

# PDA DAY

## THIS YEARS THEME IS SUPPORT

### SUPPORT

Much of the support available to Autistic children remains entrenched in outdated knowledge, training and behavioural interventions. Children and young people described as having the PDA profile of Autism, are one of the most adversely affected groups when it comes to being in environments that instill behavioural approaches. Children's strong responses in such settings are reflective of the systemic changes that are needed.

An emerging paradigm, informed by neuroscience, up to date psychological research and Autistic insights into Autistic identity, is deeply encouraging and long overdue. Whilst this new paradigm is in sight, the lengthy timescales before it will affect operational changes in our health, care and education systems, can feel heartbreaking, as many Autistic children wait to be appropriately supported and understood.

In education; assessments, advice and support from Clinical and Educational Psychologists, Occupational Therapists and Speech and Language Therapists do help to inform children's education and support plans (EHCPs / IEPs). Specialist OTs who are also accredited Sensory Integration Practitioners, can provide much needed sensory assessments and recommendations about the kinds of activities needed to help support Autistic children's sensory nervous systems. As Parents, we have found these assessments to be really helpful in increasing our understanding of our son and in helping us to make decisions around support and provision.

In our area, we have found considerable disparity between a paradigm in which our son's emotional well-being and needs would be understood and prioritised, and the current choice of provision available to him. There is so much work to be done before the necessary changes are actualised. As parents, we've had to challenge many of our own beliefs, values and approaches, which were informed by the way we were raised and educated as children. As a result, we appreciate how complex this shift in thinking and approach is. We are also deeply aware of how urgently change is needed though, in order to prevent more Autistic children becoming Autistic adults with trauma and poor mental health.

The following represents an overview of some of the components of support that are helpful in PDA, within a much wider context of change:

## Support Starts with Understanding

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PAGE: CHANGING THE NARRATIVE  
ABOUT AUTISM AND PDA

### PDA And Support

**S** Sensory Diet and Breaks  
**U** Understanding  
**P** Personal Power  
**P** Positive Communication  
**O** Open Opportunities  
**R** Relational Safety  
**T** Trust

This article does not have the scope to be comprehensive, but it outlines some important considerations.

### Sensory Diet & Breaks

We all have 8 sensory processing systems: Visual, Auditory, Olfactory (smell), Gustatory (taste), Tactile, Vestibular (sense of head movement in space), Proprioceptive (sensations from muscles and joints of body) and Interoceptive (sensations from the physiological/physical condition of the body).

Understanding how our children process the world through their senses is a critical insight to gain as a parent. It is also so important for us to support our children to develop their self-awareness around sensory and somatic experiences. This needs to include support and activities that explore how we develop our interoceptive awareness too. In a comprehensive sensory assessment, a **sensory diet** (the plan needed) to best support the child's sensory nervous system would look at all of this.

There are also some really helpful resources on the STAR website. <https://www.spdstar.org/>

Offering support in a way that is helpful, can feel like walking a tight rope at times. Gaining a deeper understanding of PDA and how it presents in your child or the individual you support, is a critical starting point.

### Understanding

Professor Elizabeth Newson proposed the term Pathological Demand Avoidance (PDA) in the 1980s, in relation to a group of children described as having "an obsessive resistance to everyday demands and requests". Newson and colleagues, proposed 8 'defining criteria for diagnosing PDA' in their 2003 paper. Since then, narratives around PDA have been challenged, revised and updated. There are lots of different perspectives on what PDA is. The way we understand and talk about PDA significantly affects the approach we take. Here is a snapshot of some of the published insights into PDA:

"An anxiety driven need to be in control and avoid demands and expectations" (Christie et al, 2012).

"A difference in the part of the brain responsible for recognising and reacting to danger (the amygdala). For PDAers this part of the brain is overactive" (Riko, R. 2017).

"PDA for me is that I want to, but can't. I need to, but can't" (Daunt, J. 2018). "The individual's refusal to relinquish their freedom under any circumstances" (Thompson, H. 2019).

"Some people prefer to use the term 'Extreme' to describe demand avoidance, but again this is not without its challenges. What exactly qualifies as 'Extreme'?" (Eaton, J. 2019)

"Highly sensitive neuroception may be at the heart of PDA" (Matthews, J. 2019).

"A pervasive drive for control, autonomy and freedom" (Wilding, E. 2019).

"A relationship with anxiety and IU [intolerance of uncertainty]" (Stuart et al, 2019).

"PDA is classed as an Autism spectrum condition and entails an automatic drive to avoid all things we feel we should or must do" (Sally Cat, 2020).

"The part of my brain that receives information from the environment and assesses threat translates more of my environment as a threat than the average person. The amygdala in a PDA autistic brain doesn't know the difference between excitement and threat" (Forbes, K. 2020).

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## REFLECTIONS

### *PDA Through A Polyvagal Lens*

#### PDA DAY MAY 15<sup>TH</sup> 2020

A blend of all of these author's rich narratives have informed my current understanding of PDA.

I have also found it helpful to consider PDA through a Polyvagal lens. A Polyvagal Informed understanding of PDA would consider that:

**Via neuroception, demands are 'coded' as threats.**

**PDA is a protective response system, influenced by the way in which the Autistic nervous system is shaped, in some Autistic people.**

**Being PDA is a way of being, that defends the individual's need for autonomy and freedom.**

**The need to retain autonomy, control and freedom is synonymous with having an anchor to safety. When safety is lost, the person is afloat and the PDA individual is submerged by threat and fear".**

The PDA individual embodies and protects their autonomy, regardless of external factors or hierarchies. For the PDA individual, protecting one's sense of autonomy and freedom, is intrinsic to maintaining emotional well-being. The individual with PDA is not characterised by their response system, (although events in their life may often be shaped by it) but rather by their strengths and unrelenting need for autonomy.

**PDA individuals' strengths** commonly include; creativity, passion, ingenuity, high standards, imagination, integrity, humour, word play, fantasy / role play, intuition, finely tuned neuroception, strong leadership skills, personal power, determination, a drive to support and help others and what I would describe as unique and engaging personas and presence or put more simply, charisma.

#### Personal Power

Acquisition of personal power is an important part of healthy development. The foundation of personal power is a sense of confidence and competence that individuals gradually acquire as they develop. Personal power incorporates self-assertion and a natural

healthy striving for meaning in one's interpersonal world. Facilitating and supporting a PDA child's acquisition of personal power, requires parents to; **empower the child's agency and respect their exceptionally strong need for freedom.**

Facilitating the PDA child's natural curiosity to learn, lead, follow their own instincts and trust their own decisions, is central to supporting their emotional well-being.

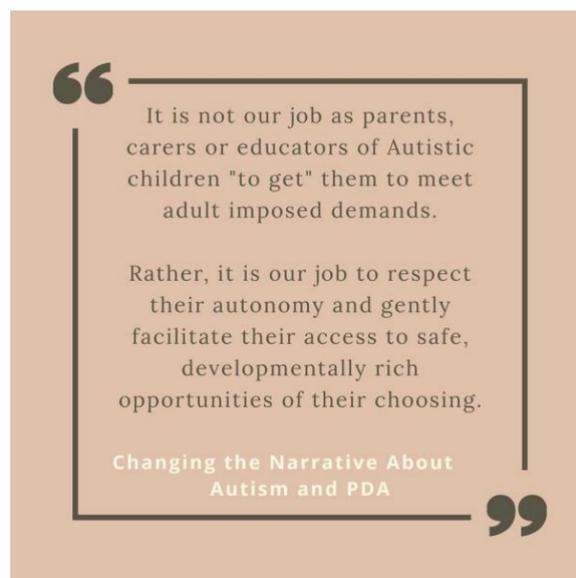
**"Personal power is more of an attitude or state of mind than an attempt to manoeuvre or control others. It is based on competence, vision, positive personal qualities, and service. When externalized it is likely to be more generous, creative and humane than other forms of power" (Firestone 2009).**

#### Positive Communication

The language we use is critical. The use of non-threatening and non-instructional language is a great starting point. It is crucial that the language we use also reflects our authentic meaning. Carefully choosing words in order "to get" something to happen, will be detected and will nearly always have the opposite effect.

For more information on PDA and language, there are numerous articles on this topic which are helpful to read. You can find links to all of these on the PDA Society Facebook page and my article on PDA and Language can be found on my page.

#### Open Opportunities



Indeed, instead of asking; "How can I get my child to do X?", we can support our children's well-being by asking instead; "How can I understand my child's *perception* of X?". By shifting our focus, we can be more curious about the different ways we can support our children's individual needs.

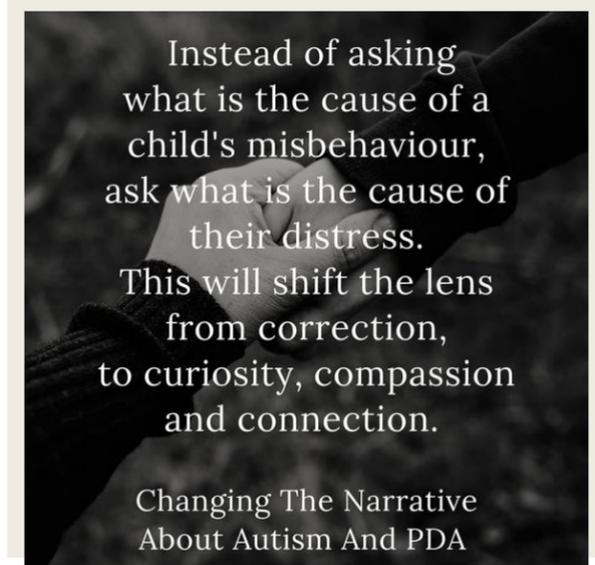
#### Relational Safety

Central to the PDA individual's sense of safety is their need to be free. We can support and respect their need for autonomy across all of our interactions by maintaining equality and by being a safe and consistent presence.

Some of our most powerful communication happens at a neural level and this is where finely tuned neuroception supports how safe or unsafe a child feels with us. Because of this it is important that we communicate authentically and with an awareness of *how we are* and *what we bring with us*. These factors all inform the co-regulatory support we offer children and how safe they feel with us.

#### Trust

Authentic communication is also a central component of trust, which must be established before any support can be effective. Children learn whether or not adults are trustworthy using their internal assessment system, which is based on factors such as fairness, respect and *how they feel* around us. Crucial in this is how we respond when children are distressed.



For more information you can follow me on Facebook @ Changing the Narrative About Autism and PDA.

