Jessica Matthews

In this article I hope to describe how Dr Stephen Porges’s theory of Neuroception has helped us, as Parents, to develop greater insight into what might be happening for our Autistic son when he is faced with “demands”. This will provide a context for my hypothesis that:

**Highly sensitive Neuroception may be at the heart of PDA**

This exploration will also cover the known and lesser known survival responses, which I refer to as the **Five Fs: Freeze, Flight, Fight, Fright and**

**Fawn.**

When PDA is diagnosed, it is specified as a profile on the Autistic Spectrum, a shift in classification which Newson initiated in an inaugural lecture in 1990 (Newson, 1990). There is still variance in recognition throughout the UK and in the wording used by different clinicians.  Some clinicians will name ASD with Extreme Demand Avoidance, others refer to Pathological Demand Avoidance: A Profile of Autism, whilst some remain true to Elizabeth Newson’s original wording and retain the word “syndrome” at the end of PDA.  The following links contain clarity in respect of the key diagnostic features:

<https://pdaguidance.wordpress.com/pda-diagnostic-criteria/>  
  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4820467/>

REPORT THIS AD

REPORT THIS AD

Since suspecting that our son was on the Autistic spectrum, I have been passionately researching about Autism. It became apparent to me very early on that understanding the central nervous system was likely to be fundamental to understanding our son.  In 2017 a specialist, independent OT helped us to think about the role of the central nervous system in relation to William’s gross motor delay and his sensory modulation difficulties.  Since then, my curiosity about the role of the central nervous system in Autistic people, has led me to read some really interesting research and to then consider this, more specifically, in relation to Pathological Demand Avoidance.

“Demands” in the context of PDA can mean anything from showering, getting dressed, using a pencil, making a choice, to going somewhere or doing something of interest.  We see in William that even the most innocuous of demands, direct and indirect can be challenging.

As apparent as William’s extreme avoidance of every day demands is, it is even more evident that he is triggered into “survival” mode; whenever the environmental conditions challenge his highly sensitive nervous system and whenever our, or other people’s responses to him deviate from being entirely calm and demand free. All of this is further impacted by his sensory modulation difficulties and auditory hypersensitivity.

REPORT THIS AD

REPORT THIS AD

Prior to being diagnosed as autistic, at 2 years old, William’s Consultant Neurologist diagnosed Congenital Central Hypotonia and Hypermobility, with some Stereotypies. When the Neurologist discussed William’s diagnoses with us he explained that “central” referred to the brain and that in some children like William, their MRIs showed delayed myelination. With this in mind, I became increasingly curious about how his central nervous system might also be involved in his highly sensitive and frequently fearful responses to objectively, non threatening stimuli, such as everyday demands.  These fearful responses also include more predictably challenging stimuli such as; deep laughs, thunder and certain tones of voice. Porges refers to these as “lower pitch sounds” which the s*ensitive*nervous system is *more likely*to be biased towards “in order to detect the movements of a predator”. (Porges, 2017)

Extremely high levels of anxiety associated with Autism and in particular the PDA profile of Autism, can present as “bouncing” from one extreme behaviour to another. This is frequently referred to as “lability of mood” and also “challenging behaviour”. In many settings the child themselves, the parenting, or both are blamed. However, what is observable is only a small part of the picture and much needed clarity and understanding can be found in the literature on Neuroception.

**NEUROCEPTION IS HOW OUR NEURAL CIRCUITS DISTINGUISH WHETHER SITUATIONS OR PEOPLE ARE SAFE, DANGEROUS, OR LIFE THREATENING. IF OUR NEURAL CIRCUITS PERCEIVE A THREAT; THE PRINCIPAL HUMAN DEFENCE STRATEGIES ARE TRIGGERED. (PORGES, 2014)**

REPORT THIS AD

  
  
The term Neuroception and its history of origin provides a fascinating story that struck me as being directly relevant to PDA.  Stephen Porges, who coined the phrase Neuroception, writes about his own personal experience of it’s powerful impact when his body’s response to an MRI was incompatible with his cognitive desire to experience one. As a scientist and academic, he was so interested to experience the process of an MRI scan, yet he became unable to do so because his Neuroception triggered the flight response.

**“I WANTED TO HAVE THE MRI. I WASN’T SCARED. IT WASN’T DANGEROUS. BUT SOMETHING HAPPENED TO MY BODY WHEN I ENTERED THE MRI. THERE WERE CERTAIN CUES THAT MY NERVOUS SYSTEM WAS DETECTING, AND THOSE CUES TRIGGERED A DEFENSIVENESS – WANTING ME TO MOBILIZE, TO GET OUT OF THERE.” (PORGES, 2017***)*

REPORT THIS AD

Neuroception evaluates risk in the environment without awareness. Perception is a conscious and aware process of evaluating or detecting risk. The difference between the two is crucial to understand, as it links directly to the question of intentionality and behavioural control.

**“WHEN WE ENCOUNTER CHALLENGING BEHAVIORS IN A CHILD, THE FIRST QUESTION TO ASK IS: IS THE BEHAVIOR’S ETIOLOGY TOP DOWN OR BOTTOM UP? … I CAME TO UNDERSTAND THE IMPORTANCE OF … CONSIDERING THE CHILD’S REFLEXIVE RESPONSES TO PERCEIVED THREAT … AS I WAS FORTUNATE ENOUGH TO LEARN ABOUT DR PORGES’S WORK” (DELAHOOKE, M. 2019)**

Because Neuroception is a neural, rather than cognitive process; when the nervous system detects threats, it does so unconsciously; *“triggering the body to engage defensively”* (Porges, 2017).This means that when triggered to mobilize (flight or fight) or immobilize (freeze or fright), the body is not *choosing* to react as it does, rather it is *compelled* to do so for its very survival. This ‘override’ occurs even if the escaped or avoided stimuli or event, is something that the person wants to do.

REPORT THIS AD

REPORT THIS AD

Understanding this neural process for the first time was a huge light bulb moment for me. Porges’s theory inadvertently, further explains the “Can’t – Help – Wont” aspect of PDA; a phrase coined by Jane Sherwin (2015). It explains the neural process which drives a person to avoid or escape threatening stimuli, which in the case of PDA is everyday demands. Porges explains how even when the desire to do something is present, the ability to do so can be powerfully overthrown by the process of Neuroception. So, in the case of an individual with PDA, we can begin to conceptualize how, when the nervous system detects threat and danger within “demands”; a survival response is triggered, facilitating a form of escape or avoidance. This may explain both the neural process and the lack of behavioural control in the “*can’t help won’t”*explanation, or perhaps more accurately; *“can’t help can’t.”*

Freeze, Flight and Fight are the three principle human defence strategies that Dr Porges refers to (2014) and Barach at al (2014) explore a fourth known as “Fright”.   
  
There is a fifth survival response that is less well documented. This **Fifth F** is known as Fawn, a term first introduced by Pete Walker. Understanding why the Fawn response is triggered and how it presents could help us to understand why some of our children’s needs remain unrecognised and unsupported for detrimental periods of time.

REPORT THIS AD

REPORT THIS AD

It may be useful to explore the first four survival responses in order, with reference to the “sequence” originally set out by Gray (1988, 2003) before finally and separately exploring the Fifth F; Fawn.

1. The survival response **Freeze** is triggered when the person’s fear response to a perceived threat, takes them into a shutdown state. This can include being u*nable* to respond to those around you, “staring” at the iPad or TV or into space in what looks like a daydream state.  It can also include falling asleep outside of normal routine, something William does when he has been overloaded with sensory, social and everyday demands.  The easily overlooked and misunderstood freeze responses, which are characteristic of a person who is feeling traumatised and overloaded, can render a child’s difficulties invisible, especially in the busy context of school.   The freeze response can also be understood as the internal process known as dissociation.  Dissociation becomes necessary in order to escape and protect the self from perceived danger.  Freeze is also referred to by clinicians as “hypervigilance (being on guard, watchful, alert)… associated with fear.  (Bracha, 2004).

For some with the PDA profile of Autism, perceived danger, or a Neuroception of threat, is almost constant in environments where everyday demands are everywhere and complex social and sensory information is overwhelming.

**2**. The survival response **Flight** is triggered when a person responds to a perceived threat with an intense urge to flee. This flight can be literal; running away, or it can be more subtle and symbolic. An example of the latter would be when the person suddenly absorbs themselves in an activity that they are passionate about; in order to feel distanced from the perceived threat.

REPORT THIS AD

REPORT THIS AD

**3**. The survival response **Fight**istriggered when a person responds aggressively to a stimuli that is frightening to them.  This survival response overrides the individual’s connection with others and the fight responses are triggered unconsciously and unintentionally.   
  
Once the nervous system has calmed; feelings of shame and regret are likely to be profound, regardless of the person’s ability to verbalize these feelings”. (Newbold, 2014)

**4.**The survival response **Fright**is triggered when a person becomes completely immobilized.  As with all survival responses, immobilization is not a chosen response, rather it is a response triggered unconsciously by the neuroceptive system to safeguard.  This immobility is a**“RESPONSE OF LAST RESORT TO INESCAPABLE THREAT”**(Kozlowska et al, 2015)

**5**. The fifth F: **Fawn** (Walker, 2013) is largely unrecognised. This survival response occurs as a result of prolonged high stress situations. When the fawn response is triggered, we may observe an uncharacteristic mode of “people pleasing” or deferring to the needs and wishes of others, whilst surrendering one’s own.  Fawn is a survival response that can be triggered when a person feels at risk from the people or environment they are in  (Bal, 2009).  For example, if I am overwhelmed by something in the environment, or by the people around me my Neuroception may trigger the fawn response “which leads to compliance in order to avoid conflict” (Bal, 2009).  Uncertainty and a lack of being able to predict whether a person or group of people may become angry if we fail to please them, is something we all weigh up. But for a person who is experiencing a Neuroception of danger, aggravated by poorly developed skills in reading facial expressions, “prosody of voice” (Porges, 2017) and the many complex nuances involved in social interactions; the fawn response may be triggered to protect the self from the perceived harm of an unknown response.

REPORT THIS AD

REPORT THIS AD

**The 5 Fs**; and the very different ways in which they present, means that those with highly sensitive Neuroception or as Porges defines it; “faulty neuroception”, may present very differently in different contexts and with different people.  I have replaced Porges’s term “faulty” with “highly sensitive” as I believe that this is about a different, rather than faulty neural process.  I embrace the science of Neurological theory, but believe in the importance of avoiding “medical model” terms; such as faulty or disordered, when we can replace these with more respectful and accepting references to “difference”.  The amended wording does not alter the theory; simply the way it may be experienced by those to whom it relates.  It also does not take away from the impact of having a highly sensitive neuroception; it is possible to validate the difficulties that difference creates for the person and their loved ones, without describing something inside of a person as faulty or disordered.  
  
The fawn response is much less likely to be triggered in an environment where the person feels safe; with a person who is well known to them. If as part of a trusting relationship, kind and gentle responses are the norm, then that person is established as predictable.  “Our nervous systems like predictable” (Porges, 2017) predictable is safe.  In safe relationships the Fawn response is much less likely to be triggered. In less well known relationships or contexts such as school or hospital, the “Fawn” response is more likely to be triggered to avoid conflict and to maintain feelings of safety until back in the refuge of home.  When a neurception of threat is detected at home with those safe adults; one of the first four survival responses are more likely to be triggered.  In relation to PDA this may translate as demands being followed for some of the time for some people in these lesser known and more difficult to predict contexts.   When the PDAer follows some demands for some people, some of the time, it can be very confusing to those around them.  These changeable responses are actually very adaptive though and do make sense when considered within the context of a Neuroception of threat.  I view this theory as one that would sit, supportively, alongside the literature on masking.

REPORT THIS AD

REPORT THIS AD

I am not suggesting that PDA is a linear process of demand = immediately triggered survival response.  PDA is much more sophisticated and complex than that.  I am suggesting that one of the Five Fs are triggered as a result of a Neuroception of threat if and when “first line of defence strategies” have failed.  William uses many of the “first-line strategies” that Jane Sherwin describes in her book including:

**“IGNORING IS A FAMILIAR FIRST LINE OF DEFENCE TO AVOID IMMEDIATE COMPLIANCE. IT IS AS IF IGNORING GIVES … BREATHING SPACE … OR SHE MAY SIMPLY NEED TIME TO PROCESS THE REQUEST AND COMPLY, ONCE SHE FEELS THAT THE INITIAL DEMAND HAS BEEN DILUTED BY TIME.**

**SWITCHING TO A DIFFERENT TOPIC IN ORDER TO DISTRACT FROM MY INITIAL REQUEST IS ALSO A COMMON STRATEGY … OR SHE MAY PROMISE ‘WHEN I’VE FINISHED THIS’ OR OFFER A LIST OF IMAGINARY REASONS WHY NOT”.  (SHERWIN, 2015)**

It is once these more social strategies have failed that I see William become triggered into a Neuroception of threat.  At this point I expect and prepare to respond calmly as one of the Five Fs is triggered.  Our aim is always to provide conditions that will help disengage William’s Neuroception of threat and help him return to a Neuroception of safety.

REPORT THIS AD

REPORT THIS AD

All of Porges’s work has implications for the kinds of conditions those with a highly sensitive neuroception need; in order to “achieve a neuroception of safety”.  Applying the guiding principles of neuroception, has the potential to lead to much deeper levels of understanding of PDA and therefore more therapeutic responses from caregivers.  
  
There is a link here between the guiding principles of Neuroception and the exciting and pioneering work of Raelene Dundon, a Clinical Psychologist who looks at PDA through a trauma informed lens.  I am not aware of anyone in the UK who is working therapeutically with people who present with the PDA profile of Autism in the way Raelene is, but would be very excited to hear from, or about, anyone who is.

**“I SHOULD CLARIFY THAT I AM NOT SAYING THAT PDA IS CAUSED BY TRAUMA – I BELIEVE THE CURRENT VIEW THAT PDA IS A PROFILE OF BEHAVIOUR THAT PRESENTS AS PART OF AN AUTISM SPECTRUM DISORDER. HOWEVER, WHAT I AM SAYING IS THAT THE REACTION AN INDIVIDUAL HAS TO A DEMAND IS SIMILAR TO A TRAUMA RESPONSE.” (DUNDON, 2018)**

REPORT THIS AD

I also believe, and see in William, that his most extreme responses to demands are similar to a trauma response.  The Five Fs are all responses that someone who is or has experienced trauma may have; they are responses that help protect the self from the trauma in a given situation.  If we consider PDA in these terms, we may find it easier to respond to extreme demand avoidance with the essential calm and gentle approach required.  When we hold safe space for a person, it is poossible for them to return to it more quickly, rather than if we join them in their triggered space; their neuroception of threat.

**“WHEN NEUROCEPTION TELLS US THAT AN ENVIRONMENT IS SAFE AND THAT THE PEOPLE IN THIS ENVIRONMENT ARE TRUSTWORTHY, OUR MECHANISMS OF DEFENSE ARE DISENABLED. WE CAN THEN BEHAVE IN WAYS THAT ENCOURAGE SOCIAL ENGAGEMENT AND POSITIVE ATTACHMENT.” (PORGES, 2014)**

Doing this is never easy, we still struggle everyday.  But what we have found is that increasing our insight has increased our ability to authentically empathise and this has enhanced our ability to offer William the responses and environment that he needs and deserves.  Porges’s Theory of Neuroception has also helped us to consider in more detail; the conditions we need to ensure William has beyond the home environment too, in particular the essential and non negotiable conditions that he will need in his individualised education plan.

REPORT THIS AD

REPORT THIS AD

**“WITH THAT KNOWLEDGE, WE NEED TO STRUCTURE SETTINGS TO REMOVE SENSORY CUES THAT TRIGGER A NEUROCEPTION OF DANGER AND LIFE THREAT. THE REMOVAL OF LOW FREQUENCY SOUNDS WOULD BE A GOOD START *(as well as)* CREAT*(ing)* “SAFE ZONES” THAT TRIGGER THROUGH NEUROCEPTION A PHYSIOLOGICAL STATE OF SAFETY” (PORGES, 2017)**

Understanding and applying the principles of Porges’s work to Educational and Clinical settings, in relation to PDA, could help shape crucial support and accommodations for this vulnerable group. There are exciting, empowering and hopeful messages within Porges’s work and it has great utility in terms of understanding the requisite conditions required for PDAers to feel safe enough to thrive.

I would love to hear your thoughts and feedback on the themes raised in this blog here or over on our Facebook Page  
  
<https://www.facebook.com/ChangingTheNarrativeAboutAutismAndPDA/>

REPORT THIS AD

**References**

Bal, R.  “Fight Flight Freeze Fawn Responses And The Pitfalls Of Empathy” Resolving Trauma and PTSD  (2019)

Bracha, S. Williams, A. E. & Bracha, A. S.  “Does ‘Fight or Flight’ Need Updating?”  Psychosomatics 45, No. 5 (2004)

Delahooke, M. *Beyond Behaviors: Using Brain Science and Compassion to Understand and Solve Children’s Behavioral Challenges.*PESI Publishing and Media, 2019

Kozlowska, K. Walker, P. & Carrive, M.   “Fear and the Defense Cascade: Clinical Implications and Management.” Harv Rev Psychiatry. 23, no. 4 (2015) 263–287

Newbold, Y.  *The Special Parents Handbook.*Amity Books, 2014

Newson, E. (1990) *Pathological Demand Avoidance Syndrome: Mapping a New Entity Related to Autism?*Inaugural lecture, University of Nottingham

Porges, Stephen W. “Neuroception: A Subconscious System for Detecting Threats and Safety.” ZERO TO THREE 24, no. 5 (2004) 19-24

Porges, Stephen W. *The Pocket Guide to The Polyvagal Theory: The Transformative Power of Feeling Safe.*New York: W.W. Norton, 2017

Sherwin, Jane A. *Pathological Demand Avoidance Syndrome: My Daughter Is Not Naughty.*London: Jessica Kingsley Publishers, 2015  
  
Walker, Pete.  *Complex PTSD: From Surviving To Thriving.*CreateSpace Independent Publishing Platform, 2013

Sherwin, Jane A. *Pathological Demand Avoidance Syndrome: My Daughter Is Not Naughty. (*2015)London: Jessica Kingsley Publishers,