I have kids. I've pulled off normal my entire life, why tell now?

But this is who I am. Actually, it's who I always was – I just didn't know it. A lifetime lived as different, weird, alien, other. A certainty that I was weak and less-than. That I did not belong here. A conscious, constant knowing that shaded every decision, from cadence to career. And now I know differently. This is who I am. I started to feel a deep responsibility to the little ones coming up behind me. If I self-identify, if I come out, I tell the world that being wired-up differently is okay, it's maybe even amazing! And more than that; I tell myself.

Self-disclosure should be completely up to the individual; it should only matter what I want and how I feel. Reality is: there's a lot at stake. The prejudice is real. The judgement. The looks. I have fought to avoid 'the looks' my whole life and now I invite them? But as I learned more and understood more, the reasons to tell became stronger. If I came out, I would:

- Acknowledge and accept that I had challenges rather than weaknesses
- Show my children that I am okay with myself, and so give them permission to feel the same
- Create more positivity for parents of newly diagnosed children
- Add my story to the mix. I would join the call for neurodiversity; one story at a time.

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Self-identifying is not mandatory. The same way you don't have to tell people your marital or family status, your favourite food, or your medical history. It's a personal choice, it has to be. I don't always tell people I'm left-handed, drink fizzy drink instead of alcohol, or am allergic to fruit. It is every person's right to decide who they are and how much they tell.

The Label

Even the label itself is not straightforward. Am I autistic? Or do I have autism? Am I neurodivergent? Are others allistic? The use of language can come with hooks and layers, and the more you read, the deeper the attitudes and ideas can be. For me, it feels like 'autistic' is who I am – innate and integrated to everything about me. As true as my being left-handed and as matter-of-fact as my having freckles.

As a writer, and someone who is coming in to the autistic community late, it was (and is!) important to me to nail the language. The way we label and frame things is powerful – especially to people outside our community, and to our children.

"I'm grateful to follow the voices of those ahead of me, and to put out a call for those who follow: We can be, do, or have anything."

Whenever we talk about autism, we describe what is possible and what we believe – and we spread that information. I was relieved and happy to find Te Reo Hāpai – the Language of Enrichment, a Māori language glossary for use in the New Zealand health sector, researched and written by Māori language expert (and -shout out- my cousin) Keri Opai. His work is uplifting, strength-based, and his Māori interpretation of autism means 'in my / his / her own time and space,'

I feel that takiwātanga honours who and how I am as an autistic person. A word that encapsulates how I feel and the best way to be with me in a clear, concise, and empathetic way. Having takiwātanga as a conscious and connected way to describe autism is a gift. And distinctly New Zealand.

How Do You Tell?

Once I knew I wanted to tell, the how became important. I didn't want a million conversations. I don't usually, but especially not about me. Or about this. Even my initial reaction to the diagnosis wasn't completely positive at first. What I knew about autism then isn't what I know now. Could I handle seeing that reaction on the faces of people I loved? People I respected? People I met randomly on the street? And more than that, which would be worse? People screwing up their faces in disappointment? Or nodding as though it all makes perfect sense?

So, how do I do it? A coming-out party? My favourite social nightmare. A bulk email? A little impersonal, a little ordinary. I decided on a screenplay. That would keep me in my comfort zone, buy me some time to figure it all out myself, and provide the perfect way to package up the news in a user-friendly way. "Hey guys, I'm autistic. And it's cool - check out the movie! Bye now, I'm off to live under my weighted blanket!" But before I could finish my script, a magical opportunity showed up to push me forward.

TEDx

TEDx events are independently organised speaking events based on the global TED Talk style phenomenon.

When New Plymouth held its first TEDx in July suddenly here was exactly what I had wanted: an opportunity to package up my news in a succinct way, to use my writing and speaking skills, and to 'come out' in a way that was public, but kind of intensely private at the same time. Okay, but we've all seen TED Talks – and the best ones really go there.

I am a certain kind of brave (I've been known to go to the supermarket at Christmas time) but am I this kind of brave? Iti nei, iti nei - one step at a time. My interview with the TEDx organisers was the first, most vulnerable I had ever been out-loud in-public about my diagnosis. And to my surprise; it felt good. Scary good. Amazing. Whether they accepted me or not, I was determined to finish my screenplay and be okay with the new label for my regular self.

The day I was accepted for TEDx I was excited, terrified, honoured, and humbled. And those feelings only intensified as time went on. The day of the talk itself? Overwhelming. Huge. Magical. People laughed, they cried. They still write to me and tell me what it meant to them to hear themselves – or a loved one – on that red dot with me.

So, if you decide to come out, what do you get? Relief. A new perspective on your strengths and weaknesses. A sense of peace. Self-acceptance. Support and understanding.

When I was diagnosed, I read the statistics. That scared me. I read the information that saddened me. What resonated for me, were the stories. The successes. Actually autistic. The frontline. People who live in the world as I see it and who are figuring it out, too. A label doesn't have to be a restriction, it can be an opportunity: to see what's possible in spite of and because of the diagnosis, and there is so much strength in our community.

I'm not special. I'm not the first, the best, or the last of my kind. I'm a baby in the world of autism. There is so much to learn. I only have my story to offer, but our stories can be so much more powerful than the statistics. They have to be. I'm grateful to follow the voices of those ahead of me, and to put out a call for those who follow: We can be, do, or have anything.

Diagnosis: autistic! Congratulations – but actually... the label is up to you. The t-shirt is itchy. The blueprint is blurry. And there are no special benefits. What you will get, is freedom, opportunity, and a community of incredible people who get you. And that can make all the difference. Why rock the waka? Because you're in it. We're all in it. He waka eke noa, we're all in this together.

Thank you for blazing the trail, for telling your stories, and for welcoming me into the A team. I am so happy to be here, and I will make you proud.

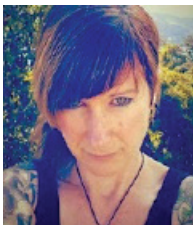
Jolene Stockman (BBC, Distinguished Toastmaster) is an award-winning writer, speaker, and business owner who spoke about her adult autism diagnosis at the New Plymouth TEDx event in July 2018. Her presentation 'How to be Normal (and why not to be)' is on YouTube.

Jonathan Squirrell, 14, who created the Journal cover, was born in Sheffield, England, moved to New Zealand when he was five and received a diagnosis of autism at the age of three.

His interests are drawing, writing poetry, animation, Minecraft and Aetherlight. He is also a keen reader. Jonathan lives in Red Beach, north of Auckland with his parents, an older sister and a younger brother. He goes to KingsWay School in Red Beach.

He specialises in cute, stick men.

Fear, learning and my vagus (nervous system joke!)



*When **Tanea Paterson** accepted an offer of help from Otago Museum, it was a monumental step for her as an autistic person. She explains why.*

There are huge rewards from providing the necessities, some framework and intermittent, constant reassurance. And then most importantly stepping back, but not all of the way.

AUTISM MEANS differences in how we observe, receive, and process information.

We have unique differences in our social structures and functions. We have differences in how we communicate and use spoken and non-spoken language. These things all have powerful effect on how we interpret the world and each other. It can be challenging for autistic people to express their true selves to non-autistic people. Ergo, we are not always interpreted accurately.

There are misunderstandings ranging from fairly minor, to overwhelmingly serious. To an autistic person, whose world may not feature a large range of human interaction, even the 'fairly minor' misunderstandings can have major effect.

The most common being withdrawal, isolation and inertia. There are many things autistic people want to do, how do we get past the fear of being misunderstood and/or getting things wrong? I find it extraordinarily difficult to ask for help, furthermore if help is offered, regardless of if I need it, I often turn it down. Why would I do that? Because I find my needs hard to explain and I don't want to take the risk of that being misunderstood. I also suspect the person, with obvious good intentions, may not be able to 'do it' how I want 'it' done. Remember when you were little, your carer saying - 'I'll just do it myself, then I know it will be done properly."

We may feel confused if our communication is misinterpreted, we may feel guilty for taking another person's time or we may feel so disappointed in ourselves for not being able to 'do it right, without help' that we'd rather just leave it. Sometime that means ignoring an offer of help, is it embarrassment or perfectionism? You may turn down a meal and go hungry, because what if the food was yuck, and last time you made yourself ill eating someone else's food. All because you didn't want them to feel bad if you said you didn't like it. Maybe you walked home in the rain because you felt guilty about the five kilometre diversion the vehicle owner would have to take to get you to your address.

It can be overwhelming to take someone up on their offer, or 'give something a go'. The fear of being seen as a manipulator, something autistic people get accused of a fair bit, or getting things wrong, can be too much to even contemplate. Fear and anxiety, whether situational or physiological (hence the vagus nerve title) or both, are the main drivers, autopilots and well the entire pit crew too. Instead of leading the motivation for movement, which is the intention our mammalian brain has, they often serve to divert them to the nearest warm, dark cocoon. Safety of course is always THE most important thing, however so is building self-efficacy through autistic representation.

OFFER OF HELP ACCEPTED

This year, I said yes to an epic offer of help. One that didn't just involve me, three people I am close with, the iNDx crew, also took on something I said yes to. And 28 more people joined us. I said yes to the offer of help from the Otago Museum. A place I had known my entire life, that I felt the same kind of connection with as I would a wise kaumatua or kuia. This particular 'yes, thank you' was intense.

I can't explain the fear I had being offered a space for our idea of an Autistic Art Show. I have Ehlers Danlos Syndrome and have been very unwell and immobile for sometime.

Going from fairly active, to bedridden is extraordinarily challenging, it was affecting my mental health quite badly. I felt stuck and scared. And to be brutally honest I felt helpless and useless.

It is an understatement to say I 'needed' a project, this really couldn't have come at a better time. Although I could have said no, my basic survival instinct did the math and the benefits out-weighed the risks.

I know there are many other autistic people like me, who have ideas, projects, dreams. I know many feel stuck, in so much as they need others to help them make their ideas a reality. This makes me feel sad for all of the wonderful things they, and we may be missing out on. I was fortunate to have met people offered the help. People who were willing to allow me and my team to make the decisions, guide the process and do it 'our autistic way', no matter how different that was from the 'typical way'.

I want to let other autistic people know sometimes things that seem unachievable, might just be possible. If you can peak past the crippling fear and say 'yes please help'. And just as importantly, to those supporting autistic people to give them opportunities to do things in their way. It may 'look different' and that is the point. We need different in our society, or how do we progress?

"If 'independence' as the 'ultimate goal' why do others speak for us, make decisions for us? Walk beside us, comfort us when things don't go exactly to plan. Our process may seem strange with its timing and sequence, if you are not afraid, we won't be (as afraid) either."

It is hard not to step in and say 'what are you doing that for?' when things look unusual or 'wrong'. However, doing that is a sure fire way of bringing potential to a close. There are huge rewards from providing the necessities, some framework and intermittent, constant reassurance. And then most importantly stepping back, but not all of the way.

This is what the Otago Museum did for us. The trust they had in us to manage this project really was what made it possible. Them trusting us helped us to trust ourselves.

We hadn't done anything like this before, it was a 'see how it goes' situation. Potentially the biggest challenge was within ourselves, faced with an uncertain process. We really had to use our passion and excitement for the project as a buffer to the sheer terror and anxiety of 'what if's'.

Rachel, our main contact from the Otago Museum was absolutely respectful to our decisions. Rachel supported us without influencing decision making and by doing so fully respected our autistic led kaupapa.

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iNDx Autistic Artist Exhibition

iNDx
ART EXHIBITION

From August 10th until the 23rd at the H D Skinner Annex, Otago Museum there was a unique art exhibition. What was it that made this exhibition groundbreaking? The organisers and every single artist are all autistic.

iNDx showcased 31 artists from around New Zealand, one from Melbourne and videos that we screened onsite and in workshops from autistic advocates from the UK and America. The art on show varied from knitting, to photography and written word.

Five artists came from Studio 2 in Dunedin. Studio 2/Margaret Freeman Gallery is a small gallery and studio space in central Dunedin where disabled people are supported to create artworks. We had artists create at Art Space, which is an art focussed daybase run by IDEA and also Dunedin Artsenta.

Artsenta is an art studio for people who use mental health services and are interested in being creative.

Some of our artists see art as a therapeutic hobby. We also included artists who have undertaken formal training such as a painting diploma, design certificate, creative studies and a Bachelor degree in photography. One of our Artists Tom Fox has been inspired, we like to think by iNDx, to complete his Masters Degree in Fine Arts, now with autism being woven into it.

"I don't consider what I made was art – turns out I was wrong – go figure!"
– Anonymous

Some of our artists are just beginning their journey both art, as well as with their understanding autism. Others, as you can see, are bona fide professional artists. We were excited to have had such a diverse range people come together for this project. And even more excited that we will be doing it again in 2019!

Comments received:

This show is so good. I love the obvious diversity of experience and perspective, and the words that accompany make it all richer.

I now have a better understanding of autism. This art is amazing and beautiful. So many talented artists here. I am a local artist. I always enjoy viewing other work.
Thank you x

A vibrant exhibition. Some very appealing images, and poetry that says a lot. More alive than lots of exhibitions I've been to.
Thank you.

Continued from page 8

There was no, "what are you doing that for?" or "how about you do it like this".

The iNDx crew didn't have a clear step by step map to follow, which is extremely challenging as autistic people. We did amazingly well at supporting each other, when we all had moments of uncertainty or confusion. The camaraderie and teamwork of iNDx, as well as having Rachel and Craig nearby to answer our questions, but not force ideas on us is what made is possible.

The museum staff were open to learning about autism which led to wider social understanding. They organised 'quiet hours' in the main museum areas to widen access and promote understanding of sensory differences in autism. This project went beyond an art exhibition.

By taking on this project, I personally learned so much. I learned that I could organise quite a lot from my bed, thus I may not be so helpless or hopeless after all. Our many artists taught me a lot about taking risks. They taught me about trust, and about embracing anxiety as excitement, as opposed to fear. This was the first all autistic led project I have been involved with. I learned that autistic led projects are extremely important to be promoted, embraced and encouraged.

Who benefits from autistic led projects

Autistic people involved and their whanau, our entire community, the wider community, the museum staff who were keen to learn new ways to interact with autistic people and the kid who went home afterwards to 'study' the booklet of biographies.

We ended up with a total of 28 artists and another four autistic advocates (three from overseas) who participated by allowing us to screen their films. We proudly turned no artist away, although the curators had the unenviable task of filtering a few pieces out due to space constraints!! Every artist who submitted work had at least one, sometimes multiple pieces on display.

The connections that were made through the exhibition that wouldn't have otherwise connected were invaluable. The autistic community tends to have few 'social events'. The entire process can be overwhelming and over stimulating. We need extra time to prepare and time to recover. There is often a need to have a purpose or a central theme and focus to bring autistic people together. The iNDx art exhibition gave our group that. Many had never met before and may not have 'in person', however we were all connected by being a part of this project.

It gave the artists a sense of self efficacy, identity and pride. We also asked this of the editing and communications team at the Otago Museum.

We would like for the bios to remain as authentic to the individual as they presently are. We understand the format is not 'traditional' or streamlined, however we think that adds to the theme of the Exhibition.

Individuality, appreciation for autonomy and a celebration of how diverse and unique autistic people are.

We also have a couple of limited speaking artists and their support persons didn't feel comfortable writing words on their behalf.

We would rather the artist didn't see a 'reframed' 'edited' bio and description and feel that someone thought they needed changed to 'fit in'. This is the opposite to what our intentions for the show are.

We held workshops over the weekends where we had open dialogue about all things autism. For some it was the first time meeting other autistic people in real life. It gave people the ability to ask 'sticky' questions and to connect with other people like themselves. The sense of shared identity and comradery and developed ongoing relationships. These things have deep meaning for our often isolated group.

I wanted to share some things that helped me to achieve this, hopefully they can also help others to achieve their plans, no matter what they are.

Lessons and learnings

For autistic people;

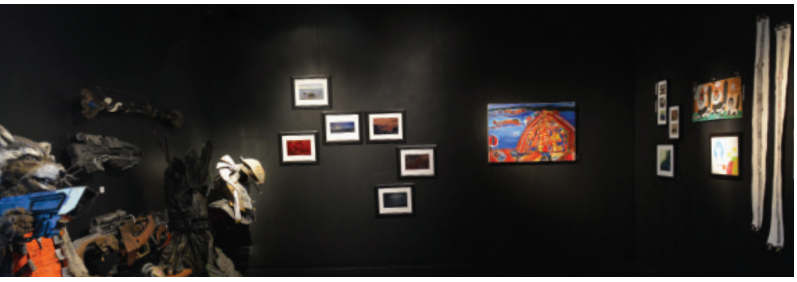
- Most things are flexible and fixable.
- We need to take calculated risks as individuals and groups
- There is a way up, under, through and around most obstacles.
- We need to learn that it is ok to get things wrong. And that other people do too, regardless of who they are.

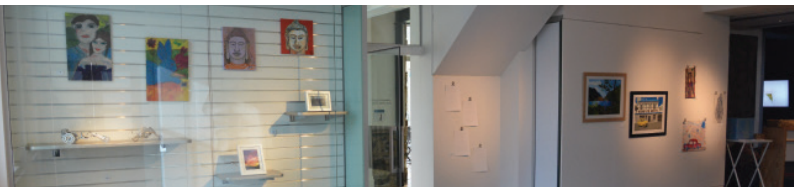
For people who support us;

- Diversity of thoughts and ideas make the world better for everyone.
- Find articles, books and movies that show real world stories
- Tell real world stories of your own or someone that you know
- Reassure

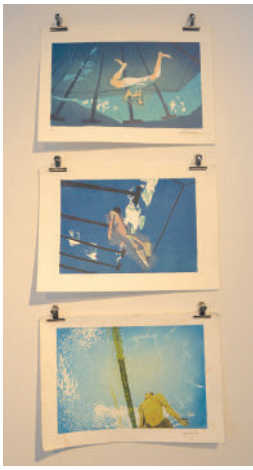
Teach about the art of making mistakes.

- The vagus nerve is the longest of the 12 cranial nerves.
- iNDx represents : i = identity, ND = neurodivergent, in capitas to represent importance, Dx = diagnosis and is representing the shorthand abbreviation for diagnosis.
- Tanea Paterson is a substance use practitioner/ counsellor.





"I enjoyed being a part of this exhibition and seeing the other artwork and the food at the opening. I enjoyed meeting and speaking to a lot of people, and re-meeting people I remember from a long time ago" *– Allan Hegan*



Self-awareness found after years of confusion

*When **Kyle Hefferon** was at primary school she wondered how and why other children thought and did the things they did. Now she knows.*

AT A SMALL country school in Taranaki, I was moved ahead a year at the age of seven as I was doing well academically.

At this stage I knew I was smart because other people told me. But I never could understand how I knew things, I just did.

At the age of nine, moving to a larger school where I did not know anyone was scary. It was confusing, and with so many children around I found it hard to keep track of what was happening. I began to feel stupid and lazy; feelings that continued for most of my life.

Having no qualifications, I worked in physically demanding jobs from the time I left school at 15. I became a workaholic, always needing to prove myself. Every time I started to become successful, I would develop physical ailments such as allergies, or tendinitis, making it impossible for me to continue in that role.

I had always secretly dreamed of tertiary education, but believed it was out of my reach. I enrolled at an Auckland university when I was 25 and loved the learning experience but couldn't do the assignments. I began having nightmares and couldn't sleep properly. I was told to access student support services, but I didn't know how. So, I just stopped going to class and returned to full-time work. My doctor put me on a mix of pills, advising me that I was depressed.

I have never spent long without having to interact with medical professionals or some form of government agency. People who have known me have never been able to comprehend the terrible bad luck I have when interacting with these services. This left me feeling isolated from family and friends, as I couldn't explain to them what was happening. And often my attempts to explain myself were met with disbelief.

In 2014, I enrolled in a bachelor's degree at the University of Waikato. It was extremely stressful, and I contracted school-sores three times in my first semester. Sometimes I couldn't sleep for days after my assessments and exams. I encountered memory loss, forgetting whole days of class at a time. I would suffer sensory-overload from the noise during group discussions, or certain smells, leaving me unable to do my work. No-one could understand what was wrong with me, as on paper I appeared to be a successful student. I still didn't realise that the majority of the population did not experience things the way I did.

I was accessing disability support, but there was little they could do as I did not have a diagnosis. Doctors would refer me to the counsellors. Eventually one counsellor told me to go back to the doctor, as she believed my issues were medical.

In January 2017, out of pure luck I saw a psychologist who had previously trained with children on the autistic spectrum. When she suggested I could have attention deficit hyperactivity disorder and autism spectrum disorder,

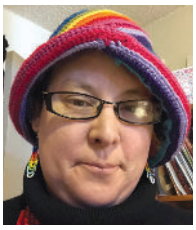
I was in disbelief. No one had ever suggested anything like this before. Learning about these conditions became an obsession for me. The more I learnt, the more it made sense. In my attempts to access diagnostic services, I came up against many of the barriers that are becoming commonly recognised as facing adult women. Conditions such as obsessive-compulsive disorder, borderline personality disorder, and anxiety were thrown around.

In April this year I graduated with a Bachelor of Social Sciences, and in June received an official autism diagnosis from a team of clinical psychologists which I accessed through the public health system. Now I am about to start my thesis for a Master of Disability and Inclusion Studies at Waikato University where I intend to utilise the knowledge gained through my experiences of autism assessment and diagnosis.

These days I am less stressed, sleep better, and am happy with who I am. Having an awareness that I interpret the world differently to most people grounds me in whatever environment I may encounter. This has given me the ability to make sense of my past and to create my future with new-found self-awareness.

Kyle Hefferon is 38 and is mother to Ryan, 7.

A long ride to finding my tribe



*Autistic author, advocate, presenter and mentor **Jeanette Purkis** describes the journey she went on after being told she was a nerd.*

If anyone has an issue with my being autistic then that is most definitely their issue, not mine.

IF YOU TAKE your metaphorical time machine back to Melbourne, Australia in 1994 you might see a much younger me being told by a clinical psychologist that I have something called Asperger Syndrome.

I didn't properly know what that meant. Few people did in 1994. My understanding was that it was a diagnosis of 'nerd.'

To me, the diagnosis meant that I would always be a nerd and never be accepted by anyone for the rest of my life. Understandably, I wasn't overly keen to embrace my newfound neurodiversity!

Those diagnosed as adults these days often have a different view to the one I took. The diagnosis is often seen as a liberation.

"For many people it isn't as simple as 'find your tribe' and that is actually okay. I think sometimes people feel afraid to express publicly that they are having difficulties in accepting themselves as autistic and I know this so well."

People find their 'tribe' and understand things about themselves that they haven't articulated before. Finding out they are autistic is a great thing for so many people.

So what drove my inability to accept that vital part of who I am?

A hard road

I spent most of my school years being subjected to bullying, violence and abuse.

This would start from when I got on the school bus and continued pretty much unabated throughout the day and then I had it again on the bus home.

Thankfully we didn't have Facebook in the 1980s because I would doubtless have been cyber-bullied at home too if we did! I was a kind child and never hated or blamed the bullies. Instead, I was terrified of them and internalised all the hatred they gave me. For surely if so many people hated me that much, I must be fundamentally unlikeable?

I was always academic at school, and was considered gifted. I wanted to talk to the teachers and came top of the year every year in all of the non-physical education subjects. The most common insults I received related to my divergent gender and to my nerdiness.

Desperate to be accepted, I joined a socialist group at the age of 15. As a socialist all I had to do was agree with the views of the party and I was accepted. I spent the next few years doing everything I could to distance myself from the studious person I was at school who earned the 'nerd' tag which I hated so much.

My negative focus to life and self-hatred resulted in some very destructive acts and a relationship with a person who was a dangerous criminal when I was 20. I spent from 1994 to 1999 involved in drugs and crime and 'masking' very convincingly indeed, fooling even myself that I was a scary criminal!

'New millennium = a new life'

Things changed in 2000. I decided the new millennium would equal a new life for me. I changed my focus from negative to positive. This involved enrolling in university, intending to get a degree so I could get a professional job one day.

At the end of my first year at university I got very unwell with mental health issues.

In the past this would have resulted in me committing some crime and going to jail but this time was different. This time I accepted help and reminded myself of the friends I had made at university and my aspirations for a better life.

I had a new feeling: hope and self-respect. Very soon after this change I started to wonder about the autism diagnosis I had received some years previously. I asked my mum to send me the diagnostic report. I read it and it made sense. I joined the local autism organisation and borrowed books and videos about autism.

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While I did accept my autism, I was still quite uncomfortable about discussing it.

I found it easier to tell people that I had been in prison than that I was autistic! To me it was like a shameful secret and if I told people I expected them to stop being my friend.

Autistic peers, a mentor and a book

This all changed in 2004 when I was invited to do a course alongside 20 other autistic adults so that we could give presentations about autism at schools.

I had never been in a room full of autistic people before. It was an amazing experience and quite overwhelming to be among so many others. I discovered we were all quite different but quite similar too.

MENTOR: Donna Williams.

The most incredible thing I could have imagined happened as part of that course - something which altered the course of my life in a very positive way. I met my first autism world mentor and someone who I have endless respect for, Donna Williams (who was also known as Polly Samuel).

Donna was the first actually famous autistic person I had met. She had written nine books and was renowned around the world as a commentator and advocate around autism. We became close quite quickly and after I told her about my own story she encouraged me to write an autobiography. I didn't think anyone would be interested in my life story but Donna sent it off to her publisher along with a foreword she had written and they said 'yes'.

I was so excited to be an author that I almost forgot how uncomfortable I was being 'out' as autistic. I had media appearances and got asked to speak at autism events.

People wanted to know my opinion as an autistic person. It was terrifying and wonderful.

It took me a few more years to completely respect myself as who I am and feel I belonged in the neurodiverse community.

This momentous realisation happened at a conference for autistic women and girls that I attended in 2009. When I was in a room with 100 autistic women I finally felt that I had found my tribe. It just felt so good. I didn't have to hate myself or hide my 'nerd'. I could be who I am and that was a great and valuable thing. Being me was OK. In fact it was beyond OK. Being me was golden.

Proud of my pride

These days I can and do talk to everyone who is interested about autism and my work as an advocate.

If anyone has an issue with my being autistic then that is most definitely their issue, not mine.

I willingly say I am king of the geeks and that this is a good thing. This is the culmination of a very long and difficult journey which has ended in self-acceptance, respect and pride.

My difficulty in accepting my autism was so closely bound up in my self-loathing of the past. The more I understood and liked myself, the more able I became to embrace my neurodiversity.

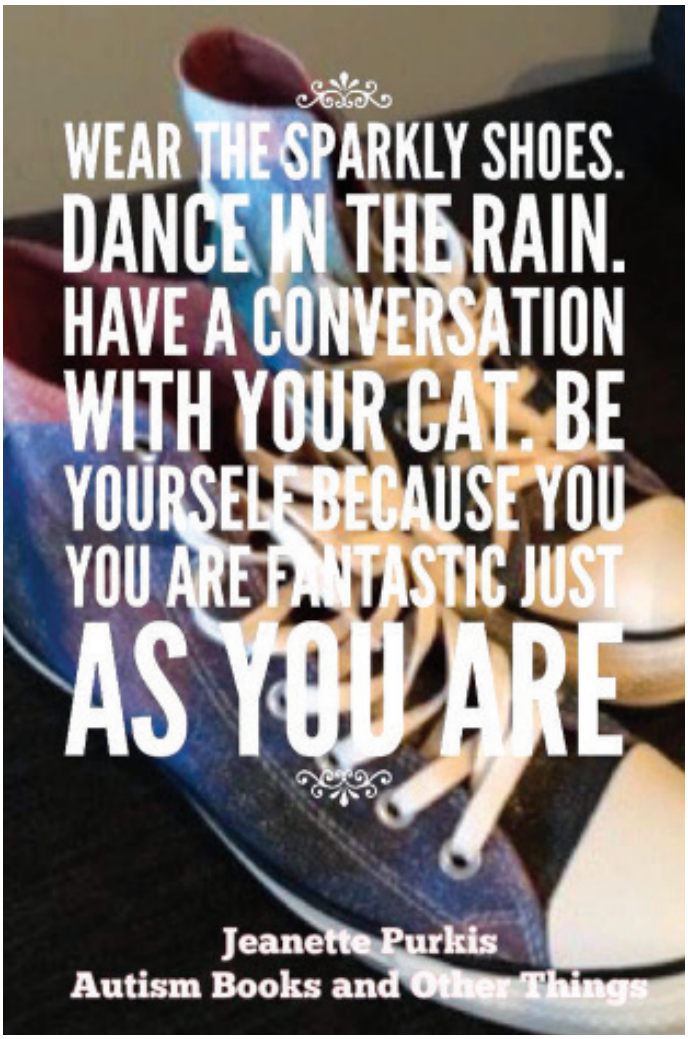
I love seeing people these days - adults and kids - seemingly effortlessly finding that space of pride soon after or at the time of their diagnosis. I think maybe the experience I had of

huge challenges in being able to love and accept myself is of value to others who are struggling with acceptance.

For many people it isn't as simple as 'find your tribe' and that is actually okay. I think sometimes people feel afraid to express publicly that they are having difficulties in accepting themselves as autistic and I know this so well.

People are at where they are at and there doesn't need to be a judgement in that space, just support and understanding.

On a personal note, I do love my place of autistic pride. I worked very hard to get here and it is very 'real.' I'm proud of my pride!



Jeanette Purkis is an autistic author, advocate, presenter and mentor, and the 2016 Australian Capital Territory Volunteer of the Year – Web: www.jeanettepurkis.com

Finding my place at university

*Like many on the autism spectrum, high school was not a great experience for **Beth Noble**. Despite this, she always wanted to go to university and continue to learn.*

I have rediscovered my love of learning, and found a place amongst peers who understand me – people who celebrate my strengths while working with my weaknesses.

I LOVE LEARNING but have always struggled significantly with the social rules and expectations of my peers, which resulted in a lot of stress and affected my exam results at secondary school.

The journey at university has not always been 'smooth sailing'; there have been lots of up and downs over the years.

It has taken time and work to learn to balance academic commitments with social activities and personal time.

Today, I've now spent longer at university than I did in high school, completing both a Bachelor's degree and a Master's degree, and I have just committed to another three to four years of academic pursuit for a Doctoral degree (PhD).

I have rediscovered my love of learning, and found a place amongst peers who understand me – people who celebrate my strengths while working with my weaknesses.

Not only have I completed my qualifications, but in recent years I have also begun tutoring new undergraduates coming through the building science programme and working as a research assistant on projects with the lecturers - giving me some work experience alongside my academic progress.

I'm not sure what I'm going to do once I complete my PhD, I'm keeping my mind open, but am currently leaning towards a career in academia or research. It is by coming to university that I have found my place, and by sharing a few of my experiences, and things I have learnt over the years, I hope to help others find their place.

Starting university

When deciding if tertiary education is the path you want to follow, remember academic performance at high school does not necessarily predict performance at university or polytechnic.

My high school results were well below what I was capable of achieving, only just meeting the guaranteed entry requirements into the School of Architecture.

While there are some choices in what you study at high school, at university you can choose your programme, courses and subjects, and align them to your interests.

Some papers may be compulsory early on, but at higher levels you truly get to decide where your interests lie and decide what you want to learn. At university, I became an A-grade student overnight, almost purely from the more specific environment that held my interest.

Choosing a place to study that will be the best fit is complex – but a really important decision. A lot of factors should influence your choice of tertiary institution. Decide whether a university or a polytechnic environment would work best for you. Research what courses and papers are available to you at different institutions, and what qualification you will gain. What support does the institution provide to students – learning, health, disability, academic etc. Consider whether you want to go to a local institution, or one further away from home.

Your choice of institution will also inform your living arrangements. Consider carefully whether you want to move away from home. The move from high school to university is a massive change in environment.

I took one 'gap' year after school where I lived at home with my parents and took several interest papers at the local university. This let me learn how the university environment worked – the differences in class timetabling, managing time, the grading system, and more.

The following year, my official first year, I changed to the university offering the course I wanted to study. It was in another city, so the year was spent in a Hall of Residence, which is an experience I regret – socially, physically and mentally. At the end of first year, as my parents had relocated closer to where I was studying, I moved back home. It took another five years, until I was 24, to get up the skills and courage to leave home again and live independently.

Getting support

You don't have to study full-time at university, there's a lot of flexibility in how you study. I'm a big proponent of "limited full-time" study – where you have a part-time workload, but are considered a full-time student in the eyes of StudyLink and the university.

It took me four years to complete my three-year Bachelors degree, taking two or three courses each semester instead of the typical four. I used to say that I considered that I had full time commitments, three quarters of this was formal study, and the other quarter was other activities that I participated in to keep up my mental health but still took energy – volunteering, social, etc. I was then able to also have some downtime, which was essential for me to cope and to succeed.

It is important to include academia, extracurricular and personal time, and "limited full-time" study enabled me to have all three components of university life.

University does require significant self-motivation and planning skills. Unlike school, there is nobody who is keeping an eye on you making sure that you are going to class or understanding the content or handing in assignments. However, there are support services in place that can help you with this if it is an area you struggle with.

Disability Services are a lifesaver. Even if you don't identify as "disabled", they're a fantastic resource. In the eyes of the university, they are the service that helps anyone who has extra needs - whether that be because of a physical disability, a neurological difference, a learning difficulty, or even just a broken arm. They can help you with all kinds of things, including finding your way around the university, note taking, adaptive technology, quiet areas, test/exam arrangements, and more.

Also, don't be put off from going to them if you had bad experiences at school with support services such as through the Ministry of Education or the New Zealand Qualifications Authority (NZQA).

I still remember going into Disability Services for the first time at university to organise arrangements to take my exam in a separate room. My advisor filled out the form with me, we

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HELPFUL SERVICES: Beth Noble in the Victoria University, Wellington library. Photo: Victoria, University of Wellington.

both signed it, they scanned it into the computer, and I asked when I would find our whether it was approved. Their answer - "Oh, no, I've approved it now, it's all sorted".

In my experience, they genuinely want to be as helpful as they possibly can and help every student succeed. There are also lots of other services, including learning/academic support, who can provide assistance with skills like writing, research, statistics, revision, and more, in both workshops and one-on-one assistance.

Get to know the staff in your courses. This can be a little difficult in first year, as the courses are often very large, but if you're registered with Disability Services they will often be able to help introduce you. It's always a good idea to have introduced yourself to the staff early in the term, as if you need assistance or an extension later they are already familiar with your name. The staff in your courses or programme can be some of your greatest advocates, particularly if you are part of a small programme.

"It is important to include academia, extracurricular and personal time, and "limited full-time" study enabled me to have all three components of university life."

Unlike high school you are not strictly required to attend all your classes, but doing so is not only is good academically, you can make a good impression by attending classes. Staff know which students are coming to class and which they have never seen. And staff are more willing to help or hear from students that they see regularly in their classes, even if they don't know you by name.

If you attend all your classes, barring illness or legitimate absence, it is very difficult to fail. Also, read the marking criteria for your assignments carefully. These lay out exactly what you are going to be marked on, and if you can tick off every item on the list, again, it is very difficult to fail.

Finding your place

One of the great things about university is that you aren't lumped into a classroom with a group of people based often solely on the date of your birthday. University has a very diverse range of people – ages, interests, beliefs, and more. There are many ways to meet new acquaintances and make friends. First year classes aren't always the best place for this, as they are often very large and can be quite isolating for someone on the autism spectrum, but there are other ways.

Clubs are a fantastic way to meet others who hold similar interests or demographics as you. In my first year, a student a few years above me in a different course started up a representative group for students with disabilities. I attended the first meeting as I'd heard about it from an advisor, and ended up working on the executive for the next four years – first as the secretary, and then as president. I made a group of friends out of this that I still see regularly – despite most having well and truly finished university and being out working now. I think the best part about this group is that we all had some kind of disability or difference, and therefore had a lot in common. We are very diverse, but all have the common experience of moving through the world with additional needs and facing barriers of different kinds.

Outside of university, taking up volunteering opportunities was also a way to meet social needs. I found it a great way to meet new people, in a scheduled setting, but still have a purpose and not be solely required to make social small talk. Today, as a postgraduate student, I also have a relationship with the lecturers and teaching staff that is closer to that of colleagues than superiors. I have had, and still have, fantastic supervisors for my thesis and other research projects I've been a part of.

Personally, even as I excelled academically, I still found undergraduate somewhat difficult socially – though it was significantly better than high school. While I made some friends outside my programme through clubs and volunteering, I truly started to get along with my peers once I entered postgraduate study. We went from classes of 60-250 students to just 10, working together with an assigned space, and we became a cohort that provided great support to each other.

Overall, it can take time to find your place at university. University is a place that has a diverse range of both academic experiences and social opportunities. I hope that some of the stories and advice here can help current and future students find their individual places as well.

- Beth Noble (BBSc, MBSc) is a young adult on the autism spectrum, who has just started her PhD in Building Science.
- www.victoria.ac.nz/architecture/study/student-profiles/beth-noble
- www.victoria.ac.nz/news/2016/11/part-of-a-community

From meltdowns to a job, how far there was to come

*"Why are you so quiet?" was the question **Francesca Pobar** was asked every day during high school. She called it different, professionals preferred difficult.*

GROWING UP, I always knew I was different, so did my mother Deborah, who is a doctor.

The professionals had a different take on it though, they used the term difficult.

I was finally diagnosed just before I turned 16, along with Attention Deficit Hyperactivity Disorder (ADHD) and Nonverbal Learning Disorder (NLD).

I finally had an explanation for why I was a bit different, and why I found certain things difficult, things that seemed to come naturally to everyone else.

So how did I go from the girl who hardly ever spoke to anyone but her parents and had regular meltdowns, often violent ones, to the girl who has a university degree, a job, and a handful of close relationships? This is my story.

I know there is the stereotype of autistic people having amazing abilities. I'm not saying I'm not amazing. Everyone is, in their own way. I'm smart. But I can't cook unless toast counts, I still use my fingers to count, I got pretty average grades in school, I even failed an IQ test, not the verbal test but the spatial reasoning test.

Another stereotype is having an 'odd' special interest such as trains. I've read that autistic females often have interests that are seen as more 'normal'.

So, deciding what to study at university and what to do with my life hasn't been easy. When I left school I ended up doing a foundation course in education and social work, but after that I decided to enrol in the Bachelor of Health Sciences degree.

Who isn't interested in health? And I've always been passionate about helping others. I actually applied for a bunch of things and was accepted into the health sciences programme which was an offer I immediately accepted.

Health sciences itself is a very broad degree, a combination of sociology, anthropology, psychology, public health and other disciplines.

I was very social (for me) at university. And by that I don't mean I partied. In fact, I didn't party at all. If I ever do go to parties I spend the whole time petting the host's cat or dog.

By 'social' I had quite a few friends who I enjoyed spending time with one at a time. I never was great with group situations. I didn't enjoy tutorials at university. At a lecture you can just sit there and be invisible. In tutorials you have to join in class discussions, do group work, and of course, the dreaded introductions on the very first day where you suddenly forget who you are, go bright red, and get told to speak up. I wonder if the educational psychologist I saw in year 12 who told me I have a 'low IQ' would be surprised to learn that I passed every course, and I graduated (and I am even doing a few postgraduate papers). Perhaps I should just turn up with my degree. Would she be surprised by the fact that I now have a job? The employment rate in the autistic community is very low which is unfortunate. Autistic people have a lot to offer.

WORKING TOGETHER: Francesca Pobar with colleague Paul Brown.

As my degree was ending, I often would wonder if I would ever get a job. I had the university thing nailed, I was in a relationship, I had friends but would I ever be able to work? That was always a big concern of mine.

My main concerns were:

1) work places always look for loud, outgoing types
2) I can't drive despite all the driving lessons I've had.

Throughout my degree I had been volunteering at the zoo, I love animals but there I mostly had to deal with people. It was my attempt to 'socialise' myself. It was just a bonus that I got to feed the giraffes.

In my final year of university, I did caregiving work, the main family I do caregiving for has an autistic son. The family are great, they have always been so accepting of me.

At the end of my final year of university I reached out to an amazing organisation called 'Be Accessible' and signed up for their 'be employed' programme where I was given a paid internship for four months.

My internship was with Auckland Regional Public Health, where I assisted with a study looking at the epidemiology of imported infections. I also assisted one of the medical officers with another study, called "Invasive Pneumococcal Disease in Auckland, New Zealand: A case series".

The next nine months of my 'employment' journey involved an administration and receptionist role at a community mental health organisation. People didn't believe me when they learned that my main role at work was answering the phones. "But you don't even answer your own phone!" and I would jokingly say back: "I don't get paid to answer my own phone".

I now work at the Health and Disability Commissioner. I've been wanting to work there for a while, no matter what the role was. I attended a couple of interviews there and ended up getting offered a job that I didn't actually apply for, but it didn't matter. They wanted me, and I was happy.

It's a great place to work, really lovely people. It did take me a while to get used to the 'open office' environment which I wasn't used to. I'm constantly surrounded by people and it can be both exhausting and overwhelming.

It is easy to compare myself to others who may seem to be doing better than me, but I try to remember that everyone has their own strengths and weaknesses.

There are still times when I really struggle and get anxious and overwhelmed. When things get tough I remind myself how far I've come.

Everyone has set backs; everyone's journey is different, and everyone has their own story to tell. This is my story.

How a diagnosis can make a difference

*The diagnosis, when it finally came two years ago for **Elroy Liddington** confirmed what he already knew but the professional who conveyed it wondered why being told having autism would make any difference at all. Elroy explains why he thinks it does.*

I don't want autistic people growing up the way I did.

I WAS A TYPICAL computer geek and it was when I was an active member of a New Zealand based online gaming forum, and one of the members had just been diagnosed as being on the spectrum, that I began to wonder

This was the first time I had entertained the thought that I might be on the spectrum as well.

I quickly dismissed this idea, as I did not fit the social identity that society has of autism although my entire life I've felt different to everyone else, felt defective, and that's kind-of been the core message I've had reinforced to me by society my entire life.

I've been continually receiving messages like "you need to try harder, you need to apply yourself more, you're lazy, you've got to work faster, try harder, stop thinking about things, just do it" all my life.

I think it's hardly surprising that I've had ongoing mental health issues (mainly depression) - I'm pretty sure anyone in the same situation would experience the same issues.

My wife and I were going down the diagnosis route for my oldest son, when we started noticing similarities between some of my past behaviour, and that of what we were researching. It went something like this: "Hey, I do that, and I've done that too - also I do this, and that... and...oh...OHHH!"

"The whole diagnosis to me was proof that the way my life has been was not my fault, nor a core failing on my part."

In 2016, after yet another issue with being able to maintain employment (in retrospect, I've always had issues with this), I needed to find out why my life was so different to everyone else, why I didn't seem to succeed (or even have moderate successes) at life.

With the help of a Health and Disability Commission advocate (free service, by the way) I pursued a diagnosis through the public health system.

When I got the diagnosis I went through a grieving process.

My whole life I had been trying to become an electrician, and to have finally reached my goal after 20 years, and then coming to the realisation that it's not really suited to me ... let's just say I did some thinking.

In the beginning stages of seeking a diagnosis the psychiatrist said to me: "What use is a diagnosis to you?"

He, like a lot of other medical professionals, did not understand the significance of what having a diagnosis meant to me. It confirms to me I am not defective.

The whole diagnosis to me was proof that the way my life has been was not my fault, nor a core failing on my part. The way that this changed my internal perspective of myself was huge.

In school, all the way up to fourth form, I was really good at English, reading, writing and spelling but in the fifth form, it all changed. Then it started to relate to characters and books which I had no clue about.

We had all these assignments to do, I would do these the best I could but I would bomb out and the teacher would get frustrated.

Towards the end of the year, he got so frustrated with me and said: "Elroy, why don't you understand, I want you to relate your life to the characters in the book" and I said "why didn't you tell me that a year ago?!?!?!?"

If I had known I was autistic then maybe school would have been different for me.

I'd always wanted to be an electrician so I moved to Hamilton to study at Wintec.

It was during this time that I crashed and burned depression wise.

I spent the next six years in a pretty bad way. I was on antidepressants for the first couple of years (1999-onwards) - turns out the type I was on didn't work that well for me because I was a zombie, slept 20 hours a day. I couldn't work.

Depression is not always just an entity in itself; it can also be a symptom of being autistic, due to how much effort it takes to put into masking, and to try and interact with everyone and everything in this world.

It's really frustrated me that someone didn't at least ask the question (was I autistic) when I did seek help.

I think any person presenting with any symptoms of depression, the first thing the professional should do, whether it be a GP, counsellor, mental health professional or whoever, should get them to take the Wired AQ-10 test to rule out depression being a symptom of potentially something else, e.g. autism.

It's a fairly simple one by psychologist Simon Baron-Cohen which first got published on The Wired website in 2001.

I score a consistent 38 to 41 on this test - the best thing about it is that only takes about five minutes to complete, and fits on one sheet of paper, so there is no excuse for this not to be done.

Back to my diagnosis (don't you love tangents – I'm great at them, but not mathematics :-)):

I ended up going through Adult Mental Health to get it.

People wonder why autistic people have mental health issues – if you could imagine being bullied your entire life, you're told you're lazy, that you can't work fast. What sort of common theme do you think that's going to have in terms of an impact on someone?

Do those missed opportunities for an earlier diagnosis bug me?

Yes, it does, because my life could have been a lot better but then I don't know really. I'm still quite angry about that. Then on the other hand, if I had been diagnosed earlier in life, I could quite well have potentially not ended up where I am in life now.

In retrospect, it is the life journey that I have walked, despite all the rocks along the way, that has made me the person I am today – if things had turned out differently (i.e. diagnosed earlier), I may not have even written this article, let alone what I'm trying to achieve.

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I've heard some of the stories about autistic people growing up with a diagnosis.

To me, it could potentially help someone so much (from my point of view, in terms of the direction in life that I would have taken if I could have identified, or had help to identify, what paths and life direction would not have been suited to me, it could potentially have saved me an awful lot of grief) and take pressure off our health-care system - but this will not happen in isolation - this needs to be a joint effort (from all Government departments, from everybody) to ensure that people that need support get support.

My wife and I married 10 years ago. We have two boys aged seven and nine.

Our nine year old has recently been diagnosed as being on the spectrum. We've known that he was since he was three, but medical professionals couldn't see it at the time.

It helps that I'm also on the spectrum to be able to relate to what he's going through. The anxiety stuff I'm going through can help him via passing on my coping skills which I've needed support to develop.

My wife (really she did, but I'll take some credit ;-)) and I came to the conclusion, after I received my diagnosis, that being an electrician in this world is not suited to my way of being in the world.

It is not in my own space and time - tōku/tōna anō takiwā – Takiwatanga, that's so me.

I want to provide peer support for other autistic individuals and in order to do that it would be nice to have some sort of qualification behind me.

That's why I've recently started a Bachelor of Social Health and Wellbeing. It's going to take me a while to complete.

In November last year I decided that through meeting and talking to some autistic people, there are so many, particularly younger people, who appear to be struggling in life, just like I did when I was their age.

Not long ago I realised that I have a not-insignificant amount of skills I have acquired in my lifetime, and a continual theme I've had (and never really paid much attention to) is people telling me I'm apparently really good at explaining things to others, which leads onto my next point:

I don't want autistic people growing up the way I did.

There are a lot of autistic people out there who have ongoing issues like I do with under-employment and unemployment, but want to do something meaningful.

My long term goal is I want to have somewhere safe and secure to work in, in an environment that suits me.

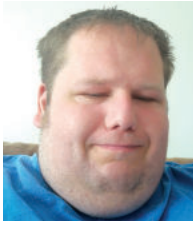
Somewhere I can go and do some work and have other autistic individuals alongside me so I can pass on my skills, teach them what I know at a pace that suits both of us.

I have recently been accepted onto the Enabling Good Lives programme which is going to be able to offer me some support around self-management/organisation (this is one spot where I struggle quite a bit – I have issues with some of my executive functioning skills), and hopefully allow me to achieve more in life, and indirectly help other autistic individuals as well.

If I did not have my diagnosis, I would be unable to access any support.

Hopefully in 2020, the System Transformation project will be rolled out nationwide, where other autistic individuals can also access the support they need to enable them to have a good life.

A failed support system



***Alex Munro** is a 26 year old male looking to get help with his mental health issues*

I HAVE TRIED to get help at least 30 times through my local district health board (DHB) in the last 12 months. I have also tried to go to a number of organisations to get help.

I have made complaints. I have got my GP and support people to ask but they all keep saying that I don't need support or meet the criteria and they don't tell you the criteria is when asked

Some of the people I have reached out to are my local MP and a few other MPs, a lawyer, a judge, a counsellor, a few psychologists

I have had a lot of support in the past with mental health teams but when I turned 18 they decided that for whatever reason I don't qualify for support so in my opinion there is a disconnect in support during the transition from youth to adult.

When I had beneficial support from the DHB they cancelled the support even though it was going well. I have recently got people saying that hang on a minute there is more going on here but people do not like criticising people because it is the health system at fault.

If I had the funding or resources, I would get a few new assessments to see if any of my old assessments have changed.

I am also looking at fundraising so I can go privately as the public system has failed me so far.

This article is to shine a light on the broken mental health system and the disconnect with other organisations. I have a number of recommendations to fix the system but I doubt that the people who make the decision will listen.

I have heard from certain people who work alongside the health system that a second look at my case should be warranted because there should be an underlying problem in their opinion.

I am very interested in the results and implementation of the mental health review. I would like to work and help implement any and all changes when we have the recommendations. I would love to read the draft unredacted version when it is ready and then the final unredacted version.

The NZ Police are more supportive than mental health services. If I had a wish I would like to have a police support system 24/7.

I would create an inclusive environment where I could go and have a chat and meet a police dog as dogs are therapeutic to healing. Obviously this would be all volunteers in a police room.

I am thankful for some of the supports I do have. I am thankful for the ongoing support from my GP and support workers.

I am thankful to the NZ Police for their ongoing support and hope it continues in the future.

How do older adults on the spectrum get any help

*There seems to **Andrew** to be a lop-sided overbalance of effort and resources placed into dealing with younger age groups while almost ignoring adults who struggle with autism. He describes his own experience.*

I HAVE higher-functioning autism (Asperger's Syndrome), I think.

..... "I think" ??

Shouldn't I be sure? Of course!

But that's the problem, no-one wants to help. I'm in my late 50s and all available help is exclusively reserved for younger children and not adults. Why?

"So"' you may say, "there are clinical psychologists and therapists listed in the Yellow Pages, so why not use them?"

Why? .....because they cost money, I can not afford.

That is one of the insidious and less conspicuous aspects of Asperger's.

It can make you potentially unemployable which in turn leads to financial incapacity, hence the unaffordability of desperately needed help.

As if to add insult to injury, from the little income that is earnt it is taxed and these taxes are used to fund "free" therapeutic services for children, but not adults!

Why?

Am I any less needy than a youngster? Haven't I paid my taxes? Where therefore do I go for help?

My only recourse is to resort to self-diagnosis and God knows I seem to tick all the five symptomatic boxes of higher-functioning autism.

I have been jobless now for over 20 years (and through no lack of trying) and it has led me into a sort of twilight existence, as if floating through life into my advanced years.

This is a continuum of a loveless, joyless childhood with no real family to speak of - distant, remote and hateful (I believe the modern, slightly cynical term "emotionally unavailable" is often applied) to the extent that I am estranged from so-called family consequently this has lead me to lead a lonely path in life already made difficult enough with having to cope with the social challenges thrown up by Asperger's syndrome.

It is hard - impossible, in fact, to shed the deep-set sadness that permeates much of my inner life, instead of ameliorating, instead it only intensified with advancing years.

For me, more so recently as I've undergone surgery to remove a malignant cancer tumour - you can only imagine the stress and distress that caused - and still weighs heavily on my mind.

Old age throws up other challenges: the death of friends.

Social isolation is a constant stalker for the autism afflicted, hard enough to make friends as it is (all my interests are engineering, scientific, technical so my 'inner circle' are drawn from like-minded individuals).

Every time one of these already rare people die there is no-one to replace them, so the circle grows ever smaller and the sense of isolation that much more pronounced.

Asperger's or not, I am a human being and I seek to have my dignity even in the face of a great deal of lost self-esteem but just little things erode the external bulwark, hell, I haven't had a vacation in over 20 years.

Something that others take for granted. It means limiting life's important external perspective on things and just the ability to re-charge one's emotional and mental batteries. All these things lead to a form of situational 'paralysis'.

Of course, none of these problems are unique to Asperger's but what the "normal" population don't appreciate is that we process situations and problems quite differently and this

Am I any less needy than a youngster?

creates an additional and extra burden over and above the original problem.

Add that to a limited social circle (i.e. no 'burden-sharing') it only makes a difficult situation even more difficult and enhances the struggle to try and stay on top of a problem.

The human downstream consequence of a lifetime spent dealing with these things and trying (not always successfully!) to overcome the challenges of daily living is that we (I, at least) end-up with a "grain-orientated" personality, i.e. bend me one way and I am immensely strong - far stronger than your average person (although some might prefer "inflexible"!). On the other hand, bend me another way and I am incredibly weak, far weaker at handling things than most.

When I originally contacted the editor to suggest the adult autism subject for a future issue I raised the issue of wanting to find others similarly afflicted.

This is still an objective I want to pursue. I have tried repeatedly; ads on noticeboards, personal ads, you name it - but all with no luck.

I just can't believe that I'm the only one wanting to reach out!

So if you're reading this and live in South Auckland and like me you'd like to become part of a slightly weird pseudo-family with others similarly afflicted and hopefully, see the value of being able to offer each other mutual support to help cope with life's challenges then perhaps you could contact the editor who would be good enough to pass them onto me.

Likewise, if you are a professional therapist experienced in this field who thinks they may be able to offer assistance then please don't hesitate to contact me.

Andrew (not his real name) is in his late 50s, born in Australia but has spent most of his life in New Zealand. His interests are all engineering/science related.

WITHOUT CLEAR DIRECTION: Illustration by Johnathan Squirrell.

Nothing about us without us!

Leith McMurray is a "late diagnosed" Aspie who is 72 in November. She has a Bachelor of Arts degree from Canterbury University, followed by a Diploma in Social Work.

Cease this expensive research into the causes of autism.

THE IDEA for establishing an organisation for aspies by aspies was something Jan Brooking and Leith McMurray felt compelled to do after attending a major autism conference in the days after the first of Christchurch's earthquakes.

Eight years on Aspiehelp is a well-established charitable trust operating out of Christchurch with the bold vision of wanting to create a world where the unique gifts and perceptions of people living with Asperger Syndrome are valued, celebrated, encouraged and employed for the enhancement and advancement of all communities.

Leith McMurray continues the story.

Before 2010 neurotypical individuals and organisations provided the service and it left much to be desired from an aspie point of view.

For us three, from Christchurch ASK Trust (Autism Spectrum Kiwis), meeting so many auties and aspies from other parts of New Zealand and Australia was an eye-opener.

It stimulated our thinking processes about making links with others all around the world. It was clear to us that there needed to be a support service for "late diagnosed" aspies by people who had lived experience.

With the help of Kevin Blogg from the Blogg Family Trust, we formed ourselves into a charitable trust so that we could seek donations for funding.

Thea Mickell Services kindly helped us enter that very fraught arena of "public begging".

Our first $1000 seemed like a pot of gold! Our annual financial accounts today reflect a throughput of over $37,000!

Being a very rare bird, we shot straight to the top of Google pages about Asperger Syndrome services and most of our first clients came to us from there.

We couldn't afford to pay for publicity of any kind. We started off with two days a week, experimenting with the structure of interviews and counselling, based on our own professional training.

Jan has a lifetime of teaching in Hohepa schools and I am a trained and registered social worker. We did not charge fees as we felt too humble to expect people to pay until we had refined our "product" and established a demand.

Once established at the church, we were able to hire part-time office staff thanks to the Ministry of Social Development and their offer to pay six months wages enhanced benefit to our helpers.

It was a confusing time as we refined our counselling technique, learned how best to direct and teach our helpers, and meantime keeping the money coming in just enough to keep us afloat.

We also ran a twice a month mid-week meet-up/social time for clients in the Upper Riccarton War Memorial Library which is now in recess as it became too taxing for us to run.

We started off interviewing / consulting as a team and found this worked really well. Jan mostly took notes and converted these into emails to send to the clients as feedback, added to other suggestions we had for them. Hence our early "files" are in our computer as "sent" emails rather than notes as such.

Initially we carried out what we later learned is called an "ecological assessment" an all-round picture of the client and family's life and environment, and how their questions about autism / Asperger's arose from this.

We found a comfortable way of working together and appreciated the mutual support. One of us might suddenly experience a brain fade and the other could take over. As the months and years passed, we acquired more and more information about the services available in the city and what could be appropriate for which clients. Similarly, what one said, the other might enlarge upon very helpfully.

We also generated a book list on our web-page and added to it over time. When possible, we added to our collection of appropriate books for our clients to borrow, to supply additional information about autism. We reject the notion that we are disordered and refuse to use that term.

Because we ourselves are aspies, we have not seen our clients as "different" from ourselves, and have always presented as friends rather than consultants. Mostly our interviews are discussions which can be extremely funny at times.

Occasionally, quite stern bluntness is appropriate (that goes both ways) but this is the aspie way and usually received with appreciation. We tend to do quite a lot of "telling" rather than "questioning".

We are not therapists and we don't beat about the bush, hence clients enter into a good rapport quite quickly. It is usual to meet people at the door, looking nervous and anxious, and farewell them with grins from ear to ear. One person said recently that, when she came into our counselling room and began talking with us, she "felt her feet were on land" at last!

By the end of our first interview with a client we have formed a plan of how to move forward and a short list of helpful things to do or people to see (e.g. getting a diagnosis).

Subsequent sessions follow through with the steps on this plan and it is so satisfying to see people relaxing and progressing with our support.

Some fairly common problems:

Parents often present with their unemployed young man (rarely, a young woman), and expect that we can provide employment at the drop of a hat. They can be very specific about what they want us to do and don't take kindly to our explanation that nothing is so simple. The other part of this is that clearly management at home is enabling the client to "stay stuck" but the parents are reluctant to change any part of the way they do things.

We see individuals whose partners are unsupportive, indeed, highly disrespectful to them, creating desperately low self-esteem, despite the fact that the client is functioning at a very high level in their employment.

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Sadly, there is a tendency to protect the critical one from meeting us, or the critical one refuses to come and see us. We have had such sad people come in and burst out weeping as soon as they got in the door.

Some people have a mental illness which they don't want to recognise or treat. Addictions are a red flag to us. We can't help such people until they have recovered, and even then, it can be a slow progress.

We would love to have a residential facility where we could house such clients for several months, away from their families and give them a chance to mature and develop independence and useful skills.

Some people are clearly autistic themselves and become involved and enthusiastic in learning more about themselves as well as their child.

CELEBRATING AUTISM: Julie McGeorge, Leith McMurray and Anna Melling from The Aspire Trust.

Quite a few clients live in remote parts of New Zealand but have made the effort to come to Christchurch to meet us and talk about their needs and future paths. We also provide some telephone consultations and emails, plus postal lending of books.

Education and toleration of difference are key!

Aspies transitioning to adulthood from school need to receive a lot of support and guidance regarding their future lives. They leave school and vanish into a black hole a.k.a. their bedroom with a computer and don't come out for years!

Some even get room service for meals etc from puzzled and frustrated parents.

Insufficient coping skills often lead to inappropriate diets and self-care and a very dysfunctional family life. They may never leave home. The imperative to earn money and support themselves simply doesn't make any sense to them.

If parents become completely intolerant, the (usually it is a male) client gets into "bad" company, taking drugs and or alcohol, petty crime, no fixed abode etc. health deteriorates, the police become involved sooner or later, incarceration in a psychiatric hospital or prison eventually ensues.

This is a direct result of the lack of support services for aspie young people.

Some go to university and cope to the point of qualifying and even moving into a professional career, only to be stymied.

A meltdown will ensue sooner or later, and without a diagnosis, treatment will be inappropriate and unhelpful. Engineering is one of the favourite jobs for aspies, but they will often need one-to-one mentoring until they have internalised the requirements and settled in.

Others, of course, manage in academic jobs or "top of the tree" positions where their aspie quirkiness is tolerated for the sake of their superior intellect and abilities.

The ones who have the intellect to get a good qualification may be stymied by the sheer effort required to finish and end up (if they are lucky) in jobs involving labour but not huge thought.

I have managed to turn around potential and imminent employment losses by appropriate intervention, but in some cases, the client then decided they didn't want that job any more anyway!

There is something in our cognitive processing which gets in the way of functioning in life and the work place for many of us- a kind of broken or missing link in the "joined-up thinking" that is needed for successful functioning in the neurotypical world.

I do believe that we need to ensure far more success in the education system by tailoring education specifically for the needs of our autistic children so that individual talents can be directed into learning which will lead to stimulating and satisfying work and high self-esteem.

Many of the world's most creative people in all works of life can be surmised to be on the spectrum. They may appear to have a very highly functioning work and social life but this is accomplished by great mental effort and private struggle. We still are very often treated as "disordered" and disabled by arrogant neurotypicals who cannot appreciate our unique brains and creative approaches to life. There are encouraging signs that perhaps this is beginning to change.

The most important imperatives are for neurotypicals to allow us to be included in plans for our support and education, and then to be prepared to change such plans to suit us.

Cease this expensive research into the causes of autism and spend the money on the practicalities of our everyday lives.

Autism does not need eradication, but visionary use of our particular abilities.

Most of the apparatus of our modern world has been invented and made by aspies after all!

- Leith McMurray recently achieved registration as a social worker 40 years after her original graduation, She also has CELTA (Certificate in English Language Teaching to Adults) from Cambridge University and was presented with a Civic Award by the Christchurch City Council last year for her work in creating Aspiehelp/The Aspire Trust.
- Aspiehelp presented "The Aspie Roundup" – two days of a pot-pourri for aspies by aspies on 16 and 17 November – an "anti-conference". www.theaspieroundup.co.nz

Mental health and autism

Catherine Trezona is the National Manager, Altogether Autism.

Two of the key frustrations for the autistic community is access to assessment and diagnosis, and access to treatment for mental health concerns.

SEVERAL OF THE articles in this Journal touch on the challenges for autistic people who are also experiencing mental health concerns.

Alex, Andrew and Elroy shared their experiences and we know theirs are not isolated cases.

Altogether Autism is actively advocating for better support and services for autistics. In June of this year, nearly 200 people contributed to our submission to the Mental Health and Addiction Inquiry and we look forward to this Inquiry's report to the Government, due out in November 2018.

Along with representatives from other autism organisations, we met members of the Inquiry panel and voiced our concerns regarding the failure of the current mental health system to meet autistic needs. Our submission is on the Altogether Autism website.

Two of the key frustrations for the autistic community is access to assessment and diagnosis, and access to treatment for mental health concerns.

In 2014 the Ministry of Health (the Ministry) recognised that there are teens and adults who have not been assessed for autism as children.

The Ministry said the responsibility for funded assessment and treatment of co-existing mental health issues for anyone over 15 years old, lies very clearly with mental health services.

Teens between 15-19 are to be assessed by the Child and Adolescent Mental Health and adults 19 and over are referred to Adult Community Mental Health.

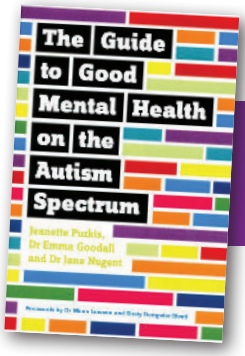
For many adults once they are diagnosed with autism any co-occurring mental health needs are not supported by mental health services as their mental health needs are seen as part of autism and therefore considered not within the scope of mental health services.

According to the Ministry, this is incorrect as mental health services are responsible for both diagnosis of autism and treatment for co-existing mental health challenges. If you or someone you know is experiencing barriers to autism assessment and/or treatment for mental health conditions, please let us know.

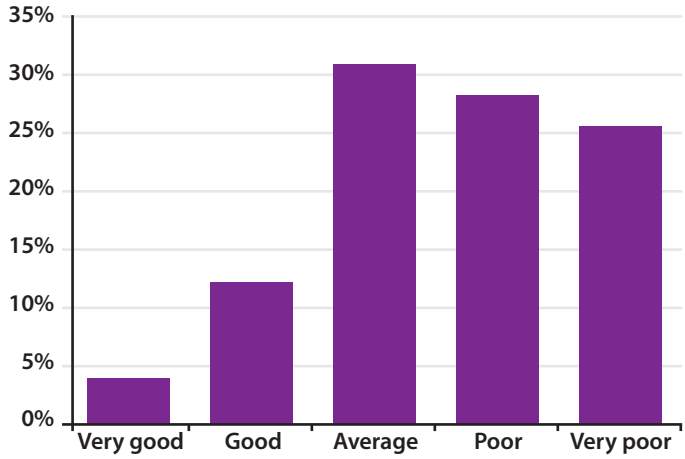
The Ministry wants to know this and we are gathering data to share with them.

We endeavour to do all we can to try to assist with this issue for autistics. If you are facing barriers to support for mental health difficulties, please contact us for information on pathways to the right services and supports. For professionals wanting to upskill on autism-specific strategies, we run a range of workshops for mental health clinicians developed and delivered by both autistics and clinicians.

We highly recommend the excellent book, *The Guide to Good Mental Health on the Autism Spectrum*, by Jeanette Purkis, Emma Goodall and Jane Nugent.

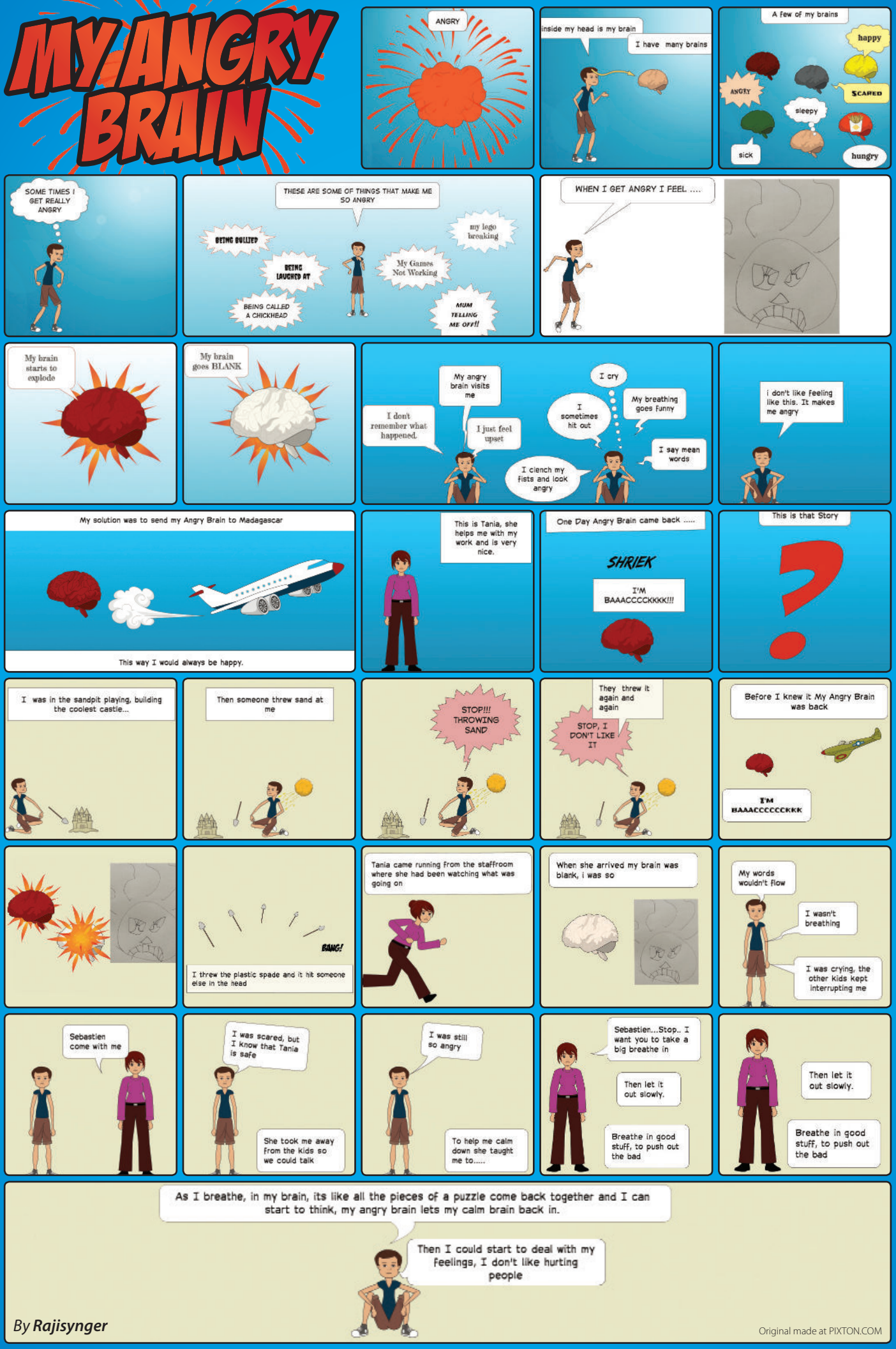


This practical book looks at common mental health issues and gives guidance on treatment options and strategies to improve and maintain mental wellness. Personal stories and mentoring advice from a lived experience ensures this book is relevant for autistic people, families and professionals.



WE ASKED: Respondents to our survey on mental health rate their overall experience in using mental health and/or addiction services.

MY ANGRY BRAIN

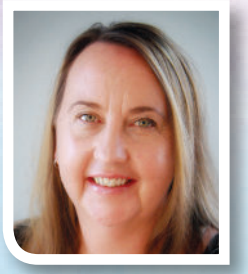


FREE **NETWORK MEETINGS** 2019

BY AUTISTICS FOR AUTISTICS

WE INVITE YOU, YOUR FAMILY, FRIENDS AND SUPPORTERS TO OUR FREE NETWORK MEETINGS THROUGHOUT THE COUNTRY IN 2019.

Hosted by autistic advocate Paula Jessop and neurotypical support Catherine Trezona.



PAULA JESSOP

CATHERINE TREZONA

We will share information on:

- NASCs (Needs Assessment and Service Coordination)
- Disability Support
- WINZ benefits
- Diagnosis – public and private
- Advocates – how to access these
- Mental Health services
- Autistic run organisations providing services for people on the Autism Spectrum
- Informal autism communities.

Followed by a Question and Answer session with the autistics panel.

Tell us what else you want to hear at the meetings.

Free light refreshments will be available.

For more information email us at: **info@altogetherautism.org.nz**
Keep an eye on our website or phone us on **0800 273 463**
Chat to us on **Live Chat**

LIVE CHAT

INFORMING·EMPOWERING·CONNECTING
ALTOGETHER AUTISM
THROUGH KNOWLEDGE AND EXPERIENCE