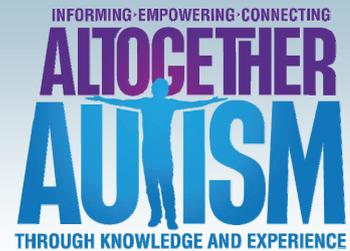


Journal

Summer 2014



Introduction

Welcome to the summer edition of the Journal. Since our last publication our inaugural conference, 'Inspiring Excellence in Autism' has been held. We were extremely honoured to have had presenters and delegates from all over New Zealand with such a vast range of knowledge and experience in the field of autism as part of our conference. As a result of everyone's contributions the event was a great success and Altogether Autism would like to thank everyone who attended and participated. If you didn't make this year's conference we hope to see you in 2015.

Our opening keynote speaker at the conference was Paula Jessop. Paula amongst other attributes is a member of our Consumer Reference Group (CRG) and a woman with Asperger's, whose presentation '*Acceptance is Not Enough*' got us off to a powerful and positive start. With this in mind we thought it would be fitting to follow on from Paula's inspirational presentation and have a theme of positive attitudes towards autism in this edition of our Journal.

Also included and in keeping with the theme are interesting and motivating articles from other members of our CRG, Betty Pulafolau, Nan Jensen as well as from members of the autism community, Dr Emma Goodall and Penni Winter.

Paula Gardner (National Manager)

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Radical Acceptance of Autism by Paula Jessop

At the Altogether Autism conference I was honoured to speak about a topic very close to my heart; the social acceptance of people on the Autism Spectrum. My presentation was received with such passion I was left stunned and delighted. So I'd like to begin with a huge **thank you** to all of those who left me glowing under a shower of praise, smiles and compliments. Such praise and acceptance of my personal thoughts shows how very far we have come in the autism community. Twenty years ago I would doubt a person on the Autism Spectrum would have been invited to give a keynote opening speech at an autism conference in New Zealand.

I am again thrilled to be given the opportunity to write about my personal subjective theory relating to what acceptance of autism might look like. Before I begin I must point out these are purely my thoughts as one person with 'lived experience' of Aspergers. Although many of my theories are based on what other adults on

the spectrum discuss with me or ideas from reading insider blogs, books and articles, these thoughts are mine alone. The opinions of just ONE person with lived experience and are not necessarily representative of ALL people on the spectrum. We are all different and even within the various autism communities of those with lived experience there are differences of opinion relating to most matters pertaining to autism.

Earlier this year I sat outside, night after night, in the stillness of the dark, pondering what 'acceptance' might be. I'd heard it many times, what acceptance of autistic people meant. Acceptance of people with 'lived experience' of autism apparently means 'accepting' our unusual behaviours from a place of understanding our 'disorder'. This of course sounds wonderful, yet, I continued to sit in the stillness of a world asleep feeling distinctly uncomfortable. Something just doesn't feel right. Somehow I usually don't tend to actually feel accepted by neurotypical people.

This pondering night after night was brought on after being told that it was not surprising someone within my world would not enjoy being around me because I am 'so intense'. What was I to expect when I was 'so intense' and behave how I do? These comments came from a person who 'accepts' me. I was left feeling like a bad person for being who I am. Most especially because the intensity of my personality is largely created from my Asperger's and is something I cannot control. I wondered if people would say to a person who is upset about being excluded from certain situations because they are in a wheelchair and there are stairs to negotiate, "well what do you expect when you're in a wheelchair".



In my presentation at the conference I discussed some of the reasons why we on the spectrum often do not feel accepted by those around us and why I think it's important for those of us who are a part of the autism community to adopt a positive attitude of what I call 'radical acceptance' of autism. My concept of radical acceptance quite simply translates to 'liking us'. Not accepting us despite the strange Autistic behaviours. Not accepting us by understanding these difficult behaviours and for giving us for being a little difficult. Radical acceptance is about actually liking us for the people we are. ***Liking us for the many wonderful, quirky, eccentric, unusual qualities we have, precisely because we are on the Autism Spectrum.***

Most of my aspie friends often discuss not feeling accepted either, even when their neurotypical friends and family say they are doing their utmost to 'accept' their unusual behaviours. Being the pedantic aspie I am, I dashed for my Oxford Concise Dictionary one night looking for the exact definition of 'acceptance'. There I found the cause of my discomfort. One definition of acceptance was 'to tolerate'. A light came on in my mind so to speak and the missing piece of the puzzle slotted into place. We want to feel more than tolerated. We want to feel liked. We want to feel more than 'accepted' ***despite*** our unusual quirky ways of being. We want to be ***liked*** for our ***unusual quirky***, uncommon ***special*** ways of being.

So what might Radical Acceptance look like more specifically? Radical Acceptance begins with truly accepting that we are on the spectrum and not trying to 'cure' us and/or turn us into 'normal' people. It means basing therapies or interventions on what might help us to thrive in the world, not what will help others find us easier to be around by forcing us to behave in less Autistic ways.

After some discussion with other adults on the autism spectrum I did discover that others also feel 'tolerated' rather than 'liked' for who they are. Acceptance of autistic people is very often described in ways which equates, ***from our perspective***, to tolerance. For many of us, we notice a distinct difference in the 'acceptance' we receive from our own kind, (other people on the spectrum) rather than those who are not on the spectrum. Most of the aspie adults I interact with tell me of only ever feeling truly relaxed socially and accepted around other aspies. Many of the people I speak with who didn't meet others on the spectrum until adults report feeling genuinely 'liked' for themselves for the 'first time'. Somehow the 'acceptance' from other aspies transcends the ideas of what acceptance of us might look like to neurotypical people. Whilst neurotypical people tend to consider acceptance means learning to understand us and accepting these 'unusual behaviours' from a place of understanding... aspies come from a place of 'intuitive understanding' of each other and ***liking*** each other's common aspie traits.

- ➡ Radical Acceptance means understanding that autism, regardless of its form, is not bad and there is much which is enjoyable for us due to being autistic. It means not assuming our experience of the world is awful or all negative due to being on the autism spectrum.
- ➡ Radical Acceptance means not projecting expectations of us to learn to behave more 'normally' or like 'neurotypical' people. It means parents, professionals and autism organisations accepting our 'insider voices' and 'insider knowledge of autism' (as the true expert knowledge of autism).
- ➡ Radical Acceptance means using positive language when discussing autism and not using terms such as 'disorder' which can make us feel hurt, offended or bad about ourselves. It means autism organisations involving autistic people in the organisations and not merely having the odd aspie as part of it in a 'token' manner.
- ➡ Radical Acceptance means true consultation with us in matters relating to services and needs of us at the highest level politically. It means the media going beyond repeated

Radical Acceptance of Autism Continued...

stories 'about' us from the perspective of parents.

➔ Radical Acceptance means loving us and liking us for who we are. Loving our wonderful qualities and moving beyond 'accepting us despite' our 'disordered' way of being. We are people who in the words of a friend, 'soak up external stimuli' and if 'external input' is nothing but negative, then it is hard for us to

motivate ourselves in the opposite direction'. We NEED those around us, be they our family or professionals or autism organisations or even the media, to avoid being negative about our autism. We NEED Radical Acceptance. We have the same basic human need as other people... to be liked and loved as we are.

By Paula Jessop

Working Positively with Your Child's School by Nan Jensen

Nan has been involved in the disability sector since 1998. Two of her four children are on the autism spectrum.

Our son Daniel is now 20. He attended four different schools from primary through High School, so we had a chance to practice working with different schools, principals, Special Education Need Coordinators (SENCOs) and teachers, and I think I now know what the essential ingredients are that can support the development of a positive working relationship with these individuals as well as with the other students and parents in the school.

Just as in a recipe, without certain ingredients the desired outcome won't be achieved no matter how hard you try.

Likewise, if a really inappropriate ingredient gets added to the mix, it can ruin the recipe even if everything else is in there.

So what am I talking about specifically?

When Daniel started school we still didn't have a diagnosis. He had an advanced reading ability (which we later found out was hyperlexia) and his teacher kept giving him books that were more and more difficult. He read them with no difficulty, but it was apparent to us at home that he didn't have a clue what they were about. His difficulties became more apparent when writing was the task – he would rip pictures off the walls, throw furniture around the room, and generally throw a fit. I tried talking to the teacher about what she thought the difficulty might be, and tried to discuss potential solutions, but it was obvious they thought he was just a naughty kid. Lunchtimes were a disaster. The other children quickly realised he was easy to wind up, so I was called down to the school (with my newborn twins in a pram) at least 2-3 times a week. Finally there was a meeting – I requested a teacher aide, the principal pleaded poverty and asked me to come each lunchtime (I pointed out the babies in the pram). Then they asked us to pay. Further meetings with the principal weren't much better – the principal suggested we go to the

school down the road. The teacher seemed supportive but once the principal was in the room, the environment screamed 'you and your child aren't wanted'.

Even once we produced a strongly worded diagnosis letter from Professor John Werry, the scepticism, blame and desire to see us gone continued. We brought a social worker with us from CCS. She said nothing, but the principal was suitably intimidated and a teacher aide was procured, but only for lunchtimes. Daniel bit a teacher over the writing issue (and drew blood) – well they still

didn't want us around, and Special Education Status (SES) (as Group Special Education (GSE) was named at the time) said it wasn't bad enough to attract funding from the severe behaviour initiative. I wanted an Ongoing and Reviewable Resources Scheme (ORRS) application to be done but the school refused. Eventually I was successful in arguing for the application (by this time a Resource Teacher: Learning and Behaviour (RTLB) had given up, and Daniel was chewing his clothing to pieces in the classroom), but when I saw the application I knew it wouldn't succeed. It was written like a school report, all bright and cheery about all the things that Daniel could do, with no mention of the issues and difficulties that arose (such as his lack of reading comprehension). When I tried to edit it, the SENCO told me quite directly that she hoped we wouldn't be successful, because there were other children in the school who needed help more than Daniel did. When I asked her why she didn't do an application for them, she said it was because their issues were due to poverty, gangs, drug use and not disability, she felt that we could afford whatever help Daniel needed!

We eventually moved to Hamilton and to another school – if we hadn't, we would have returned to Denmark, we knew we couldn't stay in that small town with so little

Attitudes start
at the top

support. So what was wrong there? What ingredients were missing? Which ingredients were ruining the recipe?

Attitudes start at the top

If the school principal isn't supportive, the chances of success are low. Likewise, if the principal is supportive (and is reasonably well-respected by staff) then there is a good chance of success. So how do you find a school principal who is supportive? There may be some out there who just aren't interested in accommodating special needs kids – in most cases this will be because of concerns about the reactions of other families, or whether the school can provide the resources that your child needs. School funding is tight and there are many demands on a smaller and smaller amount of funds. No school is given enough money by the Ministry of Education to support all the special needs children it has. A school principal is a teaching expert, an HR manager, a chief financial officer, a marketing manager, a salesperson and a project manager all rolled into one.

The principal is employed by the school's Board of Trustees, so if you are unhappy with the principal you can complain in writing to the Board. The Board's responsibility is strategy though, not management. While they must set strategy to meet the needs of students with special needs, they must also support the principal in management of the school, as long as it accords with legal requirements and the strategic plan. Schools must make reasonable accommodation for special needs students, and they must not discriminate against students on the basis of their disability. This does not mean, however, that a school is obliged to accept a student who may pose a risk to others.

In our situation, the principal wasn't supportive. Yet another family with a special needs child had a great experience at the same school. So maybe we had some influence on the poor relationship that ensued. Or maybe the difference was that our child had behavioural issues while the other child didn't?

Have expectations, but be fair

Try to put yourself in their shoes – I mean really. In an ordinary school, a teacher might have 25-35 children in a classroom. All of these children will have different needs, different learning styles, and your child won't be the only one in the room with some sort of special need. Schools are responsible not just for learning but for the social and emotional development of our children, as well as their physical safety. They are also employers of the teachers, and so the Board of Trustees is also responsible for the safety of the teachers. A child with behavioural

difficulties may present particular issues for schools because of potential danger to other students and to staff. Our children have rights, but so do the other children, their families and the teachers.

So what expectations are fair?

When we moved to Hamilton, we sent Daniel to a special school for three years. That school knew what they were dealing with and we had no difficulties with the school at that time. But after three years, it was clear that Daniel was ready to be mainstreamed again. So we approached our local school, which our three other children attended. They already knew about Daniel. When we had enrolled his twin brother, we had pretty much promised that Daniel would not be attending, and the Principal had admitted that they didn't have the resources or expertise to accommodate him. Two years later, however, we approached him to enrol Daniel.

Have a plan

It definitely helped that they already knew our family, but that is not an essential ingredient in making the recipe work. We DID go in with a plan. A plan is one of the essential ingredients. Part of that plan was for our family to work in partnership with the school. In other words, we had expectations of the school, and the school had expectations of us.

Listen, listen, listen

One thing that worked was that we took the time to listen to each other. Several months prior to Daniel starting school there, we sat down together with the principal and started planning. First it was big picture – we talked about the possible issues that might arise (Daniel getting agitated and needing time to himself, having a safe place to go to, teacher aide time, how to deal with the stress and noise of lunchtimes). We talked about various options for dealing with those problems and reality-tested them.

Have a plan B

We acknowledged that mainstreaming might not work, and agreed on a strategy for addressing issues and what we would do if what we agreed to had been unsuccessful (enrolment in another special school). We also made a plan B for all sorts of situations, and for a gradual introduction to the school.

Be Inclusive

Include everybody. It became clear to me from prior experience that it didn't help to just educate the classroom teacher about Daniel and his disability. The

Working Positively with Your Child's School Continued...

biggest problems occurred in the playground, and they were exacerbated when he was confronted by a teacher who didn't know him well enough to know not to demand an immediate apology or to stay away from him when he was agitated.

We met with the classroom teacher, who very honestly expressed his concerns about how to meet Daniel's needs as well as those of the other 29 students in the class. And then we planned how to deal with that, and we discussed our expectations. We acknowledged the challenge he was going to face and we thanked him for his willingness to try. We agreed that when the teacher aide hours were finished and the class programme was going to be too difficult for Daniel to access without assistance, that it was OK to put him in front of a computer with an educational game, or give him books to shelve in the library, or to just give him a book to read. Instead of demanding, we created a partnership.

Be a teacher (if they will let you)

I was given an hour in the staffroom with the school staff, including the caretaker. I brought a pile of books on autism, but I told them "you can borrow these for professional development if you like, but in the next 30 minutes I am going to tell you everything you need to know about working with Daniel". I explained how to deal with him in the playground if he was agitated or upset. We developed a plan for the older students to keep younger ones away, while the teacher on duty would stay close, but far enough away that Daniel couldn't hurt them or anyone else. I explained that Daniel would apologise when he was ready, but that might be 2 or 3 hours away, and he would only be able to explain what had happened when he was calm, and even then might get sequencing of events out of whack. The teachers asked questions, were interested, and they were understanding. I acknowledged that they each had up to 30 students to worry about, and thanked them for taking so much time to focus on just one.

Include the community

We also made a plan for telling the other families and students about Daniel. Daniel was included in this. He did not want to be present when his class was told about autism. He went off to do a job in the library, and some

books for young people about autism were produced. The classroom teacher spent time talking about what Daniel was like, asking the other students to include him, explaining to them how to recognise that he was agitated, and what to do if they saw him getting upset.

We sent a letter, drafted by myself, to the other families. We explained that Daniel's presence in the classroom should not affect their children's learning. We explained that Daniel could get upset if he was bullied or teased, and might not understand all the ways students relate to one another. We asked the parents to talk to their children about having Daniel in the class, and to contact the class teacher, the principal or ourselves if they had concerns. We never got a single call and there were never any concerns.

Confront setbacks head-on

There WERE incidents however. Daniel saw two students smacking each other on the bum and went up to the girl and smacked her (she was 12). She turned around and slapped him (understandably) but we believe it never became a big issue because she understood what was going on for Daniel, that he didn't understand the nature of her relationship with the other student, and she was able to discuss it with the class teacher and



with her parents without concerns. Other incidents were dealt with similarly, with older students showing excellent leadership skills and compassion. We feel certain that if the school community had not been aware of Daniel's issues, and if the school was not fully supportive of Daniel, then these incidents could have led to disciplinary action and possibly suspension. It is clear that his behaviour was related to his disability, and the incidents were great learning opportunities for everyone.

Everyone needs to be accountable – even children with autism

An important factor in all of this is the issue of accountability. Parents of children with autism are asked to understand the reasons for behaviour. We obviously don't want to punish a child for screaming when the cause of it is the lighting in a room or a piece of clothing that hurts. But when children (or anyone) damages

property or hurt people, they need to be responsible for that behaviour in some way.

We insisted that Daniel be held accountable for the consequences of his behaviour – if he broke something in anger, he was responsible for fixing it. If he made a mess, he was responsible for cleaning it up. If he hurt someone, he needed to apologise. His disability was a reason, but it wasn't an excuse. Children with autism CAN learn empathy – but we aren't helping them by excusing their behaviour and not making them accountable. This is a mistake that I've seen many parents of our children make – there's a difference between understanding behaviour and excusing it.

Of course, other children need to be accountable too. Children with autism can have trouble with sequencing of events, and when they are agitated (or even when not) they may have difficulty recounting what has happened. Daniel was accused of lying because he said a child had done something and the child denied it (and there were witnesses). Well it turned out the child had done it – one year previously! He wasn't lying, he just didn't see that the incident wasn't relevant.

It is really important that schools understand this: that a child may need more explaining to understand why, what they did was wrong, they may need more time to

calm down and they may display inappropriate behaviour (such as laughing) when they should be showing contrition. There is almost always a reason for the behaviour – it may be something sensory, but it may also be provocation by other students. Students are good at identifying a child who is easily provoked – so if the teachers are ready to blame that child, it can become an intolerable situation where the child is bullied by the teachers as well as the other children. Making the school aware of this potential scenario can help to avoid it.

Conclusion- I hope this list of basic ingredients is helpful to parents navigating the school system with a child on the spectrum. It isn't an easy task, but it can be done. If you need help, bring an advocate to meetings – they can stay unemotional if you can't.

By Nan Jensen

Nan has been involved in governance, advisory, as a support parent, advocacy and employee capacities and is a member of the Altogether Autism Consumer Reference Group. She practices in all areas of law (except criminal) with a special interest in disability. nan@quinlaw.co.nz

Autism is Not a Tragedy by Betty & Brian Pulefolau

Betty and Brian are the founders of Pasifika Autism Support Group and are the parents of three boys the eldest was diagnosed with autism at four years old.

'Show your support and raise awareness!'

I found a really interesting quote on www.pinterest.com website 'Autism is not a tragedy, ignorance is'.

Some families affected by autism may find it easier to not discuss their child's condition with others in fear that others may not want to socially connect with their family. However, I feel it is my responsibility to educate those who are not affected

and represent what my eldest (9 year old) son Roman and others may be going through. It is easy to react to a

stranger's stares or comments; however in order for a positive outcome it is important to tell them that your child has Autism. It's not an excuse, just state the facts about Autism Spectrum Disorder. You could also carry little cards with some information on autism to let them know that there's more to the behaviour and hand them out whenever your child acts out in public.

October was a month for my family to raise awareness about autism to our friends and extended family overseas. At the beginning of the month I travelled with my 8 years old son Joel to Brisbane and we held an information stall about autism at the Pasifika Vibes festival. This is an annual event and I

asked the coordinator if I could participate as a stall



information holder. We arrived a few days before the festival and I went to Autism Queensland headquarters in Sunnybanks to get some information to hand out. Joel and I met with the Marketing Manager and we had a quick look around the complex. I was overwhelmed by the facilities and the services that Autism Queensland offered. The front of the complex housed two Early Intervention centres and we know this is very effective in helping an autistic child.

On the day of the Pasifika Vibes Festival my son Joel and I set up our information gazebo in 35 degrees, which is typical Brisbane weather. We met many New Zealand expatriates who have children diagnosed or know of family members affected by Autism both in Australia and New Zealand. What drew them to our stall was our banner 'Pasifika Autism Support Group' (PASG). The support group was set up from the experiences we have gained through our son. Our goal is not only to provide information to empower and support families, but also we want to raise awareness of autism in our Pasifika communities. In our own journey, after our son was diagnosed, we were no longer socially interacting with our extended family members and did not attend cultural festivities because it was easier to avoid the stares and people asking, "What's wrong with Roman?" Also during his early years we were constantly running

after him.

At the festival people asked us where in Brisbane we are based. I had to explain that we were from Auckland and there to raise awareness about Autism to our Pasifika communities and if they required further specialist services, I was able to provide information about Autism Queensland. There were some families already connected to Autism Queensland and they told us how much support they already receive and how early intervention has helped their child develop. What is also common is that there are those who have not been diagnosed.

As a mother on this Autism journey, there is some important information that I would like to share and this is, don't be afraid to let the world know what Autism is so that so that people are aware of it!

By Betty Pulefolau

Betty and Brian were motivated to develop PASG because of their journey and experiences. They wanted to provide a place for other families to seek information and support for their children and focus on raising awareness of autism in the Pasifika community www.autismpasifika.org.nz

Time for a Rethink on Autism by Penni Winter.

Penni is a writer and artist with Aspergers Syndrome, who blogs at Stranger in Godzone; and a member of Asperger's Syndrome NZ. She is also a member of ASK (Autistic Spectrum Kiwis) a group for adults on the spectrum.

Some might ask, what is there to be proud of about being autistic? After all, they would argue, it's not like being gay or black - and surely autism is something no one in their right mind would want to have - or is it?

The stereotype of an autistic person is that of a screaming, non-verbal, 'unreachable' child, or, in the case of Aspergers, a young, male, socially inept computer geek. Autism is viewed as a 'tragedy', and the assumption is that the best thing that can happen to autistics is to make them 'normal'.

And yet few think to ask the views and opinions of those on the spectrum themselves. If they did, they would find that autistics have very different views on being autistic.

Having met a wide range of autistic people, and being on the spectrum myself, I can say that these stereotypes are just that - stereotypes. Some autistics may fit them, but the vast majority do not.

Moreover, many autistics feel that the stereotypes, and the 'autism as tragedy' mindset, are doing huge damage to autistics, both adults and children.

Because in the pursuit of that 'normality', all sorts of 'therapies', ranging from the punitive to the bizarre to the downright dangerous, (for example, the latest fad of forcing autistic children to drink bleach), are being done to autistics, especially children.

These therapies are generally expensive, time-consuming, and ultimately useless. Many autistics feel that effort would be better spent on improving support and understanding of autism.

So what is autism, if not these stereotypes? At its core, autism is a profoundly different neurological pattern - a different mindset - which affects how we view, process and respond to the world around us.

Our priorities, focus, actions and reactions are profoundly different, and generally misunderstood or devalued by others.

Even the concept that autistics are usually non-verbal is incorrect, though our spoken language capacities do vary widely. And lack of speech does not equal lack of intelligence, as the now-renowned case of Carly Fleischmann, a non-verbal autistic young woman - who was thought to be 'low-functioning' until the day she started to type what she wanted to say - has proven.



Nor is she the only one of her kind, simply the most well-known. The dividing line between 'high' and 'low' functioning autistics is nowhere near as clear-cut as many think. So if autistics aren't what people think they are, some would still ask, what is there to be proud of about being autistic? Surely it's still a 'handicap'?

Yes, there are difficult things about being autistic, I don't think any would deny that. But there is also much to celebrate and foster such as our refreshing honesty, our laser-like intensity of focus when absorbed in something, or our capacity to 'think outside the square' and try new ideas and solutions, to name but a few.

Moreover, there is a groundswell of discontent among adult autistics. We are tired of being misunderstood, mistreated, or pressured into a 'normality' that is as foreign to us as being forced to be straight would be to a gay person, or forced use of the right hand to a 'leftie'.

We are especially tired of the assumptions that our lives are worthless, that being autistic is a 'lesser' state of

being, that we have nothing to contribute to society, that we cannot speak for ourselves, or that our voices aren't worth listening to. Increasingly, we reject the idea of a 'cure' for what we do not see as an 'illness'.

In 1993, autistic advocate Jim Sullivan wrote his seminal piece *Don't Mourn For Us*, a writing that is still, sadly, as relevant today as when it was written. It was the beginning of the autism rights movement, which is demanding acceptance of autism as a different but no less valid way of being human and no, this doesn't only apply to the 'higher-functioning' or 'Aspergers' type adults.

John Grealley, who is on the spectrum and is also convener of Aspergers Syndrome New Zealand - an organisation for autistic self-advocacy - says the catchcry of the movement is, 'Nothing about us, without us!'.

"One of the key goals of the autism rights movement is ensuring that the human rights of autistics are respected. [We] want nothing less than honest transforming partnership, a proper voice for what only we can know," says Grealley.

The autism rights movement is a movement for human rights for all autistics, wherever they are on the 'functioning' scale, whatever their 'official' label or lack of it, whatever their age or abilities - and its aim is the complete reframing of the conversation about autism.

By Penni Winter

Coming Out From The Shadows by Dr Emma Goodall

Emma is an educator, author and autism consultant with Aspergers, who is passionate about educating teachers on the potential of all children on the autistic spectrum.

From Self-Acceptance to Advocacy - Sharing Hopes and Fears

This article is based on a presentation I gave with a friend at the APAC (Adelaide, 2013), this shared some of our journeys as Aspie adults who work in education.

For Aspie educators working with young people on the spectrum, expectations and stereotypes of colleagues can make it a struggle to become (self) advocates for the autistic community. As professionals, being openly autistic/aspie can help young people to have positive role models, but it can carry with it the risk of being dismissed by colleagues or managers as being less able than other educators who are not on the spectrum.

I was born in Africa, and I'm an habitual mover. I have lived in over 40 homes in 42 years, over 11 countries. I am a pre-school, primary, secondary and special needs trained teacher and have completed a PhD focusing on teaching students on the autistic spectrum in regular classrooms. I was diagnosed with Aspergers in 2012. Previously, I had assumed everyone else was different due to cultural differences in the various places I lived, but now I understand that although nearly everyone else is indeed different, it is because they are not on the autistic spectrum rather than that they have a geographically based cultural difference. I have worked

with autistic kids and adults for 15+ years, and am now working as an autistic consultant both publicly and privately.

Being told by others you are odd or different, or thinking that everyone else is odd, is a common experience for adults on the spectrum prior to diagnosis. An increasing understanding of that difference can often lead into finding others who share similar experiences. The shared difference is empowering, and gives confirmation, and my friend and I, came with a fixation on knowing and understanding everything we could about the autistic spectrum and how we could understand ourselves.

Before we were diagnosed, my friend and I focused on understanding students as individuals; which sounds obvious, but many mainstream teachers do not see students as individuals, but as a group of students to be educated. This led to us feeling and acting differently from our colleagues. Although neither of us initially identified as being on the spectrum, both of us understood and accepted our autistic spectrum students. I realised through my doctoral research that many other teachers didn't understand the autistic spectrum kids.

In education, the autistic spectrum is generally framed quite negatively. Whilst there seems to be a move to change this, reality is that it continues to be quite negatively framed. This negative framing didn't speak to us, or our experiences – we could read, talk, navigate the world and work. Finding the adult autistic spectrum community has enabled us to share others' experiences and learning, enabling us to reframe our thinking and identify ourselves with the autistic spectrum. In addition, we are able to match our understanding of ourselves and our lived experience. This results in our thinking about autistic spectrum students as having potential to have positive and fulfilling lives, like we do.

We think we have really accepted ourselves; we are strong, intelligent, articulate professional educators. We feel that our professional skills and knowledge are just as valid as colleagues who are not on the spectrum. However, we have a real passion and intensity for educating and supporting our autistic spectrum students, because we see potential in these students that some other teachers do not.

We both have long term stable relationships, something that it is often said that aspies and others on the spectrum are not capable of. Neither of our partners are on the autistic spectrum and although there are misunderstandings from time to time, we suspect this is the case in all relationships for all people.

We have a great sense of humour (we do get that it is different!), and we are ok with being atypical. One of the things that we feel is important about having educators who are themselves on the autistic spectrum is that we can role model being ok with being different, as well as role modelling managing ourselves in the worlds of work and relationships.

While reflecting on our journeys we realised that many other people in education still frame the autistic spectrum as a deficit – it is still all about what people on the spectrum can't do. Comments from colleagues and parents have included statements like; "all autistics need visual timetables to function." I know that I personally don't need a visual timetable to function, and nor do many of the young teens I work with. Visual timetables are great if needed, but if not they can create a feeling of others assuming a lack of capability. Colleagues can also make statements that are offending, for example; "that's what they're like all those autistics." In fact, those of us on the autistic spectrum are all quite different.

One of our least favourite comments is of the type, "Did you know they found a cure for autism?" We are not sure that people who talk about cures realise that this implies that we are people who require changing to eradicate inherent parts of our being! Strangely, suggesting that; "we know, acceptance is amazing," does not seem to be a socially acceptable response!

We have found that we either have very supportive colleagues, who are really accepting and helpful, with for example, my face blindness, or they are really judgmental. There seems to be nothing in between in terms of attitudes towards us as aspies who are educators. Judgmental colleagues have suddenly seen us as incapable of things they might have previously praised us for, or they have also used our Aspergers as an excuse for negative reactions to events. Sadly some colleagues express the view that if we are on the spectrum we are not capable of working with children and young adults.

On the other side there are quite a lot of positives, such as when families say I've never met anyone who has been so positive about the possible outcomes for my child. Not only have parents commented that they understand their children more, having met me and attended my workshops, but they see how their children might go on to have successful lives.

Colleagues who share that they want to hear our input, and want to learn from us, and say "its great that you explain this and it is so great to learn from you because you really understand spectrum kids" are genuinely pleased to have our input. It makes a real difference because we can help everyone to understand each other

better by sharing our lived experience and the lived experiences of others on the autistic spectrum. We both always assume competence for autistic spectrum children, young people and adults until proven otherwise. By competence we don't mean being able to do everything, the idea is more that children and adults *can* until proven otherwise, and if they can't do the whole task it is likely that they *can* do part. Those of us on the autistic spectrum *can* have great lives if others do not prevent and *disable* us from doing so.

A really interesting discussion among those of us in the autistic spectrum community is around disclosure – should we be open about our Aspergers/autism or not? The issues are around reactions and effects of disclosure; how will my boss who is deficit focused react? How will it affect my career? On the other side, how can we be good role models, and how can we be honest if we don't disclose?

I am working as an autism consultant in a Resource Teacher of Learning and Behaviour (RTLB) team as the cluster autism consultant. When I took on this position following the completion of my PhD, I signed my contract conditional about being open with schools, parents/whanau and children about being aspie. I explained that I wanted to be open about my Aspergers as many families with children on the spectrum are told "I'm sorry your child has autism" at diagnosis and feel that it is a negative with no positives. One family that I have worked with had children with Aspergers who seemed to be really intelligent, they started school at 5 able to read and write, but school was disastrous! At this point and prior to the agreement with the RTLB service that it was ok to be openly Aspie, I felt that I had to disclose as I couldn't bear to not tell them that their girls were going to turn out just great, with the same potential to achieve as I had.

Everyone that comes to my workshops or presentations find out that I am on the autistic spectrum, most families are told directly that I have Aspergers. In addition this is clear on my blog, plus if you Google me it is also very obvious! Some of the schools didn't know because I've worked with them for many years before having a diagnosis. However, since APAC I have been running staff professional development for most of the schools in the RTLB cluster area and this involves explaining that I have Aspergers. My colleagues are also busy referring teachers to my book on teaching students on the autistic spectrum!

However, I still worry that people who I don't know will judge me as incompetent if all they see is my label, though I'm learning that people see the title Dr before

they see the Aspergers and that the Dr seems to override their concerns about the Aspergers...

We really want everyone to presume competence in every person on the spectrum whether or not they are oral. We think that living well with autism is not only possible but can be done in the way that the rest of society thinks of as successful also. It is possible to develop a career through a special interest for example. There are other ways of having a good life too; being able to get up and make your own choices for the day is a good life. In being open we are sharing that autistic adults can be happy, successful, and capable (and yes we admit that our families will tell you otherwise at times).

What we are trying to do is change other people's stereotypes and prejudice. There is no typical autistic, we are all very different, but for some unknown reason educationalists' think all autistics are the same and they come out with some bizarre ideas. In my workshop, I tell participants half way through I am on the spectrum and it really freaks them out, because they know by that point I have qualifications, where I work and what I do. Participant's question, "how can you be on the spectrum? You are articulate, you can't be." My workshop does explore some of the things I can't do, but the main impact for participants is a shift from seeing *can't* to seeing a more nuanced presentation of the autistic spectrum. Participants are presented with the idea that someone who is intelligent and articulate *can* have social difficulties, extreme sensory difficulties, but still achieve. This seems to enable participants to develop an understand that our experience as aspies and auties is so different from their experience as non-spectrum people.

Over time we think we have provided real insight to colleagues, students and their families/whanau. For example, that oral skills do not demonstrate cognitive skills; sensory sensitivities are a real experience, people can earn a living from their special interest, kids can work while standing up, adults can work with no shoes on, autistic kids have potential and they grow up into autistic adults – we don't just disappear! As people on the autistic spectrum, we are all going to manage much better if we are valued and supported to be who we are, and who we want to be.

We know from research there are neurological differences, the autistic brain is wired differently and this does result in real differences in the ways we experience the world and the way we respond to it. Only through those of us on the spectrum being self advocates, can we help educators understand these differences and only then can we change the stereotypes and erase prejudice.

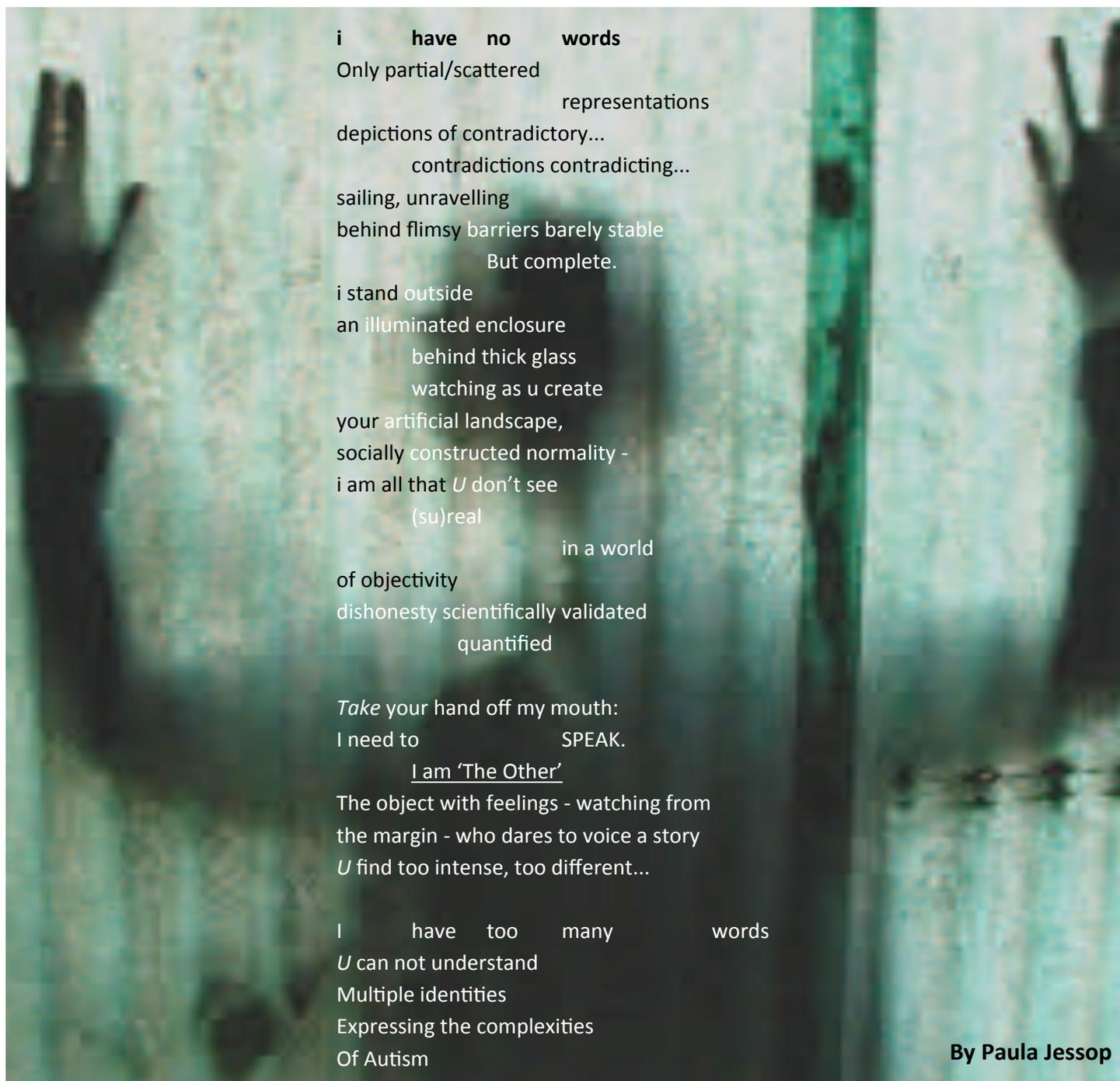
We acknowledge that it can be hard going to work everyday combating prejudice, particularly since both my friend and I are quite emotionally sensitive. We use secret and closed pages on Facebook to rant and process. The autistic spectrum adults' groups are great for having fun and having a laugh and being ourselves with unconditional acceptance and socialising. Colleagues we have disclosed to enable us to be accepted and they can also act as interpreters for us at times. My colleagues also compensate for my face blindness when other colleagues change their hairstyle, which results in me not recognising them.

We really hope that in the future, every adult on the spectrum can be open, in particular that every educator

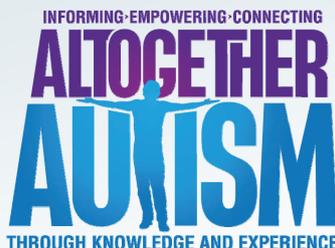
on the spectrum can be open without any negative repercussions, as this openness will contribute to a shift in the way autism is seen, so that the positives will be valued and people are supported to live well to manage the negative aspects. We really hope everyone on the spectrum will be valued and celebrated for their contributions to society.

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