

ALTOGETHER AUTISM JOURNAL

ISSUE 2 2018



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

Success across the spectrum

Beat of a different drum

Expressing autism through art

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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Commitment to listening encouraged



THERE IS plenty happening in our sector at the moment with two nationwide consultations underway.

We are encouraged by this government's commitment to listening to the voices of a wide and diverse range of people, as seen in both the Education Conversation and the Mental Health inquiry.

Altogether Autism was invited to nominate six people to attend the education summits in May and we met Minister Carmel Sepuloni in Parliament last month.

In addition, I attended the Learning Support forum hosted by the Ministry of Education in June, where we received an update on the Education Conversation and gave feedback on Associate Education Minister Tracey Martin's draft Learning Support Plan.

Several people have described this large scale review of our education system as a once-in-a-lifetime opportunity to influence the future of education in Aotearoa New Zealand and we appreciate the responsibility upon us to make the most of this moment in history.

We have long been expressing our concerns for the current education system and its failure to truly include many of our autistic students, and we have a real hope that change is coming.

The Mental Health Inquiry is another badly needed national consultation. While we know that depression and anxiety is not an intrinsic part of autism, the reality is that many autistic people experience poor mental health. Our view is that this need not be the case but that major change is needed in the way we recognise and support mental wellbeing for people on the spectrum.

Thank you to everyone who completed our autism-friendly mental health survey. We made a submission to the inquiry on 4 June and met with the panel on 27 June, to ensure the particular needs of the autism community were made known. We will continue to take every chance to advocate for autism and mental wellbeing and update you via our website and social media channels.

We chose Collaborating for Success as our regional network theme this year, and I have really enjoyed meeting many of you as we hosted these meetings throughout the country.

Paula Jessop, Tanea Paterson and Myrlene Forsdyke shared their personal journeys at some of these meetings, and your feedback tells us how much you value hearing their honesty and courage. We give a big shout out to our colleagues at Parent to Parent, as they support Altogether Autism in delivering these regional meetings.

Explore Behaviour Support Services has also generously shared their expertise at many of our network meetings.

Although we are in the heart of winter as I write, we are cautiously optimistic that spring is coming, not just in the regular cycle of the seasons, but also in the ability of the education and mental

health environment to truly see and support autistic people, their families/whānau and the professionals who walk alongside them.



May this hope become reality soon.

Catherine Trezona – National Manager, Altogether Autism

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Success across the Spectrum – Autism through the ages



Altogether Autism Professional Expert Group member and clinical psychologist Jenny Gibbs is "very excited" about this latest journal.

IN MY 25 years work as a psychologist I have met many people with autism.

I am constantly amazed by both the commonalities and the differences in the experience of autism both for the person themselves and for those who live with and love them.

Personally I think the term autism is problematic because it implies that autism is one entity.

I think that many of the debates and misunderstandings that arise within the community of people that are involved with autism - autistic people, their families and the professionals who work in the field - arise because without necessarily realising it we are talking about different entities.

I personally prefer to think of "The Autisms" as a reminder that the differences are important and need to be made explicit to help with understanding and to prevent us talking past each other.

One of the great things about working in one place for a long time is that I have been fortunate enough to follow people I met as preschool children into their adult lives.

We know that autism looks different at different ages and stages. We also know that it can be quite hard to predict how a pre-schooler with a new diagnosis of autism will be affected in their later life (although we know that factors such as the child's intellectual ability and their family functioning are important predictors).

For families it is a journey into the unknown and their attempts to make their child "normal" are understandable.

Some people's lives have been limited by the conditions that can accompany autism, such as intellectual disabilities, communication challenges and mental illness.

For others, their autism has been a source of exceptional talent and ability which has made a difference to society.

The majority of autistics however, like the majority of the human race, are somewhere in the middle, leading ordinary lives with all the joy and despair and hope and challenge that come with being alive, with the additional challenges that come with being a minority group in society.

This journal describes some of those wonderful ordinary and extraordinary lives for people with one of the autisms and some initiatives that aim to enhance their wellbeing.

Congratulations to our readership survey winner

Jennifer Cole has been reading the Journal online for just over a year. Her daughter, aged five, has only recently been diagnosed, so Jennifer's now navigating life as a parent with a child on the spectrum. The Journal, with its broad range of topics, is a boon.

"(I like) anything about kids on the spectrum and how to cope with being a stressed-out mum and how to help her cope.

"Personally, I'm interested in the mechanics, in the how and why. Most people aren't interested in that, but I am.

"I'm one of those mums that take in as much information as I can, so I love reading the articles."

See results back page and in full on our website.





Ride for Autism Awareness a Huge Success



*Every teacher deserves the right training, says **Sarah Blythe**, and thanks to her and all those who participated in the Autism Awareness ride in Feilding on March 4, several Manawatu teachers got that specialist training. She writes about her experience.*

IT'S A SIGHT and a sound I will never forget.

There they were, motorcycles and their mainly leather-clad riders waiting to set out from Gary Worsley Motorcycles in Feilding for the ride to The Wines in Himatangi Beach.

And it was all for autism awareness and the opportunity to train Manawatu school teachers and educators into how to understand, educate and build acceptance for all children living with autism.

We raised \$6956, \$3010 of it on the day itself through registrations. Six weeks later the teachers were at Lytton Street School, in their school holidays, learning from the experts at Altogether Autism from their PRISM professional development series programme.

The teachers who attended the training said it was amazing and wish they had this training ages ago.

They said it could have helped them so much in the classroom previously and they could not wait to use some of the techniques.

One comment that stuck out was a from a lady who has been a teacher for 20 years and said in her whole time of teaching she has never ever been offered any training like this.

It's given some of our teachers around the Manawatu more knowledge and understanding of autism.

I believe it's given our children on the spectrum a chance to be able to succeed to the best they can in an environment that has understanding. Every teacher deserves the right training, and every autistic child needs a teacher to understand them to help them succeed at school.

So we are going to do it all over again in March next year.

Why are we doing it?

Two years ago my partner Codie and I were told our son Neko was on the autism spectrum. The diagnosis helped explain why Neko behaved the way he did.

At Lytton Street School in Feilding, where Neko finally settled after months of unhappiness at a previous school, teachers used the Walker Learning Approach.

The approach provides authentic personalised learning effective across all cultural, economic, geographical, religious and social spectrums. It aims to bring deeper levels of engagement to children in meaningful and relevant strategies that enhance academic skills alongside the development of skills for life particularly in areas of social and emotional development, resilience, self-esteem and independence.

After our not so successful start to Neko's school years, this was a godsend for Codie and me.

So it got me thinking. How could I help other children like Neko?

That's when the motorbike fundraiser came to me.

There were 134 people registered on the day, mostly motorbikes but a few cars as well.

Blair Worsley from Gary Worsley Motorcycles came on board as the main sponsor and organised the ride route.

Thanks to him and some other generous sponsors, we raised money from raffles, t-shirts, cash donations, auctions, a sausage sizzle and a golf tournament.

The amount we raised meant we could offer 34 teachers the training they needed. Thanks to the publicity, we also had other swimming instructors from the Makino Aquatic Centre in Feilding keen to get training as well.

Next year's ride will start in Feilding and also finish back in Feilding.

We are hoping to turn it into more of a community event and get the community behind us supporting us and also an awesome day to spread more knowledge and give people more understanding around autism.

PUT IT IN YOUR CALENDAR
Sunday 3 March 2019
 and we will see you there

Marching To The Beat of a Different Drum



When Patrick Ward opened his mouth to sing in the Westfield Five Minutes of Fame competition seven years ago, his mother Kate had tears rolling down her face. This kid can sing, she thought. The pair opened up to Altogether Autism editor Mary Anne Gill about how the theatre now plays a significant part in his life.

IT MIGHT have taken Patrick Ward 20 years to get comfortable in his own skin but now that he is, he's making each post a winning one.

Starring roles in musicals and dramatic plays and lots of As at Waikato University, where he is doing a Bachelor of Arts degree majoring in Screen and Media Studies and English, mark this Wellington-born but Waikato-raised young man as someone to keep an eye on.

His mother Kate McKegg, a director at Knowledge Institute Ltd, remembers there was always something different about Patrick.

He was her surprise baby, the youngest of three by a long way, not planned but much beloved.

It was three years after he was born, when the family had moved to Te Awamutu, that Kate sensed there was something special about her son.

"He had the ability to focus on things when he was very, very young.

"At the beach he would sit on the tractor for long periods of time and was totally uninterested in going in the water. He had this real focus."

Then there was his literal interpretation of instructions, followed to the letter.

Unlike her other children, Patrick did not have friends. Kate did not worry until her quirky son struggled at Pokuru Primary School in Te Awamutu.

"He could read, but maths and science, no way," she says.

He transferred to Hillcrest Primary School because Pokuru, a small country school, did not have the resources to support Patrick.

But still the family had no idea what was "wrong" with Patrick until he had what appeared to be an epileptic seizure in a store.

A referral to the Child Development Centre at Waikato District Health Board in Hamilton came up with a diagnosis – Asperger's.

Psychologist Jenny Gibbs met the young boy and effectively found that Patrick walked to the beat of a different drum, not necessarily the wrong drum, but one that others, like those he went to school with, found somewhat odd.

"When I think about Patrick then, when he was a little boy, he was up and down the steps all lunch time, happily singing away," says Jenny.



MOTHER AND SON: Patrick Ward with his mother Kate McKegg

"One of the people who had picked on me, came up and said they were sorry, they just didn't know about what I was going through"

He started to feel excluded at primary school, pushed out of activities and ridiculed.

At middle school, the anguish continued for him.

"Some people might not view what they (the students) were doing as

actual bullying. I definitely felt unnecessarily harassed."

Even some of the teachers struggled with him.

"They would talk to me in a way that I was stupid. There were just lots of things that I hadn't learned yet."

Kate was horrified when she saw first-hand the sort of treatment meted out to Patrick while on a school camp.

"What I saw was horrendous bullying. They would go into his room in camp and take all his clothes and then put them all through the (other) buildings.

"When there was a call for people to pair up, they would deliberately exclude him."

In his last year at middle school, students were asked to share things about themselves.

Patrick bravely told them what Asperger's was and what that meant for him.

■ Continued page 6

"One of the people who had picked on me, came up and said they were sorry, they just didn't know about what I was going through."

Kate had already sensed that Patrick's friends were not in the main crowd.

"The people Patrick is attracted to are really nice people, genuinely interested in and engaged in what he's interested in."

Then came the talent quest which changed his life.

Five Minutes of Fame was a competition for children aged 5-18 to showcase their singing, dancing or musical abilities on stage.

Patrick entered the competition at Westfield Chartwell singing Fireflies by Owl City. He made it past the first round but missed out in the second round.

"I remember you standing there singing that first song, I had tears rolling down my face. I thought 'wow, this kid can sing,'" says Kate. "I didn't know he could sing, I didn't even know he had tone."

That competition ignited Patrick's passion for performing. He has had roles in a number of plays and musicals at Riverlea Theatre in Hamilton, including Guys and Dolls.

Last year he acted in Boot, a drama about male sexual assault. He was cast as the victim and in a strong show of method acting, related to how he was ridiculed and bullied at school.

In early 2018 he was in Twelve Angry Men at the Gaslight Theatre in Cambridge playing juror number seven, the baseball fan who wanted to get out of the jury room to go and watch the game.



There were lots of lines to remember, something which did not faze him at all.

His preference is for musicals though and his ambition is to become a film director.

"I find I really connect with stories, very fantastical, very spirited in that kind of way. Mostly because I have lived in a space where people don't necessarily accept that."

There is a confidence about Patrick which belies the struggles he had growing up. Clearly the theatre has brought about a lot of that but so too has a supportive family and close friends.

"It's taken me a long time to get comfortable in my own skin. For a long time no one allowed me to be comfortable."

"I've had a lot of obsession phases."

For a long time it was The Simpsons cartoon show, he loves New Zealand native birds and travelled regularly to Rotorua to see the native falcon.

He is a Lord of the Rings and Assassin's Creed fanatic too.

He also likes talking to himself, having conversations in the car.

"You are your own best friend and your own mentor and you just apply it. Listening and taking feedback is one of the things I'm really good at now," he says.

Kate is clearly his number one fan but for a reason.

"The one thing that's important is to focus on their talents and gifts, not the deficits."

Her advice to parents of a young child diagnosed with autism is to try not to be fearful.

"Focus on the things they're obviously talented at, where they are able to flourish and find their tribe. Find things they can shine at. They're not the same as other kids but that's okay."

"And don't have fears at age six, there's a talent there that's yet to come out."

Her advocacy role in Patrick's life has been critical.

"Paddy needs us to be his advocates, he doesn't need your judgement," she says.

And as for that different drum he marches to?

In the words of Henry David Thoreau in his book Walden published in 1854:

"If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away. By doing so, men may find happiness and self-fulfilment."

"Focus on the things they're obviously talented at, where they are able to flourish and find their tribe. Find things they can shine at. They're not the same as other kids but that's okay".

Dungeons, Dragons and Autism



Tanwen Ward runs social support groups for children, teenagers and young adults on the autism spectrum and has just started offering Tabletop+, a table-top role-playing game group for autistic teenagers and young adults. She discusses Dungeons and Dragons which has great potential to develop social, intellectual and creative skills.

WHEN I MENTION that I play Dungeons and Dragons, people often don't know what I mean.

I imagine that the typical stereotypes come to mind – the pimply teenage boys in mum's basement, the geeky outcasts hiding away in the school library, dressing up as wizards and elves and much more.

Although some people scoff and smirk, I've found that most are just interested to find out more.

I got into Dungeons and Dragons when I found out some friends were playing and, being a self-proclaimed video game geek, I was all too excited to join in.

After over a year and a half of playing it myself, however, I've come to cherish the weekly sessions as a way to bond with my friends, increase my creativity and confidence, and let my imagination run wild!

I was getting so much out of playing that I started looking into the research behind Dungeons and Dragons and other similar games to whether there was published evidence for the benefits I was experiencing myself.

What follows is the results of some of that research, which outlines the benefits of playing Dungeons and Dragons.

What is Dungeons and Dragons

Dungeons and Dragons is a cooperative table-top role-playing game.

It was the world's first official fantasy role-playing game, and many of the fantasy video games we play today are based on it.

The original game, created by Gary Gygax and Dave Arneson, was released in 1974.

Since its release, there have been nine different versions of the game with hundreds of associated rulebooks, supplementary books, campaigns and novella.

Television shows such as Stranger Things, The IT Crowd, Community, The Big Bang Theory and Futurama, have featured table-top role playing games which seems to be

increasing their popularity within a range of age groups.

In Dungeons and Dragons, players and the Game Master or Dungeon Master sit around a table, with character sheets describing their player characters and a set of polyhedral game dice.

The Game Master, using campaign books, supplements or their own story, describes the setting, situation or challenges ahead of the players.

The players then, guided by their own imaginations and their dice rolls, describe what their character would do in response.

Many typical adventures involve seeking out treasure, overthrowing tyrannical leaders, investigating mysteries and ridding the world of evil creatures.

What are the costs and benefits?

Dungeons and Dragons, and other table-top role-playing games, are not only a way to escape reality and take on the persona of the hero of a story, but they also build a range of social, intellectual and creative skills.

Players work together to overcome obstacles put in place by the Game Master and while playing in character, the players must work, improvise and cooperate, as if they were someone else.

In a 2006 study, a Dungeons and Dragons-like game was used to assess the therapeutic effectiveness of role-playing games within an outpatient group of 9-11-year-olds (Enfield, 2006).

Each of the children taking part had been referred for therapeutic intervention due to impulsive and disruptive behaviour.

Two of the boys had been diagnosed with attention-deficit/hyperactivity disorder (ADHD), one demonstrated aggressive behaviour and autistic traits, and one had a history of abuse and neglect.

Following the end of the intervention, and after two school terms, school and home reporting showed that all four of the

■ Continued page 8



Exploring the ruins of the old fortress, you've encountered many sights of crumbling walls, stained floors and destroyed furniture. The air is heavy with moisture and the reek of rotting plants. You walk down the vine-infested corridor with your companions – a dwarven cleric, a half-elf bard, an old human wizard and a gnome rogue. You, a half-orc paladin, lead the party as you search for the missing Tome of Mystra. After checking the door for traps, you safely open it and enter a wide room, not unlike the abandoned halls you've already passed through. In this room, furniture is strewn about in various states of disrepair, tattered banners hang on moss-covered walls, the faint smell of an old fire hangs in the air. Suddenly, out from behind some of the overturned tables jump a gang of goblins, cackling with their shortbows drawn – what do you do?

boys were far less impulsive and their social functioning had improved significantly.

The cooperation required to overcome the obstacles put in place by the therapist (who took on the role of Game Master), resulted in the boys spending longer amounts of time engaged in conversation, planning manoeuvres and cooperating.

Each demonstrated increasing confidence in leading the group and problem-solving, skills which transferred into home and school life.

At school, teachers reported that the boys were less disruptive in class, had improved their grades and significantly decreased the number of reported detentions.

At home, families reported that the boys were more confident, used less negative self-talk, and were eager to take on more responsibilities within the home (Enfield, 2006).

Another study investigated the use of group role-playing games in the development and practice of social and emotional self-regulation skills among gifted children and adolescents (Rosselet & Stauffer, 2013).

Similar to Enfield (2006), Rosselet and Stauffer (2013) used a Dungeons and Dragons-like game across a series of weekend-long workshops, once per school term.

Behavioural observations were made during the game, and players were given a debrief afterwards.

Individual and group feedback addressed social interactions, cooperation, leadership abilities, problem-solving and role-playing skills.

At the completion of the weekend, participants and their parents were given a report summarising the accomplishments of the participant and further goals to work on.

Rosselet and Stauffer (2013) described one of the participants specifically, who demonstrated autistic tendencies, and had been referred for treatment due to low self-esteem, problematic behaviour, bullying and low academic performance.

That participant started the series of workshops showing low social interest, disruptive behaviour and impulsivity.

By the end of his fourth workshop, he had improved academically, and his family were reporting better interactions at home.

The researchers made several conclusions regarding the role-play game intervention.

Firstly, players were able to build their identities through embracing their characters and interacting with each other in a secure environment.

They were able to experience negative consequences while receiving support from their peers and the counsellors to better react to different scenarios.

Secondly, players were given the opportunity to express emotions of aggression and frustration in a safe way for both themselves and their peers.

Participants were able to see the effects of their actions, without significant real-world consequences, which resulted in them becoming more socially interested and more conscious of the way their behaviour impacted their relationships with others.

Thirdly, by exploring themselves through their characters, the participants were able to identify ways to develop

relationships with each other and enhance their sense of belonging.

Finally, the researchers found that, due to the verbal nature of the games, players significantly developed their social interaction skills.

Participants were able to identify how certain types of interaction affected the group dynamics and were able to better manage their interactions to accomplish group goals (Rosselet & Stauffer, 2013).

A survey, conducted between 2010 and 2011 in Finland, sought to explore the views of 161 people who partake in role-playing games with regards to their social and mental development (Meriläinen, 2012).

Although some negative aspects were identified, such as time consumption, stigmatisation and the sometimes-elitist nature of the role-playing community, the overall views of role-playing games were significantly positive.

The study found that the majority of role-players reported the positive development of group skills, empathy, social skills and mental ability.

When compared with a control group of non-role-players, respondents viewed themselves as more imaginative than their non-role-playing peers and tended to have a strong positive self-image (Meriläinen, 2012).

Conclusion

Research into the use of table-top role-playing games tends to include very small groups of participants, and can be few and far between, however from the conclusions of the studies mentioned above, table-top role-playing games appear to have many benefits to explore.

Stepping into the shoes of the hero and playing a role you aren't offered in reality provides opportunities to develop social skills, emotional understanding and life-long relationships within a safe, unambiguous environment.

Further research into this field should provide some interesting results, and I am excited to see what the future of role-playing games holds.

As a significant number of the autistic community already have interests in fantasy and science fiction, whether through books, comics, games or movies, table-top role-playing games could prove to be a brilliant alternative or supplement to traditional social skills interventions.

If you or someone you know would like to get involved in the role playing community, contact your local gaming shop for advice on where to find groups, and look out for local services offering autism-specific groups.

"I've taught myself to relate to other people by attempting to see life from different points of view. I think it's because of this that I'm not completely obnoxious today." (Meriläinen, 2012, p. 61).

Tanwen Ward is a level-17 Pixie Sorceress, Game Master, and Facilitator at Enrich+ Spectrum Energy in Hamilton. She has a Bachelor of Social Sciences with First Class Honours, majoring in psychology, and plans to embark on PhD studies in 2019.

Resources:

Enfield, G. (2006). Becoming the hero: the use of role-playing games in psychotherapy. In L.C. Rubin (eds.), *Using Superheroes in Counseling and Play Therapy* (227-241). New York, NY: Springer Publishing Company

Meriläinen, M. (2012). The self-perceived effects of the role-playing hobby on personal development – a survey report. *International Journal of Role-Playing*, 1(3), 49-68.

Rosselet, J. G. & Stauffer, S. D. (2013). Using group role-playing games with gifted children and adolescents: A psychosocial intervention model. *International Journal of Play Therapy*, 22(4), 173-192. DOI: 10.1037/a0034557

Keeping it real: Updating the ASD Guideline



The “living guideline” process keeps New Zealand’s ASD Guideline up to date, relevant and “alive”, writes Christchurch-based researcher, Marita Broadstock.

NEW ZEALAND led the way in 2008 when we were the first in the world to produce an autism spectrum guideline to take a “whole of life” approach to autism.

It was the result of six years’ collaborative cross-sectoral work led by the ministries of Health and Education.

Internationally recognised for its scope and quality, the New Zealand Autism Spectrum Disorder (ASD) Guideline provides an evidence-based resource for people on the autism spectrum, their families and whānau, educators, service providers, and policy makers both here and overseas.

Its recommendations for best practice improve autism service delivery and coordination, which contribute to those on the autism spectrum leading better and more independent lives.

The guideline directs people toward practices that are known to work best, and away from those that don’t.

The living guideline process allows the guideline to remain useful and current

Autism is an area attracting burgeoning research attention so it was recognised that the guideline could quickly become redundant as the research base grew and new approaches emerged.



Joanna Curzon

Before the guideline was even published, a bold plan to establish a world-first “living guideline” process was in train. The late and dearly missed Joanna Curzon (Ministry of Education) was the driver for this and indeed the guideline itself.

A living guideline is one that is regularly updated and refined to reflect new evidence and to meet the changing needs of the people for whom it has been written. It is alive because it continued to have real meaning to those who use it.

At the core of the living guideline process is the Living Guideline Group, an advisory group of sectoral experts. First convened in 2009, membership has included educators, people with lived experience, health professionals and service providers. The group currently has eight members and three ex-officio members and seconds expertise as needed.

Dr Matt Eggleston, a child psychiatrist based at Christchurch DHB, chairs the group.

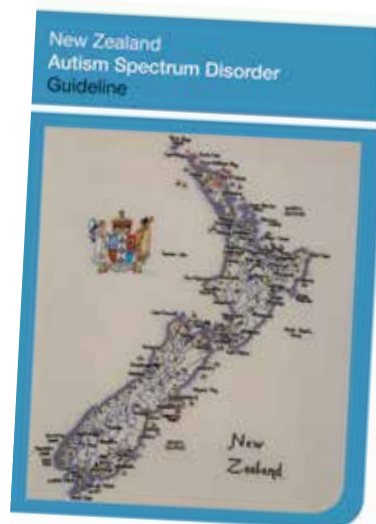
The living guideline process of updating aims to bring rigor to every step. Every year, the Living Guideline Group identify and prioritise an area of the guideline for updating. They consider a full systematic review of the topic which is undertaken using a strict methodology, accessing multiple bibliographic

databases to capture research across a wide range of disciplines.

Studies are included based on explicit criteria, critically appraised using validated appraisal tools, and then synthesised into a comprehensive evidence review.

The group debates the quality and consistency of this evidence and its clinical implications within a New Zealand context, and develop recommendations (graded by level of evidence) and directions for good practice - the key outputs for the work.

Following a focused consultation process, a full account of the entire process including the systematic review is published online as a supplementary paper to the guideline.



The guideline remains an influential, contemporary resource because of its enduring currency. To date, eight supplementary papers have been completed and the ninth, on sexuality education, is close to publication. In 2016, a second edition of the guideline was published, incorporating the recommendations and good practice points of seven completed review updates.

The living guideline process has allowed gaps in the original guideline to be addressed, such as the emerging area of gastrointestinal issues for autistic people. And it has permitted a timely response to new developments, such as the impact of an overhaul to diagnostic criteria for Autism Spectrum Disorder (in the DSM-5).

The process also allows for the quick transmission of safety information, such as the group’s recommendation that serotonin inhibitors are ineffective and potentially harmful for some people on the autism spectrum with fixed interests.

FREQUENTLY ASKED QUESTIONS

How are members of the Living Guideline Group recruited?

New members are recommended by the group and ex-officio Ministry representatives according to several criteria, including:

- experience with autism as a health practitioner, educator, service provider, or service receiver (i.e. a person with lived experience)
- familiarity with autism research and developments in practice
- the capacity to engage with the technical nature of the evidence
- the ability to work collaboratively in the consensus-driven deliberations of the group.

How are areas for update identified?

Group members suggest potential topics, a preliminary literature search undertaken, and a brief proposal drafted for each. Topics are then individually ranked by group members, rankings scored, and the highest scoring topic selected for update.

Ranking is based on the perceived likelihood of topics leading to the following:

- a shift in evidence requiring changes in guideline recommendations
- increased consistency in evidence-based professional practice
- improved outcomes for people with lived experience of autism, their families, whānau and carers.

What sort of research studies are included in the reviews?

It varies between update topics. The living guideline process uses a “best evidence” approach. A validated “hierarchy of evidence” identifies the most robust study designs that are least prone to a range of biases. For topics evaluating a particular practice or intervention, controlled studies (comparing a group of people receiving one intervention with those not, ideally with random group allocation) are higher in the evidence hierarchy than case studies (where the experience of an individual receiving the intervention is described). Higher order study designs are included in a review and where lacking, study designs from lower levels are included as representing the best available evidence.

Controlled, larger sampled studies tend to use quantitatively measured assessments of outcome. This approach does not mean that the voice of autistic people are not included. Quantitative measures completed by people on the autism spectrum are vital to gauge the impact of an intervention or practice from their perspective (and not just of those around them). The rich descriptive details provided by qualitatively assessed measures have also been included in several update topics, depending on the research question, and the evidence available. Qualitative accounts from case studies have been included in the supplementary papers updating cognitive behaviour therapy (in describing adaptations for adults on the autism spectrum), supported employment programmes (in describing features), and the impact of ethnicity (describing cultural differences in perceptions of social skills, and in support availability, and in illustrating barriers to uptake of a programme).



Daniel Smith

Are autistic people involved in the living guideline process?

The guideline work aims to be (and is increasingly) responsive to the voices and perspectives of people on the autism spectrum across the process. The group itself includes the expertise and lived experience of Daniel Smith, a member of

Altogether Autism’s consumer advisory panel, and previous chair, Matt Frost, who is now the Ministry of Education’s ex-officio representative on the group. Several members also have family members on the autism spectrum. The consultation process has included consumer advisors from



Ava Ruth Baker

Altogether Autism, Autism New Zealand and autistic-led advocacy groups, in addition to key professional bodies, service providers, and government policy makers working in the autism sector. In the update on the implications of changes to the diagnostic manual DSM-5, the section on the neurodiversity movement relied extensively on suggestions and references provided by ASK Trust’s Dr Ava Ruth Baker.

Responding to autistic advocacy, efforts are ongoing to improve the language of the guideline to reflect a more strength-based perspective of autism as neurological difference rather than disorder. Prompted by Daniel Smith, the group recommended at its meeting in November 2017 that the word “disorder” and term ASD be removed from the guideline’s future editions and supplementary papers where not necessary to refer to a specific diagnosis or study sample characteristic.

The supplementary papers are very technical and make heavy going reading. Who are they written for?

The systematic review part of each paper is written primarily to inform the group in developing new and revised recommendations and good practice points as key outputs. As such it is written in an academic style and is not intended for the general reader. The key outputs are summarised in tables near the beginning of each report and are

incorporated periodically into new editions of the guideline. These are intended for a broad audience.

Are the recommendations and good practice points independent of government?

Yes, whilst the living guideline process is funded entirely by central Government (through co-sponsors ministries of Health and Education), it is managed independently by contract-holder Insight Research. Ministry representatives have an ex-officio role on the group as observers not involved in its prioritisation decisions or development of recommendations. The ministries receive the supplementary paper as a final document for sign-off prior to public release. This process ensures that the group makes its recommendations based purely on best evidence from international research independent of government policy or funding priorities.

The impact of ethnic culture on services

The most recently published update considers the effect of ethnic culture on the recognition, diagnosis, education, treatment and support for people on the autism spectrum. Whilst the original guideline addressed some of these aspects in chapters dedicated to Māori and Pacific people, there was a view that these issues are so pervasive that they needed to be threaded across the entire guideline. As group members, Adjunct Professor Jill Bevan-Brown and Dr Vijaya Dharan were key proponents of this topic and assisted in identifying areas of the guideline where ethnic considerations could be usefully incorporated. The group developed eight new recommendations and good practice points and revised eleven. This update informs guideline users of:

- the potential for bias based on ethnicity in service delivery and practice
- the need for proactive strategies to ensure services are accessible and appropriate for people from ethnic minority communities
- the need for interpreters and translators when assisting immigrants and others where English is not their first language
- the need for interventions, services, education and supports to be culturally responsive
- the need for professionals working with people on the autism spectrum and their families and whānau to reflect on their own cultural beliefs and experiences, and to have professional training in cultural responsiveness.

Acknowledgements

This work is co-funded by the ministries of Health and Education. Thanks go to (current) group members Matt Eggleston (Chair), Andrew Marshall (Deputy Chair), Tanya Breen, Sally Clendon, Vijaya Dharan, Sue Kinnear, Martyn Matthews, Daniel Smith, and past members Jill Bevan-Brown, Ian Evans, Debbie Fewtrell and Matt Frost.

- Marita Broadstock, MSc, is an independent research consultant at Insight Research and is responsible for producing the systematic reviews and supplementary papers and managing the living guideline process.

Useful Resources/Links

Living Guideline Group Supplementary papers:

<https://www.health.govt.nz/our-work/disability-services/disability-projects/autism-spectrum-disorder-guideline/living-guideline-group-keeping-asd-guideline-date>

New Zealand Autism Spectrum Disorder Guideline:

www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline

Insight Research: www.insightresearchltd.com

Resources:

Marita Broadstock, New Zealand Autism Spectrum Disorder Guideline supplementary paper on the impact of ethnicity on recognition, diagnosis, education, treatment and support for people on the autism spectrum. Christchurch: INSIGHT Research; 2018.

Coming home to autism: a parent's story



Tara Leniston and Andrew Fowler seemed to have it all, she an actress, he a property consultant and former reality TV star. The birth of their son Dylan in 2010 sealed the couple's happiness but then two years later, the toddler was diagnosed as being on the autism spectrum. This is Tara's story.

CHRISTMAS 2011 was the first time I started to notice that Dylan was withdrawing from everyone, including me. His eye contact started to wane and he was no longer responding to his name.

The whole family was visiting and whereas before Dylan had been a smiling babbling baby, loving all the attention my family lavished on him, he now started to scream when anyone touched him and preferred to hide under the table, playing with his cars.

At night, he would bounce for hours in his cot, flapping his hands and making sounds.

I first took him to the doctor a few weeks before his second birthday. I was told I was worrying over nothing and that he was a perfectly normal boy and all children developed differently. I went away still knowing something wasn't quite right. I kept a diary of all his traits and started to observe other children in the playground.

As a first-time mother, I wasn't sure what was normal and what wasn't. But it was clear from looking at the other children that Dylan was quite different. I returned to the doctor adamant that he must be going deaf, as he was no longer responding to me at all. The doctor begrudgingly referred me on to the ENT (ear, nose and throat) department. Dylan passed the assessment with flying colours. After the assessment, I was met by a lovely paediatrician who had been observing our session and I was asked to come back a week later for a series of tests and for them to observe Dylan. Over the next few weeks and months Dylan was observed and I was then given the news that he was on the autism spectrum.

I asked if there was anything I could do; they politely told me 'No, I am afraid not.' They told me there was no cure and they had no idea of what the future would hold for him.

I walked out of there feeling like all the breath in my lungs had

They told me there was no cure and they had no idea of what the future would hold for him

gone. I was scared and distraught, my mind flashing to scenes of the film *Rain Man*. Was this what my boy was going to be like? When I got home and put Dylan to bed, I sobbed and sobbed. My heart ached and I wanted it all to be just a bad dream.

The next morning, I woke up with a fire in my belly and my head racing with thoughts. I wanted to know everything there was to know about autism. What would help? What therapies should he do? How would I get support?

One of the first conversations I had was with my sister who offered me much-needed support and cried with me. Her husband was studying diet and nutrition at the time, and suggested I take Dylan off dairy, wheat and gluten. He told me the effects this has on most people's bodies and that it might help Dylan; with this information I started researching some more. I promptly took Dylan off wheat, gluten and dairy, which was difficult as he had many food adversities and his main food staples were bread and milk. I found gluten-free options and switched Dylan from cow's milk to goat's milk. Within two weeks, Dylan's eye contact started to improve and he started responding to his name. I couldn't believe that such a small change could have such a huge effect. Maybe I could not cure autism but I could sure do as much as possible to give Dylan the best possible chance at living a fulfilling and healthy life.

The brain is at its most adaptable from the birth until the age of eight, so I had a few years to do as much as I could to give Dylan the best chance of not only being able to integrate into society but also to enjoy it.

Over the next few weeks a friend put me in touch with her friend who did play therapy with autistic children. She came and did a few sessions with him and referred me to some books to read, giving me games that I could play with Dylan to connect with him. If he didn't want to be in my world, I would go into his.

■ Continued page 12



ALL IN THE FAMILY: Tara Leniston and Andrew Fowler; Tara with children Dylan, 8, Luca, 5 and Naia Rose 10 months; Dylan with the family dog Mowgli

I found a local play group for children with special needs and began going twice a week. I went on courses and read many medical books on autism and the gut. I got Dylan into a specialist school setting which he attended three days a week. It was intense as it pushed Dylan out of his comfort zone, but offered him a routine in which he thrived. Luckily, with the support of my partner, I was able to stay at home and research and go on these courses that would arm me with the knowledge that I needed to help my child.

I wanted to write this because I wanted to help parents like me. Hearing the news that your child has autism may be one of the worst things you will ever hear. The loss of control, the unknown, the what-ifs. There were books I read with diaries from other parents which offered some comfort but at the same time filled me with fear. There were also conspiracy theory books on why my child had autism and books with so much medical information or so full of words I couldn't understand that it sometimes took me months if not a year to get through them.

- Tara Leniston's family moved to New Zealand in 2003 where she starred in her first motion picture Meet me in Miami. Before that, she was born in England, then lived in Ireland, Korea, Sweden and Hong Kong. Her mother Julie Madden lives in Christchurch while Tara and Andrew now live in the UK with their three children.
- Dietary interventions are one of the alternate ways in which many families try to help their child on the autism spectrum. Even though there is a lot anecdotal evidence on this, the New Zealand Autism Spectrum Disorder Guideline (Ministry of Health and Education, 2016) states that there is insufficient evidence to make any recommendation with respect to the use of gluten and casein free diet. For more information, see our articles on the website.
- Tara and speech language therapist Rhian Grounds recently published *Coming Home to Autism: A Room-by-Room approach to supporting your child at home after ASD diagnosis*.
- This article draws from two chapters in the book.
- Andrew's story appears on our website: www.altogetherautism.org.nz



BEST FRIEND: Dylan with Riyaz



Go into the draw to win a copy of
Coming Home to Autism

Email info@altogetherautism.org.nz

- your name
- contact telephone number



PLAYROOM: Making a quiet space for the children is important



BROTHERS TOGETHER: Dylan and Luca's bedroom



FAMILY TIME: Bronwyn Markey with husband Andrew and their two children Harry and Ben

FRAGILE X - FROM A TO X



*If you are parent of a child with autism you've probably experienced a journey like ours. If you're a professional working with children/adults with autism you've probably met families with a story like ours writes **Bronwyn Markey**.*

PARENTS ARE aware their child "isn't quite right" from an early age so they question their GP, Plunket nurse, other parents, and Google in a desperate search for answers.

At first not believed, not taken seriously. At the end of it all is a diagnosis of Autism Spectrum Disorder (ASD).

There's no cause, no reasons why, and no cure.

Our story is a little different.

Over a period of six months we found out that both our sons have autism. We did find out the cause but this gave us more questions than answers.

When our first son Harry was born I was excited. I had a wonderful pregnancy and a complication free birth. At first he slept well, didn't cry much and I was blissfully happy.

On day 13 everything changed. Harry started to refuse naps during the day and it felt like he was crying all day, until, exhausted, he would pass out at around 11pm. Evenings were spent with our family walking around the house rocking, singing and patting Harry, trying to settle him. Days were spent walking all over our neighbourhood as the moving buggy was the only place where Harry would really sleep.

For the next few months, I worried endlessly. My GP and Plunket nurse were convinced there was nothing wrong. I

questioned the mums in my coffee group but their babies seemed much more content than mine. I stopped going to coffee groups as I felt out of place with all the happy mums and happy babies. I felt isolated and alone.

At four and a half months we hired a sleep consultant and Harry's sleep improved. He still cried a lot but it was definitely less than before. I returned to the coffee group gatherings. All the babies happily laid on the floor holding toys, examining and reaching out for them. Not Harry though.

At six months old Harry lay on the ground staring at the ceiling. He never reached out for toys, never tried to pick things up or examine the world around him. I blamed myself. Obviously I wasn't playing with him enough, wasn't stimulating him enough.

As we continued to attend coffee group, Harry never seemed to be at the same place developmentally as the other babies. I continued to blame myself and thought maybe I wasn't cut out to be a Mum. My partner tried his best to reassure me but something just didn't feel right.

At nine or 10 months, Harry started to rock back and forth in his highchair and flap his hands. I had heard of autism and I was suspicious that this was what was going on. But even that didn't sit quite right. Harry was social, loved to be around people and had good eye contact. Back to the GP and Plunket nurse we went. They were both insistent that he was young and these behaviours didn't mean anything, he would grow out of them, he wasn't too far behind. I tried to believe them but I just knew something wasn't right.

By this stage I was six months pregnant but feeling terrified of having another baby. If Harry was "normal" and this was how "normal" babies behaved I wasn't sure I could cope. Harry still woke up once or twice in the night crying, sometimes screaming, for hours and we were concerned.

■ Continued page 14

Diagnosis

Then my sister's son, at seven years old, was diagnosed with Fragile X Syndrome. I had never heard of this before but it didn't take long with Google for me to realise that I had the answer I had been searching for. I was devastated. Though I was sure, Andrew wasn't and my GP remained unconvinced.

Life carried on and I tried to ignore the constant nagging thoughts that were telling me that Harry had Fragile X. Ben was born and within days he was acting similar to how Harry had as a newborn. I continued to nag at Andrew that Fragile X was a real possibility and he agreed to see a paediatrician.

The paediatrician quickly noted the physical signs, took a family history and agreed that it was highly likely that Harry had Fragile X Syndrome. A simple blood test, four week wait and we would have our answer. It came back positive. Harry was dual diagnosed as having Autism Spectrum Disorder and Fragile X Syndrome.

There was a 50 per cent chance that Ben would be positive so we knew we had to get him checked. Ben was very different to Harry he was more engaged with the world around him but as time went on he missed more and more milestones.

Incredibly, Genetic Health Services NZ initially refused to test Ben, despite an extended family history, an impacted sibling and missed milestones. Access to testing for Fragile X is a real issue in New Zealand. It took tears and begging to get the eventual agreement to test Ben.

The Grief Cycle

Ben's diagnosis was much harder for all of us to accept. Ben appeared, and still does, to be much less affected so I had convinced myself that his delays were within the realm of normal. With both boys affected, I felt all my hopes and dreams of life with children were gone.

The most valuable piece of advice we have been given is that "nothing changes for your child after their diagnosis. They are still the same person they were before".

I've finally realised that this is true. Harry and Ben, for the most part, are the happiest of kids and are loving life. But the same can't be said for their parents. When Harry was first diagnosed

his paediatrician told us "be kind to each other". We thought that was a strange comment but he was right.

There is a clear grief period for both parents post diagnosis. As individuals we all grieve in different ways and we were constantly at different places on our road to acceptance. There have been many times over the three years that we have not been kind to each other as we struggled to get over the enormous grief we felt.

My outlook was that I would not ever get to experience the events and milestones that I had always hoped for. My feelings turned towards hopelessness and then fear, anxiety and depression. I did however have an overpowering feeling of love and protectiveness towards my two boys. This was enforced by the love that they showed towards me. I knew I had to pick myself up and do whatever I could to make their life as positive, productive and fulfilling as possible.

Acceptance

Andrew and I realised that it was us, as parents that must change our ways of thinking and how we look at life. We have worked hard to get to a place that we can be the best parents we can.

We were quick to join Fragile X New Zealand. This is a parent-led charitable organisation from whom we received a great level of support and access to an enormous set of information. The Fragile X community is small by comparison to the autism community. I decided to access the many autism support services but with mixed results.

Although Fragile X and autism overlap with shared phenotypes, it is of vital importance that a child with Fragile X not be treated the same as a child with autism. We discovered many research articles written about this subject. As a parent of Fragile X children we learnt you must be very

careful to select the tools that will have a good chance of success.

At the first autism workshops I attended I felt like an imposter, like I shouldn't really be there because of Harry and Ben's dual diagnosis. In reality, I found a supportive community who was more than prepared to accept us.

We are extremely lucky to have a paediatrician experienced with Fragile X who has an active interest in the condition, and is willing to take guidance from offshore specialists in the

"Parenthood is about raising and celebrating the child you have, not the child you thought you'd have.

It's about understanding your child is exactly the person they are supposed to be. And, if you're lucky, they might be the teacher who turns you into the person you're supposed to be"

– The Water Giver



Harry



Ben

field. Unfortunately, there are paediatricians who haven't had exposure to Fragile X before.

I have met many parents who have a child/children with autism and not heard of Fragile X let alone been offered testing for it. The Ministry of Health document "New Zealand Autism Spectrum Disorder Guideline" outlines the process for diagnosing ASD;

"There are genetic factors in the causation of autism, but as yet there is limited information on how these genetic factors work and even more limited information on potential gene-environment interactions. There are a small number of single gene disorders which are associated with autistic symptoms. These include fragile X, Rett syndrome and tuberous sclerosis"

AND

"Clinicians should consider the possibility and importance of genetic factors for each individual and carry out appropriate investigations, as indicated by clinical assessment. Clinicians should provide genetic advice where indicated and ensure onward referral, where necessary."

Early intervention with Fragile X is critical and with the mistakes we made using wrongly applied techniques, we must ask; "why is this advice not being followed?"

As Harry nears five and the start of school is looming we are grateful that we have both diagnoses. We have been able to target treatments and interventions to suit his needs and we are hoping the diagnosis will make it easier to access the support he will need. Of course, we hope the same for Ben and luckily for him we know more now than we did with Harry.

I believe we are getting there as a family. I am grateful to have Andrew on this journey with me and I believe we are nearly at the same place in terms of acceptance.

My big wish is for increased awareness of Fragile X and that genetic testing will become more common. Through raising awareness, I hope many more parents of Fragile X children are able to get the targeted interventions and support they need.

- Bronwyn Markey is the mother of two pre-school with Fragile X Syndrome and Autism Spectrum Disorder who is working hard to increase awareness about Fragile X and the need for genetic testing in children who present with signs and symptoms of autism.

What is Fragile X?

Fragile X syndrome is the world's leading cause of inherited mental impairment.

It is also the leading identifiable cause of autism. About 6% of autistic people turn out to have Fragile X and 50% of pre-school fragile children meet the diagnostic criteria for autism.

Fragile X is a genetic disorder that affects about one in 3600 males and one in 5000 females.

Fragile X syndrome is caused by a mutation in the FMR1 gene on the X chromosome, causing the FMR1 gene to be turned off. This silencing of the gene stops the production of FMRP, an essential protein for normal brain function. The lack of this protein causes Fragile X syndrome. The impacts also overlap with autism and 50% of pre-school Fragile X children also meet the diagnostic criteria for Autism Spectrum Disorder. Fragile X is the leading cause of inherited autism.

1 in 260 women and 1 in 800 men are carriers of Fragile X syndrome. The mutation is related to the X chromosome, only a mother can pass Fragile X to a son.

Survey Results Show Journal Readers Overwhelmingly Positive

INFORMATIVE, INTERESTING, RELEVANT. These were the three words our readers chose most often to describe the Altogether Autism Journal in the latest reader survey.

A total of 176 readers completed the survey we ran on our website from January 9 to February 28. This is a 36 per cent increase in respondents since our last survey took place in April 2016, and we're really thrilled by the feedback.

The print version remains the preferred format for Journal readers (52%), although the majority of survey respondents said they read the Journal electronically either via email or on the website (61%).

When asked about the design of the Altogether Autism Journal, 98 per cent of responses were positive with many commenting on the easy-to-read layout and good balance of images and text. However, some readers wanted to see better quality and more variety of photos and images in the Journal.

We were blown away to learn the Altogether Autism Journal is our readers' second most relied on source of information about autism — ahead of Google, social media, news media, other websites and publications.

Who were our readers?

Over 75 per cent of Altogether Autism Journal readers are a parent or main caregiver of a child on the autism spectrum, and almost 14 per cent of our readers are on the spectrum themselves. Many of these people also identified as professionals working with people on the spectrum or in the autism community — 45 per cent in total.

Of our readers who identified as professionals, 55 per cent said they work in education. But our Journal is also read by support workers, behavioural therapists, health professionals, psychologists and ASD coordinators.

What do they like to read?

Stories from a personal perspective proved to be the most popular type of article with 85 per cent of survey responders indicating they enjoyed reading them. This was closely followed by research articles (79%) and news and event stories (62%). This is a significant change from 2016 when research articles were most popular with readers.

Education, sensory sensitivities, behaviour and support services were the topics our readers most wanted to learn about.

We want to thank everyone who took part in the 2018 readership survey. Your feedback will help shape the future direction of the Altogether Autism Journal so we can continue to deliver an informative, interesting and relevant publication for our valued readers.

See back page and website for more.

Asperger's no excuse when it comes to challenges for Tauranga teen



Katherine Speidell is not afraid to be different, as Altogether Autism writer Pip Stephenson discovered when she visited her in Tauranga recently.

KATHERINE SPEIDELL'S close-cropped, pink hair is only temporary, a reminder of her inclusion in the recent 'Shave for A Cure' for blood cancers.

It is yet another example of how Kat, as her friends call her, pushes the boundaries as a young leader in her various communities.

That ability saw her selected as one of 18 young people from Australia, New Zealand and Asia to attend the 20-day Global Leaders Delegation throughout Europe starting on January 4.

At just 17 years old, Kat, now in her final year at Papamoa College in Tauranga as deputy head girl, was the youngest eligible age to take part in the delegation.

Up against masters students from universities all around the country, Kat didn't think she had a chance at securing a spot in the delegation — not that she let that stop her from applying when she heard about the opportunity.

"I read through it and I thought: I don't think I'm going to get in to this, but I can't not apply and know that I didn't have a chance."

Crimson Education, the organisers of the delegation, thought otherwise. Kat made the cut, perhaps not surprising considering her impressive list of accomplishments last year. Co-leader of the Papamoa Enviro Council, Rainbow Youth Facilitation Alumni and Project Ignite Summer Student Incubator mentor — Kat completed over 400 hours of volunteer work in 2017 and received the Papamoa College Lions Award for Community Service.

The opportunity to travel across Europe visiting top universities like Oxford, Cambridge and the London School of Economics, as well as historical sites and government facilities, was a well-deserved honour for this busy, high-achieving teen.

Stopping in Prague, Czech Republic for five days to attend the International Youth Leadership Conference alongside

"Having an entire group of people that were excited and driven meant we could open up and be ourselves"

approximately 70 young people from around the globe was a highpoint of the trip.

The conference provided a unique opportunity to develop skills in public speaking, leadership and teamwork with attendees taking part in debates and a range of simulations like United Nations Security Council meetings and an International Criminal Court trial.

"Going into it I definitely thought I'd be more nervous or homesick, but it was just every day was so full and there were so many cool people, I didn't even have a chance to feel anything like that, because it was just so fun. Cold — but fun."

A personal highlight for Kat was visiting the large hadron collider at CERN, the European Organization for Nuclear Research, in Switzerland where Kat says she was "literally squealing out loud with excitement" and the headquarters of the United Nations in Geneva, "the epicentre for human rights".

But perhaps the most valuable thing Kat returned home with was new friendship.

"In a lot of situations it would have been [challenging travelling with 17 strangers] but because the group of people that ended up being chosen were all really passionate and driven and just so motivated it was hard not to get along immediately.

"So many of us come from a background where we're constantly striving towards goals and being around people who say 'oh you'll never get there' or don't have the internal drive to keep doing stuff.

"Having an entire group of people that were excited and driven meant we could open up and be ourselves. And even though it was only three weeks, we're already planning a reunion in July and we all correspond daily. Definitely lifelong bonds formed."

Kat has Asperger's, but she says "it doesn't come up super often day to day."



PERSONAL HIGHLIGHT: Kat Speidell visited the large hadron collider at CERN, the European Organization for Nuclear Research

Including Neurodiverse Children in Education



Children's Commissioner Andrew Becroft spoke in April this year to a group of people gathered by the Otago Child Protection Trust. He discusses the need for a child-centred focus in providing appropriate educational support for neurodiverse children.

ADDRESSING NEURODIVERSITY in children is one of my priorities.

Part of the action we need to take, as communities, is to ensure we honour the right of all children to education and support children for whom this right is at risk.

What constitutes appropriate support for neurodiverse children becomes clear if we work within a genuinely child-centred frame.

Here are some ways each of us can contribute to a genuinely inclusive education.

- **Develop an accepting culture.** Parents of neurodiverse children often struggle to get their kids accepted. Boards, teachers, staff and parents need to promote a school culture that accepts diversity. This may mean reassuring some people their children's education is not at risk when a child with challenges is included in class. Indeed, there may be real benefits in generating sympathy, compassion and understanding.
- **Give teachers the tools they need.** Provide professional development to help teachers offer a diverse learning environment meeting the needs of all children. Encourage them to avoid using restraint or 'time out' unnecessarily. Resource them to work with students who have specific learning needs. Provide more and better trained teacher aides.
- **Advocate for funding for eligible students.** Make sure children at your school get their full entitlement from the Ministry of Education. Report to the Ministry if a learning need is not being met due to lack of funding.

- **Be creative about sourcing community support.** Among other avenues, some schools seek sponsorship from local businesses to ensure all children have their education rights met.
- **Make sure board decisions are child-centred.** This is particularly important when it comes to inclusion and exclusion. Give thought to including two to three students on your board.

The Office of the Children's Commissioner plays its part too.

- We advocate to **principals** to ensure all children are enrolled in a school. No child can be left behind.
- We advocate to the **Ministry of Education** to improve funding for learning support and to set in place a properly resourced education system that genuinely engages all young people.
- We advocate to **boards** to ensure their decisions are in their best interests of each and every child.
- We advocate for schools to **listen to children's voices** so these voices play a meaningful part in decision-making about children's education and therapeutic treatment.

Schools can build resilience in children. Keeping children in school, engaged in learning, contributes markedly to helping them avoid poor outcomes.

But this is only true if their experience of school is positive. We must reduce bullying, encourage restorative rather than solely punitive approaches to behavioural issues, and provide students more support to ensure they maximise the benefit of their education.

Together, we want New Zealand to be a place where it's great to be a child, where family, friendships, feeling safe, being able to play and be connected to community are supported at all levels of society, from the Prime Minister to the local school. We want Aotearoa to be a place where all children can develop and thrive.

■ Continued from page 16

"I think it's definitely something that influences everything I do and it's a part of me that I think is really important to my identity. But, it's not something I want to use as an excuse to not accept challenges.

"I think no matter what type of unique situation someone faces — regardless of whether or not they have a diagnosis or whatever else that might be unique to them — it's really self-defeating to say because I'm on the spectrum I can't do this. That's not to say it might not be more difficult because how my mind works, but that actually makes it an exciting challenge."

It's a powerful message for the young people supported by One: Unique Minds, an organisation offering peer mentoring and social groups to young people on the autism spectrum, where Kat's employed in the role of chief operating officer.

"One of our business mottos that makes us a bit unusual is regardless of what position anyone holds in the business, everyone needs to be involved on the ground some way so

you can stay connected with the roots of what's motivated you to get involved in the first place."

While Kat has big goals for the future, she's not too concerned about pinning down the details just yet. She hopes to take a gap year to work and travel, before embarking on an undergraduate conjoint degree in business and law. She wants to stay in New Zealand — initially at least — although postgraduate study at Oxford University or an Ivy League college in the US beckons. But nothing is set in stone.

"It's better to figure out a rough plan and give myself room to change," says Kat.

And as for the hair? She thinks she might go purple next.

- * Our autism community prefers the use of the term autism but we have chosen to go with Kat's preferred terminology of Asperger's.



Kat Speidell

Gold medal-winning Special Olympian still challenges herself



Kym O'Grady went from being bullied as a child to the top of the podium in China. Pip Stephenson finds out the Hamilton woman still doesn't think of herself as successful, yet.

THE GOLD medal Kym O'Grady won in dressage on her supplied mount at the Special Olympic World Games in Shanghai nearly 11 years ago, holds pride of place in her Hamilton home alongside all the other ribbons and medals she's won through a successful career.

While others would consider the glittering displays as evidence of success, Kym, 34, concedes she has still got a way to go before she considers herself successful.

It's a surprising admission from her as she sits next to the framed gold medal, pictures and souvenirs from the 2007 Chinese Special Olympics Games.

There are other medals for equestrian and swimming too, and a mass of ribbons from regional and national competitions sitting in a heap on the kitchen table.

Winning the gold in Shanghai for dressage was an extraordinary achievement considering Kym didn't even expect to go to China. Named a non-travelling reserve, Kym only found out she'd be joining the team two weeks before the games were due to start.

Kym first started riding horses at the age of four when her parents took her to Riding for the Disabled in Te Aroha. But it wasn't until 2005, just two years before the games, that Kym started competing.

The O'Grady family moved to Hamilton when Kym was five. She attended Puketaha School, a small country school just north of the city.

Growing up on the autism spectrum wasn't always easy.

"I got bullied for just not fitting in. And I didn't do the normal things kids experience like getting invited to birthdays and playdates. I had no friends. I always thought when I was growing up my brother and Mum's friends' kids always got good jobs and good things.

"Now I've got good friends, but when I was younger it was really hard. And I was naughty - or I came across as naughty - and I got in trouble for being naughty. But I was just frustrated."

Kym struggled as a child, sometimes lashing out in frustration when things didn't come as easy for her as it did for others. A failure to recognise or accept Kym was different meant her actions were frequently mislabeled bad behaviour.

Growing up on the autism spectrum wasn't always easy

"The hardest thing for me is I look normal, but I think differently and take longer to process things - that's a major for me. And I get extremely tired and frustrated sometimes. I can't do things like others."

Things changed for Kym at age 14 when she went to Salisbury School in Nelson, a boarding school for girls with complex learning needs.

Kym now shares a flat with a friend and works two days a week at Aspire Community Support. She credits her parents for supporting her to be independent and encouraging her to succeed even when she doubted herself.

Kym is a support worker at Hamilton community support organisation Aspire and before that worked in reception.

On Tuesdays and Fridays she helps make meals and organises art and craft activities at a residential home, she even takes two residents swimming.

The new job is a ray of hope for Kym who has worked hard to manage her depression over the years.

But it's an ongoing journey. Kym says she still has good days and bad days. She manages her mental health with the help of a life coach to talk through her depression and help iron out some of life's problems. She also tries to stay active, running and swimming, and enjoys getting into the kitchen.

Art is another important outlet. Kym's turned her small garage into a studio where she can draw, paint and decoupage.

The new job has helped too, giving her confidence and an opportunity to help support others who may be facing their own challenges.



INDEPENDENCE VALUED: Kym O'Grady at home

Other than the odd trek, Kym says she doesn't ride horses much these days. But she's still heavily involved in Special Olympics as a swimming coach and on the Asia Pacific Advisory Committee for sports rules in swimming.

She's also a Special Olympics Global Messenger, raising awareness by speaking in the community about intellectual disability, the Special Olympics and her experiences.

It's a role that will see her travel to the Dominican Republic in November for a Global Messenger conference, something Kym's excited and nervous about in equal parts. But she's not letting herself be fazed by this new adventure.

"I suppose everything I've done in life has been a challenge. I'm always willing to do anything that's a challenge."

Expressing autism through art



Art has unlocked Ammon Matthews' creativity and art remains his motivation to get up in the morning, Altogether Autism editor Mary Anne Gill discovers.

AMMON MATTHEWS stumbled into being an artist surprising not only himself with his ability but also his mother Sharon Matthews who herself is a talented artist.

"It's blown my mum away. She tells people how proud she is and what a shock it was to find I was good at it. She says: 'goodness I thought your brother had all these gifts and you were sitting under my nose all that time,'" says Ammon.

The 29-year-old spent his childhood growing up in Hamilton not enjoying school, bullied by his classmates and teachers and struggling to find an identity.

It was seven years ago when he was told he had Asperger's and was on the autism spectrum.

His mother had thought he had a literacy problem but once she and Ammon got their heads together, the path his life took made so much more sense.

Ammon found it difficult to socialise preferring the solitude of home and church with his family. While art has not completely changed that, it is starting to make a difference.

"I just had to find different tools for my perspective. One of them is art. It's how I can express my autism and open up a lot of things in my life."

Ammon's face clouds over when asked whether art has helped him escape the bad memories.

"I didn't do anything embarrassing at school, never caused any trouble. They just had no tolerance with me, thought I was a lazy thinker.

"I used to get bullied quite a lot. It was physical as well as intellectual. It traumatised me and I still think about it to this day.

"I'm moving forward with my art."



Timothy Folkema

Since 2014 he has been supported by Progress to Health, and in particular, autistic peer mentor, Timothy Folkema.

Ammon has goals, and being supported by Progress to Health, it means the next few months are going to be busy.

Firstly, Ammon has completed a pencil sketch of Jacinda Ardern and intends on drawing Helen Clark next.

"They're locals, prime ministers, and I really believe in people who can make a change".

Secondly, he is designing a book showcasing local Hamilton artists, with the feature on the city itself.

A third goal is an art exhibition featuring other artists like Ammon, hopefully resulting in a more permanent exhibition space (an autistic art gallery).

"That's the most challenging one. It will take autistic people out of the box and enable the artists rather than disabling them; creating an alternative platform," says Timothy.



MOTHER AND SON: Sharon and Ammon Matthews, artists at work



PET THERAPY: A younger Ammon Matthews with the family cat

Ammon is a graphite artist who creates lifelike portraits, with specific attention to detail. He has completed commissioned portraits of deceased, from photos, as a way of honouring them. "I really value them, they should not be forgotten," he says.

Each of the portraits he does takes around two months to complete.

Ammon wants to delve into colour at some point though and meet some of the other artists around the city who will feature in the book and also at the art gallery.

Art has unlocked Ammon's creativity and art remains his motivation to get up in the morning.

He loves it when he goes to The Church of Jesus Christ of the Latter-Day Saints (Mormon) services in Hamilton to sit at the front with the children who watch him as he draws.

"They always seem fascinated by me. I finish what I do and then gift it to them. I love that," says Ammon.



PRIME MINISTER: Ammon Matthew's pencil sketch of Jacinda Ardern

A Message In Colour

When Talia Waldegrave caught up with the Janson family in Raglan for UNO magazine, she found a supportive family.

THE HEARTY aromas of an autumnal lunch hit us as soon as we arrive at the Janson homestead.

After a slow journey to the laid back west coast town of Raglan, nothing could be more welcoming.

But then to our surprise come the hugs, smiles and incredible hospitality from Yaniv's parents, Annick and Robin.

We've come to talk to Yaniv about his art; however, he is nowhere to be seen. Many of us would shy away at the thought of writers and photographers knocking on our door but for Yaniv, living with Asperger's, shyness is all too familiar.

While we wait for him to get used to the idea of us being here, Annick gives us a tour of the home, accompanied with narratives on Yaniv's unique journey into the art world.

"Yaniv likes to be near his art, so we had a bed tailor-made just for him that allows him to store his paintings underneath.

"His bedroom overlooks the Raglan harbour and he actually painted a picture of this view, perhaps from photos he had seen, years before he had even been here.

"So far, Yaniv has won eight awards. The first time he painted on a large canvas, he was a finalist in the National Contemporary Art Award and the Wallace Trust Award. For both he was the youngest. We used to hide his age at the time because we thought people wouldn't take him seriously.

"When Yaniv was at kindy, he used to dabble in art and it was quite unique even at that age, but later on when we tried to give him brushes and paint, he just wasn't interested. At 16, his art teacher held an exhibition among the students. Huddled around Yaniv's painting was a mob. That's when we knew he had a special gift and we had to nurture it.

"As soon as he painted one piece, people would walk by and say 'Can I buy it?' For months we didn't have any paintings because they literally sold wet!

"One day we were contacted by an organisation called Eg Art that works with the European Commission. Eg Art helps artists with disabilities and they hold exhibitions throughout Europe. The first one was called Chemins Croisés at the Galerie Celal in Paris, between Centre Pompidou and the Louvre. Yaniv was the first New Zealand artist to be invited. He sold three paintings at that show.

"We love to travel and took all of our children to Paris when Yaniv was about two. Of course we went to the Louvre and our older children wanted to get out of there right away. We managed to see the Mona Lisa. When we were back in Paris for his exhibition, he spent nine hours wandering the entire gallery. This time it was me who got tired!"

Changing the world one painting at a time

"Yaniv's first exhibition was in the Waikato Museum in 2008. It was here that he realised he could share a message with people through his paintings, which fuelled his interest in social and environmental issues. This started a long-term dream to exhibit at the United Nations, so it's been a passion for a long time.

"One Saturday morning he got a call from someone at UNESCO and we thought, 'This must be a joke.' It wasn't. They had stumbled across Yaniv online and asked if they



could put the link to his book Changing the World One Painting at a Time on their website. UNESCO reaches hundreds of thousands of teachers worldwide, so we were very honoured."

"So far, Yaniv has won eight awards. The first time he painted on a large canvas, he was a finalist in the National Contemporary Art Award and the Wallace Trust Award. For both he was the youngest"

Rather than print the book and destroy forestry, Yaniv suggested the book be available as a PDF to teachers all over the world.

"He is always considering different yet ethical ways of doing things."

A feast for the senses

Vibrant in appearance is Messy Earth, an artwork made entirely by test pots; 22 of them poured straight onto canvas. Yaniv explains:

"There was no paintbrush, just test pots. It took many days to dry. I chose to use 22 because it's my favourite number as well as the favourite year of my life."

Sir James Wallace certainly liked it and is now the proud owner. As one of his biggest fans, this is the fifth painting of Yaniv's that he owns.

Ron Epskamp, Gallery Director of the Exhibitions Gallery of Fine Art says he admires artists like Yaniv, "His perspective requires us to view our world in a unique way."



RAGLAN HARBOUR: Yaniv Janson's bedroom overlooks the harbour. This is how he sees it on canvas. Photo: Tracie Heasman

Flowers is due to showcase and again, not a single paintbrush was used. Instead, flowers were dipped in paint and water was poured on top to create texture.

Similarly tactile is Freedom, where paint was squeezed through tubes from above.

"There are many colours on it and if you touch it, it's rough. I'm happy for people to do that. Every gallery has a sign saying, please don't take photos, but I make a sign to say please DO take photos, please DO touch.

"Normally I try to imagine the paintings in my head but if I can't imagine them well, I look on the internet to get some inspiration. Sometimes I am inspired by Raglan and the harbour. I walk around the mountain and take pictures on my camera."

Obstacle or opportunity?

Realising there was traction here in New Zealand to spread his ethical message, Yaniv created the 'Taking Action Project' which connects with organisations to raise awareness that artists with a disability have a contribution to make.

Yaniv's own offerings to the art world were quickly recognised and he became a finalist for the Attitude Award, celebrating achievement in the disability sector - a huge nod to his achievements with Asperger's.

"Yaniv donated a painting, which was auctioned at the ceremony and fetched \$3,000. The entirety of this went to KidsCan."

The purchaser has now become one of his greatest supporters and close friends, Wellington CQ Hotel General Manager, Olivier Lacoua.

Portfolio, Since the Beginning and Changing the World One Painting at a Time are all published books housing Yaniv's colourful works.

"Olivier buys my books to give to his VIP guests. Just yesterday he ordered another 20."

The message

Using a mix of acrylic and water on canvas, including numerous test pots, Yaniv's paintings convey an ethical and poignant message, he told me.

"Rich, Middle Class, Poor draws attention to the everyday living conditions of the rich, the middle class and poor people. The rich people live in a multi-coloured village on the mountain and the brown village by the ocean. They have more money and food. They choose what colour house they want. They see at least the ocean and other things from their home. The middle class people live in the silver village by the bottom of the mountain. They have to share their home with other people who are middle class. Their houses are all the same. They only have a medium amount of clean water and food for living. The poor people live in the bushes. They have no clean water, no home, no nice view, and almost no food.

"I am passionate about the message in my art because I don't think any other artist has done this before."

■ Continued page 22

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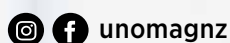


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Continued from page 21

Sole focus

Yaniv has won more than 18 awards, participated in more than 40 exhibitions and sold more than 160 paintings.

From 4 to 14 June, an exhibition of Yaniv's paintings called Please Do Touch, featured in the United Nations Headquarters in New York coinciding with the annual UN meeting of the Convention of the Rights of Persons with Disabilities.

The exhibition reflected the UN's 17 Sustainable Development Goals. Yaniv says he was inspired by these goals and turned five of them into themes to help make his paintings: Life Below Water, No Poverty, Clean Water and Sanitation, Climate Action, and Sustainable Cities and Communities.

The idea of Please Do Touch came from his desire to let people experience art through different senses, and to push what is done and not done in the art world.

"I come up with my own ideas and I feel like I'm different from other artists," he says. "I'm shy and don't always find it easy to talk with other people but it's important for me to show that disability is not a barrier to achieving. Disabled people can

**"I come up with my own ideas
and I feel like I'm different
from other artists"**

make a valuable contribution to society. I think I do."

Artistic appreciation

Yaniv is quick to credit his mentors. Close friend and Distance Delivery Mentor Marcel Baaijens has always been a great support. Despite his recent move to Australia, he is in regular contact with Yaniv.

"Each time I sell a painting, I rush to the computer to email Marcel. Although Marcel is no longer my teacher, it is still something exciting we share together."

The high school teacher that discovered Yaniv remains in the picture too. A resident of Raglan herself, she visits with the family a few times a week.

Quite possibly his biggest supporter of all though is his mother, Annick. Remembering every exhibition, every piece of art and every milestone, she is as delighted as any mother would be, encouraging Yaniv to be proud of his notable achievements.

- Our autism community prefers the use of the term autism but we have chosen to go with the author's preferred terminology.



PASSIONATE MESSAGE: Yaniv Janson at work in his studio

Sophie fearless in seeking out new challenges

SKY WALKER: Sophie Turner high above Auckland



Actor. Singer. Gymnast. In show business terms, 14-year-old Tauranga performer Sophie Turner is what's known as a triple threat, reports Pip Stephenson.

FANS OF PERENNIAL New Zealand children's television favourite What Now may recognise her as Izzy, the smart, bossy and often sarcastic girl from 'Mysteryville' — a 10-minute segment about three young sleuths solving weird and wacky mysteries which screened last year.

Sophie insists she's not like Izzy at all. In person she's bright, bubbly and full of barely-contained nervous energy.

Sophie lives with obsessive-compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD) and Tourette Syndrome (Tourette's). She's also been diagnosed with autism.

Taking a role on national television in front of tens of thousands of Kiwi kids was a dream come true for Sophie, who says she always wanted to be 'gunged' — the What Now custom of drenching people in slime.

She has also learned to manage her tics — the involuntary, repetitive vocal and physical movements associated with Tourette Syndrome — by holding them in with the help of sheer will and medication.

Sophie likens her tics to an "icky" feeling that can't be ignored forever.

"It's like when you sneeze; you have to sneeze. You can only hold it back a certain amount."

Sophie's decision to try acting came out of the blue after she heard about auditions for the musical Annie in Auckland in 2014, recalls her mother Sarah Julou.

After the unsuccessful Annie audition Sophie, who had found the experience "great fun", joined Tauranga Musical Theatre and has appeared in six productions including Beauty and the Beast, Mary Poppins and The Very Best of Broadway.

Since then she's sung with the New Zealand Men's Choir and will sing in front of a 13,000-strong crowd for the second year running at the 2018 A Night Before Christmas celebration at Bethlehem College.

"Singing is actually known to help Tourette's — and it does help," agrees Sophie.

No fear

Sophie has been involved in gymnastics since she was two years old but gave it up three years ago when Tourette's and OCD began affecting her performance and impacting on her competition scores and those of her teammates.

Sophie started tumbling instead — a fast-paced gymnastics discipline where competitors perform somersaults and twists on a straight track — and competed with the Bay of Plenty squad at nationals in Christchurch last October.

Sophie's not afraid to seek out the extreme, which includes completing the SkyWalk 192 metres above Auckland with nothing but a rope attached to a rail circling the exterior of the Sky Tower to keep from falling.

She completed gymnastic poses, hanging off the edge with little fear.

An 'ordinary' girl

"If I don't tell people I'm on the spectrum they see me as ordinary," says Sophie.

"I think one of the problems with high-functioning autism is people look at Sophie and don't see it. In fact, that's probably the biggest battle she has," says Sarah.

Sophie agrees. "They look up my disabilities online and think 'Sophie doesn't have that'."

Sophie says Tourette Syndrome isn't all about shouting swear words and OCD is not all about cleaning.

"There's a lack of understanding around high-functioning autism and OCD — they don't understand how complex it is. Particularly in education," says Sarah.

"There's a lack of understanding around high-functioning autism and OCD, particularly in education."

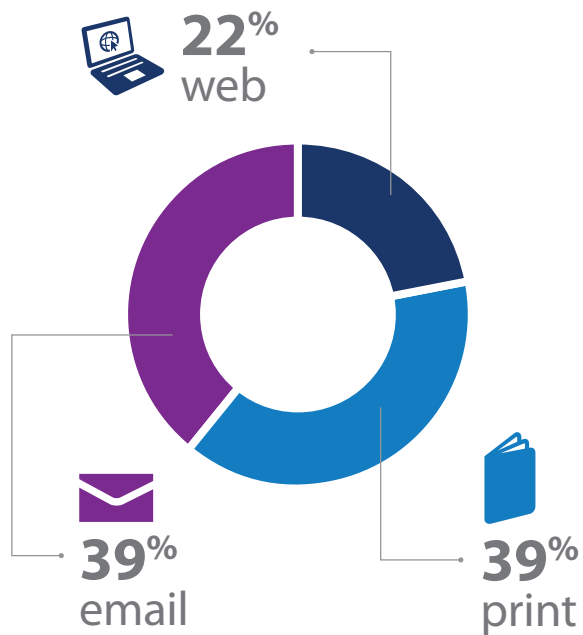
That's one of the reasons Sarah homeschools Sophie and younger brothers Malachi and Reid, who are also on the autism spectrum. That, and bullying from other children who would try to trigger Sophie's OCD and Tourette's behaviours.

Sophie and Malachi have attended Tauranga-based Mockingbird — a parent-run group that caters to the individual needs of neuro-diverse children aged five to 18. It runs three days a week from a small room behind a church and currently supports 33 children. Sarah sits on the board and is responsible for finding funding for the group.

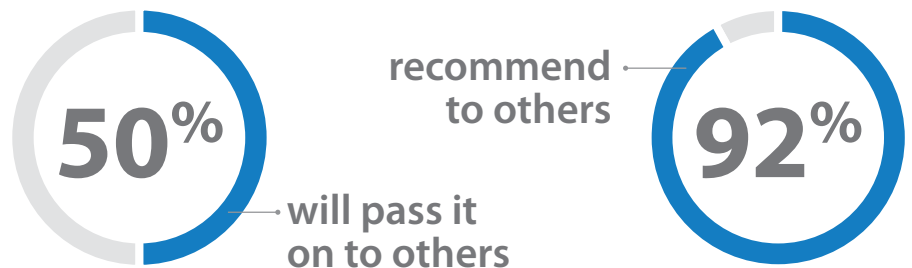
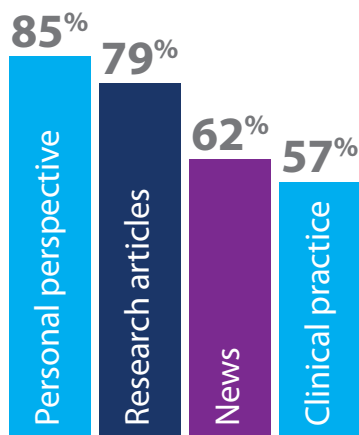
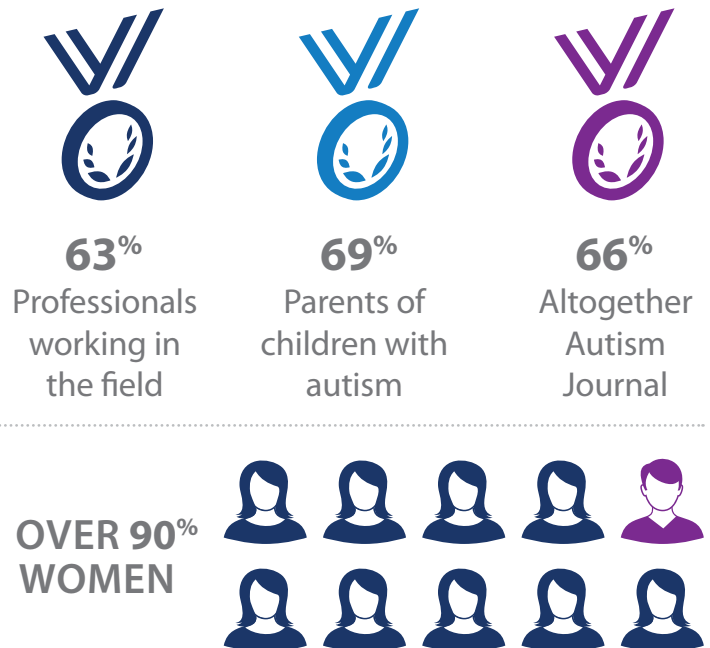
"It's been amazing ... That's been a huge factor in Sophie's successes over the last 24 months. If I'd said to Sophie two years ago 'sit down and write a song' she wouldn't have got past the first sentence. It's given her the space to be creative without the pressure."

Journal survey results

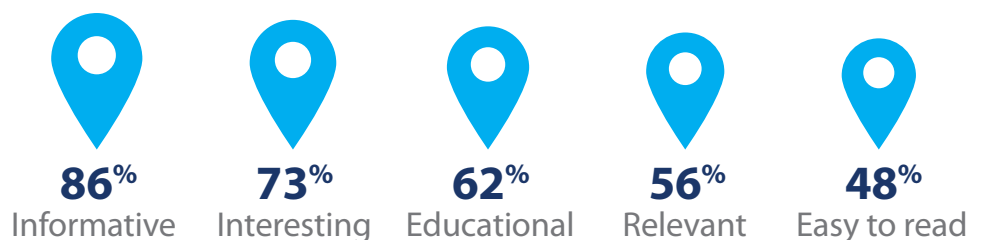
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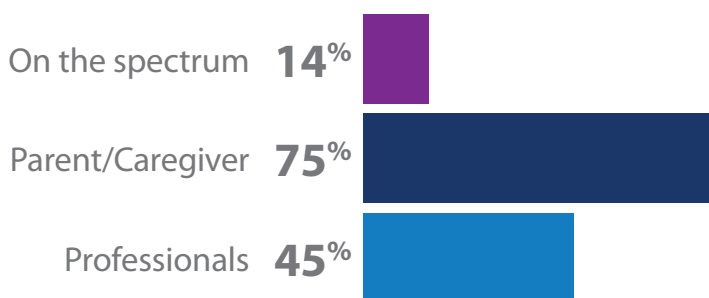
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