

ALTOGETHER AUTISM

JOURNAL

ISSUE 1 2018



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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Setting the agenda for 2018



KIA ORA KOUTOU.

Ngā mihi nui kia kōuotū katoa.

Happy New Year! I hope you had a restful Christmas and summer is going well for you all.

This edition of our Journal is featuring autism and education, from pre-school to tertiary, and everything in between. Do let us know if these articles are helpful. As it is the start of a new year, we are keen to hear suggestions for our

2018 editions. Each edition is generally based around a theme, so let us know what themes you would like us to cover.

We are also inviting your feedback via our readership survey on our Altogether Autism website. What do you like, what don't you like and what suggestions do you have for things that would make our Journal a better read for you? All survey responders will go into a draw to receive an Altogether Autism gift basket.

Late last year I had the delight of being interviewed by Margaux Sabourin. She is a recent Health Economy graduate from Paris, specialising in autism. A year ago, she created an association 'Un Monde Bleu' to research care and inclusion options available for people with autism around the world. She then fundraised to enable her to travel the world exploring different facilities and solutions offered to people with autism. Her aim is to inspire French authorities to review and improve their care options and the information provided to individuals. Margaux was particularly impressed with the quality of the information we provide here at Altogether Autism and envious that we have such a service in New Zealand.



INTERVIEWED: Margaux Sabourin and Catherine Trezona.

On Sunday March 4, I will be in Feilding to support Riding for Autism, an innovative fundraiser hosted by Sarah Blythe. Sarah's goal is to raise funds to sponsor educators to attend PRISM Autism workshops for educators in the Manawatu. There will also be a Golf Day on the same day as an additional fundraiser with the same aim of supporting teachers and raising awareness of autism. All cars and motorbikes are welcome to join Riding for Autism.

We and John Craven from Specialisterne Australia continue to meet with potential employers of autistic talent. The response from these businesses is very favourable and we will let you know as soon as we are ready to launch the first programme. If you are an employer and interested in learning about the benefits of hiring autistic talent, please contact us.

Just a bit of housekeeping. Vodafone recently discontinued its email services and advised customers to change to another email account. Many of our electronic subscribers have email addresses on the affected platforms listed below. Please let us know if you are one of those who have changed your email address.

- vodafone.co.nz
- wave.co.nz
- paradise.net.nz
- vodafone.net.nz
- quik.co.nz
- clear.net.nz
- ihug.co.nz
- pccconnect.co.nz
- es.co.nz

We welcome hearing from you by phone, email, Facebook, Instagram or Twitter – or even kanohi ki te kanohi / face to face

Noho ora mai.

Catherine Trezona – National Manager, Altogether Autism



EMILIA'S BOOK: Author Ali Beasley with Emilia.
Photo: www.nicholsonphotography.co.nz

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Emilia's Colours, The Gift of Autism

ALI BEASLEY lives in Nelson, New Zealand, with her husband Keith and their two teenage children, George and Emilia.

A diagnosis of autism when Emilia was seven had a profound impact on the whole family, which Ali explores in this honest, intimate work. *Emilia's Colours* shares the highs and lows of living with a child with a major disability in words that are frank, touching and ultimately hopeful.

From her initial feelings of shock and grief, Ali gradually learns to develop resilience as she comes to accept and even embrace her daughter's condition.

Through caring for Emilia, she discovers the importance of looking after herself as a parent, and restorative yoga becomes her 'go-to' place for inner healing.

The book's opening chapters consider the many and varied challenges that Emilia faces, including stress, anxiety, anger and communication difficulties. Ali describes the hard reality for parents trying to cope with these challenges, which have an enormous impact on family relationships and activities, and childhood friendships.



ALI BEASLEY

She goes on to look at the ways she and Keith have learned to seek and find support on a parenting journey that began without a map – and at the gifts autism has provided them, by teaching values such as patience, gratitude, courage, compassion and humour.

Emilia's Colours concludes with personal impressions by close family and friends of what Emilia means to them, and the effect she has had on their own lives. Throughout the pages, heart-warming photographs capture Emilia in all her colours, together with the people who love and care for her most.

In writing her personal story, Ali hopes to support other parents who may be struggling to cope with the volatile, unpredictable nature of life with an autistic child.

She also aims to raise awareness and a better understanding of this 'invisible' disability among those who may not have encountered autism first-hand.

To purchase 'Emilia's Colours' for NZD \$23.95, go to www.alibeasley.com.

Ali continues to write about Emilia through her blog on the website.

- Reviewed by Bev Sellers, an editor and professional writer.

WIN! BOOK GIVEAWAY

We have a copy of *Emilia's Colours, The Gift of Autism* to give away to a lucky reader.

To enter the draw for this wonderful book, send your name and address to

info@altogetherautism.org.nz by 28 February.



CONGRATULATIONS TO:

- JODIE HICKEY-SMITH, PORIRUA
 - LINDA STOWERS, AUCKLAND
 - DOROTHY VAN DEN HOVEN, TAURANGA
- who won a copy of *The Parents' Practical Guide to Resilience for Children aged 2-10 on the Autism Spectrum*. Thanks to all those entered.

Mother's navigation through the challenging education system



Education borne of both her personal experiences and those of her autistic child in the education system is one of Joanne Dacombe's areas of passion.

You can see why many autistic families struggle to get needs met.

I FOUND the education system unaccommodating to my own needs due to being hearing impaired and undiagnosed as autistic.

However, the education system was just as difficult to navigate for my son diagnosed with additional learning needs of autism, attention deficit hyperactivity disorder (ADHD), and dysgraphia.

Even with formal diagnoses there was no special assistance provided; no teacher aide, no Resource Teacher of Learning and Behaviour (RTLb), and no additional supports to help with some of his health needs.

There was also a lack of understanding of autism. The whole process created a huge amount of stress for our child, as well as for us as his parents. For many parents this scenario ends up leading to withdrawal from the school system and home schooling, something I was not sure I would have the executive functioning to do.

Our experience led me on a journey – a journey to try for improvements in a system that seems to largely ignore us. It might seem harsh to make that statement but only one percent, of an estimated 24 percent of children with additional learning needs, are eligible for Ongoing Resourcing Scheme (ORS) funding.

This funding provides specialist services and support for students with the very highest needs for special education. It helps students join in and learn alongside other students at school.

There are other avenues for assistance but many parents are not guided through these so are not aware of them.

The special education area is very challenging to navigate. It encompasses huge bureaucratic systems, tons of jargon and acronyms. There are RTLbs, IRF (Interim Response Fund), HHN (High Health Needs), and the Intensive Wrap-Around Service (IWS), for example.

The language also changes – for example the new term for special education is learning support. The people also change, notably teachers, specialists, schools, learning support, and Special Education needs co-ordinators (SENCOs), for example. Add being autistic on top of all that and you can see why many autistic families struggle to get needs met.

There are many areas to navigate: preschool, primary school, intermediate, high school and even university. Transitions are hard for autistic children and also for many autistic parents, many of whom remain undiagnosed themselves.

This is complicated by the different challenges such as additional learning needs being 'discovered', transitions and then different services such as speech language therapy, in each of those domains but also varying in different regions throughout New Zealand.

I attended Ministry of Education (MOE) Learning Support forums, called "Success For All", where MOE staff promote and discuss some of the projects they have in the pipeline.

Some of the projects are:

- the Bay of Plenty pilot around a single point of entry for Learning supports
- extending the Bay of Plenty pilot out to 30 more locations
- the Dispute Resolution Process currently being trialled in Auckland, Manawatu and Nelson,
- new approaches for Learning Support
- Better Insights which is about the MOE looking to develop a vision and plan around the data it collects and uses for learning support Strengthening Support for dyslexia, dyspraxia and autism around teacher capability
- New Approaches to Behaviour Support.

It is an opportunity to talk directly with the ministry at these forums.

I am concerned that many teachers are poorly equipped to recognise autism and, more importantly, autistic needs in the classroom.

My daughter and I once ran a presentation for teacher aides at my son's previous primary school, at the request of one of his previous teachers who was now the SENCO.

The talk was very well received and we then ran the same presentation for teachers. Later the SENCO hosted presentations by professionals in the field for other SENCOs in our region. She also undertook to send teachers for training in autism.

I was encouraged to make a submission when the Education Council was undertaking consultation around initial teacher training. Their work has since been expanded to look at all teacher capability across the board. I await the increase of knowledge and capacity that needs to happen.

Autism New Zealand is active in the education space – often providing training to Early Childhood Centres, teachers, and parents who choose to attend professional development in this area.

I wish I had known of them in the early days of our journey as they provide a valuable resource with outreach coordinators, as well as education training programmes.

Instead, like many parents we had to learn to muddle through. Even today, many parents are not told how to navigate the complicated system, have little idea about school policy – which can vary from school to school, and have no idea about how to access the information they need or the help they may feel their child requires.

GPs and specialists often neglect to refer children to autism organisations such as Altogether Autism, which has a government contract to provide information, or Autism New

"I am concerned that many teachers are poorly equipped to recognise autism and, more importantly, autistic needs in the classroom"

Zealand, to enable parents to receive real practical help on their journey.

I think many doctors make the assumption the children they see before them will get support in school via a teacher aide, when the reality is that may not be likely.

This lack of real support is not only frustrating for students and their families but often results in an escalation of autistic behaviours, such as meltdowns, which can see students face 'kiwi' suspensions, stand-downs, and finally expulsion from a school.

Autism New Zealand frequently deals with suspensions of young students because of a lack of knowledge and accommodations by schools towards autistic students.

We – students, their families, and their peers - all deserve better if we are serious about a truly inclusive society.

Autism New Zealand outreach coordinators are prepared to go into schools to educate, to advocate, and to provide some real strategies around accommodations that students may require.

As a disabled person I am involved in Facebook forums such as VIPS – Equity in Education whose members are active in education advocacy.

I am involved in offline forums like Education For All – a group of advocates who believe in inclusive education across all sectors: pre-school, primary, intermediate, high school and universities/polytechnics.

Inclusive education is not the same as mainstreaming which often ends up as 'main-dumping.' It is about meeting the needs of all students in the education system with resourcing, training, and funding.

The needs may not be equal but all students deserve the equal right to be fully engaged and to fully participate in their education for as long as they want.

The members of Education For All come from a range of perspectives; the group includes school principals, school trustees, disabled people, organisations connected to disabled people, and so on.

Joanne Dacombe has spent 21 years working at the Reserve Bank in the area of monetary policy. She was diagnosed with autism later in life and has a son on the Autism Spectrum. Joanne currently serves on the Board of Autism New Zealand as well as the Board of the ASK Trust, an autistic led organisation for autistic adults.

Children's participation in education essential



*Children's Commissioner **Andrew Becroft** has set five priority goals one of which is for all children to perform in the education system. He tells Altogether Autism why that is so important to him.*

IT WAS A great privilege to speak at the High and Complex Intellectual Disability Conference in October on "Is New Zealand delivering for our children?"

Children and young people constitute nearly 25 per cent of our population: 1.12 million New Zealanders are under 18 years old.

We may think of New Zealand as a great place to grow up – and indeed most of our children do well, and some do outstandingly well. But 20 per cent are struggling, and 10 per cent do as bad if not worse, than most comparable OECD countries.

This is not the New Zealand that I grew up in. It has been a big motivator for me in taking up this role. Twenty-seven per cent of children live in households on low incomes, and 12 per cent are missing out on seven or more items they need for every day living.

We have just launched the 2017 Child Poverty Monitor, where at least I was encouraged to see that the growth in child poverty has been halted, and indeed slightly reduced. I really hope to see some significant progress in the next few years.

At the start of this year, I set five key priorities:

- Helping to achieve better outcomes for tamariki Māori
- helping build and monitor Oranga Tamariki
- encouraging government agencies and non Government organisations to be more child-centred and to seek out children's voices and involvement
- improving children's engagement in education
- improving youth justice.

There are 800,000 children in the education system and 20 per cent are struggling.

Participating fully in education is essential for children to achieve their full potential. It is also their right. In any year, there are 800,000 children in the education system and 20 per cent are struggling.

Supporting children with neurodevelopmental disorders and other disabilities and encouraging schools to adopt an appeal system from suspension or exclusion decisions will help all children to be engaged in education.

As a society, we are rapidly learning more about neurodevelopmental disorders and other disabilities and how to support children better to learn and have fulfilling lives. I am optimistic that we can use that knowledge to manage complex and challenging behaviour without resorting to the youth justice system, as has happened in the past. In this respect, history may judge us harshly.

Since I took up the role, I have seen a high level of commitment by parents, caregivers, government, non-government and community organisations to do the best possible for our children. I was encouraged by the very dedicated people at that conference in October. I am sure that with our collective effort and will, we can make sure that all New Zealand children can flourish and thrive.

Before he became the Children's Commissioner in July 2016, Judge Andrew Becroft was the Principal Youth Court Judge from 2001, and a District Court Judge from 1996. The Office of the Children's Commissioner works to ensure that New Zealand is a place where all children and young people thrive. This is the first of regular articles Judge Becroft will write for Altogether Autism.



GROUP: Big group times, such as music time are encouraged but children are not forced to participate in activities they do not want to join.

Playgroup provides care and support



Spectrum Playgroup in Lower Hutt provides an environment of care and support for children on the autism spectrum and their families. So what makes the playgroup, funded from Givealittle donations and aided by professionals that can see the benefits, work so well? Mary Anne Gill talks to its founder.

CAT NOAKES-DUNCAN has an infectious enthusiasm about something which would test most other parents.

Yes she has three children, two of them on the autism spectrum, and yes the early childhood teacher is training to be a specialist in teaching children on the spectrum; but that did not stop her from founding a community playgroup that seems to be making a difference in Lower Hutt.

"When parents get that diagnosis, they want somewhere to go straight away. They want someone to have eyes on their child and provide hands on help. What actually happens is they go on a waiting list and they wait.

"What I know as a parent and an early childhood teacher, is that early intervention is important," she says.

Cat, husband Thomas, a lecturer in restorative justice at Victoria University, their two sons and daughter live in Naenae, Lower Hutt. In October 2016, after her second son's diagnosis, Cat felt an overwhelming need to do something. Waiting for specialists was not an option.

"The thing with community playgroups is they are such an easy model so I thought 'why don't I start a community playgroup for kids on the spectrum?'"

She talked with her friend Brynlea Stone, a speech language therapist with an interest in community living who worked at Kimi Ora School.

"She thought it was a great idea and was willing to volunteer her time as our resident speech language therapist."

Then came a meeting with Klara Hibbert and Heather Drysdale from the Hutt Valley DHB's Child Development service who also gave the idea the thumbs up.



Louise Ryan-Stickle, an amazing resource person within the wider community, came on board and they took to social media, founded a Givealittle page, secured a venue in Seddon Street and opened the doors.

It has been non-stop ever since. Cat, Louise and Brynlea form the key group who manage the playgroup as volunteers.

"We don't claim to be specialists. We are a bunch of families who get together with their children," says Cat.

"We provide families with support, we let them know they are not alone.

"Traditional community playgroups are great places but for someone with a disability or who is different, they can be painful places. If you have a child developing differently or behaving differently, that's a really painful experience.

"For parents, they can come to playgroup and relax, they know their child is in an environment where they are not different, where everything – no matter what it is – is normal."

For many of the children, it is their first experience of relating with other children in a tolerant environment of care and support.

"We bend over backwards for our parents to let their kids be kids and we totally celebrate the small things."

Cat talks about the child who had no verbal language but then started screaming.

"It's all about communication and we celebrated that. We think that's amazing because she's using vocal ranges, she's squealing really high, she's squealing really low and it's all communication. We're all about it. We just love those

Continued from page 6

moments. That mum is so proud and we're so proud with her.

"All of the parents are super understanding of where each child is at and what each child needs.

"One mother recently told us about not being able to take her child to a regular playgroup but finally being able to relax at Spectrum as her child is not under pressure to perform in any way or obey any rules.

"Our culture is fluid and adaptable," says Cat.

"Another mother talked about how her son sits in the car for half an hour before finally deciding to go to kindy. He runs through the gates at Spectrum.

"Our parents are able to talk together and share knowledge, ideas and experiences of specific interventions and therapies."

Cat and Louise ran a workshop at the Altogether Autism conference in July. The feedback was encouraging, says Cat.

"We discussed the challenges so many of our families face.

"For example one of our Māori mothers has had her child on the waiting list for assessment for over two years and her child is about to turn five and go to school.

"Many Māori parents worry they may be seen as pushy if they keep asking questions."

Some parents with newly-diagnosed children on the autism spectrum are looking for a cure while others take the view they just want their child to be happy and thrive.

"Almost without exception, there are huge fears about sending their children to school."

Brynlea gets alongside children and their families to support the child's communication and social interactions. She is moving to Christchurch soon and Cat is optimistic the Ministry of Education will be able to replace her with another speech language therapist.

"The playgroup model will be more sustainable if we have buy-in from the likes of Ministry of Education and district health board professionals.

"Voluntary models are always more fragile and long-term sustainability remains an ongoing challenge," says Cat.

Heather is the developmental services coordinator and Klara a massage therapist and therapy assistant for Hutt Valley DHB's Child Development service.

"That provides families with support and shows they are not alone. That positive relationship we have with the DHB has positive spinoffs for our families," says Cat.

Funding is an ongoing challenge. The playgroup recently successfully applied for funding to run a gross-motor development programme within its weekly session.



KEY VOLUNTEERS: Louise, Cat and Brynlea are the key volunteers who run the playgroup.

"With this funding we will purchase outdoor play equipment, gym mats and climbing frames. We will create a programme to help our children develop gross motor skills and a love of outdoor play."

The course Cat is doing is the Massey University Postgraduate diploma in specialist teaching. The Ministry of Education provides funding for those teachers wanting to specialise in working with children on the autism spectrum.

"It's an amazing course but I just wish more people would do it. There is just not enough uptake in the community."

The part time long-distance course is over two years or another year if a teacher decides to do a Masters.

The Ministry funding provides tuition fees, travel contribution and study leave.

Cat is paying her own way because she did not qualify as she was not actually working as an early childhood teacher when she applied. Neither does the teacher aide taking the course with her. She just wants to add to her skillset and go back as a teacher aide with that specialist knowledge.

Cat recently appeared on Radio New Zealand's Nine to Noon show where she pleaded for better training for teacher aides and for the scope of the study to be expanded to include former or part time teachers.

"There's definitely a need out there. We've proven that at Spectrum Playgroup. We're upskilling families so they know they have the skills to meet the needs of their children. We're empowering them to take on their next steps, no matter how challenging."



ICE AGE: Water Play with ice is a regular activity at Spectrum Playgroup, dinosaurs frozen in ice is a favourite.

Teaching autistic students who demonstrate 'challenging behaviours' at school or pre-school



Emma Goodall is autistic, an educator and an autism adviser. She writes about how that means she questions everything.

I HAVE demonstrated my fair share of 'challenging behaviours' over the years.

Being who I am has led me to question everything, not the least of which is what we mean by challenging behaviour.

As a result, I initially came to the following definition:

"Challenging behaviours are those that hurt or damage self, others or things/the environment around."

However, after being involved in two years of highly successful trials in schools and pre-schools in South Australia to reduce 'challenging behaviour', I have come to a different conclusion.

For many autistic children and students, behaviours that harm self/others/things present once the survival instinct of fight (or flight, or freeze or flop/drop) has kicked in.

Our survival instinct kicks in when our sympathetic nervous system signals to the brain that we are in imminent danger. The problem is that in autism, as with a range of other neurodiversities, our brain gets the signal wrong. So, for example, anxiety or frustration can be misread by our nervous system and then our brain as danger. This tips us over into survival mode and we enter our default state for us of either flight or freeze/hide/flop/drop or fight. If approached or interacted with in the first two states, this sends signals to the brain that the danger has increased and so we have to 'fight' in order to ensure we survive.

One of the reasons that neurodiverse brains get the signals so wrong is that many of us have an inaccurate and/or low level of interoceptive awareness. Interoception is the sense of our internal self, the signals from our body that indicate our state of being. For example; our temperature, our heart rate, breathing rate, muscle tension, body placement, thirst, hunger, pain etc. This awareness of sensation is governed by our insula in our brains. The way that humans experience emotions is that we become aware of our body state through our insula and then interpret the collection of body states, for example sore tense shoulders with pain across top of the skull in my case is interpreted as frustration. Emotions and feelings are signalled by at least two body signals. If you have a fluttery tummy, but can't read/notice a second signal, it will be hard to identify if you are feeling sick, in love, nervous etc.

When people with good interoception start to feel frustrated or angry or upset, they know this and can do something about it. However, when people, including autistic students, have low levels of interoception or inaccurate interoception, they don't know when they are beginning to feel an emotion as they do not notice the body signals. Often these are the students that seem fine and then, all of a sudden, 'lose it'. Both meltdowns and shutdowns are examples of sympathetic

This approach is not an instant fix, it is a highly effective long-term strategy.

nervous system overload, where the brain signals imminent danger and the survival instinct kicks in. At this point the student is unable to think, their behaviour is automatic.

Through the two years of trials in South Australia, we have confirmed what neuroscience, psychology and occupational therapists are saying: interoception is necessary in order to be able to self-regulate and that we can teach interoception in schools. Neuroplasticity is the concept of brains being able to change as they learn new skills. Through our use of regular interoception teaching (2-3 times a day for 1-5 mins each time), we have found that students, including those on the autism spectrum, develop a greater and more accurate sense of interoception. This directly correlates to lower levels of harm to self/others/things and an increase in pro-social behaviour, such as kindness.

"Interoception is necessary in order to be able to self-regulate and we can teach interoception in schools."

An interoception activity is one that changes the state of the body and the student is guided to notice. So for example, warm up stretches become an interoception activity if the student is guided where they could feel their muscles change. Each person will feel the stretch slightly differently once they actually notice it. However, in the beginning, many neurodiverse students, along with students who have experienced trauma, do not feel anything.

Schools and pre-schools that implement our free interoception curriculum¹ all show significant decrease in behaviours that harm self/others/things within 8-10 weeks. This decrease varies from 30-85% depending on how often teachers pre-empt behaviours by utilising interoception activities. So, for example, in classrooms where teachers encourage individuals to engage in interoception activities as soon as they notice that students are off task, within a term 'challenging behaviour' is rarely seen. Another way of implementing the interoception approach to managing behaviour is to start the day with 20 mins of interoception. In classes, including at special school, where this has been done, students have been able to be co-regulated or able to self-regulate for the rest of the day within 6-8 weeks.

When children can't read we teach them, when they can't write, we teach them. In the interoception approach, when children can't self-regulate we teach them the skills to help their insula work better, which enables them to become aware of their bodies and connect to the way they are feeling and so be able to manage this. All these steps are required in order to be able to self-regulate. Without giving students the opportunity to develop their interoception they will NEVER be able to consistently manage themselves. What this means in practical terms is that in the classroom students who often harm selves/others/things or withdraw frequently, need to develop better interoception.

This approach is not an instant fix, it is however a highly effective long-term strategy. To be most effective it requires

a shift in understanding of 'challenging behaviour' to one that distinguishes deliberate behaviour from survival instinct behaviour and where that distinction is too difficult errs on the side of it being survival instinct. This means that when a child exhibits these behaviours that teachers understand that approaching the child WILL escalate things. Pre-empting behaviour becomes the key strategy, through use of whole class regular interoception activities which we have repeatedly shown decrease the sympathetic nervous system activity in students (i.e. calms them down on a bio-chemical level). Once students become aware that interoception activities help them to 'feel' and to 'feel better', they can be prompted to do these at regular intervals throughout the day.

Autistic students have reported that after one or two terms of daily interoception they are now able to self-regulate and manage life much better. Additional activities to support areas of interoception that we cannot teach such as thirst and bowel health have also been shown to positively impact on classroom behaviours. A hydration chart is used to enable students to know when they are optimally hydrated to seriously dehydrated. Our data indicates that students who are dehydrated exhibit far more behaviours of harm to self/others/things. Data from across pre-school to high-school has shown that the use of hydration (or urine) charts improves focus and engagement in learning whilst decreasing behaviours of harm. Teaching around the hydration chart involves a discussion about what colour (clear) and smell (none) urine should have if we are optimally hydrated and why we need to be hydrated (our brains require water to work properly). Hydration/urine charts can be placed on the back of toilet doors and students encouraged to drink when needed. Most students love this simple strategy to improve their wellbeing and want to ensure their family members are also optimally hydrated! Our pre-schools and special schools have found that their children are able to self-manage drinking

after a short time and this results in massive improvements in behaviour and engagement in learning.

We also use Bristol stool charts to empower children and young people to take control of their bowel health. This is because we had data from our Centre for Disability Health that indicated that the number one cause of challenging behaviour in students on the autism spectrum in South Australia was constipation. For those of you who have never had constipation, it is an incredibly painful, and dangerous condition. People, including children, can die from untreated constipation. However, for many autistic children (and adults), they do not know that they are experiencing pain and so do not seek help or treatment. Their brain however, is receiving the pain signals and this increases the sympathetic nervous system response. As it ramps up and the child, young person or adult is oblivious to this, they can't and don't do anything about it, which means it keeps ramping up until it overloads and results in the survival instinct kicking in. Teaching students about bowel health using the Bristol stool chart, we have been able to refer families to their GP to seek support to manage constipation. This has always resulted in decreasing and even eliminating behaviours of harm.

Families can use all these strategies at home for children of all ages, including parents themselves. I personally have improved my interoception through these activities and as a result am much better at self-regulating my emotions².

Dr Emma Goodall (PhD, MEd, Bedhons) is an autistic, educator, author and researcher. She is the senior autism adviser for the Department for Education and Child Development in South Australia.

Resources:

¹<http://web.seru.sa.edu.au/pdfs/Introception.pdf>

²<https://mindfulbodyawareness.com/resources/>

Relief care makes difference in family's day to day life

NOAH LI loves Māori TV – but not just any old Māori TV. For Noah, who has autism and Down Syndrome, it must be in te reo on Freeview channels 5 and 15.

When Noah's father Chris lists relief care jobs at Mycare, you can guess what he and his wife Florence are looking for in supporters for their son. The favourite channel and proximity to their Tawa home makes a happy pairing for them all.

Relief care for a few hours at a time makes all the difference for the Li family, allowing Florence and Chris to catch up with errands and chores.

"We need that space and time every now and then. With Noah at home, it's hard to do simple things like vacuuming the floor or mowing the lawn, because he doesn't like those noises."

On weekdays, Noah attends school, but for more than a year now, Chris and Florence have been using Mycare to find and hire relief carers for weekends and school holidays. Chris says it's been fantastic for giving them a break.

"They're good people," he says of the workers they've found at Mycare. "We need short-term respite care so we don't worry so much about a carer's age or skills, but more about how they will help Noah do what he wants to do. Even though Noah doesn't understand Māori, if you've got a TV with Māori Freeview channels, that will do the job! That's autism!"

"TV is the main grounding thing for Noah. He's stuck on watching that routine, and when he's watching the same channel he settles in within half an hour.

That's what makes him happy."

Previously, Chris relied on word of mouth to find relief carers, "just asking around people in Tawa if they had friends who could do the job". The options were limited.

When a friend suggested the family try Mycare, Chris quickly got the ball rolling.

"It was easy," he says.

"I looked through the people advertised (at Mycare) who were close to where we live, contacted them by phone, and that was it – it happened straightaway."

Seeking quality relief care is an ongoing task for parents like Chris and Florence, so Chris says he's rapt there's another resource he can count on.

"Mycare is a big website, covering the whole country, so there might not always be a lot of people living in my area, but over time, quite a few have come up."

Ultimately, Chris would love Noah to have a network of five or six trusted relief carers, and he's using Mycare to find them, looking ahead to the future when Noah turns 21 and leaves school.

"I can't rely on just one or two people because they might not always be available, and then we'd be stuck," says Chris. "I need a handful of people so we can rotate around. It's good for Noah too, to go to different people's houses, to help normalise his life a bit."

• www.mycare.co.nz

Mycare helps people to find the support they need in their local community.

The education system for school-aged children with autism



When it comes to accessing supports in education for children with autism there are no clear and consistent pathways across the country writes Altogether Autism researcher Rebecca Armstrong.

THE AMOUNT of support a family may receive by way of education if their child is on the autism spectrum will vary across the country.

It depends on the severity of the needs of the child, the decile rating of the school, the availability of services and specialists, and the attitudes and priorities of the school.

The priorities of the Ministry of Education are to assist children to join in and learn alongside peers in an inclusive environment (Ministry of Education, 2010).

Establishing individual needs

If you feel like your child needs extra support or you have concerns regarding their progress it is recommended to discuss this with relevant people to get further advice. This may include your doctor, the teacher or principal, staff at the local Special Education Office, a Special Education needs coordinator if your school has one, your iwi health authority or the public health nurse. Once the kinds of needs are identified and discussed then the best types of supports may be identified (Ministry of Education, 2010). There are a number of learning supports available through schools and the Ministry of Education (MOE).

What are the special education provisions?

Special Education use the words 'moderate', 'high' or 'very high' to categorise a child's needs and determine the amount of funding that may be allocated. Children with moderate to high needs (4 per cent of school aged children) are expected to be supported by their school using school based funding and services.

- **Special Education Grant** – Schools receive a grant to support all their children with special education needs. The number of students on the roll and the decile rating determine the amount the school receives. Schools have the discretion to choose how their SEG grant is allocated.
- **Resource Teachers: Learning and Behaviour (RTLb)** – RTLb are specialist teachers who work across a number of schools. They support schools to manage additional learning and behaviour needs of students. This usually includes supporting teachers to manage different learning requirements, implementing class or school wide strategies and /or work directly with the student or small groups of students. RTLb funding is calculated using the number of students on the roll and the decile of each school in a cluster. Your child's classroom teacher would be the person to speak to about getting a RTLb support.
- **Moderate support for physical, hearing, vision** – Your school can call on specialist teachers in the child's area of need e.g. resource teachers: Vision. Physiotherapists and occupational therapists provide support if your child has a physical disability. The aim of this service aligns with the overall aim of assisting your child to join in and learn alongside peers – whatever that may look like.
- **Regional Health/Hospital Schools** – A teacher from a health school can teach children when a child is too unwell to attend school, is in a health funded mental health

There are a number of learning supports available.

programme or is returning back to their usual school after a period of absence. It is available from year 0-13 in Auckland, Wellington and Christchurch. However, teachers are still available throughout the country.

- Depending on your child's needs you may also be able to get assistance through the MOE for transport to school, special equipment and modification/accommodations to school buildings (i.e. a fence built around the perimeter).
- If children are classed as high needs or very high needs (less than 3% of school aged children) they may also be eligible for services provided by the MOE, including:
- **The Ongoing Resourcing Scheme (ORS)** – The government funds ORS and it is designed to provide specialist services for children with the highest needs. There is very specific criterion to meet to qualify for ORS funding and generally only the children in the top one percent of high needs are funded. To qualify students must have ongoing extreme or severe difficulties in learning, hearing, vision, language use or communication.
 - **School High Health Needs Fund** – If your child has high health needs (e.g. epilepsy) this funding may be available for a teacher aide.
 - **Severe Behaviour Service (SBS)** – This service is for students in years 1-10 whose main difficulties is their behaviour which significantly impacts on their own or their peers' learning and safety. Schools apply for this service in consultation with parents. Referrals are made through your local Special Education Office. A psychologist or a specialist education advisor will provide support for the child, your family/whānau and your child's teacher.
 - **Intensive Wrap around Services** – This is part of the SBS. A small number of children with high behaviour, social and/or learning needs may be eligible for this service. Needs must be complex and challenging across environments. The idea of an IWS is to provide support at school, at home and in the community. Referral is made after consultation with school and parents or caregivers, by MOE Special Education staff, the RTLb or ORS fund-holding school.
 - **Communication Service** – This is to support children who experience difficulties with talking, listening and understanding language. This is usually focussed on children in their first three years at school. A speech and language therapist will assess the individual's communication skills and identify the needs. They may work one on one with your child or train teachers and other support staff to identify and adapt classroom programmes to meet the child's needs.

Individualised Education Plans

An individualised education plan is a collaborative process for addressing your child's individual needs and how these will be met within the school environment. It includes detailing individual roles and responsibilities and identifying strategies for addressing different specific needs such as those relating to learning and behaviour. They are living documents and are reviewed regularly to track progress and adapt criterion

for success when necessary. A plan involves a team of people that support your child such as educators, teachers, specialists and ministry support team. The team includes family/whānau, peers, and friends. The child is also encouraged to be involved and provide input.

In summary there are a number of services offered through Special Education and schools. This is only a basic overview of what may be provided by schools or the MOE. It does not detail independent services. If you would like more information on these services or other supports available please contact Altogether Autism on 0800 273 463 or enter a request for personalised information on the Altogether Autism website.

If you would like to know how to apply for the funding or if you are unclear about any part of MOE's service and have questions about the help your child or student may receive

please talk with staff at your local Special Education office, or call the Special Education information line on 0800 622 222.

Rebecca Armstrong, MAppPsy, is a researcher for Altogether Autism and Parent to Parent.

Useful Resources/links

- Links to resources for working with students with autism: <https://www.education.govt.nz/school/student-support/special-education/supporting-children-and-young-people-with-autism-spectrum-disorder-asd/resources-for-working-with-students-who-have-asd/>
- New Zealand ASD Guidelines: <https://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline>
- For a comprehensive list of learning support and links to further information see: <https://www.education.govt.nz/school/student-support/special-education/>

References

Ministry of Education (2010). Services and support in special education for children at school: Information for parents and caregivers for children with special education needs. Retrieved from: <https://parents.education.govt.nz/assets/Documents/Special-Education/Services-and-Support-in-Special-Education.pdf>

Autism awareness ride to train more educators

Just over two years ago Sarah Blythe and her partner were told by the early intervention team that her son Neko was on the autism spectrum. It has been a journey of discovery for them resulting in a fundraising ride for autism. This is her story.

GETTING A DIAGNOSIS of autism for Neko when he was four, gave us answers finally about why he behaved the way he did and we thought it would help others understand. Sadly it hasn't that been easy along our journey.

Before Neko started school I asked to see a paediatrician to get an 'official' diagnosis.

Neko, now 6, attended an amazing early childhood centre and kindergarten. Both were fantastic in the way they supported us as a family and helped Neko achieve the best he could in his learning environment in social situations where sometimes he struggled.

Our wee boy was happy and achieving so well.

We hoped, when he started school in 2016, the Ministry of Education would offer us more support, but it was not as smooth as in pre-school. Simple things like even getting him there became a struggle.

My once happy boy started changing; he was unhappy and would often become angry easily once he got home. He would have a meltdown as he felt this was his safe place and had learnt to hold it together all day.

He was in time out a lot in school and I did not feel I had the full support of his teachers and that they understood him. He was just seen as being naughty for pushing or hitting as he didn't have the social skills to be able to say how he was feeling.

Once we were told he did not have autism and that it was our parenting. It was heart breaking to watch and very upsetting to be basically told that you are not doing your best job as a parent. We ended up pulling him out of that school.

We then moved to a smaller town where we found the perfect school for our son and he settled in amazingly. His new school follows the walker learner approach and he adjusted so well.

It is great to have an awesome bunch of teachers on board that communicate and listen and support our boy the best they can so he can achieve.

After our first experience, my heart breaks not only for Neko, but for all those other children on the autism spectrum who are so misunderstood. There are a lot of people who still do not have any understanding about autism.

You do not see people standing outside the supermarket spreading awareness and fundraising like you do for other conditions. So it got me thinking that I wanted to do something to help.

I thought why not spread the message or organise a ride for autism awareness?

I got talking to a lovely guy who had organised a similar one for a different charity. He was a great help and pointed me in the right direction.

Then I thought about what I would do with the money raised from the event?

What better way to spend it than use it to help educate our child educators as it is not a part of their core teacher training.

I feel every teacher deserves the right training, and every autistic child needs a teacher to understand them to help them succeed at school.

I feel by organising this ride on Sunday March 4 and talking about autism, it will open the door to help others understand, to help educate and build acceptance for all those children and adults living with autism.

We need to remember not every disability is visible.

Neko is my motivation for this ride. Seeing the struggles he has had has pushed me to want to do something. I want others to understand and accept him and not only him but all the other people out there on the spectrum.

This has been a huge challenge for me but totally worth it. I've been lucky to have the support of my mother helping and so many amazing other people jump on board to help and be a sponsor.

I truly believe alone we can do little, together we can do so much.



FAMILY AFFAIR: Sarah Blythe, her partner Codie, and sons Neko and Mataeo.

Challenges parents face having their child's needs met or accessing support through the education system



Autism is complex. It represents itself in children in different ways and by gender. Lynne Hansen looks at the challenges parents face in having their children's needs met and how they access support through the education system.

CHILDREN WITH high-functioning autism run the risk of being misunderstood due to their more subtle differences, traits and difficulties.

Referral for assessment of autism spectrum disorder (ASD) may be delayed in these children, especially girls, as people have not recognised that their challenges are explained by autism.

Once a referral for assessment of autism is made, there are differences around New Zealand regarding where the assessment takes place, who does the assessment and how long you will have to wait for an assessment. In some parts of the country wait times are up to two years.

It took nearly three years for my daughter Amy, now aged 9 ½, to get an assessment.

When she was five, a private psychologist said Amy showed traits of autism and gave a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) which we now know is not the case.

What that meant for us as parents was that we could not access much support if any while she was attending an early childhood centre and were often phoned by teachers and asked to collect Amy from the centre due to behavioural issues.

My understanding is it is harder to assess girls at an early age for high functioning autism even if difficulties are present due to the appearance of social skills as well as being good at masking social deficits, so often the need for a diagnosis is not always apparent or it is missed or the child is labelled odd quirky obsessive etc.

My husband and I knew when Amy was two that there was an obvious difference in her developmental stages and communication difficulties were clearly apparent at an early age. There was, as well, extreme behaviour which highlighted to us that she was frustrated in not being able to communicate effectively her needs and struggled to regulate herself in situations that made her anxious.

Those early years were tough.

My husband, a director and manufacturer, was very busy working in the business and away at various times. I was studying and trying to be the best mum I could to our lovely daughter and hold it all together.

We sought help from various sources such as our family doctor, we attended family counselling, private specialists and had dealings with an early intervention teacher who came in to support the early childhood centre around Amy's behaviour. A speech therapist assessed Amy but ASD was not mentioned.

The second challenge was understanding the Special

Parents are emotionally charged which can be misunderstood by educators.

Education processes.

Before Amy's diagnosis, my husband and I worked with the primary school to support her and support the teacher around managing her extreme behaviour. I even recall writing a letter giving the teacher permission to physically remove Amy from the classroom if need be.

That was awful and a very challenging time for our family. We did not understand why she was the way she was nor did we understand the process to access Ministry of Education (MoE) services. Nor did we understand the role of the various people such as the resource teacher Learning and Behaviour (RTLb) and we were very reliant on the Special Education needs coordinator (SENCO) at Amy's school to push for this.

Lucky for us we had a proactive supportive principal who applied straight away to Special Education to access their educational psychologist, to build a plan going forward to support Amy on a daily basis. However we did not have enough support to fully understand what was happening.

I remember going to our first individual education plan meeting not even knowing what it was or what my role was in the meeting as

a parent or what I needed to do to prepare for the meeting.

People who worked in the education system and understood the process, ran the meeting with me as a spectator, leaving me feeling disempowered and once again uninformed. Yet I was probably their greatest resource.

The power of knowledge and good relationships

Thankfully four years on Amy has a clear diagnosis of autism so we know what we need to manage and where we need to support her.

I became more knowledgeable about autism and confident about parenting a child with autism. I now work as a coordinator and facilitator for Altogether Autism.

I run most of my daughter's individual education plan meetings and work closely with my daughter's school providing daily support and information and strategies that are needed at the time as these are a moving target!

I have built a strong relationship with my daughter's school working alongside them, often asking: "What do you need from me, how can I support you?"

The third challenge is communication. Often parents struggle to communicate effectively what they want for their child and sometimes they struggle to articulate their wants and desires for their child in collaborative meetings. On the other hand the school or educators often don't initiate communication with the family unless there is a problem, leaving parents feeling dreadful. It is so critical for teaching

staff to keep communicating regularly with the parents and share good news stories as well as the challenges.

The fourth challenge is how to manage expectations. My work with families who have children with autism means I have learnt that expectations from both parents and the school are often not clearly defined or communicated effectively initially or in an ongoing way, leading to a breakdown in the relationship between parent and school.

Parents are emotionally charged which can be misunderstood by educators as parents placing unrealistic expectations on schools when in fact they are just wanting support and acknowledgement of their child's individual needs and their personal journey.

While in some cases parents don't feel they can place expectations on schools particularly if their child comes with behavioural issues, in other cases parents may have expectations that cannot be met. I see parents move their children from school to school placing huge expectations on schools and educators because they do not understand the environment with which the school operates or the correct process involved in negotiating issues with schools or school boards.

Once issues get to that stage the relationship is broken between both parties as parents are seen as intrusive and unreasonable. What schools and parents need to do is make it clear what the working relationship should look like going forward and confirm that the expectations placed are reasonable.

Having resources and timeframes provides the fifth challenge.

Once a problem is identified, it seems to take too long for support to be put in place which increases the chance of more issues developing for that child be it behavioural or educational. To be told that school resourcing is very limited and that MoE staff have a huge workload and long waiting lists can be crushing. I have also found some MoE staff intrusive and lack compassion in their dealings with some families as clearly they are fatigued and overworked.

In some cases the level of support from the MoE or RTLB services seems inconsistent and reliant on the skill set of the individual staff member.

Working alongside families over the past four years I have been in many school meetings and been disappointed at the level of knowledge on high functioning autism and how to effectively support a child so they can be successful in the school environment.

At the same time there are times when people step outside of their role and offer opinions that they should not. I will never forget a teacher saying to me when Amy was five: "I know what autism looks like and she is not autistic".

From this teacher's collective teaching experience over years of teaching she placed herself in the expert seat. (Only paediatricians, psychologists and psychiatrists are able to make a formal diagnosis of autism.)

Teachers and MoE staff need to be prepped or given a process, guidelines or even a structure on consulting with or talking to parents about children diagnosed or undiagnosed around supporting their individual needs.

Here is an example of a positive and effective approach. My husband and I fund a lunchtime programme in my daughter's school to create a safe environment for children who are like Amy to go to and do something they enjoy. It's a creative club where they do art etc and is very successful. Amy runs it with the help of the teacher. It not only gives her a self-esteem boost but supports other children. This is a proactive approach as opposed to reactive behaviour management.



OUT WITH MUM: Lynne Hansen with daughter Amy.

If I had one dream it would be that every primary school would invest in this. In my ideal world, teachers and special education staff would be knowledgeable about working with children with autism, there would be more consistency in the help that people get, parents would understand what was available and what to expect, parents would be considered experts on their child and an equal member of the team and be consulted by school staff about what works and what doesn't for their child. It would be great if flexible teaching was the norm and educators looked at ways to build on an individual's abilities or strengths and to support the development of the child's interests.

I would like to believe that our schools have a broader vision and lose the old thinking and look past the differences and challenges that our children present with, instead look at ways to manufacture opportunities where they can grow and learn.

CORE ISSUES

1. **Lack of training** for Ministry of Education staff, teachers and support staff.
2. **Clarification of roles** – Special education needs coordinators operate differently from school to school dependent on their skill set which leaves room for individual interpretation.
3. **Process** – Ministry of Education needs to have a clearer process for parents to understand how to access support and resourcing for their child. That process should include who and how and what, give a clear timeframe and follow a child right through the education system.
4. **Advocacy service** – At present there is no such thing, we need to be able to walk alongside parents at times they are exhausted and to be able to offer independent advocacy support, to help them navigate a system that seems all too hard to understand.
5. **Resourcing and timeframes** – This is always an issue that comes up in school meetings, schools often say they have no resources they learn on the run.
6. **Working relationship** – Supporting a child with autism is a moving target and their needs change.
7. **Old thinking and old working model** – It would be great if educators looked at ways to build on an individual's abilities or strengths and to support the development of interests where flexible teaching is the norm.
8. **Behaviour support** – The Special Education service within the Ministry of Education is the only place a school can access and build a plan to support a child with autism and behavioural issues. There is usually a lengthy wait list.

How Dragon Ball Z got Timothy through high school



*Music, poetry and a desire to help others in the Hamilton community are key to survival for Timothy Folkema today but as **Mary Anne Gill** writes, it was all so different when he was a bullied teenager because of his autism.*

WHEN A TEACHER AT Havelock North High School 14 years ago opened up her classroom for three days each week during lunch-time, she was not to know it would make such a difference in Timothy Folkema's life.

Timothy, who had been diagnosed with autism the year before while at intermediate school, describes the teacher as a "genuinely good person" who gave up her lunch break to ensure there was a place for the bullied teenager to hang out with his friends.

Today, the 27-year-old community support facilitator with Progress to Health* in Hamilton talks about how "us alternative people" could go in and play card and computer games without the irritating "pesky little flies" (aka bullies) making their life a misery in the corridors.

Dragon Ball Z got him through high school, he laughs.

Timothy was born in Wellington in 1990, the younger of two boys. The family moved to Havelock North when he was about seven into a Spanish mission art deco house across the road from Havelock North Primary School.

"Some of the worst years of my life actually was the school. Some of the teachers would verbally abuse me and the students would physically abuse me because I was seen as different."

He had a variety of health problems, including a visual impairment, so his autism went undiagnosed until he was 12 when a group of visiting trainee psychologists were in Havelock North doing free diagnoses.

"I remember even before I was diagnosed I reacted in certain situations that were different.

"The kids used to bully me and I did not know how to respond and I was not raised to respond violently so I wouldn't. I would do weird things like try and speak to them in German to do something different, I was looking for a way out of a situation where those people were hurting me."

The bullying continued at intermediate school.

"I had many, many situations where I had suicidal ideations. I had friends who had ended their own lives. I didn't know about self-harming or that sort of thing. It sounds horrible but I didn't know it was that easy to end your life. I could really have ended my life.

"I felt I had no support. My parents had always said: 'We'll let God sort it out' so they didn't invest in any counselling."

He supports that stance though as he feels God did sort it out and is a great believer of a cooperative approach with the physical and spiritual realms.

In his last year at intermediate, he met another guy who was autistic and who loved Pokémon.

"I was fascinated by him, a really interesting character. He would run around the school playing these Pokémon games in his head, imagining his whole world with Pokémon characters everywhere."

Timothy asked if he could enter his world.

"He started describing everything he saw. And I thought 'kids are mocking this guy and beating him up because he's

"Education is in drastic need of a shake up when it comes to autism"

different and here he is with this whole world inside his head."

It sparked a friendship which continued into high school. There they met another boy who was autistic.

"We formed a group and we got into trading card games."

The main one was Dragon Ball Z, which follows the adventures of Goku who defends the Earth against villains.

The three friends had nowhere at school to do their duelling and battling other than in the library which, because it was a quiet place, meant they could not be their usual vocal selves.

If they played it in the corridors, the "pesky little flies" would turn up.

"They would poke us, annoy us and wind us up because they knew they would see some fireworks."

His friends' trigger points were easy to spot and they resulted in classic, violent meltdowns which Timothy struggled to understand.

It was then the teacher opened up her classroom.

"It was a safe space. Even those kids that used to wind us up, they'd come and get involved. They wouldn't press our buttons because she was sitting there, eating lunch, chatting with students, she was really chill. It was a non-invasive kind of relaxed atmosphere which was really useful."

It resulted in a good learning environment.

"When you are looking forward to something, the neuro science is pretty basic. If you want to do something, then your mind is going to be open and receptive. We'd be more open and better at learning things.

"Then, after lunch, we'd had that thrill and excitement. For the next two classes, we were totally amped; in a positive mode and learning."

In his role today at community-based Progress to Health, Timothy talks to a lot of schools about how to support people living with disabilities and long-term health conditions.

The organisation has particular expertise in facilitating support for people living with mental illness.

What that teacher did at Havelock North was not part of any programme, he says.

"She wasn't doing it to tick a box, she was just a really genuinely good person. She saw a need and decided to fill it."

JUST AS TIMOTHY and Havelock North High School were gelling and he had a trusted circle of friends, his parents moved to Hamilton.

"I lost everything. I was just starting to get into a space where I was comfortable with people. On one hand though, it was kind of sad, but on the other, I could develop a new me. I was in a space where no one knew who I was.

"People saw me (in Hamilton) as an individual and they just treated me like anyone else."

He was good at two subjects, English and Music and was a very good pianist.

When he left high school, he enrolled in the Bachelor of Media Arts and Design course majoring in commercial music.



FUNK THERAPY: Timothy Folkema – keys/organ, second left, with Chris Field – bass, Matthew Mooney – drums, Tevita Tuvuki – vocals, Farai Zvingwe – emcee, Daphiney Owen – vocals. **LOOKING AHEAD:** Timothy Folkema.

He also learned how to teach English as a foreign language.

"I was putting in a lot of energy. With my autism, my way of learning isn't neurotypical. It was a lot more challenging for me because these things are designed around being neurotypical."

Autism, he says, is a part of who he is although lack of education means the majority of people he meets do not understand.

"Whether I choose to say I am a person with autism or I am an autistic person – at the end of the day Tim Folkema is Tim Folkema."

Education is in need of a drastic shake up when it comes to autism, he says.

"Kids who are 16, 17 or 18 have left school with no qualifications because school was such a traumatic time for them. They don't want to go back to study, let alone go back to school. Many of them are living off their parents, in their room playing video games.

"It's not about whether schools should implement programmes or design something. What they need is if they have to design anything, they should co-design with autistic people. It should be flexible enough to accommodate different people on the spectrum.

"If you get a whole bunch of autistic people to design something, it's going to look completely different from what some neurotypical teacher because of their training or research, think it's what an autistic person needs.

"In our heads, we're translating this way, way differently."
So what's the answer?

"Part of my response has always been by the community for the community. We need autistic people in schools, educating or being teachers or doing something.

"We need more of our community involved in the wider community to help effect change. Otherwise we're just going to be facing these same terrible results, like youth suicide.

"They're (schools) trying to do the best thing in their opinion

but they never bother to ask us. And so it ends up becoming detrimental and harmful to who we can be and our potential as human beings."

After he graduated from Wintec as a music producer, Timothy formed a band, Funk Therapy and they made the final of Battle of the Bands in Auckland last month (December) where he was named best instrumentalist.

The band performs regularly at Nivara Lounge in Hamilton playing hip-hop, funk, jazz, rhythm and blues, Latin, metal – you name it, they do it.

You Won't Be Forgiv'n

I am me
My own little self
Left to my own devices
I am mocked
Laughed to scorn
It's not at all the nicest
Why should I care?
What will they do?
Lower my self esteem?
All I care about is the weight of my bag
It's pretty extreme
To all of those bullies out there in the world
Think.
What life are you living?
Re-consider your choice in mind
– you won't be forgiv'n.

Timothy Folkema – Age 13, March 2004

"Music is a therapeutic source, it's the main outlet for me. When energy becomes too much for me, I turn to music. If I struggle to process emotions, I will put that out on the piano. I play anything, I write songs. That's the output of energy for me through the fingers at the piano."

He wrote poetry when he was younger. He penned one called "You Won't Be Forgiv'n" when he was 13 about the kids who were beating him up (see graphic).

His mother sent it to Dr Tony Attwood, a world renowned clinical psychologist known for his knowledge of Asperger's Syndrome.

"He replied back that it was a really nice poem. That poem definitely says something about the 13-year-old me."

The 27-year-old Timothy has other ways of proving who he is now and how his concept of community can work for him and

others on the autism spectrum.

He tells about how it blew him away when a mother broke down in tears when he described himself to her.

"You've just said more about my son in 10 minutes than I have known in his lifetime."

- * Progress to Health is a community-based organisation providing support to people with long-term health conditions and disabilities. It has support centres in Hamilton, Ngaruawahia, Tokoroa and New Plymouth.
- Dragon Ball Z is a Japanese anime television series which developed into a gaming franchise both online and on video.

Future schooling and girls on the Autism Spectrum



*Retirement from education after nearly 40 years teaching meant outgoing Tauranga Girls' College principal **Pauline Cowens** could reflect on the increased awareness of autism in girls and the potential for technology-enabled learning to enhance their success.*

WHEN I BECAME a principal 17 years ago, I cannot recall the term 'autism' ever being used as a descriptor for those girls who were misreading social signals, were challenged to communicate and interact with others and found flexibility of thinking difficult.

Fast forward to 2017 and there are now girls at every year level in school whose profiles of social interaction make the use of the term autistic useful shorthand for describing their behaviours and to alert educators to the challenges our current learning environments may create for them, and that we may need to help them overcome.

In recent years the greater awareness of the many ways in which autism can present has led to more frequent diagnosis. Identification means that communication with these girls and about these girls is facilitated. In the context of future learning, this increased rate of identification and awareness of autism sensitises educators, individually and at a systems level, to the needs of these girls.

As principal of a large girls' secondary school, I recently took part in our annual middle leadership development days. There was discussion on future learning that is technology enabled (e-learning). We reflected on what changes technology is bringing to girls' access to learning and how to support their success in the techno-enabled learning journey that is now part of their lives.

The central theme of our discussions was basic communication, how that is changing in this techno-based world, and the implications and opportunities to be used to the best advantage of girls. Words such as curiosity, creativity, flexibility, resilience and empathy emerged to describe our future learners' skill development. I reflected that these words were in direct contrast to the profile that we understand as the autism spectrum.

Creating conditions for girls to accept failure, accept shades of grey rather than black and white, be explorers who learn with and from each other was identified as the future challenge for all girls. I wondered how much greater this challenge might be for girls with autism, who may prefer to work alone and to focus on intellectual rather than social pursuits.

I had other questions. How do we ensure that in planning towards the future we are more inclusive of our girls on the autism spectrum and ensure their potential is unlocked, giving them success equal to, or beyond, that of their peers?

Do we, when we accept that girls will be quieter, more compliant, 'calmer', contribute to the masking of autism in the school environment? Is a girl who is quietly content with her own company, who minimises social interactions, less visible than a boy who does the same? Do we then miss that she views the world with a different brain, through another lens. What is our responsibility as educators to be alert and aware of that possibility?



Technology is an enabler of individual learning; can we harness that to advantage those with autism to take better advantage of the learning environment?

Back to the theme of communication, flipped now to include the affinity many on the autism spectrum have for interacting with and via technology. For these girls there is comfort that comes from technology use, enabling access to the world around them, and learning at their own pace and to their passions. Can the potential that exists in shared technology communication be better utilised to be inclusive of our autistic girls' particular gifts? Can that dimension be recognised and unlocked, for our girls, and for parents wanting to understand the school journey?

Lots of questions and, for me, one thread of potential; that in the move to student-centred, technology enabled learning, we need to create useful questions that teachers should be asking around autism awareness and inclusion. Not how to include in the same way that we do for all students, but how to work with the autistic student and with their family, to capture things such as their technology lens and ensuring technology plays to their strengths.

When we can recognise that autism brings strengths as well as challenges, then we may have a change agent for the face of education and inclusion.

Pauline Cowens grew up in Rotorua and attended Rotorua Girls' College. She entered teaching in her early 30s working at schools in Auckland and Hamilton where her main subjects were science and biology. She was teaching at Waikato Diocesan School for Girls when she accepted the associate principal job in Tauranga in 1999 and then a year later the principal's role. In her retirement she plans to use the time now available to her to continue to be a learner and explorer, contributor to education, silversmith and writer. At least that is the current bucket list.



WINNER: Youth Guarantee Most Improved award winner Angelo Scott with his cookery tutor Bill Bryce.

Youth Guarantee award winner's big moment

WHEN ANGELO SCOTT won the Most Improved award at the 2016 Ara Youth Guarantee Awards, it was an emotional moment for the whole family, father Peter Scott says.

"We weren't expecting an award. It's the first time in his life he has won anything. It was a big moment for us as well. I burst out crying. The lady next to me asked why I was crying and I said, 'that's my son', then she started crying and my wife was also crying!"

Angelo's training at Ara Institute of Technology, Christchurch has been a big journey for the whole family. Angelo has autism; a developmental disability that makes learning difficult and social interaction challenging. After secondary school, he joined Workskills, a supported learning programme at Ara designed especially for students with intellectual disabilities. He was then able to transition into the Youth Guarantee programme, a fee-free training programme for 15 to 19 year olds, supported learning stream - the only level two supported learning programme in the country.

Tutor Bill Bryce said that Angelo's improvement in his Youth Guarantee supported learning cookery class had been "exceptional".

"When Angelo first arrived, for the first few days I was worried. He was not sure how to hold a knife properly and was very quiet. At the start he would not try things because of lack of confidence and would expect help but not ask for it.

"However his improvement has been exceptional. In cookery he is excelling. He will now attempt tasks and will ask for help directly if he needs it. He always tries hard. He smiles now, whereas at the start he was quite frightened. He beams, especially when I tell him that he has done something well."

Seeing this young student blossom has been hugely rewarding. "I seem to have made a connection with him. In fact I would like to think I had a good connection with all

the students. They have all improved so much, but Angelo perhaps had further to come than most.

"I have 18 to 19 years of experience in teaching. As I come to the end of my teaching career I have been doing the odd bit of thinking back and reflecting. It feels a bit like everything I have learned so far has just been preparation for teaching these type of students. I do find it very rewarding, stimulating and challenging of course."

Angelo's parents have nothing but praise for the programme and the staff. "We are full of admiration for Ara; the way they have treated him and us as well," Peter says. "We are just blown away by the whole thing. We can see him going forward, coming out of his shell, he is responsible and just so happy. He has not missed a day of class; even when he was a bit sick he insisted on going.

"For us it is a 100/100 result."

Angelo has been cooking at home too. Asked how he liked his cooking class, he said it was "really cool".

The awards ceremony were the icing on the cake for all concerned. "He had a huge beaming smile on his face and held eye contact the whole time when he approached me for his award," Bill says.

"I think we made a good choice."

Angelo is still at Ara and is now in the Humanities department furthering his skills by continuing with the life skills' course. He will finish next year.

Tutors Barbara Ross-Davis and Lesley Ryan have achieved excellent results with Angelo, says Peter.

"We are so pleased we were able to get Angelo in at Ara as they have done the most wonderful job with him."

When he joins the workforce sometime later this year, he will have the skills to support him.

Variability in support services for tertiary students with autism



Christchurch-based registered clinical psychologist, with a specialty in working with adults who have Autism Spectrum Disorder, Charlotte West has first-hand experience of autism with three sons on the autism spectrum. She writes about that and the challenges her clients face.

SERVICES FOR CHILDREN and adolescents on the autism spectrum in Canterbury have increased greatly over the past few years, but there is still great variability in services for autistic adults.

Clients are often referred to a clinical psychologist by their doctors or by the Canterbury District Health Board. They present with a range of difficulties: most often depression or different forms of anxiety. Some are survivors of sexual abuse while others are tertiary students who struggle with their courses.

Over the past few years I've met a number of students who feel so overwhelmed by their studies and university life that they choose to withdraw from their studies. I see them at their most vulnerable, feeling alone and believing they have failed. Their sense of failure isn't restricted to academic subjects, but includes managing the demands of social interaction, time management, and self-organisation all of which are important for students to accomplish as they move into tertiary study.

When students who have a diagnosed disability attend tertiary institutions in New Zealand, they can access help with their learning through support services at each institution.

Usually an individual support plan, outlining the specific unique challenges and needs of each student, is drawn up. This plan is given to teaching staff at the beginning of each academic year, to explain their students' differences. It allows them to develop a "reasonable accommodation", a kind of "workaround" permitting assessment of learning which meets requirements for the course while recognising the student's difficulties.

"Reasonable accommodation" for disabilities is mandated in the Human Rights Act (1993).

These support plans should include full details of the way each student's autism impacts their ability to succeed, including - difficulties with social communication. Individual strengths should also be included in the plan. The individual learning plans should also accurately describe the student.

The university's Disability Support Services (DSS) team explained that lecturers are given a comprehensive research-based reading selection to help their understanding of autism. Each lecturer should have had some idea of all their student's difficulties.

It's become personal now. I have three sons, who are 27, 25 and 19 years, all with autism, and all with unique strengths and challenges. They remind me that if you meet one person with autism, you've met one person with autism. This understanding is basic to those who work in the field of autism.

My youngest son, after a schooling experience which allowed him to flourish, set off to university bright-eyed and bushy-tailed. My heart sinks as I watch him struggle with the very things some of my clients have had to contend with, losing confidence and hope. His learning support plan is very similar to the plans of other students I've worked with. I don't see him accurately reflected in the plan.

My dream would be to see all tertiary institutions deliver standardised disability support.

Despite the best intentions of the DSS, the core characteristics of autism as they impact on my son's functional skills are only partially detailed. This led me to explore some of the other tertiary institutions in Canterbury.

Ara, which is our local polytechnic, has to my mind the most comprehensive information on their website. It explains how students are supported, the kinds of disabilities which can be assisted, and information about many different learning needs. It includes a Melbourne University document about transitioning to tertiary studies, which I think is very good. Ara uses a similar format for an individual Access Plan as Canterbury University does for their Learning Support Plan, drawing up a description of strengths and disability-related needs, and lists the supports that will be put in place. This is then sent to the student's lecturers.

Lincoln University produces a one-page summary of autism and functional skills impacted, which is easy to read and

absorb. In addition each student has an individual Learning Support Plan. Both are given to the teaching staff to raise awareness of their students' needs. Each individual has a time-tabled, regular meeting with their support staff, for difficulties to be addressed and supportive connection.

Christine Brennan, Ara Disability Service co-ordinator, told me that Disability Service staff from the Canterbury tertiary institutions "collaborate with each other with a goal of having some consistency of approach and sharing good practice ideas." They all use a shared Code of Practice to help them do this. "This communication across disability support teams in tertiary institutions is common both regionally and nationally."

However collaborative preparation of an individual learning support plan requires the student to have good self-knowledge. In my experience this is often challenging for autistic students.

My clients often have difficulty recognising or describing their feelings or challenges they experience. They lack the confidence to approach teaching staff to discuss their difficulty. I think information should be sought from multiple sources, including parents or other professionals involved with the student.

As a clinician and a parent, my dream would be to see all tertiary institutions deliver a standardised disability support service. This would involve respect for, and reference to the Human Rights Act, and the right of all students to access the curriculum. Recommendations for appropriate "workarounds" would be made when needed, to aid students' learning and assessments.

Since many people with autism cannot initiate meetings or ask for help, regular meeting times with these students would be set up with them, to help identify the support needed to help each student succeed.

I'd like us to loudly celebrate those institutions which excel in their support for our students and simultaneously to keep asking for change where it's needed.

"However collaborative preparation of an individual learning support plan requires the student to have good self-knowledge. In my experience this is often challenging for autistic students"



Supporting students on the autism spectrum

Tertiary study can be difficult for some people on the autism spectrum. Katy Sinton, Inclusive Education co-ordinator at Lincoln University, talks about the approach the Canterbury university takes.

AS A SMALL university on a compact campus, Lincoln offers an environment which is easier to navigate and more personal than a larger institution. Students quickly become known as individuals to both teaching and support staff. These features offer clear advantages to students on the autism spectrum.

Inclusive Education at Lincoln developed a support framework which builds on these inherent strengths.

Using the professional assessment of the student's condition as the basis, support strategies are agreed and, if the student wishes, a document is written which fills out the picture of the student's strengths and weaknesses. It includes an account of behaviours which may be challenging, with some explanation of when and why they might arise, and anything else relevant.

A meeting with each lecturer may be arranged for early in the semester, with this document as a starting point.

Examples:

- 'Some of X's social behaviour may be different from neurotypical people. If this behaviour appears, she is not deliberately being difficult, lazy or untidy. It is part of her condition.'
- 'X prefers not to make eye contact.'

Where appropriate, the student is assigned a mentor, who may also act as a note-taker. This person is a member of the Ministry of Education's Inclusive Education team of casual staff (not a fellow student). He or she helps the student understand and manage the demands of university life, with the aim of encouraging independence, and acts as a support person e.g. to introduce the student to the lecturer.

Practical resources available to make sex education easier



Talking and learning about sex can be a difficult subject for people on the autism spectrum but it need not be, writes Annette Milligan. She is a trained secondary teacher and registered nurse who has been working in sexual and reproductive health and trained education for nearly 30 years. She is the managing director of Health Click Ltd, which produces resources to teach young people about sexual health.

PEOPLE OF ALL abilities – and those who have some limitations whether they be physical, learning or other difficulties – all have a right to sexuality information and loving, safe relationships.

So let's start with the basics – knowledge.

Think for a moment about where you got most of your sexual health information. Was it your parents? Was it your teacher? Or were you like the vast majority of us and found out mostly from our friends. Children teach each other about sex and sexuality, even if you don't. They hear things and whisper it among themselves. Sometimes that information is accurate, and sometimes not.

But what about the person who has a disability or learning difficulty? How do they learn if their peer group doesn't have this information, or their friends can't speak very well, if at all?

Often children with learning and developmental difficulties simply don't learn about sex and sexuality at all unless someone has the resources and takes the time to be very specific about making sure that they have basic knowledge.

It's important to do this because people with learning and developmental difficulties are vulnerable to abuse and it's important to do everything we can to make sure they know right from wrong – good touching from bad touching. And it's important because everyone has the right to have an intimate loving relationship which is consensual and safe at the appropriate time in their lives.

Some people have no interest in sex their whole lives – and that's just fine. But others are really interested in sex, and often, they find another special person in their lives they want to share that sexual relationship with. This is often a really difficult subject for parents and teachers.

The parents of children with any developmental difficulty has to be more involved in every part of that child's life. Not many parents are like me, and have worked in sexual health for years. That is exactly why we have developed the resources to help parents, teachers, carers and therapists teach about intimate care and sexual health.

My background is in nursing and teaching. I have been a sexual health nurse and educator for nearly 30 years.

In 2000, I joined forces with others who had expertise in technology and developed resources on DVD. The one which is especially designed for people with autism and other learning difficulties is the one called "Me" – because it's all about me.

It's about my friendships, relationships, my body – how it changes through puberty, how to shower, how to wipe my bottom, manage my periods, masturbation. It's about how I get help if a part of my body is sore and it's about contraception, staying safe and what to do if people are doing things to me that I don't like.

Teaching about sexuality can be difficult – at Health Click we understand that. The scripts were hard to write, and many people throughout New Zealand helped us to get the words and the topics right, so parents and carers don't have to make up social stories – they're already done for you.

So go on, take a breath. It isn't easy, but your child needs you to teach them. You can do it! Just reach out for good resources that help you on the way.



Taking the mystery out of meeting the needs of diverse learners



*In this combined article by the Ministry of Education and a resource teacher Learning and Behaviour (RTLb), the Ministry provides some background and context to the ASD and Learning guide on the Inclusive Education website. Christchurch-based **Amanda Haywood**, outlines the parts of the guide she has found most useful in her work with teachers.*

Creating learner profiles can be a very empowering experience.

ADDRESSING ATTITUDES towards inclusion in schools is less likely to be about inclusion as a concept.

It's more likely to be about addressing the fear of failing a student or fear of failing the other students in the class.

That's what the Ministry of Education deduced from research we carried out in 2011 when we asked principals to identify the barriers to and motivators for being inclusive.

There's no denying the challenges that face our teachers and schools in responding to the diversity of their communities. We need a continuum of supports and interventions where parents, students and teachers feel confident and well supported. The Inclusive Education website is just one of the supports on that continuum.

In this article we provide some context to the site, but we thought the greatest value for readers would be in asking a resource teacher, Learning and Behaviour (RTLb), to review the ASD and Learning guide on the site and point out some of the useful parts of the guide for teachers (and for parents and medical professionals to refer teachers to).

Context

So here's some quick context. Firstly it's vital to stress that a website does not replace people, specialist advice, professional development, or resourcing. But we hope it can help take some of the mystery out of meeting the needs of diverse learners.

The website provides a window into what teachers and school leaders are doing that's working. Around 26 'guides' (these are guidance, not required guidelines) draw together practical, hand-picked ideas and strategies from New Zealand and around the world.

Teachers can access the online guides directly, or work through the strategies and suggestions in the guides with others. We've asked Amanda Haywood, an RTLb and specialist Ongoing Resourcing Scheme (ORS) teacher from Te Horanui, RTLb Cluster 36, to provide a brief summary of the parts of the ASD and Learning guide she has found most useful to support her in working with students with autism and their teachers.

Useful strategies to explore in the guide

By Amanda Haywood

AS A PRACTITIONER working with a diverse range of students with autism and their teachers, it's important to have ready access to a variety of strategies and resources. The ASD and Learning guide on the Inclusive Education website identifies five key strategies or areas for assisting learners with autism in the school context, all with supporting resources and references to further readings and/or guides to strengthen understanding and build teacher capacity.

The first identified strategy is information about autism spectrum disorder. Within this section of the kit there are some excellent video clips viewing the world from the perspective of a person with autism, what it may feel like to

experience sensory overload and an introduction to what it means to have autism. I have found this part of the resource particularly useful to share with classes where there is a student with autism, to give the students insight into how a student with autism may perceive the world around them. Building empathy and understanding in the peer group for students with autism is imperative. I have also used these clips when working with teachers to develop their understanding of autism. The clip about sensory overload is particularly useful when collaborating with teachers to problem solve mitigating the effects of working within a busy classroom.

The second strategy on identifying needs and strengths has been extremely valuable when working with students with autism that are transitioning from early childhood to primary school, or primary school to intermediate/secondary school. The emphasis on identifying student strengths and interests is key to building effective partnerships between the student and their teachers. The transition examples in the website guide are exemplary in supporting this strengths based approach. The one page template about a child transitioning to primary school has the student pictured in the centre, with brief comments in bubbles around a photograph of the student pertaining to indicators such as how the student communicates, what their interests are, things that keep the student calm, and how the student relates to others. I have found this one page summary about the student, based upon a strengths approach, a useful piece of documentation to allow me to get a holistic understanding of all the student's capabilities.

Equally useful is the learner profile, examples of which are also found in the second strategy of the online guide. Creating learner profiles can be a very empowering experience for the student. Identifying student interests, how they learn and what helps them to learn, what makes it difficult for them to learn and their hopes and dreams gives the student a voice and also assists in allowing new teachers to 'understand' and thereby build a trusting and positive relationship with the student. Feedback from teachers is that the learner profiles have given them both the opportunities to engage in communication with the student about areas of interest that have assisted in building a positive teacher/student relationship, whilst also actively assisting the teacher to make the necessary adjustments to their classroom environment, or teaching that proactively addresses any behavioural triggers before they arise.

The third strategy in the guide is on supporting key areas of learning and wellbeing and is fundamental to the role of both an RTLb and an Ongoing Resourcing Scheme (ORS) specialist teacher. Developing social skills in students with autism is important. The hyperlinks to resources on developing social skills have served as a springboard for generating ideas to individualise and personalise strategies for students.

The final two strategies identified in the ASD and Learning guide relate to whole class strategies in the Year 1-6 and

the Year 7-13 classrooms. Once again, there is a wealth of resources under each subsection, relating to presenting information, building confidence in the learner, developing organisation skills and supporting student collaboration. I have found the checklists a valuable resource for working with teachers to identify areas of need. Further resources within this section that I've used extensively with both students with autism and their teachers are the visual examples of presenting work (such as flow charts) and the use of assistive technology such as speech to text function to make literacy attainment accessible to all.

I would recommend that all professionals working with students with autism take the time to engage with this online tool to further build their own capacity to work successfully with a diverse range of students.

From dilemma of difference to designing from the edges

That brings the Ministry of Education to one of the points of tension we had to navigate when building the site – that of labelling disabilities by creating guides about eight different disabilities, including autism. Disability labelling can reinforce difference and the belief that teachers need to be specially trained in “special education” to be inclusive.

A diagnosis or a label is certainly important to make sense of what we're seeing and experiencing. We determined, if our website users were starting here, then we needed to meet that need. But not surprisingly, if you view all of the disability-specific related guides on the site, we'd estimate that a high proportion of the strategies across those guides are common across a range of disabilities.

As an illustration, we have eight educator booklets that feature in eight of the website guides, with quick summaries in the centrefold. We've taken the strategies from the centrefolds of the ASD, ADHD, Down syndrome and dyspraxia booklets. There are 13 strategies that are common irrespective of the disability, ranging from using visual tools, to specific routines and structures, and reference aides. Imagine the relief of teachers when they realise this. And the big question is, how many of them would benefit other students in the class?

Students don't need their teachers to be experts in autism or ADHD or Down syndrome. They need them to be adaptive experts who are highly efficient and innovative at planning and flexibly delivering the curriculum in ways that work for everyone, and at making adaptations available for everyone to benefit from.

Let's not over-simplify things though. That doesn't mean teachers and school leaders don't need specialist advice (sometimes they do), and it doesn't mean to say that a website replaces this specialist advice.

What the website does do is encourage us to share our collective wisdom and help teachers to feel that they are not alone. There are some “awesome” teachers out there (as our kids would say) having significant impact on the learning of all children and young people. We've filmed some of them, talking about the strategies they use, demonstrating how their classes work (see our video. We've filmed their students too talking about what works for them. Those teachers and their students require us to innovate for everyone.

We'd like to see leaders of learning using the website guides and videos to encourage insightful, inspiring and courageous learning conversations where teachers can learn from each other, their parents and students; where teachers are not afraid of failing their students, but have the courage and confidence to try, inquire and try again.

(If you know of teachers who are like this, let us know – through the website, we need to share their learnings with others.)

Educator booklet Autism Spectrum Disorder (ASD): A Resource for Educators

<http://inclusive.tki.org.nz/assets/inclusive-education/resource-documents/NEW-AUTISM-booklet-17-10-web.pdf>

ASD and Learning website guide

<http://inclusive.tki.org.nz/guides/autism-spectrum-disorder-asd-and-learning/>

How ASD can influence learning

Tear out and keep as a handy reference

CHALLENGES

Will vary from student to student but often include:

- ▶ sensory regulation
- ▶ settling into learning
- ▶ coping with change, unfamiliar routines and a lack of structure
- ▶ verbal communication
- ▶ processing, receiving and making sense of things
- ▶ expressing information and ideas
- ▶ social interaction
- ▶ abstract thinking and processing complex information.

STRENGTHS

Will vary from student to student but often include:

- ▶ honesty
- ▶ processing visual information quickly
- ▶ special interest in particular topics and/or activities
- ▶ strong rote memory
- ▶ strong preference for well-planned, structured, routine-based learning environments
- ▶ retaining particular facts and details.

Communication, connection and the challenge to become better listeners



*Many children on the autism spectrum first come to the attention of a speech language therapist because of late developing speech. Auckland-based speech language therapist **Simone Horrocks** offers her perspective.*

Every single human being has the ability to communicate.

THE FIVE PRINCIPLES that underpin Te Whāriki, the Ministry of Education's Early Childhood Curriculum are: Wellbeing Mana autua, Belonging Mana whenua, Contribution Mana tangata, Exploration Mana aotūroa, and Communication Mana reo (MOE, 2017).

Together they form a powerful touchstone that is worth revisiting time and again over the course of a person's development and have the potential to form a strong foundation in anyone's life.

Associated goals and learning outcomes for the "communication" strand include: Developing verbal and non-verbal skills for a range of purposes; enjoying hearing stories and retelling and creating them; recognising print symbols and mathematical concepts and using them with enjoyment, meaning and purpose; expressing feelings and ideas using a range of materials and modes; and discovering different ways to be creative and expressive (MOE, 2017).

These early communication goals underpin almost every aspect of our academic and social development. But communication cannot happen without connection.

Talking or signing alone in a room may be "speech" but unless the message is received, understood, and acknowledged by another, communication has not taken place. With connection comes trust which in turn builds confidence. Confident communicators are more able to express themselves and share what they enjoy and are interested in. An increasing body of scientific evidence tells us we learn better, and retain our learning better, when in a positive frame of mind. Being understood and feeling accepted by others means that students are also more likely to share problems and needs earlier (Diamond, 2014; Dornyei & Ushioda, 2011).

As a wide range of complex issues related to communication and social interaction are a core diagnostic feature of Autism Spectrum Disorders (ASD), speech and language therapists (SLTs) are uniquely placed to offer support and advice.

So what is speech and language therapy and how can it help?

Means, method, and motivation...

Most people's understanding of speech and language therapy is that it involves "fixing" unclear speech. While this is one area of an SLT's practice, they are also trained to work with communication difficulties in the broadest sense, including all the ways we get our message across and understand others.

For example this might include working with children who have late developing speech or language; people of all ages who experience times when they become dysfluent (stutter) or have difficulty getting the words out (selective mutism); find it hard to join in with social conversation; respond by repeating what others say (echolalia); use a lot of learned phrases or "scripts" (stereotypical language); or have difficulties understanding humour or abstract language.

SLTs also recognise the ways in which acquired disorders, neurological conditions, or differences in a person's cognitive

or thinking skills can cause more subtle breakdowns in communication. For example this might include difficulties with planning and organising, understanding time, identifying and expressing thoughts and emotions, managing impulsive behaviour, "reading" body language, or understanding the intentions of others.

And because language learning takes place in a social and cultural context, the work of an SLT is also about supporting inclusion, enabling participation, and creating social opportunities, which may involve education, training, and coaching others in a variety of settings.

Whether a person is verbal or non-verbal, SLTs are specialised in creating a profile of a person's communicative strengths, skills and abilities, which includes assessment of comprehension, or what a child or young person understands.

Many children on the autism spectrum first come to the attention of an SLT because of late developing speech. While most of those children will go on to start using spoken words, some will not. Estimates vary, but it is thought between 25-40% of people diagnosed with ASD do not go on to develop functional language (Beukelman & Mirenda, 2013; MOHE, 2016).

It is important to remember that while a non-verbal person may not use speech, this does not mean they do not have the ability to communicate. Every single human being has the ability to communicate and we are all sending messages to others all the time. This could be anything from a reflexive shiver to communicate discomfort, a smile to indicate pleasure, use of eye gaze or an intentional blink to signal "yes" or "no", to a gesture, a drawing or a written word.

Advising, assessing, and coaching those who may benefit from alternative or augmentative forms of communication - known as "AAC" or assistive technology - is another area of an SLTs expertise. AAC could include any of the forms of communication mentioned above as well as vocabulary systems (paper or electronic) that use words; picture symbols; and/or text to speech software.

It is natural to think that introducing alternative forms of communication might further delay the development of speech, however research overwhelmingly shows us that use of AAC can actually aid speech and language development. In addition, early introduction of AAC has been shown to reduce frustration for both the speaker and the listener, and promote social interaction (Beukelman & Mirenda, 2013; MOHE, 2016).

One of the most powerful ways to set someone up for independence in later life is to ensure they have a method of independent communication. This is something that should be introduced at the very earliest opportunity as confidence and competency take time to develop. It is also important to know that people of any age are likely to benefit from assistive technology and it is never too late to start.

Parents should be mindful however that one particular method, known as Facilitated Communication (FC) and

the closely related Rapid Prompting Method (RPM), which involves aided or assisted pointing, or “supported typing”, often with associated claims of “unlocking hidden potential and ability”, has no evidence of efficacy, and its use has been opposed by the New Zealand Ministries of Health and Education, alongside many other professional bodies around the world (ISAAC, 2014).

It is less well known that SLTs are also able to help with swallowing disorders and difficulties with eating and drinking, including those who have sensory issues and are often labelled “fussy eaters”.

So how can I access support from a speech and language therapist?

Depending on their specialisation, most SLTs offering government funded support are employed by either The Ministry of Education, working in schools or early education; the Ministry of Health, working in hospitals or community care; or for ACC supporting rehabilitation. In some areas SLT services are also available through community providers contracted by the Ministry such as Spectrum Care, Explore, McKenzie Centre (Hamilton), and the Champion Centre (Christchurch).

Parents, caregivers, Plunket, educators, GPs, or anyone concerned about a child’s learning and development can request assistance and support by contacting the following services:

For children from birth to 5 years

Child Development Service Ministry of Health (MOH)

Early Intervention Service Ministry of Education (MOE)
Early Intervention Service teams work closely with specialists with from the Ministry of Health, to provide assessment and support, depending on your family’s needs and communication goals. Parents and caregivers can self-refer.

The (MOE) Communication Service - targeting children aged 5 to 8 years

The focus of this service is to develop the skills of the team around a child with speech, language and communication needs, to support learning and participation. Referral generally comes through a member of teaching staff but parents may also make a referral through their area co-ordinator.

The (MOE) Ongoing Resourcing Scheme (ORS) - support from 5 to 21 years

Children with “high” or “very high needs” may be eligible for support for the entire period of their schooling. Parents are advised to initiate the application process several months before schooling begins, with professional advice and reports required in support of the application.

Some SLTs may work across these services, generally with the adults who spent most time with the child or young person

in the home or an educational setting. SLTs also provide training for educators, parents and caregivers, through courses such as Hanen Centre’s “More Than Words”, which supports social communication, and “Incredible Years”, which focuses on skills for managing problem behaviour.

In November 2016, The Ministry of Education announced changes to the provision of these services, with the aim of strengthening inclusion, streamlining access, and collating more individual data on which to develop more tailored and dedicated solutions. Early in 2017 a pilot scheme was launched to trial what will become National Learning Support Services, replacing what was previously known as “Special Education” (MOE, 2017b).

To learn more about LEARNING SUPPORT SERVICES and how to make referral go to:

<https://www.education.govt.nz/ministry-of-education/regional-ministry-contacts/learning-support-services/>

For more information about CHILD DEVELOPMENT SERVICES go to:
<http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/child-development-services>

For more information about INCLUSIVE EDUCATION including excellent resources and whole class strategies for supporting communication and language development go to:
<http://inclusive.tki.org.nz/guides/autism-spectrum-disorder-asd-and-learning/>

Private practitioners

Alongside funded services, there are many SLTs working in private practice. For more information about how to find an SLT in your area go to the New Zealand Speech-language Therapists’ Association website: <https://speechtherapy.org.nz/find-a-therapist/>

SLTs specialise in many different areas of practice, so as with any professional, check that anyone you engage has specialist knowledge and training in ASD.

University clinics

Canterbury University, The University of Auckland, and Massey University Auckland campus all offer Bachelors and/or post-graduate training for SLTs. Services are available to the public in their University clinics, provided by students working under expert supervision. Services may be free or significantly less than a private practitioner, making this is a good option for families who don’t meet criteria for funded support. For more information go to:

Canterbury University Speech & Hearing Clinics

<http://www.canterbury.ac.nz/science/schools-and-departments/communication-disorders/speech-and-hearing-clinic/>

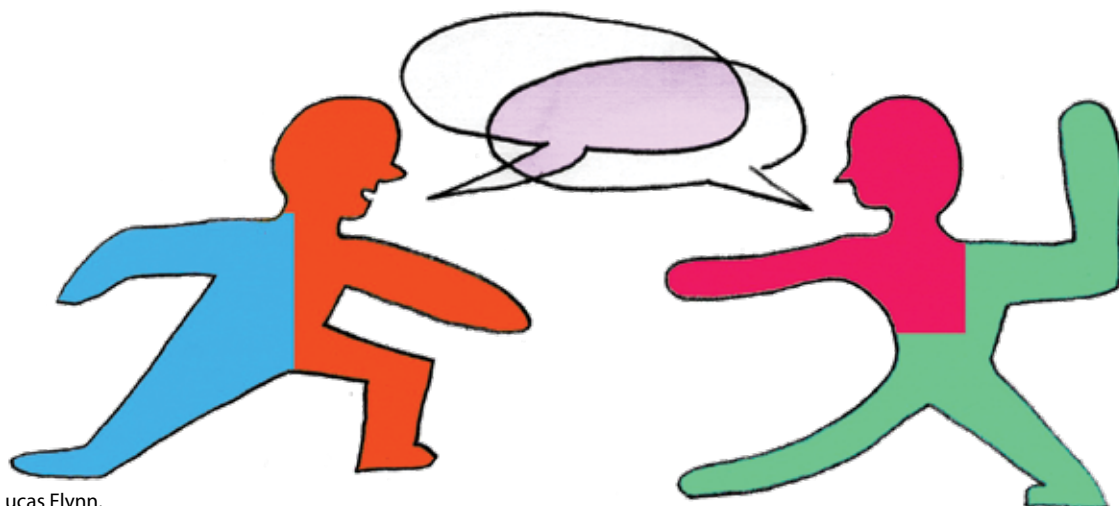


Illustration by Lucas Flynn.

The University of Auckland Speech & Language Teaching Clinics

<http://www.clinics.auckland.ac.nz/en/about/our-services/speech-language-therapy/slt-our-services/free-speech-language-therapy-clinics.html>

Massey University Speech Therapy Clinic

http://www.massey.ac.nz/massey/learning/departments/institute-of-education/professional-education/speech-and-language-therapy/speech-language-clinic/speech-language-clinic_home.cfm

ActivEating

Massey University also offer a special programme based at their Speech Therapy Clinic for children and families managing difficulties with eating and drinking. It is run by one of the clinical educators who is also a NZSTA Expert Advisor for Paediatric Feeding and Swallowing. For more information about ActivEating, including a link to a recent documentary about their work, "The Secret Lives of Fussy Eaters", go to:

http://www.massey.ac.nz/massey/about-massey/news/article.cfm?marticle_uuid=BF0DB55E-4A59-464F-BD9D-3D362EA42C9A

Talklink Trust / Wahanga Tu Korero

The TalkLink Trust hold a contract with the Ministry of Health to provide assessments for Communication Assistive Technology, to enable a person with a disability to communicate more independently and effectively. The service is available nationwide and anyone is able to refer using the form on their website. SLTs work as part of a highly specialised team, offering individualised assessment, training, and technical support. Information about funding and eligibility along with resources and news for AAC users can also be found on their website: <http://www.talklink.org.nz> - or on their Facebook page <https://www.facebook.com/TalkLinkTrust/>

Talking Trouble Aotearoa New Zealand (TTANZ)

TTANZ is focussed on the speech, language and communication needs of children, adolescents and adults who are involved with care and protection, justice, mental health or behaviour services. Their team of specialised, practical and energetic speech-language therapists provide clinical services, research, professional training and consultation, and deliver court-appointed Communication Assistance roles in legal settings. TTANZ operates as a social enterprise/profit-for-purposes organisation where any profits generated after individuals carrying out work have been paid are used for pro-bono, training or research activities. Professionals, families, caregivers and youth can self-refer. For more information and contact details go to: <http://talkingtroublenz.org>

Best practice versus current realities

Communication is seen as a "high-priority learning area", for children and young people with ASD. The New Zealand Autism Spectrum Disorder Guideline (2016), and best practice guidelines internationally, state that SLTs should be involved in the diagnosis and assessment of ASD; communication goals should be included in individual plans for all children and young people with ASD; with assessment and intervention suggestions provided at a minimum of once a year by an SLT, and more often in early childhood (ASHA, 2017a; MOHE, 2016; RCSLT, 2015).

As the support needs of a person with autism are broad and varied, to ensure potential is reached and inclusion is achieved, collaboration is key. SLTs need to be seen as an integral member of any team working with, and alongside, a person with speech, language or communication needs.

And as autism is something a person grows with, not out of, this support should be available as needed throughout a person's lifetime.

Currently in New Zealand, government provided communication support services are based on need not diagnosis, but in practice we are seeing that many children and adults with ASD are not meeting the criteria for funding. Due to operational and service delivery issues, we are hearing reports of families experiencing long waiting lists and inconsistent services, and a call for more training and support in schools (ESC, 2016; Sayers, 2016). Distressingly, there are also an increasing number of reports of students with autism being denied access to education as a result of "challenging behaviour" (Cooke, 2017; Kershaw, 2017). And many adults on the autism spectrum have described how exclusion, isolation, and the resulting longing for intimacy contributes to low self-esteem, anxiety, and depression (Howlin et al., 2015; Muller et al., 2008).

In 2016, in along with over 400 parents, caregivers, advocates and professional organisations, the New Zealand Speech Language Therapy Association (NZSTA) contributed submissions to a report by the Education and Science Committee (2016) into the delivery of education for students with dyslexia, dyspraxia, and autism spectrum disorders. Recommendations presented to the New Zealand House of Representatives include calls for better information and access to services; more consistent provision; clearer pathways; and increased funding to support students with ASD from early years, right through into tertiary study and beyond (ESC, 2016).

Challenging behaviour is very often a natural response to an intolerable situation. When a person is in crisis they are far less likely to be able to express their needs, and if they don't already have access to effective communication methods, and relationships with people they trust and connect with, they are unlikely to do so.

The space between the early identification of support needs and "challenging behaviour" is one we all need to engage with.

Relationships – and strong lines of communication – need to be established over time, and through shared positive experiences, and not just as a last resort.

Means, method, motivation... and opportunity

Developing language skills, competence, and confidence as a communicator depends on having rich and varied opportunities to engage in motivated and meaningful social interaction in everyday life.

No one is born with these skills. If we return to those powerful bedrock goals outlined in the Early Education Curriculum Te Whāriki, we see that developing capability comes through experience, discovery and use – and most importantly of all – "over time with guidance and encouragement" (MOE, 2017a, p. 1). It is important therefore for us all to notice not just what a person has still to learn but what they are already doing and most importantly of all what they initiate themselves.

This could be as subtle as where a person directs their gaze; whether they orientate their body towards or away from something; what they reach for or discard; what they collect, share, write, talk about, choose, or make.

When we initiate something independently, we are communicating something about what motivates us, and the things that motivate us, are opportunities for connection.

But communication is a two way street and the way we respond matters too. By slowing down, observing, listening – and then by acknowledging what we have seen or heard

– we create a connection. Resisting the urge to then fill a “silence”, talk for someone, or take the lead in guiding an exchange, demonstrates respect for that connection, and shifts the power back to our communication partner.

Noticing, acknowledging, and then creating a space for a person’s response may seem fundamental, but it actually takes practice and sometimes patience, and there is no more powerful way of maintaining that connection, and letting a person know that you care about what they have to share.

And a final word for students and young people on the autism spectrum...

Remember the people you work, play, and learn with, may not know as much about autism as you do. And even if they do, they don’t know you, the way you know yourself. So remember to share your thoughts, experiences, interests, likes and dislikes – in any way you can. Advocate for yourself. Persevere until you know you have been heard and understood. Your message is important. Keep the lines of communication open.

Simone Horrocks (BSLT Massey University) is an NZSTA registered speech language therapist working in private practice providing strength based support to individuals and families on the autism spectrum. She has also worked as a teacher aide in Special Education and as a volunteer buddy to families with special needs. The views expressed in this article are her own.

References

- American Speech-Language-Hearing Association [ASHA]. (2017a). *Autism. Roles and responsibilities*. Retrieved from https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935303§ion=Roles_and_Responsibilities
- American Speech-Language-Hearing Association [ASHA]. (2017b). *Position statement. Facilitated communication*. Retrieved from <https://www.asha.org/policy/PS1995-00089/>
- Beukelman, D. R. & Mirenda, P. (2013). *Augmentative & alternative communication: Supporting children & adults with complex communication needs* (4th ed.). Baltimore, MD: Paul H. Brookes Publishing Co.
- Cooke, M. (2017, October 10). Kids excluded from school crying for help. *Radio New Zealand*. Retrieved from <http://www.rnz.co.nz/national/programmes/checkpoint/audio/2018617358/kids-excluded-from-school-crying-for-help>
- Dornyei, Z. & Ushioda, E. (2011). *Teaching and researching motivation* (2nd ed.). Harlow, United Kingdom: Pearson Education Ltd.
- Diamond, A. (2014). Want to optimize executive functions and academic outcomes?
- Simple, just nourish the human spirit. In P. D. Zelazo & M. D. Sera (Eds.), *Minnesota symposium of child psychology. Developing cognitive control processes: Mechanisms, implications, and interventions* (Vol. 37, pp. 205-230). Retrieved from http://www.devcogneuro.com/Publications/adele_minnesota_symposia_chapter_2014.pdf?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&st_uids=9421921&query_hl=4&itool=pubmed_DocSum
- Education and Science Committee [ESC]. (2016). *Inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools: Report of the Education and Science Committee presented to the House of Representatives*. Retrieved from https://www.parliament.nz/resource/en-NZ/51DBSCH_SCR71769_1/cd88907f3c87d07b8b1db046417ed1e43fcd3e85
- Howlin, P., Arciuli, J., Begeer, S., Brock, J., Clarke, K., Costley, D., ... Einfield, S. (2015).
- Research on adults with autism spectrum disorder: Roundtable report. *Journal of Intellectual & Developmental Disability*, 40(4), 388-393.
- International Society for Augmentative and Alternative Communication [ISAAC]. (2014). ISAAC position statement on Facilitated Communication. *Augmentative and Alternative Communication*, 30(4), 357-358. Retrieved from <http://www.tandfonline.com/doi/full/10.3109/07434618.2014.971492>
- Kershaw, A. (2017, September 14). 'Worrying rise' in number of children with autism being expelled or suspended from school. *Independent*. Retrieved from <http://www.independent.co.uk/news/education/education-news/autism-expulsion-rate-rise-school-pupils-students-department-education-asd-a7946701.html>
- Ministry of Education [MOE]. (2017a). *Principles, strands, goals and learning outcomes*. Retrieved from <http://tewhariki.tki.org.nz/en/principles-strands-goals-and-learning-outcomes/>
- Ministry of Education [MOE]. (2017b). *Learning support (previously special education) update*. Retrieved from <https://www.education.govt.nz/ministry-of-education/specific-initiatives/learning-support/>
- Ministries of Health and Education [MOHE]. (2016). *The New Zealand autism spectrum disorder guideline* (2nd ed.). Wellington, New Zealand: The Ministry of Health.
- Muller, E., Schuler, A., & Yates, G. B. (2008). *Social challenges and supports from the perspectives of individuals with Asperger syndrome and other autism spectrum disabilities*. *Autism*, 12(2), 173-190.
- Royal College of Speech & Language Therapists [RCSLT]. (2015). *Autism guidelines and supporting resources*. Retrieved from http://www.rcslt.org/clinical_resources/autism/guidelines_and_supporting_resources
- Sayers, T. (2016, September 30). NZ Special-needs Education at 'crisis point'. *Stuff*. Retrieved from <http://www.stuff.co.nz/stuff-nation/assignments/share-your-news-and-views/16071436/NZ-special-needs-education-at-crisis-point>

RESOURCES

There are lot of really good resources for anyone looking for ideas and strategies to support communication and language development, and the websites included in this article will lead you to many of them, but if I could choose only two to get the conversation started, it would be these:

SPECIAL BOOKS BY SPECIAL KIDS

This fantastic personal project is both an accessible educational resource and a celebration of all about different ways people get their message across. Its founder, Chris Ulmer, has a background in media and communications and teaching:

“This journey started when I was a special education teacher in Florida. My classroom consisted of the same seven students for three years. Going into our final year together we started this blog. After six months we had 100,000 followers and I began receiving requests to interview people outside of my classroom. I now travel the world to interview humans of all diagnoses and backgrounds. It is my goal to create a more accepting world; one video at a time.”

Since it was founded in 2016, the SBSK Facebook page has had over one million views, and is fast becoming a growing global community.



Find out more about SBSK on their website: www.specialbooksbyspecialkids.org



on Facebook: www.facebook.com/specialbooksbyspecialkids/

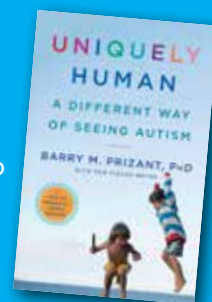


or Instagram: www.instagram.com/specialbooksbyspecialkids/

UNIQUELY HUMAN: A Different Way of Seeing Autism by Barry Prizant

Simon and Schuster Paperbacks 2015 ISBN 978-1-4767-7624-8

With inspiring stories and practical advice based on forty years of real world experience and research, Dr Barry, who is a speech language pathologist (SLP) with a special interest in childhood communication disorders, challenges us to shift our perspective and understanding of autism from a “checklist of deficits” to “a unique way of being human”. Full of practical, usable strategies, the book includes chapters on difficulties with emotional regulation; supporting enthusiasms; teaching social understanding; the importance of listening; and the relationship between anxiety, control and trust.



"For a long time, we thought those with more severe disability could not learn; now we know we did not yet know how to teach. Similarly, what we call the inability of persons to communicate may very well be our ineptness in listening."

Gunnar Dybwad (1909-2001) Advocate for the rights of persons with disabilities

Advice to parents of newly diagnosed autistic children



Many parents, when their child is newly diagnosed as autistic, or when they first begin to suspect it, feel stunned and overwhelmed. Penni Winter is an adult on the spectrum and offers her advice.

PARENTS, I know you have big questions – such as, is it your fault, what does being autistic really mean, and what your child's future is going to be. It's all very uncertain and scary, and I mean no disrespect for your struggles.

But there is no need to panic. Being autistic is not a calamity, or a fate worse than death, or the end of all your hopes and dreams for your child, or even of a meaningful life for yourself.

Yes, no doubt you'll have heard or seen or heard terrible stories about autistic kids and their parents' battles. People will tell you autism is caused by vaccines or bad parenting, or you'll read stories in the media that suggest any number of bizarre causes, from corn syrup to motorways to the Internet. (No I'm not kidding.)

You need to be aware of two things. Firstly, that the media's, and hence popular, image of autistics is not even close to the real truth. It's a lot of scare-mongering and negativity, for the most part, and patronising at best. The media rarely think to ask actual autistics about their views or experiences, so it gets it wrong.

Secondly, that there is an entire 'autism industry' out there, which exists for no other reason than to fleece scared parents of their money. You may hear about a lot of very strange so-called 'treatments', many of which are useless, possibly illegal, and even downright dangerous. Be very selective, and do only what you feel will work.

And before committing time and money to any treatment, the 'Big Question' to ask yourself is, "would this be considered abusive, if done to a non-autistic child?"

If yes, then it's abusive to an autistic one too.

Even more 'mainstream' treatments need to be looked at closely, for example those which demand 40 plus hours a week of therapy, or which promise to make your child 'indistinguishable from their peers'.

To scared and overloaded parents, this may sound like a good thing. But what other young child is expected to work a 40 plus hour week? And is this goal of normalisation really the right one to aim for?

The problem with trying to 'normalise' autistics is that autism has a huge unseen cost. Because autism is central to our neurology, trying to make us 'not autistic' basically tells us that we are substandard, that there is something 'wrong' with us, and that we must learn to hide it to earn others' approval. Even if we learn to 'pass', we are still autistic underneath – and that passing is a huge struggle, setting us up for a lifetime of low self-esteem, depression and anxiety. Is that really what you want for your child?

Autism is genetic and neurological, i.e. we are born with different brains. Think PCs and Mac computers. No-one says that a Mac computer is lesser than a PC, simply because it has a different operating system. We are the Macs of this world.

Our autism is not a detachable part, a disease, or an epidemic. We simply think differently, react differently, and handle our emotions differently.

Our autism is not a detachable part, a disease, or an epidemic. We simply think differently, react differently, and handle our emotions differently.

And nothing is going to change that. You may train your child into a veneer of 'normal', but that's all it ever will be.

So what do you do instead? Five pieces of advice that may help

1. **Accept your child as they are.** Stop expecting 'normal' from them. Put aside your fears, and others' judgements. Accept their autism. Put yourself in their shoes. Observe them, and do your best to understand how they view and react to the world, and why. If you accept their differences, embrace them even, it will reward you.
2. **Resist the quacks and the ignorant.** Beware of anyone telling you that you must do this or that, or your child is doomed, or that you're a bad parent, or that if you do such-and-such, your child will be magically 'cured'. Approach your child as an individual, not a statistic. If there is a specific problem – meltdowns, communication difficulties, toilet training – work on that, not attempting to eliminate the autism. Go for the 'maximisation' approach, not the 'normalisation' one¹.
3. **Find other autistic children for your child to socialise with.** Many will tell you this is a bad idea, because your child will copy the other autistic kids, and start "looking more autistic". This is based in the 'autism-negative' approach², which thinks being openly autistic is a bad thing. But every one needs their peers – and other autistics are ours. It will pay off in increased self-esteem and self-understanding for your child. They will see that's it okay to be autistic, okay to be themselves.
4. **Find your own peers.** Find other parents who take a positive and accepting approach to autism, at the same time steering clear of the 'I'm-going-to-make-my-kid-normal-whatever-the-cost' types. They will understand your problems, and offer support without demanding you change your child wholesale.
5. **Above all, listen to adults on the spectrum.** Yes, sometimes they will be a bit blunt or even aggressive or rude-seeming for your taste, but they've been there, done that, and know what your child is likely experiencing, and can offer advice on dealing with things like sensory overload or social difficulties. Keep an open mind. Ask yourself, if you wanted to know what it's like to be a member of a particular minority, would you ask those who aren't of that minority, or would you go straight to those who are? It's the same here – we are the real 'experts' on what it's like to be autistic, and we care about your child - because one day, they'll be one of us.

References

¹ <http://strangeringodzone.blogspot.co.nz/2012/04/while-back-i-posted-piece-on.html>

² <http://strangeringodzone.blogspot.co.nz/2016/09/autism-negative-or-autism-positive.html>

Penni Winter is a writer and artist and is also a member of Autistic Spectrum Kiwis, a group for adults on the autism spectrum.



WINNER: Warren Goodwin in his various guises and in middle as Rocket, from Guardians of the Galaxy, with Rohan Anakin, left, and Zed Sanerivi Ramsay. Photo: Otago Daily Times

From trash to treasure

Dunedinite Warren Goodwin has attracted international attention, writes **Lucy Green**, with his incredible, hand-crafted sci-fi costumes. We share what motivates him and learn what's next.

TO STEP INTO Warren's Dunedin flat is to dive head first into another, more whimsical, world. In what surely feels like heaven for science-fiction fans, his home is packed with movie and fantasy collectables, all neatly displayed and themed like museum pieces. Hundreds of figures have found a home with Warren, who began collecting as a young boy.

"I've always liked futuristic things. I like all the different stories and the characters," he explains.

But the real magic is to be found in Warren's own award-winning creations. Two huge Daleks of Dr Who fame sit imposingly behind his couch, with an oversized Groot (a tree-like superhero) appearing ready to burst from his roots at any moment.

"I did woodwork and metalwork at school and I enjoyed art. I started making costumes when I was 11."

Now in his 30s, Warren uses his creative talents as a way of connecting to a local, national and international community of people who share his passion for what is known as cosplay. For the softly spoken man, the cosplay world gives him an opportunity to use his talents to channel his unique world view and break out of the isolation he has experienced during his life. "It might not be considered 'normal'," he says, "but I have always seen things differently."

This incredible ability to 'see things differently' extends to turning others' trash into treasure using a range of self-taught techniques. Scraps of wood, car parts, electronics and Christmas lights are just some of the more unorthodox materials he's hand-fashioned using his sewing machine, hot glue gun and other tools. As a result, many of his creations feature moving parts and lights.

His CCS Disability Action support worker Gwyn Dobie visits Warren once a week and in addition to offering whatever practical support Warren chooses, is often by his side scouring second-hand and fabric shops across the city.

"It's a different world for me! But Warren can turn the most surprising things into costumes. There's no doubt he has real talent," she says.

Warren's talent is matched by an incredibly generous spirit. His works first caught the attention of local events organisers and Warren and his costumes have subsequently featured

in numerous charity parades, community events and expos across New Zealand. He also often donates figurines from his own collection to charities.

"I don't really make costumes for myself, more for others' enjoyment. I make characters that I think other people would like to see and will make them happy. It feels good to help other people. It makes me feel like I have more purpose."

Each creation takes many hours of hard work and he often stays up until the wee hours to meet the deadlines needed to deliver new experiences for event-goers. And others too have begun to take notice and recognise his skills.

Robin Versteeg, Warren's CCS Disability Action Service Coordinator, believes Warren has what it takes to turn his passion into a business.

"I'm really focused on working with Warren to ensure we can create a really sustainable option for him," says Robin.

As well as working to successfully secure funding from the HE Fairey Family Trust to build a website Robin's connected him with Antony Deaker, Ara Toi Project

Coordinator, Enterprise Dunedin, Dunedin City Council. Antony is tasked with supporting local artists to turn their talents into employment.

"I have been amazed by Warren's skills, talent and knowledge. Warren is held in high regard and is known to be a very generous person," he says.

Antony's role has been to work with Warren to build a website that he can use to promote his work and secure commissioned work. Next the pair will create a business plan and business systems and processes.

"I believe Warren has the capacity and skills to progressively build a small business around his passion."

For Warren the prospect of making a living from his costumes would be the icing on the cake from something that already gives him a fantastic sense of community connection. "It would be good to work doing something I like and I would feel more valued," he says.

Lucy Green is the national communications advisor, CCS Disability Action.

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