## ALTOGETHER AUTISM JOURNAL ISSUE 4 2016

Our stance on seclusion

OGETHER

Life first, then happiness

A journey of hope

Autism no barrier to achievement



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, people on the spectrum and family members of people with autism.

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

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

Contact us at any one of the following links:



info@altogetherautism.org.nz

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## Parenting on the spectrum



In the last few months I caught up with many of you at the Taupo and Auckland network meetings.

Paula Jessop, a member of the Altogether Autism consumer reference group, shared her experiences at each of these meetings, with many parents thanking her for giving them hope with her story.

Parenting brings many uncertainties, but parenting on the spectrum comes with a unique set of challenges – whether you are parenting a child

on the spectrum or whether you are a parent with autism. We explore these challenges - and reflect on some of the joys - of parenting on the spectrum in this latest issue of the Journal.

The Altogether Autism biennial conference is on 19 and 20 July next year and the theme has been confirmed as 'Transitions'.

These transitions include learning that your child is autistic, moving schools, starting work, moving out of home or planning the care for your autistic adult sons and daughters as you age. What would you like to learn about and share at the conference? We welcome your suggestions.

On 19 October, several autistic advocates were part of the Te Pou reference group considering an autism competency framework for the workforce. The group was hosted by John Vogenthaler, Te Pou's Project Manager for Disability Workforce Development, and disability support consultant Sharon Brandford. John brought the reference group together with an aim 'to map out the skills sought by consumers and employers across workforce groups for the purpose of informing staff development and training programmes'.

This discussion is ongoing, so if you are a consumer or an employer involved in autism-specific workforce development and would like your views to be heard, please email us.

#### **Consumer consortium changes**

Also in October, Barbara Crawford from the Ministry of Health advised the sector of changes to the representation of adults with autism on the ministry's Consumer Consortium. Currently, Autism NZ provides representation for adults with autism as well as parents of autistic children. However in 2017, autistic adult representation will be opened up to the wider autism community. Nominations need to be sent to the Ministry by 31 January 2017. Contact the Ministry or Altogether Autism for a copy of the terms of reference and more information about the election process.

The Journal goes to print ahead of the Attitude Awards on 29 November. This black-tie gala event is held every year to celebrate the successes and achievements of New Zealanders who live with a disability. We congratulate well-known autism advocate and parent Wendy Duff who is nominated for the Attitude Making a Difference Award. Congratulations also to Southlander Grant McKenzie who has been nominated for the Sporting Spirit Award. Grant has Asperger syndrome and is well known for winning two gold and two silver medals in power lifting at the Los Angeles 2015 Special Olympic World Summer Games.

As this is the last issue of the Journal for 2016, I'd like to take this opportunity to wish all our readers a safe and happy Christmas and New Year. We're already planning next year's Journal themes, so if there are topics you'd like to see us cover, we'd love to hear from you.

Catherine Trezona National Manager, Altogether Autism

## Autism organisation takes strong stance on seclusion use

Altogether Autism, a free, nationwide service for autism spectrum information and advice, has welcomed education minister Hekia Parata's announcement that seclusion rooms at schools will be made illegal under new legislation.

National manager Catherine Trezona and clinical psychologist Jenny Gibbs said seclusion rooms had been established because sometimes teachers and parents did not know what else to do.



Catherine Trezona

National Manager

"Most teaching professionals who contributed to a submission we made a year ago to the Education and Science committee's select inquiry into the

identification and support for students with autism at

New Zealand schools, had not had any specialist training for working with students with autism," said Trezona.

"They reported relying on personal experience and on-the-job learning. If teachers are not being trained with positive strategies to encourage appropriate behaviour, seclusion may be used out of desperation."

The chief ombudsman's enquiry into the use of seclusion would need to provide some clarity for the autistic community around terminology, she said.

"The term 'seclusion' may describe a form of torture, although this would not be the intention in its use with students with autism.

"The term 'time-out' which has also been discussed in the context of the current debate, is commonly used to describe a form of punishment," said Trezona.

Gibbs said rather than using seclusion or time-out, the autistic



Jenny Gibbs Clinical Psychologist

community preferred the use of the term 'respite'. "The child could have 'respite' from a classroom in a comfortable, safe, low sensory room so the child has time to calm themselves. They may be prompted to go to this respite space if their behaviour is escalating, or be able to choose to go to such a room themselves if they feel they

need a break from the classroom," she said.

"Respite implies a place of safety for the child rather than punishment by seclusion or time-out."

Altogether Autism has published its position on seclusion.

"We do not support the use of seclusion where a person is placed in isolation in a room or area from where they cannot voluntarily exit," said Trezona.

"We support providing teachers with increased skills to best support the different learning styles of autistic children."

#### Read Altogether Autism's position on seclusion on page 12



As part of the theme Parenting on the Spectrum, we've spoken to three parents with autistic children who are at different ages and stages. Candace Allan, Carleen Gilbert and Tanea Paterson share their triumphs and trials; their joys and their heartaches. We know every journey is different and we're keen to hear your stories as well. We also

spoke to Kelly Dugan about how his daughter Lucia inspired him to create an accessible sensory garden in Christchurch and Estelle Pretorius, a speech language therapist at the McKenzie Centre in Hamilton provides strategies for parents and caregivers of children with autism.

Enjoy. Mary Anne Gill, Editor.

## In this issue

4	Autism no barrier to achievement
6	Life first, then happiness
8	Mother and Son's Empowerment Journey
10	A Different type of garden opens
12	Altogether Autism stance on seclusion
13	Centre shows families multi-sensory benefits
14	Daily routines support children's learning
<b>16</b>	The signs of autism
	Workshop aimed at overcoming job hurdles
19	Connecting through Support



Congratulations **Susan Harsent** on winning our book giveaway in Issue 3.2016 of the Journal. We have posted your copy of The Good Guide to Mental Health

on the Autism Spectrum to you. This excellent book is available for purchase at www.fishpond.com.au

Cover photo: Carleen Gilbert and Felix Fowler on Life first, then happiness. Photography Alisha Taylor Photography, Tauranga. ISSN 2463-3712 (Print) ISSN 2463-3720 (Online) © Altogether Autism 2016 All rights reserved

Editor: Mary Anne Gill, Life Unlimited – maryanneg@lifeunlimited.net.nz

# Autism no barrier to achievement, says parent

## By Mary Anne Gill



**CANDACE ALLAN** sensed there was something wrong with her son Kobe pretty much from the day he was born in May 2012.

"He always used to scream and scream, all night long," the Hamilton mother-of-three explains over the noise of Nickelodeon TV playing in the other room to her children and a visiting nephew.

Her doctor, friends and family suggested it was colic or reflux – Candace still had her doubts.

Soon after he turned one, Kobe got severe tonsillitis and when he was two, a surgeon took the infected tonsils out and medical staff said removal of the swollen nodes could improve the toddler's behaviour.

"I went back to them two months later and said that 'I still think something is not right can we get him assessed'. Not much had changed. He didn't say mum or dad; he couldn't wave or do anything you would expect a two-year-old to do. But he could count and knew every letter of the alphabet." On referral to Waikato District Health Board's Child Development Centre, Candace and husband Carl got the news that Kobe was "severely autistic" and had global development delays. "We had the choice of three places to go with Kobe and chose the McKenzie Centre."

McKenzie Centre is an Early Intervention service for children, aged from birth to six years, who have special needs, developmental delays and disabilities. The centre enhances a child's potential for growth and development. At McKenzie Centre, children and their families get information, therapy, support and guidance on all aspects related to the child's development and well-being, to help the child realise their potential.

"Getting that early intervention was amazing, I would encourage people to do that. It was a life saver for us. It gave us someone to talk to who takes the time to get to know each individual child and family. They then work alongside the families, early childhood education centres and anyone else involved to get the most out of the kids. We were so lucky to have the support of the McKenzie Centre - they have been amazing," she says. Earlier this year Candace became a parent representative on the McKenzie Trust Board and enjoys the opportunity to provide a parent's perspective.



FAMILY STRENGTH: I-r Tyson, Kobe, Candace and Armani Allan



**REALISE POTENTIAL: The McKenzie Centre** 

Candace and Carl are both school teachers which she concedes does help in some ways – both are able to put some structure in at home that makes parenting on the spectrum a little easier in terms of managing behaviour and understanding children and their individual needs.

Kobe, 4, is the middle child. Tyson, 5, is already at Glenview School, where Carl works. Youngest child Armani is 3 and yes if you are doing the maths, that's three children under three when Armani was born.

"It's been great for Kobe having siblings all close together, it has helped with the socialisation and his ability to play and share with others. It has also been great for Tyson and Armani to learn that everyone is different and to accept people for who they are and that their differences are a good thing. I do worry about Kobe getting bullied at school (when he starts), but I worry about the other two just as much."

Candace soaks up whatever information she can about autism. "I'm constantly learning, constantly sitting up at night reading things online about different strategies and things to do; talking to Suzanne at McKenzie Centre about new strategies and ideas. Looking at ways we can encourage and help him. It has tested me and taken a lot of time and effort, but it's made me such a better person and a much better teacher too," she says. Her top tip for other parents is that autism is a good thing, not a bad thing.

"Kobe can do anything, he just takes a lot more work and time than a typical kid.

"Many see the diagnosis as a negative thing and that their child will struggle through life. Rather than that they should look at the positives and think about how amazing their child can be.

"The way Kobe thinks is so amazing, he is so clever and looks at everything in life through such a different lens.

"Children with autism think a bit differently but there is nothing they can't do. They just take a little bit longer and require a little bit more support to get there. They do it though, they get there, I have seen it time and time again with my son.

"There's nothing Kobe can't do; he blows me away every day with the stuff he does. He achieves things I never thought would be possible. "Sure I had major worries and concerns when I first found out and also thought that this was going to be such a major thing for not only him but also my family. In the end, it has been such an awesome learning experience for everyone and makes us better people, he teaches me things everyday I have learnt so much from him.

"Every child with autism is different. Get to know your kid and what triggers them. You've got to stop thinking this kid can't do it because he is autistic. The label of autism should be used to get funding and support for the child but not used as an excuse not to achieve."

It is important too for parents to keep living their own lives. "It's awesome to have the support of good friends and family, and continue doing everything you usually would, family trips, going to restaurants and many more." Next challenge is school for Kobe.

"He's super clever and rote learns everything so quickly. He doesn't like to follow instructions, especially if they don't interest him which might make school quite interesting but we are definitely looking forward to what he will show us. He's quite an outgoing boy, he'd live outside, he'd live on his bike, he'd live in the mud and the sand – that's him."

Kobe loves dancing too. Candace is also a dance teacher and runs a dance school. She recently started a dance class for children with special needs and their siblings.

"I wanted him to do dance because it will help with co-ordination, following instructions, being around others, and encourage his brain to cross over by his body movements. I just think dance and the structure and discipline that goes with this is fantastic for any kid. And it's fun! It's great for him and he gets to do it with his brother and sister. The dance and music gets him going, he loves music and also loves music time at the McKenzie Centre."

Candace is convinced there's not one model that fits all autistic children. "The way he thinks is just so cool. I'd love to be in his head for just a second. He is just wired so differently and he's the most loving, caring kid. There are no hidden agendas behind anything he does.

"He will be amazing," says Candace.



MULTI SENSORY: The McKenzie Centre

# Life first, then happiness

TEEN SOCIAL SUPPORT GROUP

The objective of this group is to help our girls find caring friendship and acceptance for who they are in a relaxed and judgement-free zone. Topics include: Nail & hair care; food & mood; body image; keeping

safe; manners & decorum; skin care and make up. There are two groups: one on Fridays 12-2pm and one on Mondays 4-6pm. The course is 10 weeks, and the cost is \$200. Respite care may be used. I am also available for individual respite care for half days.

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o kids, Felix 16 and MacKenzie 11. I am

son and help run Homeschool Social Support in e Bay, for homeschooled atypical kids. I work evi kids on the autistic spectrum and deepening my

Carleen Gilbert, a mother of two – one of them on the spectrum as she is as well – shares her two-year journey of discovery and hope.

**TWO YEARS AGO** I knew nothing about autism spectrum disorder and then my son Felix turned 14 and the whole world changed for us as a family.

He was depressed, unfriendly and unmotivated.

He couldn't get out of bed and couldn't do his school work. Shutdowns daily and meltdowns too were becoming a problem.

Both him and I looked at ourselves and did internet research which pointed us to a strong suspicion of Asperger syndrome.

I self-referred to the Bay of Plenty Child and Adolescent Mental Health Service and the intake nurse asked immediately if we'd heard of Asperger's.

A diagnosis and pills came next but neither helped and he got to breaking point and we both were very frightened.

There seemed to be no practical help.

I had to change my perspective entirely on what was right for my child.

I took him out of school at 15 and stopped all pressure and allowed him time to recover but not hibernate in his room and gave him

small bite-sized programmes of activities.

My priorities are now life first, then happiness and mainstream education comes a long way down the list.

By sheer chance, a small group of Tauranga people were looking at forming a social support group for atypical kids. I heard about this through the wonderful Dorothy at Asperger's Connections in Tauranga. I went to the initial meeting at Parent to Parent Tauranga which was standing room only and both Felix and myself left knowing this was for us. We were desperate to be involved.

We formed Mockingbird in February 2016.

It is now an incorporated society of which I am the president and I am there to help on most of the three days a week that we are open from 9.30am to 2.30pm.

Even holidays we still open with reduced times because no one wants to leave.

Our approach acknowledges Autism Spectrum Disorder (ASD), Tourette's, Obsessive Compulsive Disorder (OCD), Attention deficit hyperactivity disorder (ADHD) and other atypical kids as differently-abled not disabled.

We are a judgement-free zone in a cosy home-like environment.

Grab a sofa and chill.

We cater to sensory needs like light, sound and space. We are totally relaxed about time and food.

No bells ring here, no lines, no exams, no bullies.

We minimise stress to enable kids to get below the hyper-arousal line which allows them to be relaxed as their true selves.

Humour and kindness with understanding and compassion is how we work.

These kids who have seemed difficult and oppositional in the mainstream setting are now a delightful and caring bunch of kids who just hum together.

Adults with Asperger's are a valuable resource for our kids.



MOCKING BIRD GET TOGETHER: L-r Back row: Alex Berkett, Robyn McLeod, Ella McLeod, Sophie Turner, Bridget Tippett, Carleen Gilbert, Felix Fowler, Sheila Tippett. Front row: Leanne Tschumy, Lochie Tschumy, Hannah Fairweather, Ezra Fairweather, Ashleigh Poad, Malachi Turner and Conner McLeod. Photo: Alisha Taylor Photography, Tauranga.



MOTHER AND SON: Carleen Gilbert and Felix Fowler.

Amazing mentors and role models.

We have Jason Edgecombe and behavioural consultant, Ross Barker, as part of our team.

Their input has been a big part of us getting it right.

Ross has volunteered help with layout and day to day dynamics of our group. His intuitive knowledge is widely respected in our community and many parents have come to him after a long and unsuccessful journey trying to help their kids.

My son and I have been going to Mockingbird Inc since February and he is a different kid.

Much calmer and I see smiles now.

He is able to express himself far more and understand his responses to situations clearly.

He comes out of his room and I get cuddles again.

For me it has meant new life-long friendships and support from other people who totally get it.



HANDS ON: Lochie Tschumy gets to grips with telephone wiring. Photo: Alisha Taylor Photography, Tauranga.

Some parents asked me for private mentoring for their daughters. I had seen the work Jason Edgecombe has done with his Dungeons and Dragons programme, which my son goes to.

I decided there was also a need for a separate teen girls group. A place where they could make friends and feel safe to talk about their personal thoughts and feelings. Along the way I would include some chats and activities such as grooming, friendships, body image, safety and other topics parents suggested.

This has become a small business for myself which I can run from home and sometimes kids just take it better from someone else.

It might seem high hopes but my dream for the future is to see these kids right through to adulthood and a comfortable and stress-free retirement.

The other families and myself are working towards the goal of having a co-op, community place where young and old can perhaps share training, work and sustainable living.

Often anxieties make full time employment difficult for us and therefore money and housing is often an issue.

As a group we are now looking at leasing a property in Tauranga to get this going.

Our chances may be slim but we have to try and make this happen.

It is my goal for my son to be happy, have a safe community and a reason to get out of bed long after I'm gone.

If he can help some other people as well to save suffering and hardship, then I will feel I have done my job.



BOYS' TIME: Ashleigh Poad, Ezra Fairweather, Malachi Turner and Conner McLeod.



PET RAT: Sophie Turner



GIRLS' FUN: Ella McLeod, Sophie Turner and Bridget Tippett. Photos by Alisha Taylor Photography, Tauranga.

# Mother and Son's Empowerment Journey



Tanea Paterson is a substance use practitioner/counsellor. Both she and her son Josef are autistic but it took some time for them both to have a "tag" to describe themselves.

This is Tanea and Josef's journey to discovery and the challenges they faced.

"Hey Mum, it's like you are having a reverse mid-life crisis."

That from my eldest son Josef.

It wasn't until he was 14 years that we could finally give a valid name to his unique way of being. Not that we needed a name ourselves, but it seemed the rest of the world around us was desperate to use words to describe him. In the end, since they weren't doing a great job at deciding what name to use; I took it upon myself. This for me was the beginning of our self-efficacy and empowerment journey.

Regardless of why, who and how, this brought change and positivity. I could learn about what makes him so interesting and individual. I could see him in a more understanding and empathic way and I had a new interest to delve into. It wasn't as though I was sheltered from autism, far from it. Some of my favourite people on this planet are autistic; they are the people I always feel most myself with. They still are and so is my son.

I was alone when I was pregnant with him, not totally alone, I may as well have been though. Single mum at 23. It was all up to me and I thought I was doing okay. Once we hit the 'system', education specifically, things changed. We were lost in a spiral of confusion, misunderstanding and misdirection. The things that we were told and the things that I could not agree with came thick and fast. "Bad behaviour", ill-fitting labels, blame, stigma and sadness - we had our fill.

I began drowning once again in my own psychological ailments and labels. Most of those diagnoses felt like steel gowns wrapped around me, they were intermittently too small to be comfortable and then too large to hold up. I really thought I was able to show the teachers, doctors and psychiatrists what I wanted them to see and understand. I'd quietly say, "No I think there's more going on", maybe even mutter the autism word. And they would suggest it was my parenting and his absent father.

I said it louder "No! You are wrong, these behaviours that you are seeing only happen because of what you think and say about him, about us!!" and they would offer no help except medicine and parenting courses. My boy and I were bamboozled by the misfiring of information that swept past me, always leaving a smear or two. These would result in layers of 'Shut up we know best' and 'Only you can fix this by being better at parenting' or 'Ahh well look at his parents, you better do something or be prepared for.....when he is older'.

Because they didn't hear what I was saying, they listened with their eyes and their text books. They perceived our body language to mean a distant relationship, cold and uncaring. I know this because I read the words in his notes. I wasn't aware that my body language and eye contact suggested withdrawal, disinterest and failure. My words felt soft and meaningful coming out of my mouth, although not too different to pleading. Sometimes how we intend to react and be, isn't how it appears to others.

My presentation would change at times, long enough for them to see it with their eyes. They saw the strain it took to try to process their information dumps and my inability to control my nervous fake smile. They saw my lack of 'get up and go' and they saw how calm and relaxed I failed to be. My voice wasn't soft and meaningful, it was monotone and pragmatic. My body language well, rocking and pushing my nails making grooves in my skin they saw that too.

"Mum is on the methadone programme." "Has a history of depression, PTSD...#etcetera "..has a criminal record, was an inpatient in ward 10." There was more that they didn't write, there was more they didn't know as well. If they had, then they could discuss it with their supervisor, slowly blink and nod 'knowingly' to each other. They knew about 'those sorts of people' that 'chose' to make decisions like that.

What none of us knew for certain until so much later was that these situations and the rest of the scenarios for this son and his mum were underpinned by undiagnosed autism and the 'different thinking' confusion in a 'typical' world.

So I delved into my new focus interest of autism; to be fair this already had been an intellectual attraction to me. Slowly, things for us changed for the better as I begun to take some power back. However, 14 years is a long time to be experiencing those situations. It is a long time to be parenting in a way that you were told 'was best', a way that caused more harm than 'positive change'. I was beginning to experience life as a mum that felt peaceful and legitimate to our way of being.

Three years of reading about and watching autistic people talking on videos I happened upon a female autistic. She made a movie, it seemed as though she had made a movie about me. My monotonous expression cracked smiling, crying and frowning. Not the ones I had practised so well, these facial shapes felt new. Almost like when you stretch a stiff muscle and it feels fresh again. A vacuum of visuals of memories, a collage of ever changing images rolled across the inside of my eyes. "Maybe that was different to what I remember, maybe that was WHY that....." A million times those words ran by like subtitles to my life's movie. And my son, I am like him!!

It is still all up to me, and by now I am 40. The years I had spent thinking I was somehow different to my son and if I could only parent him their way, then he would 'be' how they wanted him to be. And then I thought of me and how I would feel if I was like him. And that is when I knew I was.

We aren't the same, no, we have the same cultural tendencies. Some of them are concretely the same and some at polarities to each other, however in essence concrete as well. The distance between two people shrinks when you realise, recognise and empathise with each other. Knowing I too am autistic evened out the playing field in a sense and to me that was the greatest relief.

We are still parent and child in our relationship, also now we are two autistic people who both get as obsessed, confused, anxious and overwhelmed as each other. Usually, although not always at different times, with different things.

For me gaining my formal diagnosis was like passing a master class which gave me the right to use my instincts. It was a justification of me being a good person and mum. I focussed on shedding



JOURNEY TO DISCOVERY: Tanea and Josef Paterson

as much of those smears and scars as I could and remembering and reinvigorating my true self, as much as I can. It will never be all clear, however I can continue to grow alongside and with my whanau. I can be vulnerable now and not feel like a failure, and interestingly this vulnerability makes my parenting stronger than ever.

No longer do I feel I am 'supposed to have it all together' and 'know it all'. Which inevitably leads me to fall apart when the pretendies became too much.

This is my reality, a real autistic parenting another real autistic. Now we share a stronger bond than ever, we can compare notes and language about being anxious or overwhelmed. I now know that I understand my son better than all of those teachers and doctors and even though I fell into some traps of trying to change him, I didn't stay there long enough to lose my son's trust.



PHOTO CREDIT: Tom Fox

# A Different Type of Perfect Garden opens



**By Pip Stephenson** 

**CHRISTCHURCH CHILDREN** will be enchanted by a new inclusive and accessible garden that appeals to all five senses.

The project has been a real labour of love for Kelly Dugan, founder and chief executive at SmileDial, a charity that supports families of unwell and disabled children.

It's taken more than three years of planning, but Dugan is excited to see the location at Rawhiti Domain in New Brighton "turning into a real garden instead of on paper."

The inspiration behind the garden is Dugan's five-year-old daughter Lucia, who has cerebral palsy, and the challenges she faces when joining in playground fun.

"Every time we took her to a park she ended up watching from the sidelines. There was nothing designed specifically for her. We'd have to lift her up or put her on things." While other parents may be able to sit down and read the paper or have a coffee, for many families of children with disabilities, visits to the playground can be fraught.

Dugan says parents can spend much of the time making sure kids don't touch or eat things they shouldn't, or crawl into dangerous spots under equipment.

These concerns informed the garden's overall design. Plants are edible and there are no moving swings or seesaws.

Footpaths are smooth and wide to accommodate wheelchairs and walkers, but also allow enough room for children to safely pass each other. And although the garden is unfenced, groundworks and plantings deter children who are "runners".

The aim is a playground where children can independently explore the natural environment while parents can sit and relax.



INSPIRED: SmileDial charity founder Kelly Dugan with his daughter Lucia, the inspiration behind the sensory garden project. Photo: Fairfax Media NZ/The Press



"It's exactly what I wanted - to create a place where parents can do that and not have to worry" says Dugan.

And there is much to explore. The entrance to the garden is through a tunnel made from grapevines and laced with hundreds of fairy lights.

There's also an interactive pole garden where children can play music and a dry river bed with a wheelchair accessible boat to encourage pretend play.

Bold, graffiti-art footpaths wind through the playground and a "whale wall" structure provides an undulating path.

And it's accessible, whether children are in wheelchairs or walkers, or whether they stand or crawl. "This place is designed so all kids can enjoy it," says Dugan.

There's been valuable input from the community, disability support groups and families, as well as the School of Landscape Architecture from Lincoln University. But Dugan's own experiences influenced most of the design.

"As a parent, and in my work with SmileDial, the greatest knowledge I could pull from was my own experience and the people I work with every day."

The result is what Dugan calls a Different Type of Perfect Garden.

With a vast array of stimulating sights, sounds and textures - not to mention tastes and smells - the garden is not only physically accessible, it can be enjoyed by children with vision or hearing impairments, and sensory disabilities too.

"I wanted to provide experiences for all senses. For kids, smell and touch are such important senses. It's a garden where you can touch that - you can eat it."

And Dugan says there will be some sensory surprises, including a bush that smells like rotten fish when the leaves are rubbed.

"We've got super-sour cranberry bushes, so if you eat one of those it's going to be sour and yucky, but it won't hurt you.

"People think smells and tastes need to be nice things, but have a plant that smells like rotten fish and kids love it."



OPEN FOR SAFE PLAY: Residents take time out in the perfect sensory garden.





ARTISTS IMPRESSIONS: How the new sensory garden in New Brighton, Christchurch will look.

# Altogether Autism's position on Seclusion

**ALTOGETHER AUTISM** is aware of the current debate on the use of seclusion for autistic students.

We welcome the enquiry from the Chief Ombudsman Judge Peter Boshier and the endorsement of this enquiry by the Disability Rights Commissioner.

Trish Grant, IHC director of advocacy, while condemning the practice as something from the 'dark ages', also acknowledges the use of seclusion is sometimes due to teachers and parents not knowing what else to do.



Judge Peter Boshie

In October 2015, Altogether Autism invited parents and professionals to contribute to

Zealand primary and secondary schools.

our submission to the Select Enquiry into the identification and support for students with dyslexia, dyspraxia and autism at New

Most teaching professionals who contributed to this submission had not had any specialist training for working with students with autism, and reported relying on personal experience and onthe-job learning. If teachers are not being trained with positive strategies to encourage appropriate behaviour, seclusion may be used out of desperation.

There are many issues involved in the current debate on the use of seclusion which will hopefully be clarified by the Chief Ombudsman's enquiry.

Our autistic community has highlighted an important issue about language and terminology. It is really important that there is clarity regarding what we mean by the terms we use. For example, the term 'seclusion' may describe a form of torture (although this would not be the intention in its use with students with autism).

The term 'time-out' which has also been discussed in the context of the current debate, is commonly used to describe a form of punishment (something that is intended to reduce or stop the behaviour which occurred immediately before it).

Rather than seclusion or time-out, our autistic community suggest the use of the term 'respite'. The child could have 'respite' from a classroom in a comfortable, safe, low sensory room so the child has time to calm themselves. They may be prompted to go to this respite space if their behaviour is escalating, or be able to choose to go to such a room themselves if they feel they need a break from the classroom.

## Language is powerful.

## 'Respite' implies a place of safety for the child, rather than punishment by 'seclusion' or 'time-out'.

## **Our position**

Altogether Autism does not support the use of seclusion, where a person is placed in isolation in a room or area from where they cannot voluntarily exit. Seclusion is a violation of human rights and may result in damage to a person's wellbeing.

The New Zealand Bill of Rights Act (1990) protects the right not to be subjected to torture and right not to be arbitrarily detained. The Convention on the Rights of the Child directs that discipline in schools should respect students' dignity and that governments have a responsibility to ensure that schools eliminate any discipline practices involving physical or mental violence, abuse or neglect.

Altogether Autism supports the planned use of respite. Respite is the removal of a person to a safe place with minimal sensory stimulation (such as loud noise and bright lights) for a specific short period of time.

Removal to the respite area should be done by verbal prompts or gentle guidance. Respite is not a punishment and should be in a place that is comfortable and familiar to the person, with a supervising adult nearby.

Used correctly, respite can be effective for more extreme behaviour at home and at school.

The use of respite at school should be part of a comprehensive behaviour plan, formed in collaboration with the student's family/ whānau, and in consultation with a behaviour specialist.



**RESPITE:** a place of safety for the child

This position has been developed by Jenny Gibbs, consultant clinical psychologist, Catherine Trezona, national manager, and members of our Consumer Reference Group and Professional Expert Group.

## Centre shows families multi-sensory environment benefits

By Mary Anne Gill

**A MULTI-SENSORY** room at Hamilton's McKenzie Centre provides an environment of stimulating activities and experiences to increase motivation, awareness and positive behaviours.

It is a well-used room, says centre director Trisha Benge. So much so that she's working on a funding application to upgrade the optic fibres and bubble tube which take a hammering every day.

The room was first developed in 2000 and revamped in 2006 thanks to funding from the Alexandra Lodge Freemasons and various other community groups.

The purpose-built room was the creation of the Cook family who were parents of a child with special needs.

The room includes lighting effects, sensory activities, tactile experiences and cause and effect items.

It's fair to say the classic Kiwi ingenuity and self-sufficiency culture is very much on show and Benge makes no apology for that.

"There's nothing like a Number 8 wire approach and that's probably because 75 per cent of our funding is through the government and the rest from the community. So we do what we can with what we've got," she says.





Using what you have is also important to show families they can create multi-sensory, stimulating environments and experiences during daily routines in their own home.

The multi-sensory room is just one of many tools the centre uses to help children under the age of 6 to reach their potential.

"At McKenzie Centre, we provide specialist early intervention for pre-school children who have special needs, and their families, throughout the greater Hamilton area. The centre brings together families, children, early intervention teachers, physio, occupational and speech language therapists and technology specialists to try to help the pre-schoolers reach their potential," says Benge.

# Daily routines support children's learnings

McKenzie Centre speech language therapist Estelle Pretorius, provides strategies that will empower you as a parent or caregiver of a child with Autism, to support their communication and interaction using daily routines throughout the day.

**FAMILY** is the most important influence in your child's life. You know more than anyone else, what makes your child happy, what he or she likes doing, how your child is likely to respond in any given situation, and the things he or she avoids. You are an important person in your child's early learning and development. You are an equal partner in the team around your child, as you spend the most time together. Embrace the opportunity for your child to learn from, and with you.

## Build a team around you

A family-centred approach is crucial to supporting your child's learning and participation in the community. Wrap early intervention services around your family.

Ensure that your early intervention team who may include occupational therapists, physiotherapists, speech language therapists, psychologists, and early intervention teachers provide you with practical strategies and support for your child and family, helping you enjoy and use the time you spend together every day as learning opportunities. Collaboration between team members is important when setting goals and evaluating progress for your child. As a family, you will have natural supports as well e.g. family, friends, and carers. Encouraging and maintaining these, are an advantage to the wellbeing of your family.

## Breathe and take perspective

Your child is first and foremost a child with behaviours and emotional challenges that you will find in any baby, toddler and pre-schooler growing up. Although Autism may affect functional skills and daily living in some children more than in others, it does not define, describe or explain your child's temperament or personality!

## Independence begins with predictability and routines

Children learn amazing skills, and thrive when their day is organised and predictable. Routines provide security, structure and expectations, which are foundational for learning to cope and being independent. Your child learns many social interaction and communication skills in naturally occurring daily situations, including meal times, bath and bed time, family activities, grooming and dressing activities.

Your child will learn to pay attention to what you are saying, and what is happening around him or her, become more responsive to, and process spoken language, take turns, and learn the rules and boundaries of acceptable behaviour. Involving children in predictable daily routines provides them with regular patterns in activities and hearing language in a meaningful context.

## Make your words stand out

Babies and toddlers learn what words mean when we see them in action and when they are used in a specific context e.g. when a mother changes her baby's nappy, she uses words that belong in this routine. These words may be, 'let's put your nappy on' while she shows the nappy to the child. In this illustration the mother used spoken language with contextual cues, i.e. this routine happens at the changing table and she uses visual cues, the nappy, to the child before she puts the nappy on.

During the routine the baby will hear the word 'nappy' several times while she puts the nappy on her. This baby will also hear the word 'nappy' throughout the day used by a range of people, and she will relate it to the context she learnt the word. When children learn new words, it is important that we help them understand its meaning, or function, by showing them (using an object, gesture or sign). Using the word in the context it belongs i.e. it is being reinforced as part of a typical routine, and practiced over and over, makes the word 'stand out' and become meaningful to the child. Remember also that 'less is more', keep instructions and comments short and always wait for the child's response before you continue.



INVOLVING CHILDREN: McKenzie Centre speech language therapist Estelle Pretorius investigates a toy with Chase.

## Make information concrete

Visual communication supports can enhance the child's ability to understand not only what is being said, but also what is happening and what they are expected to do. Frustration happens easily when expectations are not clear and the child is unable to understand or get their message across.

Visual supports provide the child with the ability to make a choice, to express their needs/wants, to complete a simple task and to be included in activities. Visual supports take the form of real objects, pictures, photos or symbols, but can also involve actions, gestures or signs. Examples of visuals that support daily routines are;

- Activity schedules showing what happens, and when,
- Communication boards that provide the child with options and the means for requesting activities,
- Task schedules for helping a child learn a self-care task such as the steps of the toileting routine,
- Symbols/cue cards or gestures that help a child understand the rules and boundaries of behaviour e.g. stop/wait, and
- Social stories that describes a situation and how to respond.

## Understand your child's sensory profile

Sensory processing difficulties are common in children with Autism, and have an impact on how they take an interest, engage and participate in any setting. Your child is unique in the sense that he or she will avoid or seek out a combination of experiences that are significant. Children with Autism may have difficulties processing how they hear things, how they look at things, how they smell or taste things, and how their bodies respond in relation to the world around them.

An occupational therapist will help you learn your child's sensory profile. Some of your child's behaviours, e.g. avoiding showers, may be strongly connected to their sensory preferences. You are also able to use your child's sensory preferences as a starting point to connect. If your child enjoys jumping on the trampoline, because he or she seeks movement, it is an opportunity for you to join in and create an interactive game such as 'stop and go'. Your child is more likely to stay and play if it involves their sensory interest.

## Be a fun play partner and join in with their interests

Join in with what your child is doing; copy their actions, movements, sounds and words and talk about what he or she is doing. Use exaggerated expressions and fun words that will capture attention e.g. 'uh oh!', 'wow' or 'yeah!' and add sounds to actions e.g. using the word 'bounce' when you are bouncing the child on your knee. Involving yourself in your child's play on a regular basis, builds your child's capacity to include others' ideas and provides foundation skills and imitating and learning from others.

#### There is a time and place for special interests

Your child may have a specific, intense and repetitive interest in an object or activity. The function of this interest for your child is pure delight and is often very calming and soothing. To be denied access to these activities will cause distress and anxiety.

Plan access to these activities throughout the day and use them as motivators for tasks that are more challenging and less preferred. Keeping special interests for special times can be a great tool for your child to learn to wait, and to communicate

directly towards you in any communication modality i.e. gestures, pictures, signs, words or the written word.



JOINING IN: Estelle Pretorius encourages Ethan and Robbie's interest in water

## Create reasons for your child to communicate towards you

People games are great tools for building anticipation and functional communication skills. They are fun, physical games that are shared between adult and child, without involving a toy or object. People games that are popular are; tickle games, a game of chase, peek-a-boo and nursery rhymes / songs. They build valuable foundations in joint attention, functional communication and back and forth interactions and are a great way to re-connect with your child and build stronger relationships. When your child knows a game really well, choose a place in the game to pause i.e. waiting without saying or doing anything other than an expression of anticipation in your face. Your child will want to keep the game going, and will want to show you in some way that he or she wants 'more'. Begin to respond to even the slightest attempts e.g. a look or a gesture, and later you can wait for your child to say the word 'more' before you continue the game.

## Meaningful eye contact

The presence of meaningful eye contact for social purposes may be an important skill for a child with Autism to learn; however, this may be particularly difficult because it requires the child to 'multi-task' e.g. looking at a person while having to listen to them. You can begin to build foundations for this task while you are playing alongside or with your child. Learn the art of 'talking with your face' and creating reasons for your child to look directly towards you.

An example of a game you can play, is when something happens expectantly e.g. the tower your child is building, is knocked over, you could come down to their level and show a surprised expression on your face, with a gasp of air or the word 'uh oh!' and wait for the child to look towards you, before assisting. You can also bring a toy close to your face before giving it to your child, which allows him or her to briefly acknowledge you before having the desired toy. Position yourself so you make it easy for your child to shift attention from the activity to look at you, try sitting opposite when reading a book or playing with a cause and effect toy. Add fun sounds and match a facial expression with this sound, when your child is facing you.

## Conclusion

Research suggests that there are long term benefits of functional language acquisition through participation in daily routines. By creating learning opportunities within every routine, children have repeated practice of skills, and increased social competence.

#### About the author

Estelle Pretorius, B Logopedics (Communication Pathology), is on the professional expert team of Altogether Autism and works as a speech language therapist at McKenzie Centre Early Intervention Centre in Hamilton.

# The signs of Autism:

Jenny Gibbs, Clinical Psychologist and Altogether Autism Professional Expert Group member asks when should a parent be concerned enough to seek an assessment for their child?



## THE NEW ZEALAND Autism

Spectrum Disorder (ASD) Guideline sets out clear guidelines about signs to look out for that would suggest a referral for assessment for autism is needed.

In children under three, the signs of autism involve the absence of typical behaviour, so they can be difficult to identify. The internationally recognised indicators of the early signs of autism are:

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months Does not say meaningful single words by 18 months
- Does not say two-word phrases spontaneously (not just copying) by 24 months
- Has any loss of any language or social skill at any age.

If you notice any of the above signs, see your GP or Plunket Nurse or Well Child Provider and ask for referral to a paediatrician or child development service. Do not be put off by reassurances such as "all children are different" or "let's wait and see for six months".

While there is no cure for autism there is very good evidence that early intervention is helpful in supporting communication and minimising behaviour problems.

There is also an app available to parents of children under 2 1/2 years old which can tell you how likely it is that your child



has autism. It is based on comprehensive research carried out at La Trobe University in Melbourne, Australia and includes videos of typically developing children and children with autism to help parents understand what they are looking for. The link to this app is http://asdetect.org/

The New Zealand ASD Guideline identifies key signs of autism in children aged 1-3; 4-8 and over nine.

This is because autism is a developmental condition and looks different at different ages. There are many signs that can indicate autism.

Every child or young person may have a few of these and it does not matter if they do not cause difficulties. However, if there are a lot of signs, and the child is having difficulty coping in their everyday life, it is important to discuss this with your GP and your child's teacher, who can refer for further assessment.

The lists of signs below are adapted from the New Zealand ASD Guideline and from a resource developed by the Ministry of Health to help people know when to refer.

Signs in young children (1-3) that would suggest that an assessment for autism or another developmental problem is important are:

#### **Social differences**

- Lack of social smile and lack of eye contact
- Lack of imitation of actions (e.g. clapping)
- Deficits in joint attention, such as lack of showing, lack of shared interest, or lack of involving others in joint play with toys or other objects
- Lack of interest in other children or odd approaches to other children
- Minimal recognition or responsiveness to another's happiness or distress
- Not wanting to be picked up and cuddled
- Odd relationships with adults (either too friendly or distant)
- Limited variety of imaginative play
- Lack of pretend play, especially involving social imagination (i.e. not joining with others in shared imaginary games)
- Appearing to be 'in his/her own world'
- Failure to initiate simple play with others or participate in early social games
- Preference for solitary play activities.

## Differences in language development, especially comprehension

- Unusual use of language (e.g. made up words; reference to self as 'you' or 'she/he' beyond 3 years, unusual vocabulary for child's age or social group
  Poor response to name
- Poor response to name
- Limited non-verbal communication (e.g. lack of pointing and difficulty following the pointing of others)
- Failure to smile socially to share enjoyment and respond to the smiling of others
- Unusual language development, including muteness, odd or inappropriate intonation patterns, persistent echolalia ("parroting"),
- Limited use of language for communication and/or tendency to talk freely only about specific topics.

#### Differences in interests, activities and other behaviours

- Over-liking for sameness and/or inability to cope with changes especially in unstructured setting
- Repetitive play with toys (e.g. lining up objects or turning light switches on and off, regardless of scolding)
- Over-attentiveness to small visual details (e.g. fascination with spinning wheels)
- Repetitive motor mannerisms
- Lack of flexible, co-operative imaginative play or creativity (although certain imaginary scenarios, such as those copied from videos or cartoons may be frequently re-enacted alone)
- Difficulty in organising self in relation to unstructured space (e.g. hugging the perimeter of playgrounds, halls)

#### Other factors that may support a diagnosis of autism

Over- or under-sensitivity to:

- sound (e.g. has trouble keeping on task with background noise, responds negatively to unexpected or loud noises)
- touch (e.g. discomfort during grooming, avoids getting messy, picky eater, especially regarding certain textures)
- movement (e.g. becomes anxious or distressed when their feet leave the ground, or twirls, spins, or rocks self frequently during the day)
- visual stimuli (e.g. prefers to be in the dark, feels discomfort or avoids bright lights)
- smells (e.g. seeks out certain smells).

Signs in children (4-8) that would suggest that an assessment for autism or another developmental problem is important tend to be subtler than those in younger children but include:

#### **Social differences**

- Inability to join in with the play of other children, or inappropriate attempts at joint play (may manifest as aggressive or disruptive behaviour)
- Lack of awareness of classroom 'norms' (criticising teachers; overt unwillingness to co-operate in classroom activities; inability to appreciate/follow current trends, e.g. with regard to other children's dress, style of speech and interests)
- Easily overwhelmed by social and other stimulation
- Failure to relate normally to adults (too intense or no relationship)
- Showing extreme reactions to invasion of personal space and extreme resistance to being 'hurried'.

#### **Communication differences**

- Unusual language development, including muteness, odd or inappropriate intonation patterns (e.g. "accented" speech); unusual vocabulary for child's age or social group
- Limited use of language for social communication and/or tendency to talk freely only about specific topics of interest
- Differences in interests, activities and other behaviours
- Lack of flexible, co-operative imaginative play/creativity
- Difficulty in organising self in relation to unstructured space (e.g. hugging the perimeter of playgrounds or halls)
- Inability to cope with change or unstructured situations, even ones that other children enjoy (such as school trips or teachers being away)
- Intense or unusual patterns of interest



## Identifying autism for the first time in young people and adults is usually triggered by things such as:

- symptom changes and diagnostic dilemmas where children formerly diagnosed with other conditions have matured, their behavioural and emotional characteristics have altered, and, consequently, the original diagnosis is being reconsidered
- social differences where the differences in social behaviour between the person and their same-age peers has become more obvious and is causing distress
- difficulty meeting academic expectations where the person's response to the increasing demands of the educational system is of concern. For example, there may be an unusual profile of skills/deficits (e.g. social and motor skills very poorly developed, whilst general knowledge, reading or vocabulary skills are well above chronological/mental age)
- Sensory differences including over- or under-sensitivity to sound, touch, movement, visual stimuli or smells that mean the person has difficulty coping with everyday life.
- The loss of an elderly parent who has supported their adult child.

## References / Sources:

NZ Autism Spectrum Guidelines 2016

## Workshop aimed at overcoming job hurdles

**POWERSHOP**, a Wellington-based electricity retailer, hosted a free two-day employment skills workshop for budding information technology (IT) coders in September.

The 14 potential autistic software developers had a unique opportunity to practice their job interview and coding skills at Powershop's premises in Wellington.

Powershop is an electricity retailer that has become a modern, global software company. Recently, Brian Bannister, the chief technology officer at Powershop, challenged his team of software developers to find a way to share their skills with the community.

Kieran Trezona-le Comte, one of the software developers took up this challenge and approached his mother, Altogether Autism's national manager Catherine Trezona, offering a two-day free employment skills workshop for autistic people with an interest in IT.

Trezona-le Comte had a hunch that Powershop might be missing out on potential developers due to an employment process that was not as autism-friendly as it might be.

As a reader of the Altogether Autism Journal, he was also aware how hard it can be for people with autism to get work. He specifically wanted to learn more about effective communication at work with people on the spectrum, how Powershop can become a 'super autism-friendly workplace' and "to ensure that our recruitment process was not unintentionally filtering out people on the autism spectrum".

He is passionate about coding and enjoys sharing and encouraging others, and he volunteered himself as project lead for the workshop, collaborating with his mother.

Goals of the 14 participants included 'what is needed for a career in technology', 'how autism spectrum disorder strengths can be leveraged in a tech environment', and 'skills to help in a job interview'.

Those who attended this free workshop experienced a day in the life of a developer, starting with an introduction to a 'sprint board' (a visual representation of to do/doing/done), and participated in 'stand up' a short team catch-up to review the sprint board at the start of the day.



GROUP SUCCESS: I-r kneeling: Lena Plaksina, Kieran Trezona-le Comte. I-r standing: Jarrod Saxby, Dylan Francis, Catherine Trezona, Wolf Hatch, Jackie Sowry, Brendon Turvey, Deborah Stoebe, Samuel Bishop, Joshua Drakeford, James Royle, Christopher Liolos.

Ten Powershop developers worked with the trainees on a coding exercise, which all completed successfully. Job interviews were role played with the support of three Powershop managers.

Discussions were had on whether it was okay to explain a preference for not making eye contact in an interview, and the pros and cons of disclosing being autistic to a potential employer.

"The employment skills workshop was a wonderful experience for Powershop's delivery team. Our developers, testers and managers had the chance to meet some awesome people on the Autism Spectrum and get to know, in detail, how we can be a better employer," said Trezona-le Comte.

"We loved sharing our technical knowledge with the participants, and I think they all got something out of the workshop."

After the success of this workshop, Altogether Autism is keen to collaborate with other organisations who are interested in benefitting from the strengths of autistic workers.



CODING EXERCISE: Dylan Francis, Michael Winton, and Tara Magee



SOFTWARE DEVELOPER: Kieran Trezona-le Comte of Powershop, leads a session on interview practices.

# Connecting Through Support

## A Journey of Hope with Pasifika Autism Support Group

**BRIAN AND BETTY** Pulefolau set up Pasifika Autism Support Group six years ago after their eldest son Roman, then  $4\frac{1}{2}$  was diagnosed with Autism.

In the beginning of their autism journey, they were trying to understand what Autism was and how it affected their son. At times they faced a range of feelings including confusion, isolation and anxiety about their son's future.

However, they had one question which prompted them to start their support group: "Where are the other Pacifica families and their children with Autism?"

Raising awareness of Autism within the Pacific communities was one of the reasons for setting up the group.

The word "Autism" was a foreign word to the Pacific communities and there was confusion over what support was available for families.

There is also a stigma associated with having a child with Autism or with any kind of special needs. These beliefs can prevent families from seeking help.

All families raising a child with autism spectrum disorder have hard times. Pasifika Autism Support Group wanted to help parents get off to a good start by empowering them with information, especially on what service providers were available for them, as well as promoting self-efficacy.

Strengthening parents and providing them with new knowledge and strategies about autism will give them the confidence to help their child.

Positive relationships help families to support each other and deal with challenges.



FAMILY CELEBRATION: L-R Joel (11), Roman (12), Zechariah (9), Betty and Brian at Betty's graduation.



HEALTH PROMOTION: L-R Beatrice Wright, Amina Tini, Narita Vaivai, Betty Pulefolau and Clarice Yerkovich

Family is an important foundation for all Pacific Island cultures, is central to Pacific people and many want to be present or involved during diagnosis and decision-making processes.

The group provided a way of strengthening family support through encouraging and welcoming families to bring their child and extended family members.

Morning tea was always provided and eventually everyone was bringing a plate of food to share. Grandparents can be influential in encouraging and giving positive support to parents therefore it is important to have them as part of the meetings.

Families say it's important for their cultural protocols to be valued and respected. When families feel value and respected they engage more with the services that are there to help them support their child.

The Pasifika group encouraged parents to be proactive in developing relationships within Pacific communities by providing information and increasing understanding about Autism.

Five mothers in the group provided information about Autism at a health promotion event in the Otara Shopping Centre on Saturday 10 September. By sharing their own stories, the mothers were able to engage with people seeking more information about autism or who wanted to join a support group.

For further information about Pasifika Autism Support Group www.facebook.com/PASGNZ or contact Brian and Betty Pulefolau on 021 216 7772.

# Altogether Autism CONFERENCE 2017

# Wednesday 19 & Thursday 20 July

Holiday Inn Auckland Airport 2 Ascot Road, Mangere, AUCKLAND 2022

THEME: Transitions

## IMPORTANT DATES:

Early Bird opens **1 November 2016** 

Early Bird closes 1 May 2017

Call for abstracts opens 1 November 2016

Call for abstracts closes 1 February 2017

**Early Bird** Consumers/family/whānau \$320

Full rate \$420 (after 1 May 2017)

**Early Bird** Professionals

\$540

Full rate \$640 (after 1 May 2017)

## Keynote speaker:



DR RITA JORDAN

PROFESSOR IN AUTISM STUDIES AT BIRMINGHAM UNIVERSITY

REGISTER GO TO: www.altogetherautism.org.nz FOR MORE INFORMATION, CONTACT info@altogetherautism.org.nz