In conversation with Donna Williams

Q. Donna, can you tell us more about yourself?

I was born in Melbourne, Australia, in 1963, in a time when the rate of autism was thought to be 4 in 10,000 children and autism was deemed 'childhood psychosis'. I was thought deaf and, in a 3 day inpatient hospital assessment at the age of two, was diagnosed as psychotic. Growing up echolalic, I acquired functional speech when I was between 9-11 years old.

Against a background of abuse, homelessness, illiteracy and innumeracy, I ultimately returned to school as an adult, gained post graduate qualifications as a sociologist and teacher and became the author of ten books in the field of autism. I am an international public speaker since 1994 and autism consultant since 1996, as well as an accomplished artist, singer-songwriter and performer.

I am largely known for:

- my writings about chronic fight flight and associated involuntary avoidance
- diversion and retaliation responses in Exposure Anxiety and its associated 'Indirectly Confrontational Approach'
- my dynamic 'Autism As a Fruit Salad' model, used for designing individualised programs more closely tailored to each person's 'fruit salad'
- my writings about visual perceptual processing disorders.

Q. Sensory issues are common for autistic people, can you tell us a little about your experience and also what you might suggest for professionals working with children and adults who they suspect may have specific sensory issues?
Sensory issues can derive from so many different bases that it is naive and archaic to claim they are 'an autistic thing'. One person may have problems with sensory integration resulting in difficulty processing on more than one sensory channel. So for them a sensory integration program including brain gym to build brain connectivity would be the direction...

For someone else, it will be about having an obsessive compulsive personality that struggles to tune out 'imperfections' or manage loss of control, such as handling the feeling of a clothing tag they can't easily rip out.

For someone else, it may be part of being an avoidant personality who is overly anxious and more prone to somatosensory amplification, which means they are hypersensitive to discomforts and struggle to emotionally and mentally divert their attention from these. The solution for these people is emotional work, such as social stories, but also anxiety work, such as progressive desensitisation through exposure to sensory experiences they have become anxious about.

For someone else the sensory heightening may be the product of chronic fight-flight states which leave their system charged up and reactive so that sensory experiences can be more provoking.

For someone else, and this was the case for me, general sensory heightening associated with brain connectivity issues, meaning I couldn’t keep up with incoming information. In other words, when I got a backlog of visual or verbal or emotional information I couldn’t process, then everything would seem brighter, louder, faster, more impinging. But with things like tinted lenses, receptive language processing strategies, techniques for external mentalising etc., I keep up better with information and, over time, I have better brain connectivity (including via years of brain gym) so the sensory heightening is now manageable.

So the trick is to identify WHICH base/s the sensory issues are coming from and address those accordingly. Calling them all 'the autism' is only an obscuring distraction from that necessary work.

Additional links:
http://www.donnawilliams.net/exposureanxiety.0.html

http://www.donnawilliams.net/autisminsideout.0.html

Q. What would you advise for helping to develop social skills of children with autism who struggle with reading and understanding social situations?

Social Emotional Agnosia is the inability to read facial expression, body language and intonation (the social emotional messages), and can be a brain connectivity issue or can be secondary to...
Simultagnosia (a visual perceptual processing disorder where the person cannot process the parts of a whole simultaneously and so cannot process facial expression or body language).

For those in the second group, tinted lenses can often artificially process an amount of incoming information, leaving the brain time to more fully process what is left. For the first group, non-verbal language can be formally taught much like a second language. You Tube clips on learning facial expression and body language can help. Black and white 1960s sitcoms on YouTube are formulaic and rely on archetypes, so the non-verbal behaviours are simpler, and with a pause button and someone to translate the 'stills', the person with social emotional agnosia can essentially 'take classes' in the skills of how to read non-verbal communications. They can graduate to 'people watching' sessions with a translator who can then test them on how well they are acquiring this skill. Drama skills too can often begin teaching this non-verbal language. Socially, diversity friendly dinner clubs can be important for a sense of equality, inclusion and self-esteem, and to make up for mainstream environments where the person is left out due to poor non-verbal communication skills.

Additional link:
https://en.wikipedia.org/wiki/Alexithymia

Q. Can you explain a little about what PICA is and what advice would you give to professionals when supporting an autistic person with PICA?

PICA is the compulsive eating of non-food objects. Again, there are different reasons for it. It occurs more commonly in compulsive and anxiety disorders, so sometimes chew toys can replace the need for chewing as a calming strategy and addressing health and co-morbid mental health issues that raise anxiety and compulsive disorders may lower the PICA.

Some will use PICA as part of Dependent Personality Disorder (DPD), monopolising the carer through provoking them via ingesting non-food objects. This can be turned around by ensuring that the resulting attention is not experienced as the desired 'rescue'... the yes to get no approach used in Exposure Anxiety can sometimes work in this situation.

In some with Oppositional Defiant Disorder (ODD), PICA can be exacerbated by the carer being distressed by the PICA, which then rewards the person with ODD and so reverse psychology would work better.

In some cases PICA is the product of low zinc and associated impaired senses of smell and taste. In some cases PICA is associated with visual and auditory agnosias in which the meaning blind/meaning deaf person fills the voids of associated sensory deprivation with the sounds, textures, tastes of non-food objects. In these cases strategies for these agnosias may reduce the PICA.
In my view PICA can also be part of inability to simultaneously process self and other which some people compensate for by trying to merge with sensory experiences or objects. Working in parallel with focus on the object/issue and off the person can allow those lacking simultaneous self-other to get more from interactions and associated PICA should then also decrease.

Additional links:
https://www.youtube.com/watch?v=Z0kkZk1jDEA
https://www.youtube.com/watch?v=fymDWyzTcF0
https://www.youtube.com/watch?v=OuLv-FkC34s

Q. Diet and food – Can you explain a little about the types of food and problems autistic people may experience and how to best approach this?

A significant percentage of people on the autism spectrum have IgA deficiency or partial IgA deficiency. This tends to cause higher levels of inflammation, poor gut immunity and poor enzyme signalling which means reduced digestion.

Celiac is much higher in this group and an IgA celiac test will always produce a false negative result. Food allergies and food intolerances will also be higher in this group. Those with infections every 6 weeks or lasting more than 3 months might benefit from being tested for IgA and IgG levels.

Those with asthma, eczema, hives, bowel issues or other signs of allergy might benefit from an IgE RAST (blood) test for common food allergies. Food intolerances such as Salicylates, Lactose, Casein, Fructose may require a 10 day exclusion test to rule in or out. There is a hydrogen breath test for Lactose/Fructose/ Gluten intolerance. There is a urine test for peptides to indicate whether someone can properly digest gluten and casein. Autonomic dysfunction can also cause significant bowel issues and may be improved with salt, especially in salt cravers. Autonomic dysfunction can be common in mild brain injury but can also be a feature of collagen disorders such as Ehlers Danlos Syndrome which is presently being found co-occurring with autism (collagen is important in brain connectivity and immune regulation).

Additional links:
https://www.youtube.com/watch?v=pNAyjFaRnjU
http://feingold.org/symptoms.php
Q. You have face blindness, can you explain what this means for you and what advice you would have for professionals supporting someone with face blindness?

I grew up unable to simultaneously process visuals as a whole... so I'd get the cat's ears but lose its head, get its body, lose its head, get its fur, lose its body, get the cat, lose the room... and so faces were the same... get the eyebrow, lose the eye, get the nostril, lose the nose, get the mouth, lose the rest of the face,... this is called Simultagnosia and occurs in people who have had oxygen deprivation related brain injury and also in some with Fetal Alcohol Spectrum Disorder (around 80% of whom are today also diagnosed with ASD).

As a result of the Simultagnosia I struggled not only to read non-verbal cues but was also severely faceblind. Other people may have Social Emotional Agnosia or Prospagnosia (faceblindness) as primary conditions without being due to the Simultagnosia. With Simultagnosia as the underlying cause the use of peripheral vision or tinted lenses reduces/filters incoming information allowing the brain more time to process visuals as a whole, so I often watched peripherally and as an adult replaced this with tinted lenses. But the connections in the brain relating to facial recognition were not well formed. So I can now see a whole face... and face blind people without Simultagnosia do see a whole face... but as soon as they leave and then return they are interchangeable with a large range of other people.

Because I grew up with Simultagnosia, I have poor internal mentalising and unlike Temple Grandin very poor mental visualisation. So I do my mentalising externally, my visualising externally, which also related to my skills in art and sculpture. Anyway, this lack of internal mentalising, lack if internal visualising, is part of my inability to retain any clear sense of what someone looked like. I may remember their hair colour or that they wore glasses or had a beard.

Faceblindness effects around 10% of humans. But it's in degrees. Up to 30-60% of adults on the spectrum have reported themselves to experience faceblindness. When it is severe it is disorienting. I presume strangers are known to me and known people are strangers. I recognise people by their placement, their voice, their body tone, their hair, sometimes by a jacket they regularly wear, their glasses, their beard.
As a child I wandered off with anyone wearing the same colour as my mother so soon I learned to 'get found' by sticking to narrow interests so that in the supermarket my mother always knew where to find me. I transferred this strategy to school but other kids didn't 'get it' and took it as my 'not being interested' in them.

Severe faceblindness also raised chronic fight flight states and the mirror or window reflections felt calming as 'the girl in the mirror' had familiar movements and sounds. As an adult people sometimes wonder if I have a kind of early onset dementia because I can see the same person in four different places and treat them as though they are all different people with the same name... even for as long as 2 years until I twig that they are the same person.

Strategies include things like name tags, reintroducing yourself if you re-enter the room or somewhere you're not expected or if you're dressed differently or changed your hair. When on outings have the group leader wear red, if not have your group all wear red so you can learn to stick with your group. Have activities that do not involve having to track who is who or recognise people quickly. Activities which focus on the object/issue would be more ideal. At swimming consider a uniform or have names embroidered onto swimming clothing so children can still be recognised once wet and out of their usual clothing and context. Allow a severely face blind person the first 60 seconds to register who you are and then emotionally register once they have had a chance to take in your voice and movements. Having a signature song is ideal.

Q. Can you explain a little about what anxiety exposure is and how you would suggest helping someone with anxiety exposure?

Exposure Anxiety was first written about in Nobody Nowhere in 1991 as a syndrome of involuntary and compulsive avoidance, diversion and retaliation responses. A large section of my first text book, Autism; An Inside Out Approach in 1996, was dedicated to setting out strategies for managing, even reversing Exposure Anxiety. In 2003 I wrote the first full book on Exposure Anxiety.

Exposure Anxiety is an 'Invisible Cage' of Involuntary Self Protection Responses. It is a co-morbid anxiety and impulse control disorder set in motion and maintained by chronic information overload and I believe it effects around 30-50% of those on the autistic spectrum, often the most challenged people on the autistic spectrum.

There's is considerable overlap between Exposure Anxiety and conditions such as Pathological Demand Avoidance (recognised by the National Autistic Society since 2008), Oppositional Defiance Disorder (first in the literature around 2002), Avoidant Personality Disorder and Dependent Personality Disorder.
The approach for it is an **'Indirectly-Confrontational' approach**, designed to reduce and progressively overcome the compulsive and involuntary avoidance, diversion and retaliation responses of Exposure Anxiety. Exposure Anxiety is an 'Invisible Cage' that challenges the person to either side with it or identify self with their own compulsive self-protection responses.

There's is considerable overlap between Exposure Anxiety and conditions such as Pathological Demand Avoidance (first diagnosed in 2008), Oppositional Defiance Disorder (first in the literature around 2002), Avoidant Personality Disorder and Dependent Personality Disorder.

Understanding Exposure Anxiety may be most relevant to:
* Those living or working with chronic fight-flight states
* Those living or working with compulsive avoidance, diversion, retaliation responses
* Those living or working with chronic anxiety disorders
* Those living or working with attachment disorders, anxiety disorders, Oppositional Defiance, Pathological Demand Avoidance, Dependent Personality Disorder
* Where directly confrontational approaches (such as ABA) are not working

If there were a [diagnostic criteria](#) for EA it might fit this:

1. Present from birth or infancy and persists throughout the person’s life span.
2. A marked and persistent aversion to directly confrontational attempts by even familiar others to share joint activities, communicate directly or cause self-awareness, escalating from aversion to diversion, to retaliation responses. **(Note:** this could also be present in abused children, those with attachment disorders, and those with information processing disorders, sensory perceptual disorders, sensory hypersensitivities or sensory deficits).
3. Involuntary avoidance, diversion and retaliation responses revolving around basic self-help skills and toileting even in the absence of any social audience. May later be accompanied by a tendency to mirror others when they are doing these things (can’t do as oneself) or to attribute responsibility to others or to objects to achieve these things (can’t do for oneself).
4. A social style ranging from self-isolation to seemingly aimless wandering to highly active, even sometimes seemingly socially threatening approach-avoidance behaviours.
5. A communication style which may include any range of the following:
   6. Selective Mutism, mindless (even self-hypnotic) singing or self-chatter.
   7. Short, telegraphic bursts of speech.
   8. Whispered, self-directed, rushed or overly slowed speech to the point of being incomprehensible.
   9. Highly characterised stored utterances or scripts.
   10. Persistently impulsive communications which are offensive or distancing.
   11. Obsessive anxiety-driven descriptive or intellectual litanies.
   12. **Typed communication** or artistic expression far beyond what the person can express directly or verbally. **Note:** Provided these are not better accounted for by Tourette’s tics,
Semantic Pragmatic Language Disorder, Aphasias, verbal agnosias, Social-Emotional Agnosia, personality or conduct disorders, Alexithymia, or other mood or anxiety disorders.

13. Exposure to uninvited praise and attention provokes immediate avoidance, diversion or retaliation responses. By mid-late childhood these EA responses may have differentiated into strategies of ‘can’t do as oneself’, ‘by oneself’ or ‘for oneself’ in which praise and attention are tolerated when the person has assumed a role or character but not when they are caught off guard or when being themselves.

14. A phase in early childhood where there is no remorse for involuntary avoidance, diversion or retaliation responses but by mid childhood-puberty, self-directed rage may result from progressive awareness of their own condition and desire but inability to escape it.

15. Avoidance, diversion and retaliation responses or strategies of ‘can’t do as self’, ‘can’t do by self’ or ‘can’t do for self’ significantly interfere with the person’s ability to cope with change, transitions, demonstration of academic learning and skills, ability to function in employment, ability to gain or sustain general friendships, manage healthy parenting or sustain long term intimate or sexual relationships.

16. Involuntary avoidance, diversion and retaliation responses and depersonalisation strategies of ‘can’t do as self’, ‘can’t do by self’ or ‘can’t do for self’, are not due to the direct physiological effects of any substance or other general medical condition and are not better accounted for by abuse or by other anxiety, conduct, personality, developmental, attention deficit, dissociative, attachment, mood or compulsive disorders.

Given EA is present from birth or infancy, can present in both mild and severe forms, in specific or generalised forms, and may shift dramatically in some people by late childhood or adulthood - See more at:

http://blog.donnawilliams.net/2009/06/07/a-diagnostic-criteria-for-exposure-anxiety/#sthash.D9LmYLNl.dpuf

http://blog.donnawilliams.net/2009/06/07/a-diagnostic-criteria-for-exposure-anxiety/

http://www.donnawilliams.net/exposureanxiety.0.html

http://www.donnawilliams.net/364.0.html

https://www.youtube.com/watch?v=bJNkYFuiv7g

Among aspects of an indirectly confrontational approach are the following:

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work in parallel
• be self-owning/stop watching, waiting, wanting
• focus on object/issue not on person
• small doses
• play hard to get
• always leave the person wanting more
• use 'yes but'
• use yes to get no/no to get yes
• keep praise low key if at all and focused on activity not on the person.

Q. Restrictive eating can be a significant issues for children and autistic adults, what advice would you have for supporting someone to develop the foods they can eat?

Restrictive eating can be **Food Neophobia** (fear of new foods) which you deal with like any other phobia. It can be **Selective Eating Disorder** which can be part of an **Avoidant Personality Disorder**, part of an **Obsessive Compulsive Personality Disorder**, part of **Oppositional Defiance Disorder**, part of **Dependent Personality Disorder**... so you would address it by addressing its underlying cause.

It can also be an addiction issue which is common in food intolerances like Salicylate or casein intolerance where the person builds a drug like response to the foods they are intolerant to and ends up excluding the foods which don't cause the sought after drug like associations (salicylate intolerance can involve a cocaine like effect, casein intolerance can cause an opiate like effect). In these cases you would help the person transition to a diet that avoided what they had intolerances to. Eating disorders clinics can help autistic children with eating disorders but if we call it all 'the autism' then these people won't get that help. **Helicopter parents** who are pandering and watching, waiting, wanting and reinforcing/validating phobias and avoidance do not help children with food issues work through these.

Among the strategies are to leave tiny amounts of new foods for people to try without pressure, rewarding a sibling for trialling new foods, rewarding others who have flexibility and daring, using reverse psychology (don't touch that, its special and it's for your sibling). You can also use reward charts for daring new things, and set an example of never reinforcing anxieties and phobias about foods. Involving children in cooking can also give them a relationship to food and exposure to smells which may build daring to eventually taste things. You can also transition one food into another.... so someone who only eats mashed potato, you can add a small amount of vegetable water, then over time a small amount of highly pureed vegies, and over time not so heavily pureed and increase the amounts and so transition from potatoes into broader vegetables. This kind of program can be done with pretty much any food limitation and can be designed to accommodate textural aversions too.
Q. A lot of children with autism and autistic adults experience bullying, particularly at school. What advice would you give to teachers?

There is a great video which shows how it is both the bully and the chronic victim who need intervention. It is a failure in duty of care to be aware a student has these developmental issues and not direct them to ongoing therapeutic interventions to help them developmentally with these issues.

There is also the problem of how diversity friendly a principal is, their staff, the school and its policies, the delivery of that on a class by class level and schools need to ensure they produce healthy citizens, not just kids who can read and write. Lessons on social differences, on being socially healthy, on being positive are all useful for all children.

Those with autism who develop a chronic victim stance will become socially isolated and also be a magnet for bullies.

Diversity friendly clubs outside of school can help these people develop confidence and self-esteem so they stop behaving like chronic victims.

Teaching people on the spectrum basic self-advocacy skills and basic self-defence skills is also useful.

You Tube has a range of anti-bullying materials a teacher could openly use and discuss with the class bringing the issue into the open is the first step
Q. Can you explain a little about PDA and any advice you would have for professionals working with people with PDA?

PDA is another umbrella term... just as Autism is, or ODD, or ADHD...

We all have 4-6 main personality TRAITS.... each with its own built in motivations and distress buttons.

http://www.ptypes.com/type_passions.html

Chronic stress, such as happens with chronic information overload and sensory/sensory perceptual challenges, drives personality traits out of proportion where over time they come to present more as Personality Disorders. These are not currently diagnosable until they have persisted over years and the person is in their teens or adulthood. This does not, however, mean that younger children on the autism spectrum may not function on a regular basis like someone with one or more personality disorders.

Those with Avoidant, Passive Aggressive, Narcissistic Personality Disorders can have PDA as part of these:

- Those who are Schizotypal are naturally non-conformist
- Those tending toward Antisocial Personality Disorder are driven by challenge and risk and commonly avoid demands of others
- Those with Obsessive Compulsive Personality Disorder can have PDA because they are too addictively driven by fixations and obsessional interests
- Those with Dependant Personality Disorder commonly avoid demands because they fear independence skills as they invest in helplessness as a means of monopolising the carer... so doing as a teacher or other carer instructs runs counter to this and they'd lose/monopolisation control over the primary carer.
- Those with Gaming or Internet addictions will develop PDA due to their unmanaged addictions.
- Those with chronic information overload or the associated chronic fight-flight state of Exposure Anxiety are subject to avoidance, diversion, retaliation responses may present as 'PDA'.

The way you would address someone's PDA is to address its underlying cause in that particular individual.

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If it’s due to information overload, you bring in strategies to reduce or filter incoming information, speed up information processing and give space breaks for the person to work through backlog and for their body to relax again.

If it’s due to unmanaged addictions you wean the person off the addictions, put boundaries in place, stick to them and reward them for adhering to those boundaries.

If it’s due to personality disorders you work out which are at work and assess how the environment is chronically feeding those personality disorders and bring in a consistent approach across environments that is designed to turn these back out of 'disorder' range and back into 'trait' range... to 'turn the volume down'.

Q. The understanding of autism, both professionally and more widely has changed considerable over the past 2 or 3 decades, can you tell us what you feel have been the biggest shifts in perception and understanding and what difference that has made to you?

It has moved from Infantile psychosis to emotionally-behaviourally disturbance, to the cognitive model in which everything was 'intellectual disability', to the sensory model in which everything was 'sensory' and we are now in a neurology/physiology model which is taking more seriously things like brain connectivity, immunology, the gut-brain relationship, connective tissue disorders, autonomic dysfunction.

It has moved from rigid compartmentalising of Kanners versus Aspergers Syndrome to ASD containing Kanners, Aspergers syndromes and PDDNos... it has moved from rigid compartmentalising of high versus low functioning to recognising these things occur in different combinations in different people in varying environments over periods of time... it has moved from the idea of one condition awaiting a magic bullet cure to awareness that autism can also be dynamic and change with different environments, approaches, strategies, treatments and over time....

I have strived to help the field move toward awareness that autism is merely an adjective at one level and at another is an umbrella term for the developmental impact of too many 'straws on the camel's back'... in other words... autism is 'a fruit salad' and those combinations of fruit salad, degrees of fruit salad, and the interplay of these with personality, identity, environment, will result in greater or lesser degrees of disability versus 'difference'.

I was diagnosed at age 2 in a 3 day inpatient hospital assessment as a psychotic child. By age 9-10 I was labelled 'disturbed'. By age 10 I was diagnosed with severe language processing disorder. By my mid 20s it was confirmed that I was autistic and I learned that autistic children
in the 60s were all deemed to have infantile psychosis and people no longer used such thinking or terms. 
I found my own sensory strategies and adaptations, many of which came to inform the autism world. I wrote of my own sensory perceptual and health challenges and their impact on my autism and these two have progressively informed the autism world. I wrote of the chronic fight flight states of Exposure Anxiety, inability to simultaneously process self and other, challenges with internal mentalising and all the strategies used for these and these too have helped inform the autism world.

I was one of the first three adults with autism to form our own self-help groups, which became Autism Network International - ANI - and the world’s first online autism group run directly by those on the spectrum and part of the self-advocacy movement.

I would like to say I benefited from the autism world and all of its awareness, but often I was more a contributor to that awareness rather than the beneficiary of it or autism specific services. Nevertheless, those contributions now benefit those who will follow.

**Q. What would be your top tips for professionals supporting autistic people?**

People with autism have always existed. They were called psychotic, disturbed, maladjusted, intellectually disabled... AUTistic is an adjective... meaning in one's own world, separated from the non-autistic 'norm'. But all humans have autistic moments, all autistic people have non-autistic moments. For Autism is not one thing. It is a 'straws on the camel's back syndrome... a 'fruit salad' that is made up of different combinations of sub conditions which, when unidentified and blended up, present 'autistically'. Therefore, forget the rhetoric, forget the trend in how autism is seen today, for each of these trends was archaic in an earlier decade, and so too will the current perspective on autism be seen just as outdated ten years from now. 

Autism is not stagnant, it is dynamic, and what presents at age 2 may be completely different by age 5 or 9 or 30... if you are open minded enough, innovative enough, neutral enough to at least see the personhood more than the condition, always presume competence, always look for the strengths instead of advertising the weaknesses and set a great example of boundaries, self-management, self-advocacy, adaptation and openness to development, then an autistic person at least have a healthy model to learn from.