ALTOGETHER AUTISM
JOURNAL
AUTUMN 2015

THE STRENGTHS AND CHALLENGES OF HIGH FUNCTIONING AUTISM

DEVELOPING PEOPLE SKILLS IN VERBAL CHILDREN WITH ASD

DUAL DIAGNOSIS OF ADHD AND ASD

OVERWHELMING TO OVERCOMING

AUT T'BE CONFERENCE 2015 PROGRAMME

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IN THIS ISSUE

4 **Developing people skills (theory of mind) in verbal children with a diagnosis of autism spectrum disorder**
Estelle Pretorius explains how you can help to develop theory of mind skills in your child

8 **ADHD and ASD**
Dr. Phillipa Clark explores how the DSM-5 recognises dual diagnoses of ASD and ADHD

11 **Why I stand in solidarity with the low functioning**
Penni Winter discusses the controversial 'functioning levels'

12 **To disclose or not to disclose**
A personal account of disclosing a diagnosis of autism in the workplace

14 **Overwhelming to overcoming**
Tanea Paterson shares her journey coming to terms with a late in life diagnosis of 'high functioning' autism.

16 **Aut T'Be Conference 2015**
Everything you need to know about the upcoming annual Altogether Autism conference.

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Cover image: Tanea Paterson

WELCOME

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Welcome to this special edition of the Altogether Autism Journal.

I am pleased to introduce myself as the new editor of the Journal, following the resignation of our National Manager, Paula Gardner, who has moved on to an exciting new position. We are sad to see Paula go, and are determined to continue to build on the sure foundation she has established during her eight years at Altogether Autism.

In this issue of the Journal we cover two areas. The first explores some of the strengths and challenges of what is commonly known as 'high functioning autism'; the second topic gives you key essentials for our upcoming national conference, to be held in Auckland on 22 and 23 July 2015.

When deciding to focus on 'high functioning autism' for this edition of the Journal, we anticipated it would include a celebration of the strengths of members of our autism community in particular, as well as some of the more general areas of excellence often seen in people with Asperger's. The contributors to this edition have been very generous and honest in sharing their experiences of diagnosis, identity and disclosure, highlighting some of the issues for those who work and walk in the neurotypical world. This edition also has contributions from two professionals working with people on the spectrum.

We didn't get very far into the consideration of high functioning autism before the controversy over terminology became apparent. The very term 'high functioning autism' predicates 'low functioning autism'. The commonality and differences between the two ends of the spectrum is well articulated by Penni Winter in her article "Why I stand in solidarity with the 'low functioning'". We use the term 'high functioning autism' acknowledging this is a flawed and at times controversial label, and encourage you to recommend alternatives via our Facebook page.

Turning to the second theme of this issue, we hope you are as excited as we are about getting Upskilled, Educated and Aware at the Altogether Autism conference in July. We have six exceptional keynote speakers, and over 30 presenters, bringing you a feast of information and inspiration. Registration is open on the website and early bird pricing closes on 30 June so act now! Truly, you Aut T'Be there!

Catherine Trezona
Researcher

DEVELOPING PEOPLE SKILLS (THEORY OF MIND) IN VERBAL CHILREN WITH A DIAGNOSIS OF AUTISM SECTRUM DISORDER

BY ESTELLE PRETORIUS, SLT, MCKENZIE CENTRE

Theory of Mind difficulties have a definite impact on the ability of a person with Autism Spectrum Disorder to interact and make sense of the social world. The 'neuro-typical' culture contains unwritten social rules defining the way people respond to each other, and these rules often change, as the context we communicate in changes. Our understanding of others' thoughts, feelings, likes, and wants, impact on the success we have in making, and maintaining friendships.

Theory of Mind, or People skills is the ability to attribute mental states to ourselves and others in order to understand and predict behaviour, and is an area of difficulty for a person who has autism. It may create major barriers to communication and closeness with others. 'People skills' involve the ability to:

- Communicate words and their meanings to others
- Understand what others are telling us
- Communicate without words e.g. using our body language and eye gaze meaningfully
- Responding to non-verbal messages of others
- Share emotions/affect[1]
- Responding with and to social smiles
- Communicate our beliefs, values, ideas, opinions, needs and wants
- Understand the beliefs, values, opinions, needs and wants of others
- Communicate or express ourselves in difficult situations
- Reflect on, and repair interactions that go wrong
- Adjust our behaviour to suit the social context
- Empathise with others
- Make and maintain friends
- Communicate humour and false beliefs
- Understand humour and false beliefs of others
- Share imaginary play and role play
- Respond to the needs of others by doing or saying something.

Establishing engagement and joint attention

Children begin to make sense of facial expressions and body language of people in their immediate social circle early on in their lives. They continue to build daily experiences and make connections and meanings, and as they gain functional language skills, they develop the ability to communicate these messages towards each other. Prior to the development of Theory of Mind is the development of engagement, joint attention and self-awareness. Early on in a child's

1 Affect is the experience of feeling or emotion

life they learn to be guided by the expressions on adult's face, i.e. responding to, and giving big social smiles, responding to being comforted when rocked, touched, or looked at, looking sad when an adult leaves them/turns away, and showing curiosity when facial expressions change. Along with the ability to relate to others a child develops a sense of self i.e. self-awareness, and involves an understanding of who we are, what we like, and that this may be different for each individual.

How can we facilitate engagement?

Encourage face to face interactions with your child as often as possible. Share attention by talking about what the child is doing, seeing or saying. Follow the child's lead and join in with the child's interests. Get to know your child's interest and be genuinely interested in what they do with that toy. Share positive affect and pair that with actions. Make comments stand out by using visual tools e.g. pictures, body language, eye gaze and facial expressions. Draw attention to what others are doing and point them out to your child. Imitate children's actions, sounds and play, and wait for your child to notice you. Frequently use and demonstrate the language of emotions. Regularly offer opportunities to your child to communicate directly towards you e.g. to ask your help, to ask for a toy or an action, and to make a comment or ask a question. Promote adult role play from an early age e.g. dressing dollies, pretend talking on the phone, or play with creative art materials.

Theory of Mind develops in a typical and sequential pattern, similar to other areas of early childhood development. The developmental progression of Theory of Mind was first identified by Wellman and Liu (2004). This is summarised below along with strategies to build these skills at an early age during face to face interactions with children.

Diverse desires

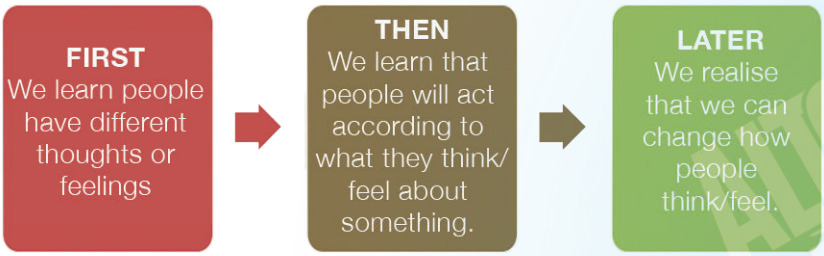
[Different people want different things, and we act in different ways to get what we want/need].

Example: A group of children are sitting in the reading corner talking about the things they like. One child walks away and returns with a book that she knows her friends might like, and shows it to them.

Diverse Beliefs

[Different people have different beliefs about the same thing. We base our actions on what we think are going to happen.]

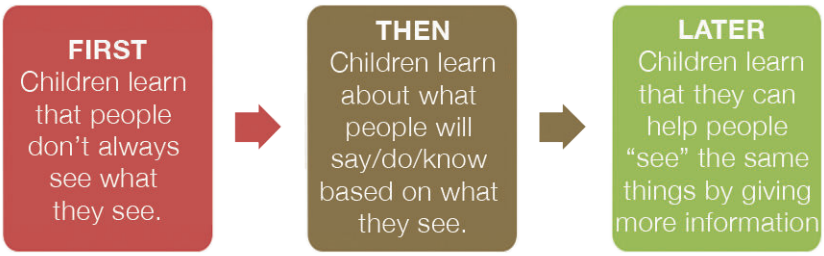
Example: A young boy kicks a soccer ball into a net, and thinks he has scored a goal; however, he has not heard the end of game whistle shortly before this. Another child looks at the boys' excited response and knows instantly that the child did not hear the whistle. He then goes over to the boy and says 'that didn't count!'



Knowledge access

[When someone hasn't seen something, they will need extra information to understand]

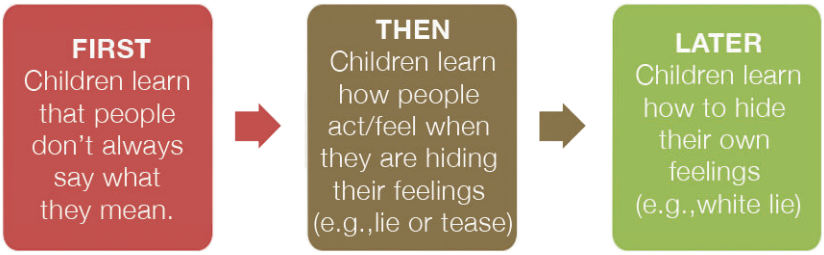
Example: A 4- year old girl talks to her grandmother on the phone; she is playing with her toy dolly. Her grandmother asks her 'What are you doing Amy?' and she describes 'I am playing with my dolly, she's wearing a red dress', because she realises her grandmother can't see what she is looking at.



Hidden emotion

[People can feel a different emotion from the one they display]

Example: At a birthday party Amy gets a birthday present from her Dad. She expected a guitar, and instead, received a baby doll. She says to her Dad 'Thanks, I love it' but she is thinking she is disappointed about not getting the guitar. Her brother, standing nearby is thinking 'She doesn't really mean that, but I won't say anything, because Dad will be upset.'



Understanding False Beliefs

[People believe things that are not true, and they act according to their beliefs, not necessarily what is really true.]

Example: Johnny and Dad have decided to make Mum breakfast in bed, for Mother's Day. Dad suggests they do this quietly in the kitchen so Mum doesn't hear them. Johnny then says to Dad 'She's going to think we forgot it is Mother's Day!' and looks slightly worried. He then says 'Mum might be sad'.

Helping your child develop these skills can look like this:

1. Frequently talk about the things that make you happy or excited e.g. 'I like going to the beach because that's where I get to swim'.
2. Model language that describe emotions and affect e.g. 'Don't worry, we will play this game again tomorrow'.
3. Identify and describe emotions of others and self. Teach intensity of emotion by representing it visually e.g. on a scale of 1-5.
4. Use language that describes the process of problem solving e.g. 'I wonder what will happen if we …', 'I have an idea....' I don't think so...'
5. Be warmly engaged with your child, and use exaggerated but genuine facial expressions.
6. Encourage pretend play, as it encourages the child to think about, and re-enact the perspectives of the person they are role playing.
7. Frequently use words that describe likes, dislikes, wants, needs, etc.
8. Talk about the characters in a story book i.e. their thoughts and their feelings, their ideas and reactions, and what they might do next in the story.
9. Build photo diaries to reflect on the past.
10. Use social stories to explain, and plan for a difficult social situation.
11. Make predictions about things that will happen in the near future, and later down the track.
12. Make all life lessons relevant to your child's experience and interests.

REFERENCES

Lantz, J. (2002). Theory of mind in autism: Development, implications, and interventions. *The Reporter,* 7(3), 18-25. Retrieved from http://www.iidc.indiana.edu/?pageId=424#sthash.2dU8YYi3.dpuf

Howlin, P., Baron-Cohen, S., & Hadwin, J. (1998). *Teaching children with autism to mind-read. A practical guide.* New York, John Wiley & Sons.

Sussman F. (2006). *TalkAbility - People skills for verbal children on the autism spectrum: A guide for parents*. Toronto, ON: Hanen Early Language Program.

Lowry, L. (2015). Thinking about thinking: How children develop theory of mind. Hanen Early Language Program.

Wellman, H.M., Fuxi, F, and Peterson, C.C. (2011) Sequential Progressions in a Theory-of-Mind Scale: Longitudinal Perspectives. *Child Development 82*(3), 780-792.

Estelle works as an Early Intervention Specialist at McKenzie Centre. McKenzie Centre provides specialist Early Intervention for pre-school children who have special needs, and their families, throughout the greater Hamilton area. Estelle supports families who have children who present with Autism Spectrum Disorder, Social Communication Difficulties, as well as other Communication Delays resulting from Developmental Delays or Motor Disorders. She has a qualification as Speech Language Therapist, gained from Pretoria University in South Africa, and gained certification in presenting a range of parent programmes which support families with children with developmental delays. These programmes provide insight and understanding into the challenges and strengths of ASD, but also teach parents effective strategies to promote communication and positive interactions with their children.

ADHD AND ASD

BY DR PHILLIPA CLARK – BM 1987 SOTON;
DCH 1989 RCP LOND; MRCP 1990; FRACP 1997.

Phillipa is a Consultant in the Developmental Paediatric Service at Starship Hospital, at the local Child and Adolescent Service, and the Kari Centre.

As a Developmental Paediatrician I am very aware that children can present with features of both Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD). In the past a doctor using the diagnostic classification system DSM-4TR could not in theory diagnose ADHD in someone who was already diagnosed with an ASD. Now with the advent of DSM-5[1] it is recognised that one person can have both conditions. This makes sense as studies have shown that between 20 to 70% of people with ASD turned out to also have ADHD when properly assessed (reviewed by Konst, Matson, Goldin & Rieske, 2014). Conversely a study of youth with ADHD found that 18% had autistic features, while less than 1% of those without ADHD had such features. Additionally youth with ADHD and autistic features were more impaired than those with just ADHD (Konst et al., 2014).

The fact that someone can be both on the spectrum and have ADHD raises some important issues. Firstly both conditions need to be correctly identified so that an optimal treatment programme can be offered. Secondly the co-occurrence of these conditions raises questions about what causes ASD and ADHD and whether they are independent or perhaps genetically linked.

ADHD is a diagnosis based on behaviours measured and compared with behaviour in other children of the same age and gender. Many children show hyperactivity, fidgetiness, impulsive behaviour, and may butt into conversations or games and have problems waiting their turn. Inattentive features are more easily missed and children may fail to pay attention, seem to be day dreaming, forget what they were doing and wander off to do something else. Once distracted it can be very hard to get back on track. If not correctly diagnosed this can look like laziness, rudeness, insolence, or lack of motivation. In America around 9% of children meet the criteria for ADHD. There is no diagnostic test, no blood test or brain scan that a doctor can order to say for sure that this is ADHD. In this it is like ASD where again there is no diagnostic blood or brain test just a careful review of behaviour and presentation. The problems faced by people with ADHD are a relative lack of skills found in the pre-frontal area of the brain, and in the part of the brain at the back of the head, the cerebellum (Schneider, Retz, Coogan, Thome & Rosler, 2006). It is believed, for example, in the developing brain, circuits that link in with the pre-frontal cortex are poorly developed in those with ADHD.

There are huge amounts of research on what helps in ADHD. Guidelines are clear that behavioural approaches and parent training are very important components of a complete treatment package (Subcommittee on of attention- deficit/hyperactivity disorder, Steering Committee on Quality, Improvement and Management 2011). In New Zealand we have two excellent evidence-based programmes – Incredible Years and the courses offered through Triple P. As a paediatrician or parent it is important to check that the child is getting a good night's sleep. I also promote the idea of a balanced diet with an adequate iron intake. Medication, however, has the biggest effect on ADHD symptoms of any intervention, particularly when we are thinking of those aged 5 and over, so it too has an important place.

A typical story of a child brought to see a doctor or psychologist is shown in box 1. I have called this child Clem.

Clem – referred now in 3rd year at school – poor attention, day-dreams, calls out and walks around when should be sitting, not getting on with peers, bossy, poor sharing, impulsive, noisy, disrupting class. No clear history of very strong interests. Sensory issues - assembly is hard to tolerate, finds being bumped when queuing difficult, poor understanding of personal space, and felt to be bright academically but not proven as cannot sit still long enough to be properly assessed by the teachers.

1. The DSM is the Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association and is used by clinicians, researchers, and the legal system and policy makers to describe a wide range of conditions. An alternative is the International Statistical Classification of Diseases and Related Health Problems (ICD) produced by the World Health Organization.

How do we untangle the problems that relate to possible ADHD from those that relate to possible ASD? Children with ADHD who interrupt, act impulsively, and call out can end up being unpopular. All the children and even the teachers lose patience. We can imagine that Clem might not be invited to other children's houses and possibly not invited to birthday parties. Do such children have genuine social interaction difficulties of an ASD kind? If they could concentrate and think before they acted, I ask myself in clinic, would their social skills and friendships improve? If they have ADHD as part of the presenting problem then the answer is likely to be yes. Whether the social difficulties will go away completely remains to be seen.

Clem was assessed with standardised questionnaires from home and school, a school observation was undertaken, and a very boring computerised test of attention was endured. A screening test of language ability showed average scores, suggesting no underlying cognitive problems. The screening tests of word reading, numerical operations and spelling were all rather lower than would be expected for children of that age of presumed at least average cognitive abilities. What was causing this academic problem? Could it be that poor attention and focus was holding Clem back?

Clem's questionnaires were consistent with ADHD with both inattentive and hyperactive/impulsive features. The history from the family, starting before the pregnancy and carrying to the present day, was consistent with a healthy child with ADHD as was the school observation. The school observation also show that Clem was resistant to writing about anything other than insects, and he showed poor judgment when interacting with peers, for example taking the ball that children were playing with and running off with it. What was this about? In situations like this, where ADHD criteria are met and there are also features of ASD, one option can be to treat the ADHD with medication (and parenting support and training) and to see which symptoms improve as a result. If social interaction and social skills improve dramatically once the child is able to think before they act i.e. is less impulsive, and less disruptive, we may find we do not need to also investigate for a possible ASD diagnosis. If someone has both ASD and ADHD consider this: the ADHD may be the element of the current situation that is very amenable to a sometimes dramatically successful treatment option.

So far I have looked at this overlap from the point of what a doctor might suggest when meeting a child who has ADHD and might also have ASD. Research continues to improve our understanding of children and adults who present with both sets of difficulties. Thus there is increasing evidence that ADHD and ASD are genetically related, and they certainly co-occur more than would be expected by chance. One way of studying this is to look at twin pairs, some identical, some not. Ronald and colleagues published a twin study in 2008 and found that ADHD in one twin increased the chance that the other twin would have ASD, and vice versa, and that this was particularly so in genetically identical twins. They concluded that both ADHD and ASD are 'highly heritable, with a moderate degree of genetic influences that are common across these sets of behaviours, as well as some genetic influences that are specific to each.' (Ronald, Simonoff, Kuntsi, Asheron & Plomin, 2008, p. 541.). This was looked into later by Martin and colleagues who studied Copy Number Variants (CNV) found in ADHD and in ASD. CNVs are missing or doubled up bits of our DNA. We all have them, but most do not affect genes and therefore are not known to be important. Martin and colleagues (2014) looked to see whether the biochemical pathways coded for by genes affected by the CNV found in their study samples showed an overlap in those people with ADHD and those with ASD. They found that CNVs in these conditions showed overlaps and those three pathways were affected in common, and this occurred more than would be expected by chance. The pathways affected were those described as the 'nicotinic acetylcholine receptor signalling pathway', 'cell division', and 'response to drug'.

In summary, therefore, it is not surprising that I meet children in clinic who appear to have features of both ADHD and of ASD. While the theoretical reasons for such combination of behaviours is of interest, what matters most to each child and family is getting to understand each individual child in order to put together an approach and package that best helps them meet their full potential both academically and socially, at home and in the wider world. Making an appropriate diagnosis is an important step in the process.

SOME FEATURES OF ADHD

Inattentive features: e.g.

- forgetting what he or she was doing
- needing requests repeated
- remembering only part of a request or instruction
- forgetting things
- loosing things
- problems getting organised with right equipment at right time
- difficulty starting things
- day dreaming
- being very easily distracted, then loosing track of what he or she had been doing
- parents needing to redirect back to homework task - repeatedly

Hyperactive impulsive features:

- Full on – as if driven by a motor
- Fidgety, bouncy, can't keep hands still, needs to fidget or fiddle in order to focus
- Impulsive – takes risks or says things, thinks later
- Butts into conversations, can't wait his or her turn

SOME FEATURES OF ASD

Difficulties understanding the experiences of others

- Reduced interest or ability to initiate or respond to social overtures from peers
- Lack of interest in what others are interested in
- One sided conversations

Difficulties using forms of non-verbal communication e.g.

- May not point to things to get others to look at them (share experience)
- May not use little or no facial expression
- May not use gestures well to convey meaning
- Reduced or abnormal eye contact

Problems in making and maintaining and understanding relationships e.g.

- Reduced imaginative play
- Difficulties adapting behaviour to different situations – how we talk to a friend vs how we talk to a teacher

Repetitive movement or questions: e.g.

- Flapping
- Echoing words or phrases
- Lining things up

Strong need for routines, insistence on sameness: e.g.

- Small changes in usual routine lead to great distress
- Some routines can be complex and have to proceed from start to finish come what may

Strong or unusual interests that interfere with family life

Unusual sensitivity or lack of sensitivity to sensations such as pain, touch, texture ■

REFRENCES

Konst, M.J., Matson, J.L., Goldin, R. & Rieske, R. (2014). How does ASD symptomology correlate with ADHD presentations? *Research in Developmental Disabilities, 35*(9), 2252-2259. Doi 10.1016/j.ridd.2014.05.017. Epub 2014 Jun 12.

Martin, J., Cooper, M., Hamshere, M.L., Pocklington, A., Scherer, S.W., Kent, L…Holmans, P. (2014). Biological overlap of attention-deficit/hyperactivity disorder and autism spectrum disorder: Evidence from copy number variants. *Journal of the American Academy of Child & Adolescent Psychiatry, 53*(7), 761-770. e226.

Ronald, A., Simonoff, E., Kuntsi, J., Asheron, P. & Plomin, R. (2008). Evidence for overlapping genetic influences on autistic and ADHD behaviours in a community twin sample. *Journal of Child Psychiatry, 49*(5), 535-42. Doi 10.1111/j.1469-7610.2007.01857.

Subcommittee on of attention- deficit/hyperactivity disorder, Steering Committee on Quality,Improvement and Management (2011). ADHD: Clinical practice guideline for the diagnosis, evaluation, and treatment of attention- deficit/hyperactivity disorder in children and adolescents. *Pediatrics* .doi:10.1542/peds.2011-2654

Schneider, M., Retz, W., Coogan, A., Thome, J. & Rosler, M. (2006). Anatomical and functional brain imaging in adult attention-deficit/hyperactivity disorder (ADHD)—A neurological view. *European Archives of Psychiatry and Clinical Neuroscience, 256*(1), i32-i41

WHY I STAND IN SOLIDARITY WITH THE LOW FUNCTIONING

BY PENNI WINTER

The whole issue of 'functioning levels' is a very important and often controversial one. There are many who tell apparently 'high-functioning' autistic adults that they cannot speak for all autistics, because they aren't 'really' autistic, or are 'not autistic enough'. There are those who say high-functioning autistics shouldn't object to how the low-functioning are treated, because we 'can't understand' how 'awful' they make life for their caregivers and families, and it's 'for their own good'. And so on and so forth. And these tactics often work. I have encountered aspies who refuse to identify as autistic, because, in the words of one, "I'm not autistic, because I'm intelligent".

Well I do identify as autistic, and as aspie, and with those 'low-functioning'. I refuse to be separated from them, and I want to make clear my reasons why.

Reason One - Defeating the 'Divide and Conquer' thing. Many so-called autism experts, some autism parents, and those in the 'autism industry' (aka, those making money off parents' desperation), take the stance that "It's all right for you high-functioning types, but 'these people' have real problems, which can only be addressed by this drastic treatment/long hours of therapy/punitive suppression/weird cures/etc/etc". What this effectively says is "We'll leave you alone as long as you can pass for normal, and as long as you don't protest what we're doing to 'those people'." It's an unspoken but nonetheless potent threat – but also a nonsense, because –

Reason Two - There is no clear dividing line between low and high functioning. Or between Aspergers and high-functioning autism, for that matter. An individual can be diagnosed at one level, or with one condition, at one point in their lives, or by one professional, and then get a different diagnosis later on or by another professional. Plus, there are many autistics who can do things like communicate via the internet, advocate on behalf of their fellow autistics, even write articles and books that get published, etc, but cannot communicate verbally, hold down a regular job, or live independently. Others need a great deal of support from family or social services to even approach 'high-functioning'. Even those who, like me, seem fully independent, have often achieved this only with lots of help, and/or after years of struggle. We still have multiple problems, e.g. social and relationship challenges, sensory overloads, melt downs, executive dysfunction, etc. None of us are 'high-functioning' in all areas of our lives. NONE.

Reason Three - All autistics are entitled to respect, no matter what their functioning level. Many are labelled 'low-functioning' because of their lack of verbal speech, but if/when they finally find a way to communicate, a perfectly functional intelligence is revealed. Others are labelled such because they struggle with basic self-care tasks. But no matter what their level of intellect or independence, they are still entitled to be treated with respect and dignity. They are entitled to the normal range of human rights, as well as those rights that specifically apply to those with disabilities.

Reason Four - I feel more in common with them than with NTs. NTs see me 'looking normal', and assume I want to be identified as such, that it's a compliment if they tell me how 'normal' I seem. When actually, it's an elaborate front I've evolved to cope with life, and frequently a strain to keep up. I often feel like a fake doing it, and long to reveal more of my true self. Apart from my family, I do not identify with NTs in general, or want to. Underneath, I know I am far more like that kid rocking and flapping in the corner than any of them suspect. Underneath, I understand why he rocks and flaps – and even do it myself, when no-one's looking. Because -

Reason Five - There is only one autism. At the core, all autistics are equally autistic. The big difference between high and low functioning is not 'how much autism we have', but 'how well we can pass for normal', i.e. how many social, communicative and life skills we are able to learn. If scientists, doctors, etc, really want to help autistics, they should be researching why some autistics can learn these skills, learn to talk, etc, and others can't, what part of our brains determines this.

For my part, I can only say this: -

I will not be separated.
I will not be disempowered.
I will not be silenced.
I will not have my true, underlying nature denied.
I will not stop being autistic, and championing the right of EVERY autistic to BE autistic, to be free, and to be given the human rights they so desperately need.

I stand in solidarity with all autistics, and I invite every autistic, no matter their functioning level, together with our non-autistic allies, to stand with me. ■

Check out Penni's blog *A Stranger in Godzone* at http://strangeringodzone.blogspot.com

TO DISCLOSE OR NOT TO DISCLOSE?

THIS ARTICLE WAS CONTRIBUTED BY A PERSON ON THE SPECTRUM WHO WOULD PREFER TO REMAIN ANONYMOUS.

We live in a world that is naturally conformist. With a social structure that has its own set of rules that the average person seems to understand just fine, and expectations for a person as a member of society that seem fairly clear to most. We live in a neurotypical world.

Which is fine, really. If we think of ourselves on the spectrum as a race group, we're the ethnic minority, and, by and large, majority rules so we just have to go with the flow. For some of us this just doesn't work, and we're outwardly ourselves regardless of what the world wants, though some of us become so adept at going with the flow that we start to look like the majority, that's the power of social expectation and conformity. We become actors playing a role on the stage of the world. Occasionally (or sometimes more than occasionally), we miss our cue, stumble through our lines, but we get by. It's only when the curtain falls and we're in the dressing room that we get to revert back to our true selves.

As an adult on the spectrum, I'm a good actor. I have a wife and kids, a good job, a house, and some nice toys to play with in my spare time. A nice, if a little compartmentalised, life. The majority of people wouldn't even pick that I had any sort of 'issue' in the background – only those that are allowed to get to know me well enough figure it out and will either drift away because it's too awkward, or accept me for who I am. But acceptance can be a double-edged sword.

I was diagnosed later in life following on from my son being diagnosed with Asperger's. With it came a sense of relief, but also a sense of fear about being 'outed' to the world as being different. My family isn't stupid and have likely figured out that I'm different before I really knew it myself, and with limitations accept me for who I am. At home with my wife and kids, I can be myself and this can be anywhere from fun to outright exasperating for them, but it is what it is. Workplaces can be different though.

I started in my first 'managerial' role in 2008, working in a technical field with staff and contractors reporting to me. It is a highly structured industry with a procedure for everything, and working within the fairly strict framework we had was sometimes challenging but still a comfort – I do so love procedures and processes, especially when they're my idea – but it was the people side of the role that I struggled with, and still do so to an extent.

As an autistic, I find people strange. Especially men, who have their own 'code' around interacting at work. Conversations at the smoko room table are hard to follow, people talk over others and there can be several simultaneous conversations. Conversations that seem so pointless, about things that don't matter. This just turns into noise in my head and I give up trying to be involved, and sit reading the paper and doing the crossword. It's a good day when I complete the crossword in under 10 minutes!

When I was diagnosed in 2013, it all became so much clearer. I knew why. I met like-minded people through my son, and connected with others on Facebook. I began to understand and accept myself more for who I was. But it still left the issue of social interaction at work. I ended up disclosing to one of my staff that I was on the autism spectrum. Being more junior to me, I didn't get too many of the usual questions ("Like rain man, right?", "How many digits can you recite pi to?") but it eased the environment in the office almost instantly, and probably explained a few things to him about why his manager was a little bit quirky. It was a good decision.

The company I work for touts itself as being inclusive and respectful of diversity. But I knew that people were

unpredictable, judgemental creatures, and I was scared of what my colleagues might think (or say amongst themselves!) if I disclosed to them. I was worried about being thought 'less' of, and being perceived as incompetent. I was a little paranoid I guess. So I formed a disclosure strategy.

I was lucky enough to be sent to Singapore for training (about diversity), and to be on the training course with a senior HR manager and I chose to disclose to him. A bit of a 'dry run' for letting my manager know back in NZ. It went real well – I shared some concerns, he came back with assurances and all the right words (he was HR, after all), I felt better.

I was more worried about what my manager would think. He is very old school – I once got spoken to for purchasing a punnet of strawberries for the team to share at work, on the company account - but on the face of it a fairly genuine person. I told him earlier this year, and I needn't have worried. His only response was a shrug of the shoulders and "everything seems to be running fine here. If you need help let me know." It was a good example of how a big issue for me could mean so little to someone else.

There is still the fear of full disclosure though. As far as I know, my colleagues don't know that I fall on the spectrum. I don't think they need to know, at the moment I'm content that they just think I'm quirky, or a little weird. I'm very conscious that once I disclose, I can't un-disclose. My current employer might accept me for who I am, but my next might not. Not wanting to sound melodramatic, but it's a need-to-know thing.

But the great thing now is that I know that I'm not alone - others are in a similar position, in a kind of disclosure 'purgatory'. Actors on the stage of the world. Maybe only their true selves when the curtain falls and they can shed a tear in the changing room at the end of the show. ■

BEYOND DIAGNOSIS: WELCOME TO THE AUTISM SPECTRUM

ASK TRUST

Written by adults on the autism spectrum who are members of the ASK Trust, the Welcome Booklet was intially aimed at the newly diagnosed adult.

The 44 page book explains, cautions and empowers.

This book is a great resource for people on the autism spectrum, caregivers, mentors, professionals, educators, cousellors, NGOs, government, media and libraries.

AVAILABLE FROM ALTOGETHER AUTISM AND WWW.ASKNZ.NET

OVERWHELMING TO OVERCOMING

BY TANEA PATERSON

I have come to realize that during my life I have rejected or 'disliked' things I did not understand, such as being a part of a wide social group, female friendships, being 'myself' and being able to freely and safely express who I am. People tend to take these things for granted as something that comes naturally. I experience anxiety and depression from the challenges of this not coming naturally to me and have a deep seated fear of not living up to societal expectations. I am writing this whilst I am going through a delicate and artistic diagnosis for autism at age 39. I say artistic due to the fact that I have spent my almost forty years with this autistic brain, and to survive (rather amazingly) I had to adapt. All of my adapting, although it has served me at times, has also made it difficult for me to remember my true being. The true essence of myself has been shrouded in a desperate need to fit in to a world that works in ways so differently to mine.

I feel as though I have pretended my way through life - sometimes it has worked. However, mostly I have been left feeling hurt, scared and confused by things that happened to me and the people around me. Just as a tree must grow around and over a rock in order to gain the light and water it needs to survive, just as a baby must cause some hurt and damage to their mothers body in order to arrive into the world, I caused hurt and harm to myself and to the ones who I was growing with and around. This came not from an inherent need to hurt, no, it was from a need to survive. I did this blind to my diverse neurological make up. I simply did not understand that others thought differently to me. I pushed, bruised and damaged the people that were in my path. Not the least, myself.

So much of my human experience makes sense now, not 'sense' in the all-encompassing clarity way, sense by acknowledging myself in a new, more empathic way. This powerful new knowledge makes me feel like less of a 'mess up'. That is not who I am, it never was. Who I really am is not reflected in my past actions. The fact is that fundamentally I am different to the majority of the population. I have a diverse way of seeing and being in the world, and my language and actions were related to my lack of understanding of myself and therefore the world around me.

So now I must find a way to explain what, who, how and why I am - to myself and to the others around me. And I must acknowledge that there will be people who look at me with their 'confused face' when I tell them I have autism and say "no, you seem ok to me, just a bit odd" (obsessive, naive etc) and "you can't tell that you struggle so you must be ok". I have worked very hard on you not being able to 'tell', so hard I am exhausted and I need to make changes. It is time to make sense of, or at least make peace with my constant feelings of awkwardness, sensory sensitivities, social anxiety, soul crushing teen age years, PTSD, depression, substance use, isolation, obsessions and sheer confusion at certain areas of life. Who the heck am I? And who will I be once I take off my 'fit in' mask and free my true self. So here goes, time to regroup, release and plan the future alignment with my true self. I am talking about acceptance. My own acceptance of being autistic

So 'high functioning autism' is it, let's analyse this a bit. I write 'high functioning' in speech marks because I think these are potentially misleading words which create common misconceptions. It appears as though it means the autism is experienced 'mildly' by the autist. This really is incorrect. Although generally more 'society abled' than others on the spectrum, a person with high functioning autism can be even more misunderstood, judged and stigmatised. I guess it would be fair to say that pressure to fit in for those at the subtler end is high, because we look 'normal'. And the societal expectations of a person who is undiagnosed are massive. I have had many labels in my life – depressed, someone with PTSD, a high school dropout, a psychiatric patient, junkie and many more. Now, finally I get a 'label' or preferably 'identity', that fits me in an all-encompassing way and I want to make better sense of how that is. I decided that in order to calm my overwhelmed self to embrace the process I must have solid data on exactly what happens for me.

I have been fortunate that - my 'not so positive at times' path led me to experience and study some interesting topics and to meet some truly amazing people. I am now a qualified addiction counsellor / substance use practitioner. During my training I learned assessment and formulation techniques that are used to support a person seeking wellness. This works well for my way of thinking as I feel at most ease when I can formulate experiences and ideas, making patterns with information helps me to make sense of them. So I decided to do some of these data collections and formulations on my newly exposed self.

My plan was to highlight particular areas of struggle and strength in order to build a framework for getting to know my true self. I then could use this data to present to the people close to me so they have a clearer picture of how autism presents me with challenges as well as bonuses. Bear in mind that I am at the nose end of this journey, so as with life in general, this is a 'work in progress'. One of the models of wellbeing that I decided to use as my basis for understanding is Te Whare Tapa Wha[1]. This is visually represented by the wharenui or meeting house. This structure often symbolises an ancestor, with different parts of the building referring to parts of their body. This image beautifully represents a connection of people, togetherness, inclusion and tautoko[2].

In the Te Whare Tapa Whā model the emphasis is on strong foundations and four equal sides illustrating the four dimensions of Māori well-being. Taha Tinana, the body, taha Hinengaro, the mind, taha whānau, the family or social group and taha Wairua, the spirit. If one of the four dimensions is missing or in some way damaged, a person, or a collective may become 'unbalanced' and subsequently unwell. The four P's are predisposed, precipitating, perpetuating and protective and when you put this together with Te Whare Tapa Whā considerations you get the 4x4 grid. The 4x4 grid formula is a way to enhance areas in need of further work as well as highlighting strengths. It is important to note that there is no 'right or wrong' placement in the grid.

	Predisposed Vulnerability	**Precipitating Triggers**	**Perpetuating Maintaining**	**Protective Strengths**
Tinana Physical	Genetic predisposition to Autism.	Communication problems. Sensory processing.	Looking 'normal' = high expectations Shutdowns/ Meltdowns.	Able bodied. Can drive. Dog and cat.
Hinengaro Psychological	Neurologically diverse/Autist. Confused sense of self.	Sensory overload. Social overload. Late identification.	High stimulation society. Anxiety. Emotional dysregulation.	Psychologist. Access to service providers. Self-efficacy.
Wairua Spirit/Soul	Feeling of being in the 'wrong place and time'.	Can misread situations. Can be pushy or challenging.	Over thinking. Catastrophizing.	Connection to the environment. Hope. Writing.
Whānau Social	Minority of a minority (Female and Autistic). Past bullying.	Feeling alone. Fear of putting true self 'out there'.	Misunderstanding or fear of being misunderstood. Tendency to isolate.	Family and friends. Online community.

The process of putting together something such as I have here is about making sense of my current situation of being a newly identified Autist. Seeing this written out is helping give me some sense of control with what is both a grieving process and enlightenment. Some healing is coming from the process of acknowledging and accepting the 'not so good' parts and highlighting protective factors or strengths. From here my plan is to use this as a basis for my next stage of 'coming out'. I can use this to collect data to present at times when I need to ask for help in the areas I struggle with. This also helps me build a framework around how to maintain and strengthen the positive areas.

Over the next few months and years I know I will have many moments of complete overwhelm and will likely have times of thinking 'this is too difficult'. In order to combat this I plan to keep gathering data about autism through keeping up to date with the latest research findings. As well as, possibly most importantly, making connections with others who are sharing similar paths to me, I also want to keep developing this grid and use it as my base to work on things for myself personally as well as my connection to others.

I have been given this powerful identity and finally have something tangible to help redesign my way of being to a better fit for me. My foundations may have been shaken and at times it feels as though the core is about to collapse, however I have some tools to guide me through. I also have some seriously great people close to me who I know will be the ones to help me to accept my ultimate self. Thank you for taking the time to read my words. ■

1. http://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha
2. Tautoko meaning to support, prop up, verify, advocate, accept, agree.

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22 - 23 JULY
HOLIDAY INN AIRPORT HOTEL
AUCKLAND

EARLY BIRD PRICE INCLUDING GST- UP UNTIL 30 JUNE 2015

$495 professionals/people working with people on the spectrum (includes conference dinner)
$295 people on the spectrum/family members (includes conference dinner)
$250 day rate (does not include conference dinner)
$130 half day rate (does not include conference dinner)
$50 conference dinner and entertainment (Wednesday 22 July 6.30 pm)

FULL PRICE FROM 1 JULY 2015.

$595 professionals/people working with people on the spectrum (includes conference dinner)
$395 people on the spectrum/family members (includes conference dinner)
$295 day rate (does not include conference dinner)
$175 half day rate (does not include conference dinner)
$50 conference dinner and entertainment (Wednesday 22 July 6.30 pm)

These rates do not include hotel accommodation but a reduced rate is offered for delegates when booking at the Holiday Inn Auckland Airport.

KEYNOTE Speakers

Lynn Berresford, Director Indigo Assessment and Counselling Centre

ASD & giftedness

Lynn is Director of the Indigo Assessment and Counselling Centre in Auckland. She has over 30 years experience of working with children, teenagers and adults with exceptional needs. She is a dedicated and skilled advocate for giftedness and "twice exceptional" ("Twice exceptional" refers to intellectually gifted children who also have a disability). She has given many presentations and workshops in New Zealand and overseas and written many articles for educators and parents. She is an advisor for the New Zealand Association for Gifted Children and she has had a long standing and close relationship with Autism New Zealand and with families challenged with autism spectrum disorders.

Kirsty Dempster-Rivett, Consultant Clinical Psychologist

Using creative and innovative techniques to develop therapeutic alliance with young people

Kirsty Dempster-Rivett is a Consultant Clinical Psychologist with 20 years experience working with young people, their families and support people. She is a passionate advocate for youth and frequently presents about creative strategies for engagement that focus on working with strengths to help address areas of concern. In this presentation, she shares the strategies she has honed over time for when "typical" ways of working are not effective, or when youth are tired of "adults" trying to help.

Paula Jessop, Altogether Autism Consumer Reference Group Member

Starting at the beginning: Beliefs and attitudes towards autism

Paula Jessop is a member of the Altogether Autism Consumer Reference Group and an Aspie presenter known for giving thought provoking speeches relating to 'lived experience' of autism. Paula's interest in how Autistic people felt emerged during graduate study when doing a research project on 'adult experiences of Aspergers'. Paula noticed a stark contrast in how the people she spoke with described their autism with typical professional views. From here Paula embarked on getting to know as many people on the Autism spectrum as possible in a quest to understand Autism from the "inside" and help Autistic people find each other. Along the way Paula began being invited to present her thoughts, views and theories of the 'lived experience' perspective. She opened Altogether Autism's last conference with an inspiring speech about 'radical acceptance' of Autism and returns this year to implore attendees to reflect upon attitudes and beliefs toward Autistic people. Paula opens the conference by discussing the importance of positive beliefs and attitudes towards Autism by those in the communities who support Autistic people. She highlights common myths about Autism and discusses how these myths impact attitudes and beliefs toward Autism that ultimately harm Autistic people. In this presentation Paula aims to turn the audience's thoughts to positive attitudes which help enhance the lives of Autistic people and the rights of Autistic people as a group.

Frank O'Connor, Organisational Psychologist

Finding work that fits with ASD

Frank O'Connor has been a management consultant since 1986 and a registered psychologist since 1987. Frank has had particular experience and interest in people at work, spanning personal, group and organisational choice processes and consequences for business performance. Based in Wellington, Frank travels where needed to help organisations advance wellbeing. He works with people in the community at large who are trying to obtain work suited to their abilities, coaching (would-be) workers and employers toward the many ways work can be done well enough and use capabilities that differ from what was expected. Intentions, policies and diagnoses don't do the work, so his emphasis is always what can be done in real workplaces by real people — people who take many forms, have many capabilities and do things in many different ways.

Helen Temperton, Child and Adolescent Psychiatrist

Diagnosis in a CAMHS - Best practice with new Ministry of Health guidelines

Helen is a child and adolescent psychiatrist who has worked in Auckland for the past 12 years. She has an interest in neurodevelopmental disorders including autism, attention deficit hyperactivity disorder (ADHD) and fetal alcohol syndrome disorder (FASD). Helen would like young people with these disorders to have equal access to assessments and support throughout New Zealand.

Bernie Wastney, Parent and autism advocate

Māori parent perspective - Living with ASD

Life changed for Bernie when son Michael was diagnosed with autism. She often felt like Alice in Wonderland who had fallen down the rabbit hole where each door she opened took her into unfamiliar territory. She had the privilege of being raised in two cultures – Māori and Pakeha. Bernie will speak from a Māori parent perspective on issues Māori parents encounter, offer tips for professionals about partnerships, ways to support the Māori child with ASD, their siblings, whānau/family and some tikanga/Māori practice taught to her by her grandmother Riripeti Karauria (Ngāti Porou). Bernie is now an advocate for Michael, others with autism and their whānau. Bernie will address some of the issues raised in the research as she shares stories about her son Michael who has severe autism, her whānau/family and how living with a child with an ASD affects their everyday lives and relationships.

"Wherever Māori live and work, tikanga Māori or aspects of it will follow them" (Mead 2003).

Ko Hikurangi te maunga, Ko Waiapu te awa, Ko Ngāti Porou te iwi, Ko John rāua ko Heni Turner ngā matua. Nō Ingarangi a John. Ko Michael rāua ko Samantha ngā tamariki, He severe autism a Michael. Ko Bernie Wastney tenei.

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EARLY BIRD PRICES END 30 JUNE 2015

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WHAT TO EXPECT
Conference Workshops

In addition to the six keynote presentations and over 30 speakers presenting on a wide range of topics, we have the following two hour workshops:

Using psychological tests when diagnosing autism: A workshop for diagnosticians and test users

Presented by Jenny Gibbs Clinical Psychologist, Child Development Centre, Waikato DHB and Tanya Breen Consultant Clinical Psychologist, Private Practice

This two hour workshop, intended for diagnosticians and test users, is a facilitated discussion on important testing issues across New Zealand. The workshop will briefly overview the recommended best practice, then have brief presentations from practitioners in child development, mental health and private practice on what tools and methods they actually use in diagnosis, and how useful they find various tools.

Discussion focus topics:

- Practical sharing of processes used across the country
- Balancing best practice with long waiting lists
- What tools are useful, and what are not
- How to access training
- The development of a system for peer support and ongoing peer review processes

The workshop is supported by NZCER, with examples of tests and manuals available for viewing.

Know your rights and responsibilities: A survey of relevant law and legal developments which could affect people with autism and their families

Presented by Nan Jensen, Solictor, Quinlaw

This workshop is offered by Nan Jensen, a member of the Altogether Autism Consumer Reference Group, solicitor at Quinlaw and a mother of two sons with autism. In her two hour workshop, Nan will provide an overview of legal issues which may affect people with autism and their families. The first hour will cover Education law (special education, school rules and discipline, Is it Legal? Is it Reasonable?). The second hour will depend on participant preference but can cover 2-3 of the following: cyberlaw, employment, compulsory care, forms of authority (agency, power of attorney, guardianship), Do I need a lawyer? Who else can help?.

This workshop is for professionals, families and people with autism.

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The conference will be a unique opportunity for professionals, parents and people on the autism spectrum to come together to discuss best practice, hear lived experiences and share learnings. Through a range of presentations and workshops, speakers will draw on their expertise and experience of the changing environment and latest developments in autism, to provide strategies for successful and positive outcomes for individuals and families living with autism.

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