

## Mental Health and Autism: Promoting Autism FaVourable Environments (PAVE)

### Abstract

*Autism is associated with unique neurobiology. Significant differences in brain structures and neurobiological functioning have been found that underpin different perceptual and psychological experiences of people with autism ("neuro-atypical") compared to those without autism ("neuro-typical"). These neuropsychological differences include hyper-and hyposensitivities to sensory input, vestibular distortions, problems filtering and processing incoming information which contribute to sensory and emotional overload, motor difficulties and consequent anxiety. Neuro-typical explanations (Outside-In perspective) of anxiety and unusual behaviours shown by those with autism, are often at odds with explanations provided by those with autism (Inside-Out perspective). Listening to these neuro-atypical explanations of emotional experience underlying unusual behaviours, offers an opportunity to Promote Autism faVourable Environments (PAVE). The PAVE approach can reduce the suffering, pain and distress that arise for those with autism in more ordinary environments, as well as aid in reduction of misdiagnoses and mismanagement strategies.*

Autism (Please see Box 1 on the opposite page) is associated with unique neurobiology: significant differences in brain structures and neurobiological functioning have been found (Baron, Groden, Groden, & Lipsitt, 2006; Courchesne, Webb, & Schuman, 2011; Minschew, Scherf, Behrmann, & Humphreys, 2011) that underpin different perceptual and psychological experiences (Baron et al., 2006; Bogdashina, 2003; Bogdashina, 2010). While each individual on the spectrum may present a unique profile, consequent differences in brain processing may be linked to unique characteristics listed in Table 1, column 2, # 1-7. These differences in brain processing give rise to perceptual distortions, problems with executive functioning and capacity to initiate, difficulties regulating emotional overload and a general search for coherence (Table 1, #8-11). Not surprisingly, anxiety is a prevalent emotion in autism.

People with more severe autism or with coexisting intellectual disabilities sometimes engage in puzzling, sometimes seemingly bizarre behaviours that can result in damage to self and others. These behaviours are often interpreted by imposing our view of the world, a view experienced in the absence of living with the impact of these autism-associated neurobiological differences. Such a viewpoint is referred to as the "Outside-In" perspective (Williams, 1996). However, personal narratives of people with autism inform us that their experience of the

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#### Keywords

autism,  
hypersensitivities,  
autism friendly  
environments

### Box 1: Autism and Autism Spectrum Disorders (ASD)

Autism is a neurodevelopmental condition defined clinically by impairments in social interaction and communication, accompanied by restricted repetitive and stereotyped patterns of behaviour, interests and activities (American Psychiatric Association, 2000). It is a syndrome diagnosis underscored by different aetiologies, the latter contributing to multi-faceted clinical presentations throughout the life span. The proposed fifth edition of the American Psychiatric Association's diagnostic criteria (DSM-5; scheduled for 2013) combines the social and communication criteria into a single criterion along with restricted behaviour (American Psychiatric Association, DSM-5 Development, 2011). The current category of Pervasive Developmental Disorders (PDD) that includes autism, Asperger syndrome, atypical autism and PDD-NOS is to be replaced by a single category: Autism Spectrum Disorders (ASD). In this paper the term "autism" refers to ASD.

world (and therefore these puzzling and bizarre behaviours), arise from their different frame of reference (Gerland, 2003; Grandin & Scariano, 1986; Grandin, 2006; Jolliffe, Lansdown, & Robinson, 1992; Nazeer, 2006; O'Neill, 1998; Powell, 2011; WeirdGirlCyndi, 2007; Williams, 1996; Williams, 2003). In this article we refer to viewpoints from people with autism as the "Inside-Out" perspective. The term "Inside-Out" was first used in this context by Donna Williams, a well-known Australian writer, teacher, artist and musician who was diagnosed with autism as an adult (Williams, 1996). (See also Caldwell & Horwood, 2008, Chapter 3: Alternative Viewpoints.) In the present article, we explain how taking an Inside-Out view may offer new insights into understanding these unusual behaviours as well as the anxiety and other mental health distress that arise in autism. This perspective may offer greater opportunities for prevention and new approaches to treatment (Bradley, Caldwell, & Underwood, In press).

In this paper, we offer suggestions for providing environments and supports that take account of the unique sensitivities and needs of people with autism. As we explain, this approach supports interpersonal communication and emotional engagement. The approach reduces suffering, pain and distress that underpin behaviours that seemingly are unusual or bizarre and arise for those with autism in more ordinary environments. We have called this approach Providing Autism faVourable Environments (PAVE). This approach is based on: (a) clinical experience with hundreds of

people with autism and intellectual disabilities over the past several decades, referred to our respective clinical services in the UK and in Canada with behaviours that characterize distress (sometimes referred to as "challenging behaviours"); and (b) familiarity with the biographical accounts by people with autism describing their experiences of such distress. PAVE mitigates the distress caused by sensory overload that results in the problem and challenging behaviours that care providers find so difficult to manage.

Substantial evidence has emerged to document the negative impact of both the physical (Gaines, Sancibrian, & Lock, 2011; Henriksen & Kaup, 2010; Mesibov, Shea, & Schopler, 2005) and emotional (Mesibov et al., 2005; Smith, Greenberg, Seltzer, & Hong, 2008) environments on those with autism as well as the positive impact of emotionally engaging individuals with autism using their nonverbal repertoire (Zeedyk, 2008; Zeedyk, Caldwell, & Davies, 2009). Our evidence for PAVE is based primarily on the quintessential (i.e., time-tested) approach in clinical practice. Essentially, this entails: (a) working in the detail and uniqueness of each clinical encounter; (b) generating clinical hypotheses about the presenting distress within the framework of appreciating the unique profile of neurobiological differences present in autism; and (c) testing these hypotheses gently with the individual concerned. This approach merges empirical with practice-based evidence (Barkham & Mellor-Clark, 2003; White, 2004).

## Box 2 Autonomic Storms

Apart from the autistic condition, autonomic storms (AS's) can be associated with injury to the brain or brainstem (Lemke, 2007). Originally used to describe the conditions of REM sleep, autonomic storms were thought to be linked to the body's attempt to resume normal brain and sleep activity. However astronauts in weightless conditions also suffer AS's perhaps related to "temporary" brain injury (e.g., from the loss of gravity) giving rise to the brain receiving confusing signals and in response reacting with strong fight or flight responses (Parady, 2011).

## Physiological and Emotional Responses in Autism

In ordinary everyday environments, brain processing differences that arise from these neurobiological differences in autism (a) give rise to "processing overload" – an experience that is often acutely painful (for example, hypersensitivity to light was rated by one individual at 8–9 out of 10, as compared with kidney stones which were rated 4–5 out of 10); and (b) contribute to consequent difficulties managing physiological and emotional responses. This results in anxiety, referred to here as "autism-specific" anxiety, because its cause and therefore treatment, are different from that of anxiety seen in the general population without autism (Hare & Malone, 2004; Porges, 2007; Powell, 2011). These every day difficulties may be accompanied by physiological arousal and a dysregulated autonomic nervous system (e.g., changes in pulse and breathing rates, heat regulation, sweating and skin colour) in response to this stress and pain. These changes constitute a physiological response called an "autonomic storm." Autonomic storms (AS's) are triggered when sensory overload becomes too great. In physiological terms the autonomic storm is a massive increase in sympathetic nervous system activity that might simply be called a hyper-stress response.

The autonomic nervous system (ANS) is part of the peripheral nervous system and consists of the sympathetic and parasympathetic systems. The ANS controls certain body functions including regulation of the heart (e.g., pulse and blood pressure), respiration (e.g., rhythm and volume), temperature (e.g., sweating and perspiration), fear responses (e.g., startle response, pupillary dilation, salivation), digestion and voiding. It functions autonomously to main-

tain the body in physiological equilibrium. As such it is mostly involuntary although aspects of some activities, in normal circumstances, are under voluntary control (e.g., voiding), while some can be brought under some voluntary control (e.g., breathing). In certain physiological/psychological states under voluntary control (e.g., meditation practices), some ANS activities usually unconsciously performed, can be altered (e.g., heart rate). In general terms, in response to perceived danger the sympathetic nervous system prepares the body for quick "fright" – "flight" – "fight" responses while the parasympathetic system shuts down bodily function resulting in immobilization. In terms of clinical observations it is interesting to note that in response to fear or anxiety, conscious control of voiding is altered so as to result some times in accidental voiding and at other times increased difficulty in bringing voiding under voluntary control resulting in retention.

Stephen Porges (2007; 2011) offers a new perspective on the role of autonomic functioning in the regulation of affective states and social behavior. He suggests there are three stages in development in the mammalian autonomic nervous system that come into play in response to perceived threat in the immediate environment: (a) the myelinated (i.e., nerves covered by insulating material and as such are faster conducting) vagus circuitry concerned with social engagement behaviours when there is no threat (phylogenetically the last circuitry to evolve); (b) the sympathetic nervous system mobilising behaviours of fight and flight when there is increasing threat; and (c) the unmyelinated vagus system (a potentially lethal ancient circuit) involved in defensive strategies of immobilization (e.g., fainting and dissociative states to behavioural shutdown and death feigning seen in animals) when threat to survival is imminent.

This theory of Porges has come to be known as the “Polyvagal Theory” (Porges, 2007; 2011).

However one chooses to understand the neurobiology of the human response to threat, the essential observations relevant to the individual with autism are, on the one hand, a display of acute escalating behavioural distress, including severe self inflicted injury, and on the other hand, personal accounts of desperation and crushing psychological pain in response to environmental events. In her book *Somebody Somewhere: Breaking Free from the World of Autism*, Donna Williams provides a vivid description of her own (Inside-Out perspective) experience as a child (with autism) responding to a threat which had elicited self-injurious behaviour (Outside-In perspective). She recalls:

There was a rip through the centre of my soul. Self-abuse was the outward sign of an earthquake nobody saw. I was like an appliance during a power surge. As I blew fuses my hands pulled out my hair and slapped my face. They pulled at my skin and scratched it. My teeth bit my flesh like an animal bites the bars of its cage, not realising the cage was my own body. My legs took my body around in manic circles, as though they could outrun the body they were attached to. My head hit whatever was next to it, like someone trying to crack open a nut that had grown too large for its shell. There was an overwhelming feeling of inner deafness – deafness to self that would consume all that was left in a fever pitch of silent screaming. (Williams, 1995, p. 9)

Autobiographical accounts help us to understand that in their desperate search for a coherent picture of what is going on in the world around them, the autistic individual tries to avoid sensory overload and autonomic storms by developing one or more of the following coping strategies (Caldwell & Horwood, 2008, pp. 29–33). (Note that the following responses may occur in any individual, but occur more readily in autism because of the vulnerability to sensory overload.)

1. Increasing focus on repetitive behaviour, which in some cases takes the form of self-injury
2. Using exit strategies to attempt to remove themselves from the source of the overload (as they rightly or wrongly perceive it) by:

- (a) avoidance (e.g., hiding their eyes, walking away)
- (b) partial shut down of individual functions such as seeing or hearing
- (c) complete shutdown (e.g. unresponsiveness with immobility or catatonic reactions)
- (d) separation by removal of source of overload through aggression
- (e) a combination of these strategies

Some individuals with autism remove themselves physically from stressful circumstances (2a). Others, on the more passive end of the autism spectrum, may have little or no spontaneous or independent capacity to remove themselves physically from stressful circumstances and just “freeze”/“posture” on the spot (2c: catatonic reactions) (Loos & Loos Miller, 2004; Wing, Leekam, Libby, Gould, & Larcombe, 2002). Sometimes “partial” shut down occurs where the brain cuts down on incoming signals by switching off one or more of its functions (2b) (Williams, 1996). Others in an autonomic storm may lash out causing injury to self, others or property destruction (2d).

Personal narratives (Grandin, 2006; Jolliffe et al., 1992; O’Neill, 1998; Williams, 1996) suggest people with autism live in constant fear of any triggers that may result in being tipped into an autonomic storm. This fear can be elicited by present or anticipated circumstances, which can trigger sensory overload and lead to an autonomic storm.

## **Promoting an Autism faVourable Environment (PAVE)**

PAVE is an environment of relationships and supports that takes into account the unique differences in neurobiological functioning and brain processing in autism by making specific environmental and support adaptations to reduce anxiety associated with these differences. As this autism-specific anxiety is aetiologically different from other anxiety disorders (or is better accounted for within a vulnerability and signal detection paradigm rather than seen as psychiatric pathology) (Bateson, Brilot, & Nettle, 2011), it is not surprising to find that medication and

other interventions to treat anxiety in the general population may be less effective when used in people with autism. (Such clinical observations are now undergoing evaluation; see <http://www.autismspeaks.org/what-autism/treatment/treatment-associated-medical-conditions>.)

However, used in combination with an Autism faVourable Environment, these interventions, including anxiety medication, may sometimes provide additional benefit. In those individuals showing physiological arousal (e.g., pulse rates consistently and significantly above the usual rate) medication to lower autonomic nervous system activity (such as a beta blocker) may be helpful in reducing arousal and associated anxiety (Ratey et al., 1987; Tyrer, 1988).

As autism manifests differently in each individual on the spectrum, there will be different patterns of hypersensitivities and other neurobiological differences in each individual. It follows therefore that an Autism faVourable Environment has to be uniquely matched to each individual after comprehensive and careful assessment.

An Autism faVourable Environment is achieved by (a) decreasing stress triggers (Table 2) and (b) assisting the individual to develop and maintain a coherent sense of self and others through a coherent sense of his/her environment, every day activities and relationships (Table 3).

Narratives of people with autism (Gerland, 2003; Grandin & Scariano, 1986; Williams, 1996; Williams, 2003) as well as reports from care-providers (Woodcock & Page, 2010) tell us that everyday environments may be experienced as extremely distressing and painful because of their sensory sensitivities and anxiety. Decreasing stress therefore includes finding ways to reduce or prevent these painful incoming stimuli (Table 1). As well, developing and maintaining coherence involves building on what is already meaningful to the individual (e.g., special interests) in ways that are meaningful to them (e.g., using visual communication over auditory) as this places less demands on brain processing (but note: not where visual distortions are present – e.g., Irlen's syndrome).

## How to PAVE

In this paper we offer tools to:

- Screen for autism-specific differences in neurobiology, by describing what behaviours to look for that may alert to such specific differences (Table 1). For more comprehensive assessment, referral to the multi-disciplinary team, where available, is recommended.
- Systematically review circumstances that give rise to stress in autism. Strategies are offered to reduce stress and resultant anxiety (Table 2).
- Assist care providers in supporting the individual develop a cohesive sense of self and the daily environment. Daily structures of support and care provider approaches are suggested (Table 3).

Three illustrative case studies provide examples of:

- How, moving from an Outside-In perspective (trying to fit behaviours into existing psychiatric diagnostic categories) to an Inside-Out perspective (understanding behaviours in terms of what unique sensory and other needs these are a manifestation of), provided therapeutic benefit (Case 1 – Susan).
- How PAVE, including Intensive Interaction support resulted in successful treatment of self-injury (Case 2-Gabriel). (For information about Intensive Interaction, see Caldwell, this volume.)
- A third case study (Pranve) illustrating how PAVE and Intensive Interaction support resulted in successful treatment of seriously aggressive behaviour is described in Caldwell: Intensive Interaction: Using Body Language to Communicate (p. 35, this volume).

Case Study descriptions provided are of individuals in the authors' practices. Permission to publish the studies has been obtained from these persons and/or their families; two families requested real names be used.

### Illustrative Case Study 1: Susan

Over several months, Susan at age 15 years developed posturing, stalling, freezing, sudden episodes of frenzied agitation, hyperactivity and screaming, accompanied by pinching herself causing bruising interspaced with episodes of complete calm. Skills of daily living deteriorated and she no longer showed interest in her detailed colourful artwork. Life events occurring around the start of this decline included stress and anxiety in the family home associated with the loss of job of one parent, subsequent parental anxiety and Susan's transition from middle to high school. Menses had started the year before. Despite many reviews by her family doctor and paediatric team, medication trials (SSRI, Risperidone, Zyprexa, Ritalin, Ativan) and visits to the ER her distress behaviours increased in severity and frequency over the next year. Extensive medical, including neurological, investigations did not identify any medical aetiology to her deterioration and changed behaviour. Psychiatric diagnoses included mood disorder, ADHD, tic disorder, general anxiety disorder and OCD; standard treatment for these disorders did not result in any recovery. Susan had engaged in repetitive behaviours from an early age (likely ways in which she was self-soothing in response to over stimulating surroundings) but careful analysis showed only marginal increase in these repetitive behaviours but significant increase in tics and stereotypies and some increase in SIB. The family then suffered several bereavements and Susan's behaviours of concern expanded to include urinary incontinence (in the absence of a UTI) and hair pulling until about ¾ scalp was bare and traumatised with picking. Of note, even at height of her distress, Susan's behaviour improved during outdoor summer camp activities compared to school term times. This, and behavioural monitoring over two years that showed smaller but consistent deterioration in the behaviours of concern also associated with allergies (spring and fall), menses and constipation, confirmed that these behaviours of concern were essentially stress related (her stress level at times essentially resulting in autonomic storm responses).

Susan had been diagnosed with autism at age 4 but had managed with only modest accommodations at school and home. Assessment by the multi-disciplinary team identified specific sound, light and touch sensitivities (preferred quiet, less well lit places and loved to touch and stroke her hair), proprioceptive and deep pressure needs (frenzied hyperactivity when she would seek out strong pressure input (e.g., from pinching herself), freezing and stalling behaviours around transitions, negative response to emotionally charged overheard conversations (even though these were not about her) and anxiety in others, especially female family members (would move into one of her frenzied episodes).

An autism favourable environment was instituted – pertinent features of this for Susan were as follows: She preferred blue light in her room; was very responsive to social stories (around transitions, the bus ride to school, preparation for time away from home) as well as visual schedules (e.g., plan for the day). When she was noticeably anxious, access to glop to squeeze in hands, bouncy sitting balls, a vibrating mat and walks all helped. These tactile/proprioceptive opportunities were also instituted predictably and regularly through the day. In addition, scheduled times during the day were arranged for her to watch favourite cartoon videos, an activity she enjoyed (and which calmed her). When a family member died, the team, very successfully, incorporated her familiarity with one of her videos (where the main character had also suffered a loss) into a more personal narrative to help her with her family loss. Over several months with implementation of these supports Susan's hair started to grow back and the frenzied episodes and catatonic-like behaviours diminished. As she was recovering, Susan continued to show emotional overload on those occasions when she started to experience pleasure in an activity (e.g., return of her interest in drawing).

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**Illustrative Case Study 1: Susan** *continued from previous page*

Progress was maintained for about a year when some behaviours of these previous concerns started to re-emerge. Attention to a transition that was happening at that time and anxiety around a bus journey and the unpredictable stops it would make to pick up others resolved this recurrence. However, it was a reminder that promoting an Autism faVourable Environment (PAVE) is not always intuitive to care providers; furthermore PAVE is not always understood as fundamentally necessary rather than optional if resources are available. Education and re-education is ongoing in these regards. Intensive Interaction therapy, firstly 1-1 with a therapist and then with the therapist supporting staff was effective in working with

Susan's breathing pattern and vocalisations to help her de-escalate at times of emotional upset. This treatment was initiated and consolidated over a period of 4 years; Susan showed remarkable improvement including academic skills moving from Grade 2-3 level to Grade 4-6 level and adaptive skills moving from the Mild to Borderline range.

In summary, effective treatment for Susan was possible when we moved from an Outside-In perspective (trying to fit her behaviours into existing psychiatric diagnostic categories) to an Inside-out perspective (understanding Susan's behaviours in terms of what unique sensory and other needs these were a manifestation of).

**Illustrative Case Study 2: Gabriel**

Gabriel is 23, has autistic spectrum disorder and very severe learning disabilities. Resident in a College, he makes no eye contact and staff are unable to engage with him. He bangs his head against the wall and pushes people aside as though they were pieces of furniture. He will not sit down and become involved in activities, preferring either to patrol restlessly or grab string or rubber gloves and, using his right hand, flick them on his left wrist. Occasionally he will half inflate a balloon and let the air out in his ear. The psychologist suggests that if one could engage with Gabriel one could engage with anyone.

I pick up first, rubber gloves and then string and work with these. Over the course of two hours he begins to flick his gloves and then looks up, waiting for my response before

continuing. By next day (four hours in total) his face is relaxed and he is looking around him, interested in his surroundings. He is also engrossed in our mutual exploration, smiling intimately and examining my face closely. Following on the balloon event, he particularly enjoys it when I blow in his ear, turning to offer me the other. Once Gabriel has learned that if he makes an initiative, I will respond, he is able to generalise – "If I shake the string you will answer (and then looking at me enquiringly), "How about if I bang the sink?"

After I have worked with him for two days I involve his support worker and he responds to her in a similar joyful fashion.

*Reprinted with permission from Caldwell (2002; 2012)*

Table 1. *Unique Neurobiology in Autism and Consequent Differences in Brain Processing*

	<i>Differences in brain processing associated with:</i>	<i>The following behaviours may alert to the presence of these differences:</i>
1 (A & E)*	Hypersensitivities to sensory input and sensory distortions	Squinting eyes, hiding eyes, hands over ears, squirms to touch, avoids touch, gags to tastes, textures and smells; difficulties focussing and concentrating; avoidance of the offending places or people or outbursts where this is not possible.
2 (B)*	Hyposensitivities including proprioceptive (body awareness) deficits and distortions	Hyper and hypo activity: e.g., kicking at walls, touching surfaces, scratching self, seeking pressure, strong hugs, unusual gaits, odd motor movements. May bump into or lean against people.
3 (B)*	Vestibular distortions	Problems with physical activities; problems starting, stopping and changing direction; unusual motor behaviour: e.g., jerking, rocking, falling, sitting down when confused.  Video-clip: Findley/Jamie (Caldwell, Hoghton, & Mytton, 2009)
4	Inability to filter out unimportant incoming stimuli so their processing system is swamped by surplus detail	Stalling and freezing in movements; behavioural outbursts; meltdowns and temper tantrums.  YouTube video: WeirdGirlCyndy (2007)
5 (C)*	Difficulties in processing speech, transitions, choices, change and anything abstract	Inattention, avoidance, anxiety, agitation, restlessness, hyperactivity, behavioural escalations; also stalling and freezing.
6	Hormonal changes and surges e.g., puberty, menses	Change in behaviour linked to onset of puberty, menses, menopause.  (O'Neill, 1998 Chapter 11; Williams, 1996 Chapters 5 and 7)
7 (D)*	Emotional overload – hypersensitivity to emotions in self and others	Sudden changes in behaviour, “out of the blue” behaviours, on closer inspection linked to emotional (both positive and negative) expression (both in verbal tone and nonverbal body changes) in others. Positive (i.e., pleasurable) as well as negative emotions in self may also be over stimulating resulting in outbursts and escalations in distress behaviour. Observe arousal level and look for hypervigilance.  (O'Neill, 1998 Chapter 4)
	<i>Problems consequent to # 1–7 above</i>	
8	Perceptual distortions (as a consequence of 1–3)	See YouTube: WeirdGirlCyndy on-line
	<i>For a sensory assessment resources:</i> <a href="http://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=076-1638-008">http://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=076-1638-008</a>	
	<i>Sample report:</i> <a href="http://www.pearsonpsychcorp.com.au/userfiles/SensoryProfileSampleReport.pdf">http://www.pearsonpsychcorp.com.au/userfiles/SensoryProfileSampleReport.pdf</a>	
	<i>* See Table 2 for more detail about items A to E</i>	

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Table 1. *Unique Neurobiology in Autism and Consequent Differences in Brain Processing* (continued)

	<i>Differences in brain processing associated with:</i>	<i>The following behaviours may alert to the presence of these differences:</i>
9 (E)*	Problems with movement (Donnellan & Leary, 1995), executive functioning and capacity to initiate. These may be secondary to sensory distortions (both in quality and quantity), arising from 1–3 above and perceptual distortions (8 above).	e.g., stalling and freezing, not or no longer engaging in usual activities (careproviders trying to understand these behaviours may miss attribute intentional states referring to these behaviours as “refusing,” “non compliant”; “defiant”), needing assistance and prompts (“attention seeking”), lack of initiation (“not motivated”; “defiant,” “could do it if he wanted to”), doing the opposite to what was asked (“oppositional”; “deliberate”; “intentional”)
10	(a) Difficulties regulating emotional overload  (b) Miss attributing emotional expressions in others as directly relating to self	e.g., (a) high arousal, hypervigilance, impulsivity, sudden behavioural outbursts, mood swings; negative response to praise, emotional warmth; negative response to “trigger” words: e.g., “don’t know,” “be careful,” “No.”  (b) gets upsets when others start to talk in emotionally expressive tones
11	General search for coherence	e.g., repetitive behaviours (Nazeer, 2006)

For a sensory assessment resources:  
<http://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=076-1638-008>

Sample report: <http://www.pearsonpsychcorp.com.au/userfiles/SensoryProfileSampleReport.pdf>

\* See Table 2 for more detail about items A to E

Table 2. *Stress and Anxiety in Autism*

*Stress contributes to anxiety*

*Stress is associated with:*

*Strategies to reduce stress and resultant anxiety\**

**A: Painful incoming stimuli caused by:**

(a) Sensory hypersensitivities to external stimuli:

- light (e.g., Irlen syndrome) and pattern

Use diffuse soft lighting, remove fluorescent lighting; where appropriate, provide coloured light or lens. Use dimmer switches. Offer sunglasses. Avoid brightly coloured patterned materials.

- sound

Use ear plugs, noise reduction headphones (e.g., BOSE Quiet Comfort 15 Acoustic Noise Reduction Headphones; Ipod with favourite music) may help. Prepare going into noisy environments. Reduce noise with double glazing, soft flooring. Reduce use of TV/entertainment system. May need to speak softly or whisper.

\* See also Woodcock & Page, 2010)

Note: Each individual has a different and unique profile A–E

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Table 2. *Stress and Anxiety in Autism* (continued)*Stress contributes to anxiety**Stress is associated with:*

- touch; light touch is often painful
- taste
- smells
- noisy, busy spaces
- emotions: e.g. anxiety in others; emotional warmth from others may be so overwhelming that the person feels as if they are being attacked and responds accordingly.

## (b) Sensory hypersensitivities to internal feedback:

May be negative responses to own emotions: e.g., pleasure, anxiety, or excitement may cause a negative emotional response.

**B: Deficits in the proprioceptive system and distortions in the vestibular systems****C: Specific processing difficulties e.g., speech, anything abstract, choices and transitions***Strategies to reduce stress and resultant anxiety\**

Teach to brush hair and teeth themselves. Cut out scratchy labels from clothes. Use: weighted blankets, sleeping bag for sleep, pressure sports clothes, weighted jackets.

Introduce different textures and tastes slowly. Avoid the provocative foods, offer in a different preparation (for hyposensitivity offer strong tasting foods).

Use fragrance-free household and personal hygiene products. Avoid provocative smells, introduce preferred smells. Use strong smelling products as motivators where there is hyposensitivity.

Provide a low arousal environment (calm colours on walls and furnishings, minimal pictures, ornaments).

May need to avoid emotional warmth. Support in neutral vocal tones and non verbal body language. Avoid eye contact and sometimes use of personal name/s.

Monitor for heightened sensitivity, intervene early and redirect to well rehearsed calming strategies and or model ways to calm: e.g., breathing; mirror emotional expression initially then model reduction in excited emotional tone: e.g., Client: "ah ah ah ah...." Care provider: "ah ah ah ah...." Do not hype up.

Provide pressure to body parts: e.g., use sports pressure clothing, weights, back packs, bean bag presses. Use outdoors activities: e.g., swing, seesaws, roundabouts, climbing walls, trampoline vibration to increase body awareness. Use visual charts for start, stop, etc. Sensory Integration Therapy may help.

Cut down on verbal language; work through concepts that have meaning for the brain: i.e., are part of their behavioural repertoire; present concepts visually (easier to process than verbal) and as objects and movements as rhythms; engage in "visual conversations" (drawing on paper the conversation); use visual stories and Books Beyond Words (Hollins, 1989-2012) to assist memory, understanding, response and shared engagement; use ipads to transmit information; present choices visually and in the here and now; predict, prepare, plan, on-going work book to assist understanding of past, present, future; visual calendars to assist in daily program.

\* See also Woodcock &amp; Page, 2010)

Note: Each individual has a different and unique profile A-E

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Table 2. *Stress and Anxiety in Autism* (continued)*Stress contributes to anxiety**Stress is associated with:***D: Emotional overload and emotional regulation**

Arousal – measure pulse rate at the most “relaxed” and most “anxious” time of day, each day for one week

**E: Executive functioning difficulties (organising muscular control to carry out movements) and capacity to initiate***Strategies to reduce stress and resultant anxiety\**

Engage with neutral emotional stance: e.g., reduce or use no eye contact or focus to the side of the head rather than directly at the face; be aware that usual greeting behaviour may be over stimulating and painful. Be prepared to de-escalate heightened emotional response through own behaviour and modelling (e.g., breathing, speed of body movements, tone of voice). An Intensive Interaction approach (Caldwell, this volume) is uniquely suited to emotional engagement and should be used routinely with those with autism prone to distress behaviours.

Consider a trial of  $\beta$  blocker for sustained high arousal.

Break actions down into smaller steps; prompt (visual, gestures); model the action/expectation; lower arousal and anxiety by prompting individual into well rehearsed strategies for same. “Accommodations” (Donnellan & Leary, 1995) include the use of gesture, touch, rhythm, behaviour rituals, sequences, changing aspects of tasks, visualization, music. Other strategies to assist in moving forward and not getting “stuck” include carrying heavy object relevant to destination.

\* See also Woodcock & Page, 2010)

Note: Each individual has a different and unique profile A–E

## Concluding Remarks

PAVE, the approach described in this article can be adopted not only by clinicians and front line workers who interact with people with autism, but also by family members and friends of those who are affected. Essentially it views the world from the perspective of the person with autism, rather than imposing our non-autism frame of reference; Autobiographical accounts of people with autism are invaluable in these regards (several included in the references at the end) and further resources are offered in the Reference Section and in Tables 1-3 with links to on line resources. We can perhaps learn most from the people with whom we work and hopefully the strategies offered here will enhance this engagement with clients. These approaches also enable better communication and rapport with persons affected by other types of intellectual and/or developmental disabilities.

## Key Messages From This Article

**People with disabilities:** “The world of an autistic person is not stagnant .... It is a deeply sensory world” (p. 17). “All things coming from the outside must be gentle, sometimes devoid of emotion so as not to overwhelm” (p. 21). Quotes from O’Neill, 1998.

**Careproviders:** “We have to give up our conventional non-autistic assumptions and let them teach us how their SPATS (Senses, Perceptions, Abilities and Thinking Systems) work in order to build bridges between the two worlds. Our approach should be to listen to autistic individuals who are willing to communicate and explain how they experience the world and not to assume that only our views are right because we are specialists/parents” (Bogdashina, Unknown).

Table 3. *Developing a Coherent Sense of Self and Others*

<p>(a) <i>Promoting a coherent sense of self through a coherent experience of the physical environment and daily program of activities</i></p> <ul style="list-style-type: none"> <li>• Care providers work to provide           <ul style="list-style-type: none"> <li>- familiarity</li> <li>- structure</li> <li>- routines</li> <li>- predict, plan, prevent: anticipate unfamiliar circumstances and events and prepare individual</li> <li>- preparation around transitions</li> <li>- reliable and predictable supports</li> <li>- visual representation of daily activities</li> <li>- social stories</li> </ul> </li> <li>• Involvement of individual in ways they understand best (e.g., visual over verbal especially when stressed)           <ul style="list-style-type: none"> <li>-building activities and engagement around their special interests: e.g., if an interest in trains find ways to teach activities of daily living and academics through trains,</li> <li>-using memory prompts especially when individual is stressed: e.g., have available portable visuals to refer to.</li> </ul> </li> </ul>	<p>(b) <i>Promoting a coherent sense of self through body awareness and relationships</i></p> <ul style="list-style-type: none"> <li>• Support sensory integration to provide powerful proprioceptive stimuli to help the individual to develop body awareness and a sense of their physical boundaries. To assist them in “understanding what they are doing when this is in deficit” (Caldwell et al., 2009).</li> <li>• Use body language to communicate (e.g., Intensive Interaction), the aim being to establish emotional engagement. Not “copying” but responding; all initiatives are valued and confirmed.</li> <li>• Validate negative affect (accepting and confirming how the individual “feels,” no matter how expressed). [e.g., Client: “I want to hurt (name),” Care provider “yes you want to hurt me”].</li> <li>• Work “through” behaviour to facilitate emotional engagement rather than trying to eliminate these behaviours.</li> <li>• Assist communication through empathic use of non-verbal behaviours (e.g., Intensive Interaction); reduce auditory in favour of visual communication (e.g., Books Beyond Words Bradley &amp; Hollins; this volume); where appropriate use visual aids [e.g., PECS (Bondy &amp; Frost, 2011; Rehfeldt &amp; Root, 2005)].</li> <li>• Help to reduce current and anticipated anxiety (e.g., quiet environment, social stories, well rehearsed anxiety management strategies, strategies to self soothe).</li> </ul>
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*(continued on following page)*

Table 3. *Developing a Coherent Sense of Self and Others* (continued)(c) *Different perspectives*

- The non-autism perspective may not represent the experience of the individual with autism and may lead to errors in understanding their motivations and behaviours.
- Explore “odd” or “difficult to manage” behaviours to better understand from an Inside-Out perspective needs giving rise to these behaviours of concern.
- Recognize that processing problems and distortions may give rise to memory problems or apparent absence of object constancy: e.g., care providers may not be recognised by body appearance but by the clothes or glasses they are wearing or the tone of voice.
- Sensory hypersensitivities to characteristics of care providers can give rise to inconsistent engagement: e.g., patterned design of clothes causing visual discomfort; perfumes and body odours giving rise to nausea.
- Behaviours perceived as maladaptive may be coping strategies seeking to maintain coherence in a sensory distorted world and defences against tipping into the autonomic storm (e.g., Gunilla Gerland holding onto fence in response to noise of motor bikes; page) (Gerland, 2003).
- Behaviours that may appear uncooperative or provocative to us are not intentional: e.g., clumsiness or “refusal” to move may be associated with difficulties with executive function and capacity to initiate.
- “Out of the blue” behaviour may represent long delay responses to a prior trigger (Bogdashina (n.d.)).

(d) *Empowering individuals with self management strategies and building self esteem: some suggestions*

- Provide support in building communication capacity (Bogdashina, 2005).
- Work with individual to develop specific stress reduction strategies: e.g., relaxation strategies; a variety are available.  
See [http://www.child-youth-health.net/en/child-youth-health/MindMasters\\_p280.html](http://www.child-youth-health.net/en/child-youth-health/MindMasters_p280.html)  
<http://www.energyconnectiontherapies.com/>  
David Wexler: PRISM (Wexler, 1991)
- Develop with individual well rehearsed redirection strategies to alternative preferred activities.
- Support regular physical activities that include deep pressure and joint compression: e.g., swimming, walking, trampolining, swinging.
- Assist individuals to develop activities related to special interests that would be valued in the work place: e.g., assist an individual who loves to vacuum clean to provide this as a service (Eagle, 2007; Grandin & Duffy, 2008); or, assist them to take part in recreational activities (e.g., Special Olympics for physical activities).

**Professionals:** Understanding the experience of those with autism will offer opportunities to provide optimal supportive environments and these in turn will work to decrease behaviours that characterize their distress.

**Policymakers:** “Autistic people do not fit into the moulds of society. This fact is not an excuse for the poor treatment so many of them receive” (O’Neill, 1998, p. 66).

## Acknowledgements

To Marika Korossy, Librarian at Surrey Place Centre, for her enduring, creative and scholarly assistance. Please direct written correspondence to either of the authors:

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