

# Parental Evaluation of Educational Provision for Children with Pathological Demand Avoidance (PDA): A Qualitative Study

“A dissertation presented in partial fulfilment of the requirements for the degree of MEd in Education at the School of Education, University of Aberdeen’

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**Date: 19<sup>th</sup> September 2023**

**Word count: 16,500 words**

“I declare that this dissertation has been composed by myself, that it has not been accepted in any previous application for a degree, that the work of which it is a record has been done by myself, and that all quotations have been distinguished appropriately and the source of information specifically acknowledged.’

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## Abstract

Pathological demand avoidance (PDA) is a term first coined in 1983 to describe a pattern of behaviour observed in some autistic individuals. PDA is a condition characterised by an extreme avoidance of everyday demands and expectations, leading to a wide range of difficulties in social communication, interaction, and relationships. In educational environments, these difficulties manifest as inability to follow instructions, complete tasks, attend classes or communicate effectively with peers and teachers. PDA Children often exhibit challenging behaviours, including arguing, negotiating, withdrawing, and displaying aggressive or violent outbursts in response to perceived demands. These behaviours can lead to disruptions in the classroom, disrupt learning for other learners, and cause significant stress and anxiety for both learners and teachers.

This study explores how PDA children engage with learning. Firstly, it examines the literature, which suggests that PDA may be better conceptualised as rational demand avoidance and exploring alternative explanations for demand-avoidant behaviours. Secondly, the experiences PDA learners within the education system, as seen through the perspective of their caregivers, is explored. Finally, the study emphasises the importance of a coordinated and collaborative approach that addresses individual needs incorporating practices that affirm neurodivergent individuals, such as a flexible curriculum, sensory accommodations, and proactive communication strategies to accommodate diverse learning styles, while fostering a supportive and inclusive classroom environment.

While research on the causation and correlation of PDA with other conditions is limited, it is important to recognise and identify this condition. By creating supportive and inclusive educational settings, tailored approaches can be implemented for PDA learners to help them reach their full potential. Therefore educators, parents, and caregivers must acknowledge and address the impact of PDA on a child's learning process through suitable interventions that promote academic and social success.

**Keywords:** Autism, Pathological Demand Avoidance, Extreme Demand Avoidance, PDA, Parent Blame, Education

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## Chapter 1: Introduction

Pathological Demand Avoidance (PDA) is a condition that results in anxious avoidance of everyday requests.

**‘Pathological’** means demand-avoidant behaviour that is extremely debilitating for a child or young person:

*“Actions are completely out of the control of the individual; they are not being wilful or rude. Nor can it be regarded as a power game or being naughty. For the person concerned a request (demand) is likely to produce a level of anxiety that is beyond anything the rest of us can even begin to imagine”* (Pritchard, 2017).

**‘Demand’** means any demand: direct, indirect, implied, or consequential. Even internal demands such as: *“I ought to”* are included (Pritchard, 2017). **Avoidance** means that the individual will not be able to do what is asked of them. It is not that they do not want to; they cannot (Pritchard, 2017).

Nearly two decades ago, Newson, (1988) discovered a distinct subgroup of children with a diagnosis of Autism Spectrum Condition (ASC) who appeared to differ from the stereotypical autistic presentation through their anxiety-driven avoidance of demands. These observations served as the foundation for PDA, which is characterised by the persistent avoidance of the ordinary demands of life (Christie, 2007; O’Nions et al, 2016).

My personal connection to PDA is rooted in my child’s diagnosis. For four years, I have been on an extensive research journey aimed at ensuring my child’s support needs are adequately accommodated. It is my aspiration that further research will enable me to contribute valuable insights to professionals working with children with a PDA profile.

### 1.1 Identifying PDA

The distinguishing characteristics of PDA include resisting and avoiding the ordinary demands of life, using social strategies as part of the avoidance, such as diverting attention or



giving excuses, appearing sociable but lacking some understanding, experiencing excessive mood swings and impulsivity, appearing comfortable in role play and fantasy, and obsessive behaviour focused on people (O’Nions et al., 2013). In the Faroe Islands, Gillberg et al. (2015) hypothesised that 0.2% of the population might be classified as PDA-autistic and that one in five autistic individuals may have PDA. However, these are merely estimates because there is no actual consensus on the definition of PDA (Moore, 2020). After all, it is not included in either the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2022) nor the International Classification of Diseases (ICD) (World Health Organization, 2019). It is not acknowledged formally or informally by many researchers, clinicians, and autistic advocates (Green et al. 2018; Milton 2013; Woods 2018, 2020), and is only briefly referenced in the National Institute for Health and Care Excellence guidelines (NICE, 2020). As a result, most NHS clinicians will not diagnose PDA, and those who do will only define it as an autistic profile if there is no other logical explanation for avoidant behaviours. There are a small number of private clinicians who are considered experts (O’Nions *et al.* 2014), but some local authority education departments will not accept the diagnosis if diagnosed outwith the NHS.

Some individuals, including some professionals, prefer to use the term Extreme Demand Avoidance (EDA), which was proposed as a more acceptable phrase (O’Nions et al., 2013). Pervasive Drive for Autonomy, an alternative for the PDA acronym, is preferred by many in the autistic community because the term Pathological Demand Avoidance implies that a person is purposefully controlling and manipulative, and ignores how anxiety is the main driver (Wilding, 2020). Using consistent terminology like PDA helps ensure clarity and consistency among researchers, professionals, and the broader community, allowing for more effective collaboration, comparison of findings across studies, and development of a shared understanding of the condition. Most PDA children experience profound impacts on their lives at home and at school (Christie *et al.* 2012). Parents highlight how their children’s demand avoidance permeates every part of daily life, including dressing, eating, bathing, and leaving the house, and family relations (Christie et al. 2012).

Newson (1988) initially thought PDA belonged in the category of pervasive developmental disorders as a distinct-but related disorder. Although the current body of research remains limited, it is expanding, and a clearer picture of the PDA profile, how it manifests, and whether and to what extent it co-occurs with other comorbidities is emerging. This is

encouraging since, without a diagnosis, it can be challenging for many families to secure any support for their child.

## 1.2 PDA in the Classroom

Educational environments bring about a rise in demands, where children are expected to follow a routine. Some of the features commonly seen in PDA children are poor emotional regulation, poor sense of self-esteem, and the need to either have a superior position or be on equal par with adults (Christie, 2007). Some PDA children are competent in the classroom and mask their challenges, resulting in explosive behaviour at home (Eaton, 2016b; Fidler and Daunt, 2021, p. 20), but some authentically express themselves in all environments. The high anxiety associated with PDA means any threats to their autonomy may trigger a fight or flight response, which contributes to poor performance if the child is not regularly monitored (Christie, 2012).

Research conducted by Gore Langton and Frederickson, (2015) found that PDA children display challenging behaviours in school, which leads to higher rates of exclusions. This demonstrates that PDA learners require significant educational support, often from multiple professionals. According to the PDA Society (2019), 70% of PDA children face difficulties in school, jeopardising their future career prospects. In order to effectively address these challenges and support learners, their families, and the school community, increased community involvement is required.

## 1.3 Rationale

Understanding the unique needs of PDA children is important. Although existing research on PDA is limited, Gore Langton and Frederickson, (2015) and Truman et al. (2021) found that PDA children face greater difficulties in school compared to their non-PDA autistic peers. Therefore, studying parental evaluations of PDA children's participation in school can provide valuable insights into factors contributing to successful school experiences. A survey conducted by the PDA Society (2019), revealed several challenges, including the need for a sense of control (96%), attendance issues (60%), and high rates of exclusion (47%).

Understanding parents' perspectives on educational provisions aids in identifying strengths and weaknesses and helps guide educators in creating inclusive environments for PDA children. Clearer guidance and diagnostic criteria for PDA are needed to ensure appropriate support. Differentiating between demand-avoidant children with and without PDA is crucial for meeting their educational needs. Parental evaluations offer valuable insights into existing approaches and interventions, promoting collaboration and inclusivity. This research explores effective PDA interventions, aiming to improve academic and social outcomes for learners. Identifying these elements helps children receive necessary support to reach their full potential. Ultimately, this research has the potential to positively impact the lives of PDA children by highlighting ideas and suggestions that schools can adopt to develop appropriate and tailored educational opportunities.

#### 1.4 Language

Speech and language are powerful ways of communicating ideas, whether abstract, functional, or concrete. Language and the connotations we give to words have an impact on how we think about the subjects we discuss.

In this dissertation, I will refer to “*autistic children*” and “*PDA children*” rather than “*children with autism/PDA,*” as this is the terminology that the majority of the autistic community prefer (Kenny et al., 2016). Language influences how a person experiences and understands their environment, and it is a vital and important part of their identity.

## Chapter 2: Literature Review

PDA is characterised by strong desire for control and disengagement from demands through complex reasoning, socially shocking outbursts, and withdrawal into fantasy as a means of escapism (Morris, 2021; O’Nions et al., 2016). The National Autistic Society considers PDA a subtype of autism due to challenges in social communication and interaction (National Autistic Society, 2021). PDA children often have passive early histories and delayed milestones, becoming more resistant with increasing expectations (Truman, 2021). Despite having fluent verbal skills, they struggle with information processing and rigid thinking (O’Nions et al., 2016). While research continues to explore and define PDA, it is recognised as an autism spectrum profile (PDA Society, 2022).

The lack of clear diagnostic criteria creates uncertainty for parents seeking educational support (O’Nions et al., 2015). Managing PDA is challenging due to the standard approaches designed for autistic children being ineffective, potentially exacerbating anxiety (PDA Society, 2022). Some PDA children can handle school but struggle at home (Syson and Gore Langton, 2020). Additionally, the monotony of the classroom environment can heighten anxiety (Fidler and Christie, 2018). The absence of a PDA diagnosis hinders parents, teachers, and healthcare professionals from accessing proper educational support (Kerbey, 2023; Sherwin, 2015, p. 42). The limited published research on PDA has sparked curiosity and significant debate. Identification, classification, and diagnosis are complex and variable and include diverse perspectives from both professionals and individuals with lived experience (Truman, 2021).

### 2.1 Demand Avoidance

Demand avoidance encompasses measures taken to avoid demands and the inability to perform tasks at specific times (PDA Society, 2022). Demand avoidance is a natural human trait. Neurodivergent individuals may exhibit higher levels of avoidance due to factors such as anxiety, sensory processing difficulties, executive functioning challenges, monotropism, and autistic inertia, which can be detrimental to academic performance and overall functioning (Buckle et al., 2021; Voelker et al., 2021). Autistic inertia refers to difficulties initiating and completing activities as is often intertwined with monotropism, where individuals focus intensely on specific interests (Murray et al., 2005). This intense focus in

non-PDA autistic people can make it challenging for them to switch their attention, not because it's a demand to comply with requests, but because they are stuck on the current area of focus, leading to avoidance of requests (Milton, 2018). PDA, on the other hand, is characterised by obsessive resistance to everyday demands and an anxiety-driven need for control (PDA Society, 2022). PDA is not an avoidance brought about by the current state of mind, but more about the request or demand that follows.

According to Thompson (2019), the condition is better defined as an individual's refusal to forfeit their freedom in any circumstance. Freedom is at the PDA child's core; if the PDA child's freedom is disturbed, control becomes the way freedom is restored. PDA individuals generally have enough social understanding to use some form of social trickery in their ongoing efforts to avoid demands. They frequently adopt strategies to stop the person making the demand, such as distraction, acknowledging the demand but excusing the self, procrastination, and negotiation, physically incapacitating themselves, withdrawing into fantasy, and physical or verbal outbursts. Non-PDA autistic children may also evade social demands, but they tend to do this in ways that aren't considered social in nature, such as by ignoring, withdrawing, or walking away.

According to some academics, PDA is better understood as Rational Demand Avoidance (RDA); an understandable and rational response to the situation one finds themselves in (Milton, 2013; Woods, 2018, 2022). However, from my own interactions with autistic children, I feel strongly that PDA demand avoidance contains an irrational component. For example, a non-PDA autistic individual may exhibit resistance to demands due to fear, uncertainty, or sensory challenges that overwhelm and lead to potential shutdown. From my perspective, this response can be considered rational. However, the irrational aspect of PDA demand avoidance arises from an internal conflict between the brain's desires and its resistance. Here, the brain remains in a state of hypervigilance and when faced with a demand or expectation, the PDA child goes beyond simple refusal by creating complex justifications and retreating into fantasy as a means of coping or coaxing themselves into compliance. Additionally, self-imposed thoughts can cause a PDA individual to become incapacitated and hinder their progression (Kerbey, 2023, p. 23).

PDA demand avoidance persists throughout life and can be managed through understanding, supportive interactions, and self-coping mechanisms (PDA Society, 2022).

## 2.2 Alternative Diagnosis

The term “*behaviour that challenges*” refers to actions that disrupt or pose a risk to the wellbeing of individuals exhibiting them, their caregivers, and/or the environment. These behaviours include aggression, self-harm, property damage, or defiance. Whilst Gore Langton and Frederickson (2015) refer to these as “*problem behaviours*”, this study opts to use the phrase “*behaviour that challenges*” in accordance with NICE, (2018) guidelines, which highlight that while the behaviours may challenge others, they may serve a function for the individual. There is ongoing debate in the research literature about the distinction between PDA and conditions such as autism, oppositional defiant disorder (ODD), and anxiety disorders (Malik and Baird, 2018; O’Nions et al., 2013).

ODD is identified in children who resist demands. It is suspected that their behaviour results from a chronic state of negative emotion and thought brought about by exceptionally difficult events (Gotter, 2017). The American Psychiatric Association (2022), emphasises that ODD is more common in households where:

*“Childcare is disrupted by a succession of different caregivers or in families in which harsh, inconsistent or neglectful child-rearing practices are common”.*

In contrast, PDA is believed to result from different brain chemistry and wiring that triggers a threat response when demands are encountered (Forbes and Doyle, 2021). Rewards may not be effective, as they may be perceived as control through compliance, whereas in children with ODD rewards are usually motivational (O’Brien, Frick and Lyman, 1994). Woods (2020) argues that PDA is primarily driven by attachment or early trauma rather than being solely associated with autism. However, I disagree with this view, based on my own experience of working with PDA children. Many PDA children have siblings who grew up in the same environment but who do not exhibit the same behaviour. Some PDA characteristics also closely resemble those of Attention Deficit Hyperactivity Disorder (ADHD), particularly during moments of anxiety or dysregulation. Furthermore, Durà-Vilà and Levi, (2018) and Sherwin (2015 p19) argue that PDA is a genuine condition that does not stem from insufficient parenting or inconsistent nurturing and cannot be fully explained by current diagnostic labels.

Kanner (1943) was the first child psychiatrist to describe Early Infantile Autism in the US. This led other psychiatrists to investigate “*emotionally cold mothers*” or “*refrigerator mothers*.” Bettelheim (1967) believed autistic children’s biological differences were a consequence of emotionally detached parents, not the cause. However, Rimland (1964) challenged this belief and emphasised that psychogenic causes were not solely responsible for Early Infantile Autism. Woods (2020) blaming parents for their child’s condition is disheartening, considering many mothers report feelings of anguish and resentment. Furthermore, O’Nions and Eaton (2020) suggest that when there is a history of trauma, a diagnostic attachment framework should be used.

Reactive Attachment Disorder (RAD) can make it difficult for children to form an emotional bond with caregivers. Allistic children can exhibit RAD symptoms before the age of five, such as emotional distancing, struggle with social interactions, or negative emotions during contact with caregivers (American Psychiatric Association, 2022). Research indicates that children with attachment disorders may face similar social and language challenges to autistic children (Sadiq et al., 2012).

Conduct Disorder (CD) refers to a repetitive pattern of behaviour where a child consistently violates societal norms or the rights of others through bullying, aggression, rule breaking, theft, or lying. These behaviours impair social, academic, or vocational functioning (American Psychiatric Association, 2022). According to Silberg et al. (2014), childhood-onset CD is strongly linked with ADHD, Antisocial Behaviour (ASB), family discord, and parental depression.

Intermittent Explosive Disorder (IED) is characterised by recurrent bouts of impulsive anger that are disproportionate to triggering events and result in harm to self, others, or animals (American Psychiatric Association, 2022). While the exact cause of IED remains unclear, a combination of biological and environmental factors are thought to contribute to development, often in individuals who grew up in households marked by verbal and physical abuse.

Borderline Personality Disorder (BPD) involves impairments in interpersonal functioning and is characterised by intense emotional experiences, impulsive behaviour, distorted thinking, and unstable relationships (American Psychiatric Association, 2022). The cause of BPD is

unknown, but symptoms often emerge during adolescence and persist into adulthood due to a mix of genetic and environmental factors (NHS, 2023). Some individuals who previously received incorrect personality disorder diagnoses now self-identify as PDA (Eaton, 2021).

Some behaviours observed in PDA resemble those seen in children with ODD or CD. However, Newson et al., (2003) found that PDA individuals exhibit more extreme and socially inappropriate actions such as provocative or shocking behaviours in public that peers would find embarrassing, like stripping off, drawing attention to themselves, asking personal questions, speaking loudly, or having meltdowns. Role play and fantasy are key aspects of PDA, and individuals may cope and comply with requests by adopting different personas or acting out scenarios. PDA individuals often engage in these behaviours when authentic self-expression is discouraged.

O’Nions et al., (2020) state that:

*“Descriptions of PDA include a formulation that places child anxiety as the driver of reactivity, and in doing so de-stigmatises the child and the parent for failures to enforce or conform with norms”.*

Nevertheless, if PDA behaviours are to be accepted as merely anxiety, mood or trauma related disorders, surely it would be in the best interests of the children for clinicians to use current diagnostic categories for such comorbidities? According to Wing et al. (2011), PDA behaviours may not be associated with autism and could potentially have some similarities with psychopathy. Psychopathy is characterised by specific personality traits and socially deviant behaviours, which are categorised into interpersonal, affective, lifestyle, and antisocial factors (Tsang and Salekin, 2019). PDA individuals may exhibit similar traits, such as a lack of empathy, frequent violent outbursts, and mood changes. However, the key difference is that PDA individuals often experience remorse and regret, and may strategically manage their identity by altering their appearance or persona to allow them to express remorse and seek redemption without feeling compelled to apologise (O’Nions et al., 2018). O’Nions et al. (2014) found that PDA children displayed levels of autistic traits similar to ASC, behaviour challenges comparable to conduct disorder, and higher levels of emotional difficulties than either group. PDA may thus be conceptualised as a ‘triple hit’ of autism, conduct challenges, and anxiety. Although there is no formal recognition or clear



differentiation of PDA from other conditions, there is a growing global movement advocating for its diagnosis. From personal observations, I believe PDA individuals exhibit extreme behaviours and have difficulty tolerating nonsensical situations. The stronger the perceived threat to their independence, the stronger their need becomes to incapacitate those making demands on them as a means of self-protection (Christie, 2012).

### 2.3 People Fixations

According to the DSM, autistic people have persistent difficulties with social communication and interaction, as well as restricted and repetitive patterns of behaviour that limit and impair everyday functioning (American Psychiatric Association, 2022). PDA Children may initially appear to have greater social awareness and communication abilities, but their underlying social skills and ability to understand social situations are often poor (Gould and Ashton-Smith, 2011, O’Nions et al., 2016)

While demand avoidance is a key feature of PDA, there is more to it than just that behaviour. People fixations, where individuals develop intense interests in people rather than objects, are mentioned less often in the academic literature (Christie, 2012). Fixations can revolve around super-heroes, fantasy characters, or individual people, including celebrities (Carpenter, Happé and Egerton, 2019). PDA learners may exhibit domineering and controlling behaviours, especially when anxious or when their autonomy is threatened. These behaviours may be seen as intimidating, cruel, unpleasant, and aggressive by others. Newson et al, (2003 p596), who coined the term PDA, describes PDA learners as autistic people with an atypical and surface-level:

*“Degree of sociability that allowed social manipulation as a major skill”.*

Manipulation is described as:

*“Behaviour that controls or influences somebody/something, often in a dishonest way so that they do not realize it” (Oxford Learners Dictionaries (Online), 2023)*

These behaviours are often driven by a desire to take control and protect themselves from perceived threats. It is important to note however that these negative fixations and behaviours

are not motivated by malice, but rather by an anxiety-based need for control (Wilding, 2019). While negative fixations can lead to challenging and harmful behaviours, positive fixations may also occur where PDA individuals adore certain people or idolise a celebrity (Fidler and Christie, 2018 p102). PDA individuals may struggle to recognise authority and resist unsolicited guidance, but positive relationships can be formed when they respect and trust someone enough to listen to them (Fidler and Christie, 2018 p109; Kerbey, 2023 p24).

PDA individuals may have high expectations of others and can react negatively when they feel boundaries have been crossed. They are often described as having a “*Jekyll and Hyde*” personality due to difficulties in social communication and inconsistent reactions (Milton, 2013; Keenan, 2018). It is crucial for adults to remain composed and not react strongly to disruptive behaviours as PDA individuals find satisfaction in reactions to their behaviour (Fidler and Christie, 2018 p8; Syson, 2015). Understanding and addressing underlying anxieties and control challenges can help in managing behaviours that challenge and help build positive relationships with PDA learners.

## 2.4 Autistic Masking

Masking, or camouflaging, is a common technique used by PDA individuals to conceal challenges during social situations (PDA Society, July 2021).

Masking is defined as:

*“The use of strategies by autistic people to minimise the visibility of their autism during social situations”* (Hull, et al., 2021 p819)

This technique enables PDA individuals to appear socially able and at ease, but internally they may struggle with social understanding (PDA Society, July 2021). Masking involves suppressing behaviours like stimming or intense interests that provide comfort but may be perceived as strange or confusing by others. It also includes mimicking nonverbal cues and relying on scripted responses to navigate social interactions (National Autistic Society, 2023). In educational settings, PDA children often resort to masking, which can make it difficult for teachers to detect their challenges. This is noteworthy as it implies that problems that arise at home might not always show up in the classroom (Fidler and Daunt, 2022 p 15). This lack of

recognition may lead to misunderstandings and a lack of appropriate support, negatively impacting the child's development (PDA Society, 2020). Surface sociability and the vivid imaginations of PDA children can further confuse professionals trying to understand their needs. Recent studies have highlighted the detrimental effects of masking on mental health, revealing increased signs of anxiety, depression, and suicidal behaviours (Bradley et al., 2021; Cassidy et al., 2018, Hull et al., 2021). Masking has also been linked to autistic burnout, characterised by chronic exhaustion, skill loss, reduced tolerance to stimuli, and mental and physical shutdown (Mantzalas et al., 2022; Raymaker et al., 2020; Rose, 2022). Whilst masking is a common coping strategy, recognising and understanding the impact of masking is crucial for providing appropriate support and accommodations for PDA learners.

## 2.5 Environment

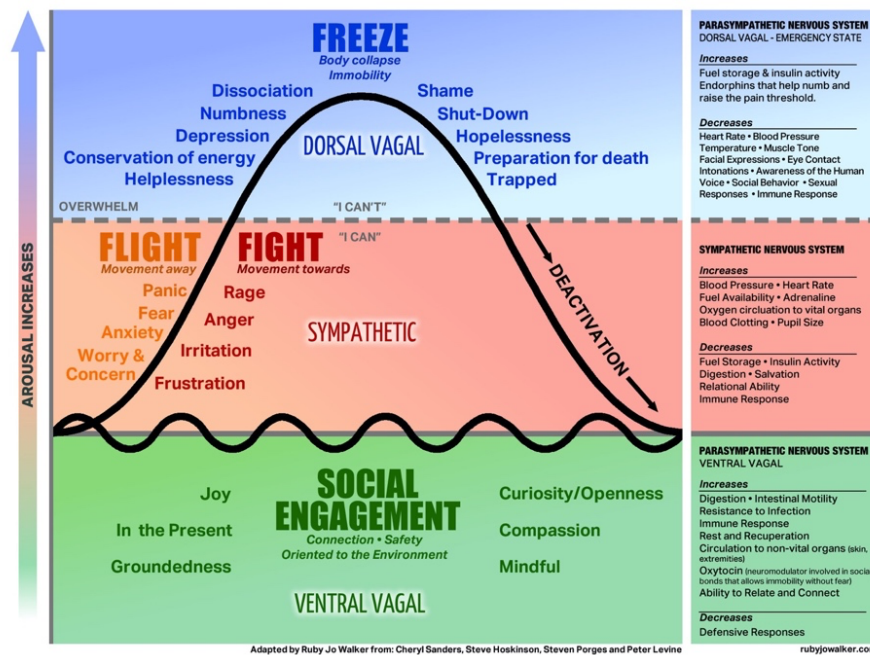
Initial academic perspectives on PDA behaviours focused solely on genetic or physiological causes, excluding trauma or environmental factors (Ogundele, 2018; O'Nions et al., 2014). However, Woods (2020) argues there is currently no solid evidence for diagnostic biomarkers and suggests that it may be careless to dismiss the influence of environmental or traumatic circumstances. My disagreement stems from personal experience of working with PDA children in early years who display extreme behaviours, despite having a stable and loving family background, free from trauma. One child's parent completed the EDA-Q (O'Nions et al., 2014) and EDA-8 questionnaires as requested by Dr Hilary Dyer - a professional mentioned in Woods (2020) - scoring highly on both. While these tools are not diagnostic, they provide valuable research insights. The child's persistent extreme behaviours were documented as consistent across environments. Subsequently, the child was diagnosed autistic with a PDA profile by an NHS clinician.

Moreover, O'Nions et al., (2018) examined the relationship between PDA and early trauma in children diagnosed with ASC. They found that although PDA was more common in children with a history of early trauma, this association disappeared when considering other factors. The researchers concluded that PDA is not directly related to early trauma and suggested it should be considered a distinct and separate entity from other forms of anxiety or avoidance behaviours typically associated with trauma.

A study by O’Nions et al., (2017) revealed that noncompliance worsened with increased demands for conformity within school. Teachers, classmates, and the child themselves may struggle to handle rapid behavioural changes, especially when they turn violent. PDA impacts children differently and interacts with other developmental factors (Christie, 2007). Higher cognitive ability allows some PDA children to reason and seek mutual resolution, whereas those with intellectual disabilities may display higher levels of physical violence due to inability to rationalise. PDA children often mask their intense feelings of inadequacy with a superiority complex, leading others to perceive them as intentionally antagonistic (Nason, 2020). Children may defy requests by labelling them as stupid or too simple, aggravating those around them. Oppositional behaviours often stem from difficulties in understanding and meeting expectations due to executive dysfunction, sensory, and social communication challenges (Nason, 2020). Thompson (2020) argues against terming these behaviours as “*challenging*”; emphasising the importance of identifying and addressing triggers within the environment because focusing solely on external manifestations of behaviours perpetuates judgment of the child. To effectively support PDA learners, a close relationship between diagnostic evaluation and education is vital. Teachers may feel frustrated and annoyed with PDA learners, who may disrupt lesson plans and view learning activities as meaningless. Appropriate educational adjustments can be challenging for teachers without clarity on learner needs (Gore Langton and Frederickson, 2015) However, helping learners understand the purpose of learning can promote autonomy (Kerbey, 2023 p63).

The Polyvagal Theory, proposed by Stephen Porges, highlights the complex relationship between the autonomic nervous system (ANS) and behaviour in response to the environment (See Figure 1). A safe and supportive environment activates the social engagement system (SES) within the ANS, leading to feelings of connection and trust, and fostering positive behaviours such as communication, cooperation, and empathy. Conversely, a threatening environment triggers the sympathetic nervous system (SNS) responsible for the fight-or-flight response, leading to defensive and aggressive behaviours. This reactive state can hinder social interactions, impair emotional regulation, and lead to maladaptive behaviours. Understanding this relationship can guide efforts in shaping behaviour.

Figure 1 Stephen Porges's Polyvagal Theory



## 2.6 Schools: Research Evidence

Placing a PDA child in an appropriate educational environment is crucial, as they often require individualised support (Christie, 2007). According to Kerbey (2023, p 21), When provided with adequate support and understanding, PDA children are capable of learning and thriving. Truman et al., (2021) examined educational experiences of autistic children with extreme demand avoidance behaviours. Through interviews with parents and professionals, researchers revealed the widespread presence of these behaviours and the challenges they pose in education. Commonly, autistic children faced exclusion due to inadequate support from educators and healthcare professionals. While the Truman study provided valuable insights from parents and professionals, it did not include perspectives from autistic children themselves. The findings underscore the importance of raising awareness, understanding, and training in educational settings, as well as the need for customised strategies, interventions, and collaboration among parents, professionals, and schools.

The anxiety experienced by PDA children at school is primarily driven by their perception of demands, potential demands, failure, and loss of autonomy (Moh, 2012). As teachers develop a close relationship with the child, they can modify their approach accordingly, knowing when to be firm and when to reduce pressure. This mutually beneficial relationship helps

build trust and boosts the child's confidence and self-esteem (Fidler and Christie, 2018). I have observed that if a PDA child has enough freedom, the need to exert control over the environment is significantly reduced. Introducing rules or guidelines may result in avoidance or destruction, although fawning may be adopted in some situations as a safe way to regain control until the negative aspects of their situation are overcome (Thompson, 2020). While group work can be beneficial, it is important for the teacher to consider its impact on other group members, as practical challenges may arise (Christie, 2007; Reilly et al., 2014). These challenges can be compounded by the child's inconsistency in behaviour across different environments at different times and with different people. Enhanced one-to-one support is necessary for most PDA children but promoting independence through standing next to or behind the child may also be advantageous.

There is a growing demand for research focused on PDA to enhance educational opportunities without compromising quality of life (Moore, 2020). Due to the vulnerability of PDA children, swift detection and access to specialist support are essential. However, this can be challenging to secure due to a lack of knowledge about the condition and limited resources (Christie, 2012; Newson, 2003). Teachers and professionals working with these learners must become knowledgeable about PDA and the best ways to support them to ensure their full potential is realised (Fricker and Fidler, 2022; Kerbey, 2023). The routines associated with schools have been found to affect PDA children's adaptability and anxiety, emphasising the need for research on improving surroundings and approaches for providing quality education (Child Development Team, ESHT, 2021).

The quality of the teacher-pupil relationship plays a fundamental role in the child's educational success, particularly in the early years. Empowering the child by giving them choices and the necessary tools allows them to function and demonstrates that their potential is valued (Dalkilic and Vadeboncoeur, 2016). However, teachers may experience significant stress at work, which can lead to physical ailments and somatic complaints (Agyapong et al., 2022). Therefore, careful staff selection and the ability to work creatively and adaptably is essential but also physically and emotionally draining (Fidler and Christie, 2018).

## 2.7 Parenting a PDA Child: Research Evidence

While parental stress amongst those with PDA children has not yet been systematically examined, existing literature focusing on autistic children acknowledges the stress experienced by parents of children with additional support needs (ASN) (McStay *et al.* 2014). Raising a PDA child can pose significant challenges and limitations for parents. This becomes more evident in children whose behaviours can be unpredictable and inconsistent across different contexts and with different people. A study by Newcastle University found a hierarchical progression of avoidance strategies in PDA individuals when faced with demands (Stuart *et al.*, 2019). The Diagram (Figure 2) from the PDA Society, explains progression in behaviours when faced with a demand.

Figure 2 Avoidance approaches seen in PDA



Escalation can occur quickly, particularly when pressured, thus individuals may transition directly from the green zone to the red zone. Effective management and reduction of Violent and Challenging Behaviour (VCB) requires collaboration between professionals, teachers, and parents, with a focus on understanding the full picture and providing non-judgmental support (Fricker and Fidler, 2022; Gore Langton and Frederickson, 2015). Parents of ASC

diagnosed children are more likely to face financial difficulties, partly due to the impact of their child's autism on parental employment (Cidav et al., 2012; Connolly and Mullally, 2023). It can be assumed that these effects are even more pronounced for parents of PDA children, who may also face blame due to misconceptions about parenting techniques (Silverman and Brosco, 2007). Moreover, families of PDA children may encounter a lack of understanding, support, and resources from various sources, including family members and educational and healthcare systems, resulting in them turning to social media for support.

## 2:8 Parent Blame

Parental blame occurs when professionals imply parents are responsible for their child's behaviour. Some parents of PDA children believe that professionals' lack of knowledge leads to criticism and false accusations of poor parenting (Gullon-Scott and Long, 2022; Truman et al., 2021). The child's behavioural variability may be wrongly attributed to poor parenting practices when in reality the parent has no control over their child's behaviour (Moh, 2012). Professional concerns about parental mental health and its impact on child behaviour and development are common. A recent survey of 1016 parents and carers of PDA children found that 87.8% experienced blame for their child's presentation or lack of progress (Running and Jata-Hall, 2023). However, blaming parents only exacerbates stress (Connolly and Mullally, 2023).

Parents cite failures on the part of local authorities and health services in refusing to acknowledge this debilitating condition with instances of blame, gaslighting, safeguarding and investigations (Newbold, 2022; Cain et al., 2022; Traves., 2022). Legal matters have also been highlighted (Charles, 2022; Nisbet, 2022). Certain factors such as marital status, wealth, and parents' professional roles appear to offer protection against parental blame for their child's extreme behaviour (Running and Jata-Hall, 2023).

The term "*perplexing presentation*" (PP) is used when a child's condition cannot be medically defined. Taking a holistic approach to assessing and managing medically unexplained symptoms is crucial because a narrow focus on medical explanations may be counterproductive (Glaser and Davis, 2018). Fabricated or Induced Illness (FII) is defined by the Royal College of Paediatrics and Child Health (RCPCH) as a situation where a child is harmed or likely to be harmed due to parental behaviour aimed at convincing doctors of the



child's impaired physical, mental, or neurodevelopmental health (RCPCH, 2021 p.11). A study by Running and Jata-Hall (2023) indicated that children with neurodivergent parents or lone mothers experience greater risk of receiving blame under the guise of safeguarding. Parents of PDA children require substantial support, as these children often exhibit severe behavioural challenges. The limited available evidence suggests that early diagnosis and adequate support lead to greater independence and abilities in PDA individuals (Elder et al., 2017). Moh (2012) proposed that parental stress levels increase when teachers provide inadequate support, while parents who do receive support report greater satisfaction and that their children have more positive school experiences.

## 2:9 Research Question

The literature review uncovered several key issues and challenges. They included the absence of a precise description of PDA, the use of arbitrary criteria to evaluate PDA, and the requirement for a multidisciplinary research strategy. This research seeks to explore:

How do parents of PDA children evaluate the quality of educational provision available to their children in mainstream schools?

### Objectives:

- To determine parental perceptions of the educational experiences of PDA children.
- To examine the impact of school experiences on these children.
- To identify the strengths and challenges that parents associate with their child's educational provision.

## Chapter 3 Research approach and methodology

Truman et al., (2021) highlights the need for more research to support educators in accommodating PDA children in school environments.

A qualitative research approach acknowledges that the researcher's perspective is crucial, while a quantitative research approach seeks facts and statistical data (Gibson, 2010). This study utilises a qualitative research approach, which focuses on understanding the meaning and relationships of social events through non-numerical data analysis such as interviews and open-ended survey results. This approach is advantageous in capturing the diverse experiences and viewpoints of parents and caregivers of PDA children and considers the complexity of the condition and its influences on behaviour (Pope and Mays, 2020, pp.45–48).

A quantitative approach, with its emphasis on statistical analysis and generalisability, may not adequately capture these nuances (Newhart and Patten, 2023). To produce trustworthy results, the research design of this study considers the experiences of parents and caregivers of children with the condition to assess educational experiences and associated impact on PDA children. By using a thematic approach, the study aims to identify effective support strategies which may help educators implement support that may reduce avoidance behaviours and lead to more successful educational outcomes.

### 3.1 Methodological Paradigm and Theoretical Framework

This study utilises an interpretivist approach (Pope and Mays, 2020, pp.19–25).

Interpretivism stresses how important it is to understand how people give their own unique meanings and interpretations to experiences and actions (Stake, 2010, pp.48–53). This is essential in PDA research, as personal experiences and perspectives can affect how the condition presents and develops. (Braun, Clarke and Gray, 2017, p.83).

This research is theoretically grounded in social constructivism (Pope and Mays, 2020, pp.23), which asserts that knowledge is constructed through social interactions and communication (Hartas, 2015). Within the context of PDA, it is crucial to consider how

social and cultural factors can contribute to a child's experiences and educational outcomes (Adams, 2006).

### 3.2 Epistemology and Ontology

Epistemology is the theory of knowledge (Pope and Mays, 2020, pp.16-20), and is concerned with how the mind engages with reality. This aids in establishing a level of confidence in data and has an impact on approaches to uncovering knowledge (Hartas, 2015).

The constructivist epistemological approach utilised in this study recognises that knowledge is produced through social interaction and discourse and that different people can have different ideas about the same thing (Given, 2008). Ontology is the science of 'what is' and refers to beliefs about the underlying nature of reality, particularly social reality, and concerns the nature of being and existence (Hartas, 2015) The subjectivist ontological perspective embedded in this study recognises that each person's experiences and perceptions shape their reality and that therefore parents of PDA children may have a different reality to that of their children.

### 3.3 Positivist and Anti-Positivist Perspectives

The positivist philosophical view says that the scientific methods and real-world data should be used to find the objective truth about social phenomena. On the other hand, anti-positivism says that social phenomena can't be studied the same way as natural phenomena and that subjective perceptions and interpretations are as important as facts (Sharp, 2012, p.5). The positivist may ask cause and effect questions, whereas the anti-positivist may reword questions with the view that knowledge is subjective as the world is socially created (Sharp, 2012, p.5). This study is anti-positivist as it recognises that social phenomena, like parental perceptions, cannot be reduced to a set of clear facts and that subjective experiences and views are essential to understanding the phenomenon. You cannot use a positivist approach with qualitative methods because qualitative methods put more weight on subjective experiences and meanings than on numbers.

### 3.4 Methodology

This study's research methodology uses qualitative research techniques. The exploratory nature of the research design aims to learn more about how to provide an environment equipped to educate PDA children.

A key factor in determining if research is valuable and whether its findings are relevant is the validity of the study (Hartas, 2015). Therefore, a significant emphasis of the study has been placed on acquiring parents' personal experiences and opinions. To achieve this goal, an online survey was constructed (appendix 3), asking parents for information and asking them to evaluate their children's strengths and weaknesses and experiences in school.

### 3.5 Data Collection Methods

The study used surveys to collect data, with semi-structured interviews being used to obtain more detailed qualitative information from a smaller group of participants. Surveys were employed to gather quantitative data from a larger sample (Sharp, 2012, pp.47–50).

#### 3.5.1 Questionnaire

The survey was created on Microsoft forms using Microsoft teams and was published (Appendix 4) on The PDA Society, The PDA Space, and The PDA support group on social media, which also served as a viable method for identifying and recruiting research participants. This was important because PDA profiles are considered rare (O'Nions and Eaton, 2020). The researcher's network partners helped distribute the questionnaire, enabling participant recruitment, which is significant due to their theoretical relevance to the research (Hartas, 2015). This study expands on Truman et al., (2021) work by focusing on parental views and examining how teachers and schools influence parents' perceptions of their children's experiences. The questionnaire from Gore Langton and Frederickson, (2015) served as a template, with additional questions relating to presentation and emphasising parental accounts of children's presentations and school experiences being included.

Surveys are widely used in academia due to their ability to efficiently collect data from large numbers of participants. They are cost-effective and can reach a substantial amount of people in a short time, making them particularly useful for studying large populations. Surveys provide anonymity, which encourages honest responses, especially when addressing sensitive

topics. Anonymity reduces social desirability bias, where participants may provide socially acceptable answers instead of true beliefs or experiences. The questions facilitate structured and comparable data collection, enabling statistical analysis for identifying patterns and relationships among variables (Sharp, 2012, p.47-49).

Despite these advantages, surveys have limitations. One concern is response bias due to reliance on self-reporting, leading to biased or flawed data. Respondents may unintentionally provide inaccurate information or withhold details. Self-reports are subjective and influenced by factors like memory recall, cognitive biases, and social desirability, which can affect data validity and reliability. Surveys often rely on closed questions, restricting participants ability to fully express their thoughts or experiences, limiting the chance of obtaining complex information. Moreover, surveys tend to prioritise quantitative data, neglecting qualitative aspects that can provide deeper insights (Sharp, 2012, p.47-49).

### 3.5.2 Interviews

Using multiple research methods to investigate an issue is known as triangulation (Carter et al., 2014). By employing multiple independent measurements, the aim is to enhance confidence in the results. Using a combination of rigorous methods provides a more comprehensive understanding than a single method. This study employed interviews as one of the methods. Participants were asked semi-structured questions regarding their thoughts and feelings about their child's educational experiences using Microsoft Teams. The interviews focused on the research question and aimed to gather relevant data. Five participants were selected and interviewed. The interview schedule is available in Appendix 5.

Open-ended questions offer flexibility in phrasing, covering topics, and discovering new perspectives (Hartas, 2015). This approach allows for detailed information to be elicited, as participants can provide clarification or additional context. Interviews can be adapted to individual participants, with questions tailored to their initial responses to foster an organic exchange of information. The researcher-participant connection encourages the sharing of experiences and perspectives, resulting in rich and nuanced data. Furthermore, this connection facilitates addressing ambiguous responses to ensure accuracy and reliability. However, there are limitations to consider. Time constraints can make interviews less

practical. There is a risk that participants will also conform to societal expectations, introducing bias and potentially leading to incomplete or inaccurate information. Participant ability to accurately remember details or events may also be affected by emotional state or the passage of time.

To ensure validity and reliability, attention was directed towards these factors to prevent biased interpretation of responses based on preconceptions or assumptions about PDA.

### 3.6 Sample of Respondents

The survey form and semi-structured interview guide were tested using a pilot study. Data collection for the main study took place between February and July 2023 and generated 362 responses.

A population refers to a group of people who share the same characteristic relevant to the study (Hartas, 2015). Selecting appropriate data sets is important to meet the study aims and objectives. Purposeful sampling is a qualitative research method that involves selecting participants based on specific criteria aligned with research questions or objectives (Wolf et al., 2016). Unlike random sampling, purposeful sampling intentionally chooses individuals or cases based on specific criteria that align with the study's focus. To distinguish PDA children from those with other forms of demand avoidance (such as sensory avoidance and autistic inertia (Sullivan, 2002)), a structured and closed questionnaire was created and only those with a diagnosis of ASC/ASD with a PDA profile were invited to participate. To ensure the sample represented the PDA population of interest, purposeful sampling was used. Data of 129 respondents whose children had a clinical diagnosis of a PDA profile of autism was collected for analysis.

### 3.7 Data Analysis

Data analysis is essential to derive meaning from the data collected. This study employed a qualitative approach. The study's research questions aided in establishing the framework for analysing participant data. Thematic analysis was used to identify patterns, themes, and concepts in the data (Saunders et al., 2009). By employing comparative analysis and using

graphs to depict variations in parent survey replies, the credibility of results increased (Saunders et al., 2009).

Thematic analysis is widely used in qualitative research to gain a deeper understanding of participant meanings and perspectives (Guest, 2012). Going beyond description, it explores underlying meanings, ideas, and concepts that emerge from the data. It identifies recurring patterns, connections or divergences, allowing for a comprehensive understanding of the phenomenon being studied.

Different approaches, such as interpretative and categorical aggregation, were used to analyse the data and provide a nuanced account that contributes to theory development and practice (Stake, 1995). As part of this process, overarching conclusions were drawn from the data, with a focus on highlighting the most significant findings. Quotations and passages were used to effectively summarise these findings, while also capturing common themes that emerged. This deductive approach was employed to ensure empirical and unbiased conclusions based on available information (Braun, Clarke and Gray, 2017, p.304-309). These techniques enhance the research's credibility, reliability, and attainment of objectives (Houghton, 2015).

### 3.8 Ethical Issues

Ethics in academic research encompasses principles and guidelines governing researchers moral and responsible conduct, ensuring ethical practice, participant welfare, transparency, and research integrity (Brown, 2003). This study adheres to the Ethical Guidelines for Educational Research (BERA, 2018), prioritizing participant rights, privacy, and dignity (Brown, 2003). Throughout the study, individuals were treated fairly, sensitively, and with respect, recognising their rights and differences (BERA, 2018).

Informed consent, obtained from caregivers, involved providing comprehensive information on the study's purpose, procedures, risks, and benefits, enabling informed decisions to protect well-being and research validity (Nayak and Narayan, 2019). This allowed individuals to make informed decisions based on their own values and circumstances, while protecting their well-being and the scientific validity of the research. Anonymity was ensured using unique codes instead of names, securely handling data, and maintaining confidentiality within General Data Protection Regulation (GDPR) and Data Protection Act 2018.

Research integrity was maintained through adherence to standards of honesty, transparency, objectivity, and accountability, including accurate reporting, avoiding data manipulation, and acknowledging contributions (Brown, 2003). A conducive environment was fostered through respect, inclusivity, active listening, clear expectations, flexibility in data collection, and emotional support (BERA, 2018). Risks to participants' physical, psychological, and emotional well-being were carefully considered and minimised. Voluntary participation without pressure or manipulation, along with the right to withdraw at any time, were ensured (BERA, 2018). The study underwent ethical review by an ethics committee, outlined in (Appendix 1), to protect participant rights and well-being. Before deciding to participate, individuals were fully informed about potential benefits, such as contributing to knowledge and personal satisfaction, and risks, including discomfort and time constraints. The researcher transparently disclosed her personal interest in PDA, emphasizing credibility and objectivity (Brown, 2003).



## Chapter 4 PRESENTATION OF FINDINGS

The following chapter provides a detailed analysis of the data from the survey questionnaire and interviews. Responses were analysed qualitatively, as described in the Methodology chapter, focusing on PDA diagnosed children. Analysis of parental responses revealed recurring themes and patterns that illustrate difficulties faced by families with PDA children, the various factors influencing the child's behaviour, development, and parents' perceptions of their child's education. The findings of this analysis are discussed in detail in chapter 5.

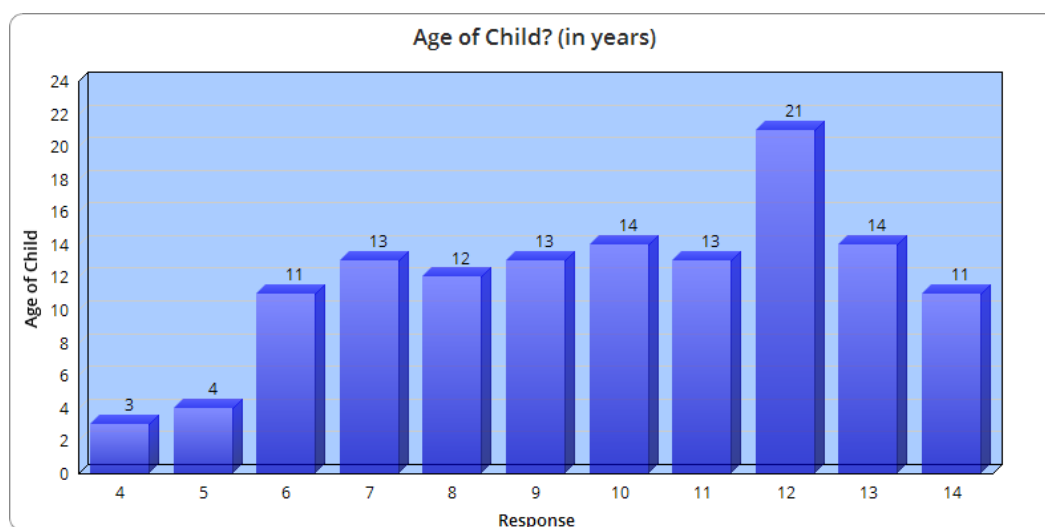
### 4.1 Analysis of the Survey

The survey received three hundred and forty-six responses. Of those, ten were disregarded as being outwith the age range specified (Appendix 3). Due to the volume of responses and time limitations, a decision was made to focus on the data provided by one hundred and twenty-nine respondents whose children had a clinical diagnosis of a PDA profile of autism. Responses were analysed using Microsoft forms, as described in chapter 3.

#### 4.1.1 Demographic information

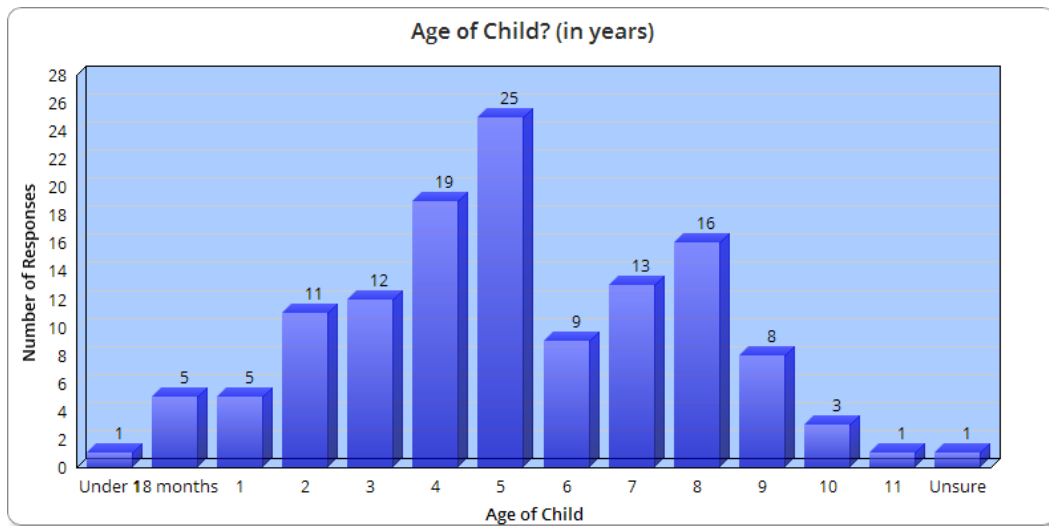
The survey questionnaire targeted parents of children with a PDA profile. The average age of their children was 9.86 years, with most of the parents having a child aged twelve. The graph below (Figure 3) displays the distribution of the demography:

*Figure 3 Age of Child*



Additionally, parents commonly first observed extreme demand avoidance behaviours in their children when aged 2-8, with a peak between the ages of 4 and 5. This coincides with the start of school and introduction of routine-related stress. The graph below, Figure 4, illustrates the distribution of participants based on when parents first became concerned about their child's demand avoidance.

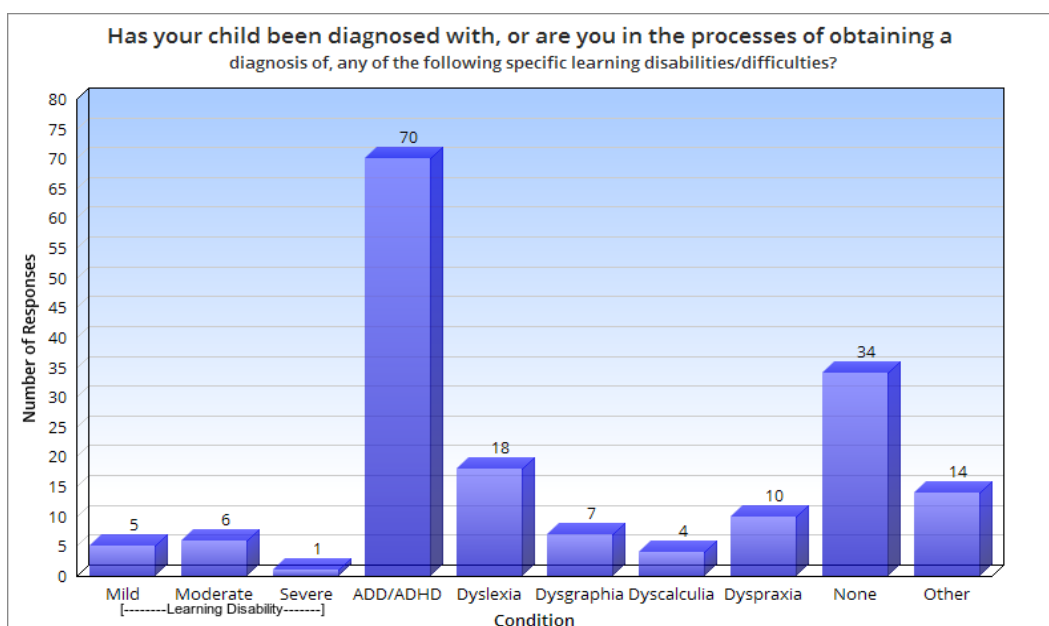
Figure 4 Onset of Concerns Regarding Age Demand Avoidance



#### 4.1.2 Presentation of Findings

The data highlighted that PDA often coexists with other conditions or comorbidities, as illustrated in Figure 5.

Figure 5 Range of Comorbidities



ADD/ADHD was the most frequent comorbidity, reported in 70 cases. Other diagnoses, including learning disabilities, dyslexia, dyspraxia, and OCD, were mentioned but in fewer instances. Therefore, parents must prioritise a comprehensive assessment to address the various needs of their children when PDA is identified, to ensure needs are appropriately addressed.

The findings indicate that PDA children face difficulties in social communication and interaction, as shown in Figures 6 and 7.

Figure 6 Eye Contact Analysis.

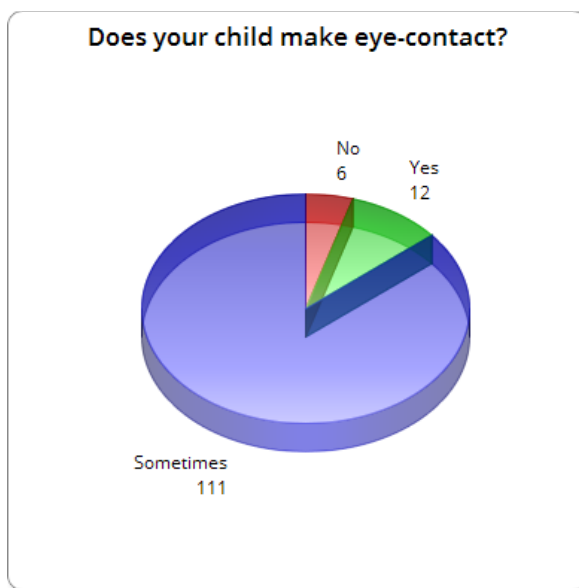
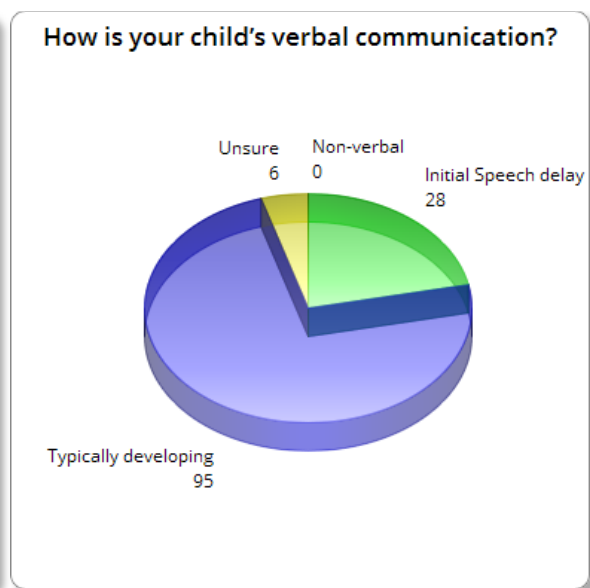


Figure 7 Verbal Communication Analysis



While most autistic children struggle with eye contact, according to the analysis only 5% of the PDA participants (n=6) do not make eye contact. The majority occasionally make eye contact (n=111), with a smaller number consistently making eye contact (n=12).

Additionally, the data (Figure 7) revealed that all the participants' children were either verbal or had minimal communication difficulties. Most children exhibited typical verbal skills (n=95), while a smaller group initially experienced speech delay but quickly caught up (n=28). These findings indicate that although most PDA children possess strong verbal abilities, a significant portion may still face challenges in nonverbal communication, which can impact social interactions and relationships. Thus, these findings suggest that relying solely on eye contact and verbal communication may hinder a referral for diagnosis, as discussed in the literature review (see Figures 6 and 7).

Figure 8 Repetitive Movements Evaluation.

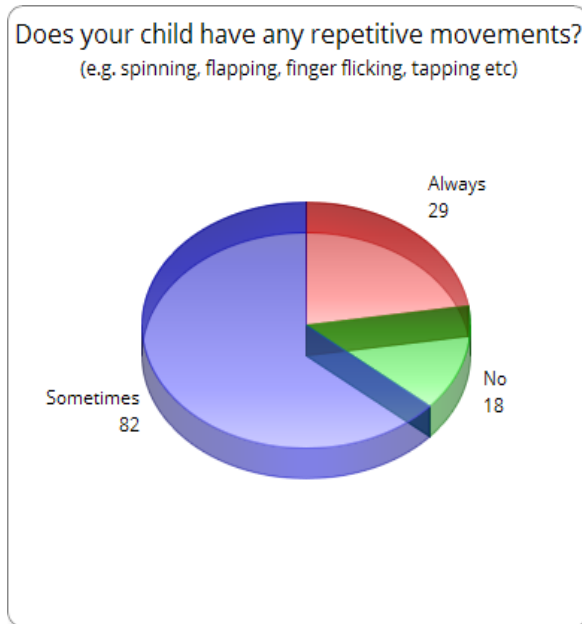
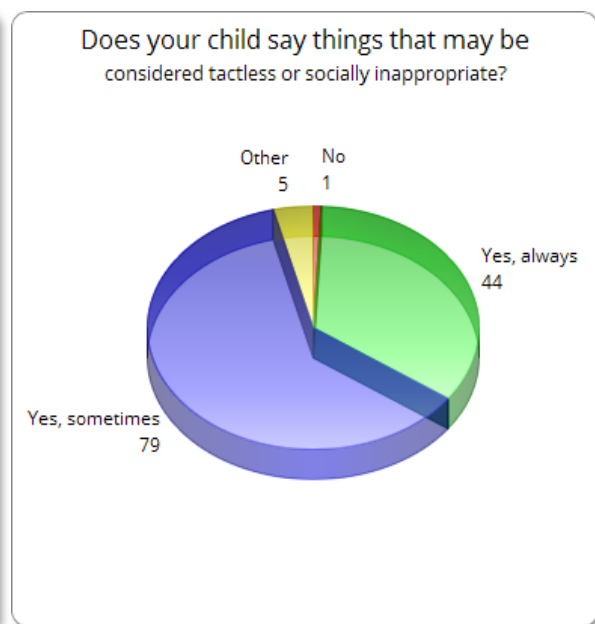


Figure 9 Inappropriate Communication Analysis



Repetitive movements, also known as stereotypic behaviours, are commonly seen in ASC diagnosed individuals (Morgan, Wetherby and Barber, 2008). These movements include rocking, spinning, flapping, or tapping. The results (see Figure 8) found a high prevalence of repetitive movements, with most parents reporting occasional (n=82) or constant (n=29) repetitive behaviours. This aligns with the typical characteristics observed in autistic individuals. Only 14% (n=18) reported no identified repetitive movements. However, it is important to note that some children with a PDA profile may exhibit subtle repetitive behaviours that can go unnoticed due to their surface sociability or because they have strategies to suppress or mask these behaviours around others (PDA Society, 2022).

Figure 9 demonstrates that 95% of parents reported their child saying things that may be considered tactless or socially inappropriate. This further supports the notion that individuals with ASC may not always grasp social norms or appropriate behaviour in certain situations.

Figure 10 Pretend Play Observations

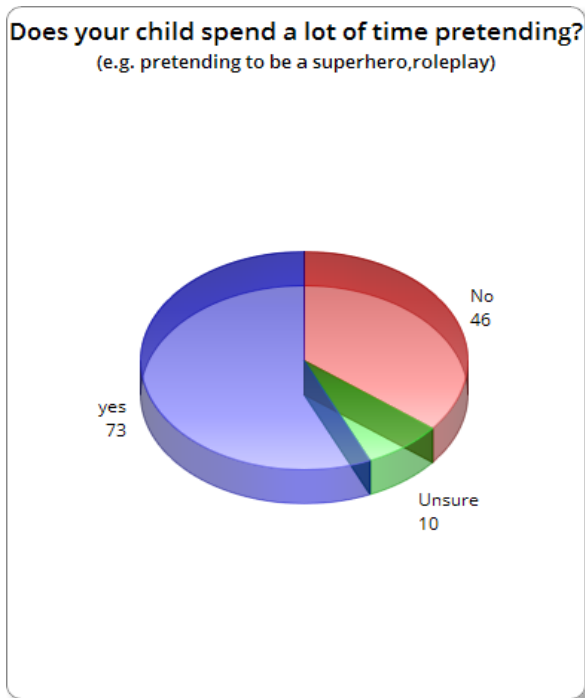
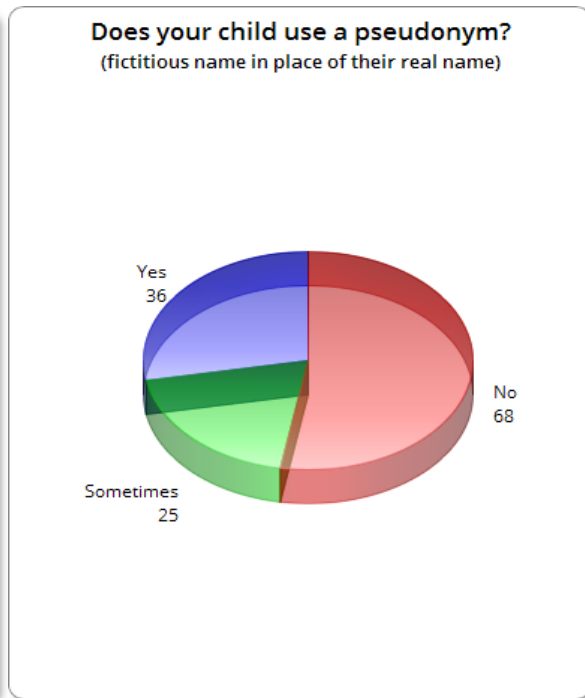


Figure 11 Pseudonym Usage



Withdrawal into role play and fantasy is one of the key features of a PDA profile (PDA Society, 2022), However, it is interesting to note that only 56% (n=73) of parents reported this trait (see Figure 10). It is worth mentioning that twenty-two parents of older children mentioned that their child used to exhibit this behaviour when younger. One parent specifically stated:

*“She used to but that has largely stopped in the last year. I think she may still in her head.”*

This was echoed by another parent:

*“He did when he was younger, now as a teen he created elaborate stories about a fictional social life he pretends to have when speaking to his peers.”*

In addition, it was also noted that 27% (n=36) of the children would make use of a pseudonym in place of their name (see Figure 11), with one parent saying:

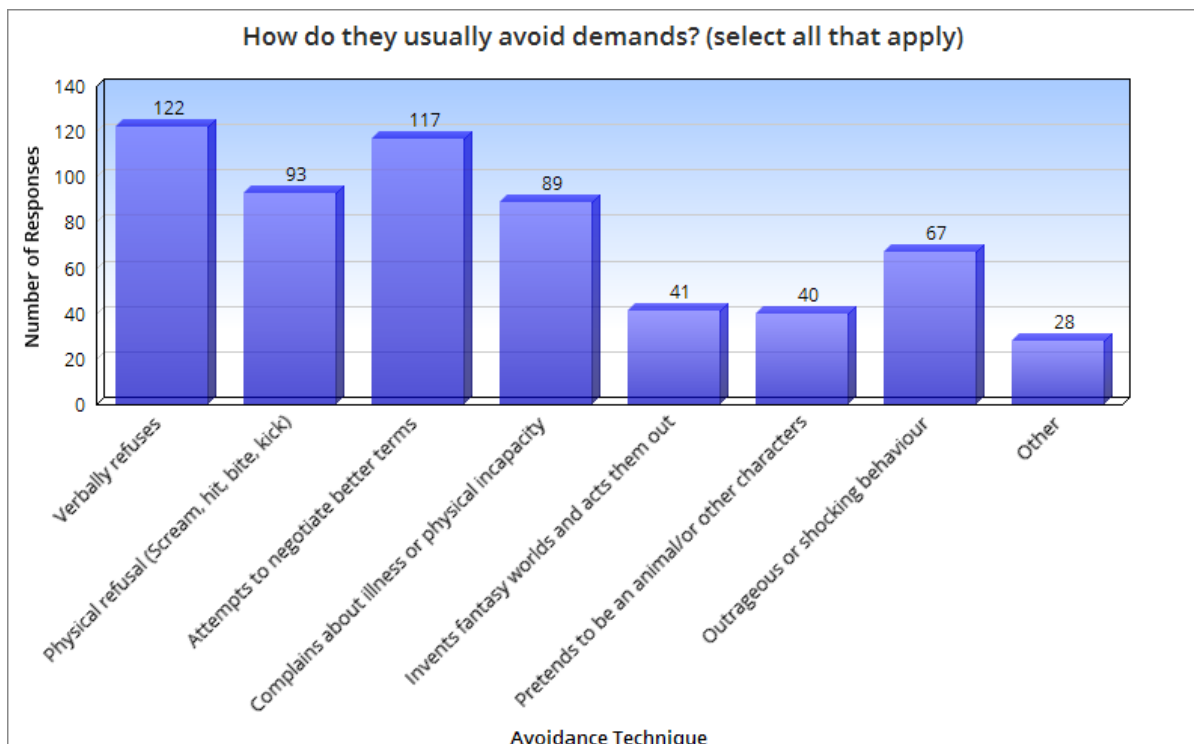
*“She had a period of wanting to completely change her name (legally), but then went off the idea as she matured.”*

It was also found that thirty-two children previously used a pseudonym and that one child previously:

*“[C]alled himself ‘Bowam’ when in aggressive/attacking mode, then would switch back to himself. Age 9 he said Bowam didn’t exist, and he made it all up.”*

These findings suggest that the key feature of role play and fantasy may be more prevalent in younger children who may learn to internalise this behaviour masking from others.

Figure 12 Avoidance Mechanisms of Demands



Additionally, the data revealed (see Figure 12) that all PDA children in the study exhibited a tendency to resist demands. Parents emphasised that children would use verbal refusal (n=122), negotiations (n=117), physical refusal (n=93), complaints about illness or physical incapacity (n=89), or shocking (n=67) behaviour to emphasise resistance to requests and demands. These were found to be the most frequently used avoidance techniques, and parents

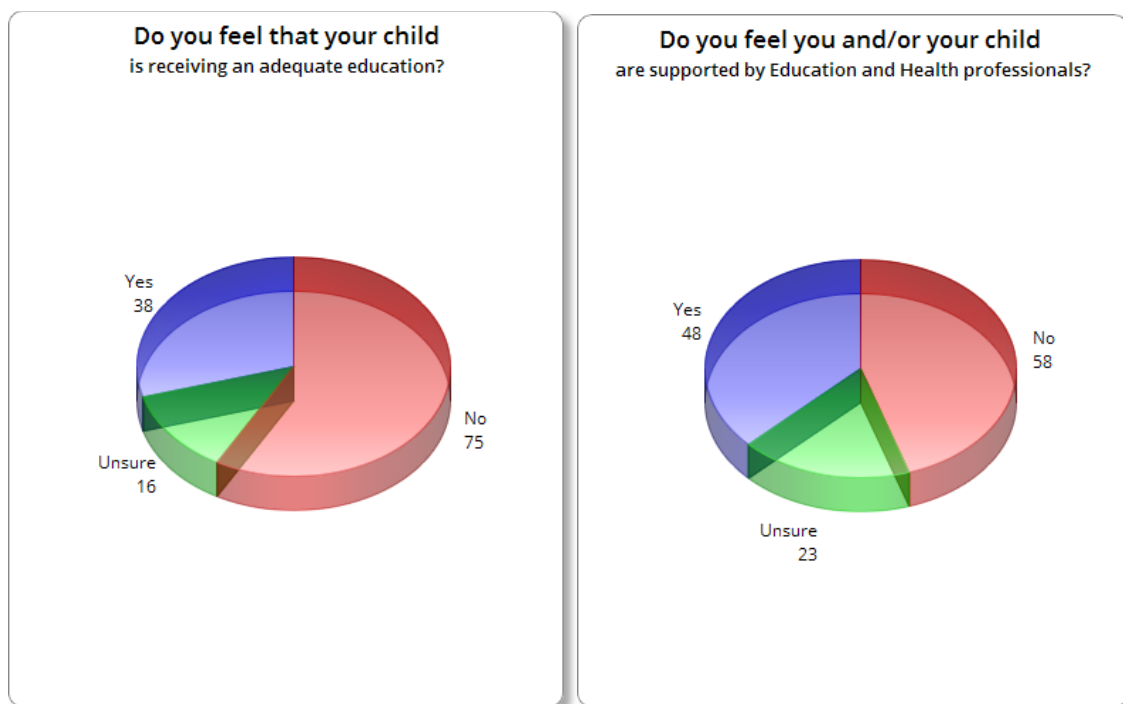
also had their children being classified as stubborn, difficult, or naughty and excluded from school as a result. One parent shared:

*“My child got suspended for 1.5 days 7 months ago, hasn’t been back since.”*

The behaviours and social challenges faced by PDA children can impede their healthy development. Additionally, parents and teachers face increased difficulties in effectively supporting these children due to their behaviours and challenges.

Figure 13 Evaluation of Adequacy of Child’s Education

Figure 14 Support from Education/Health Professionals



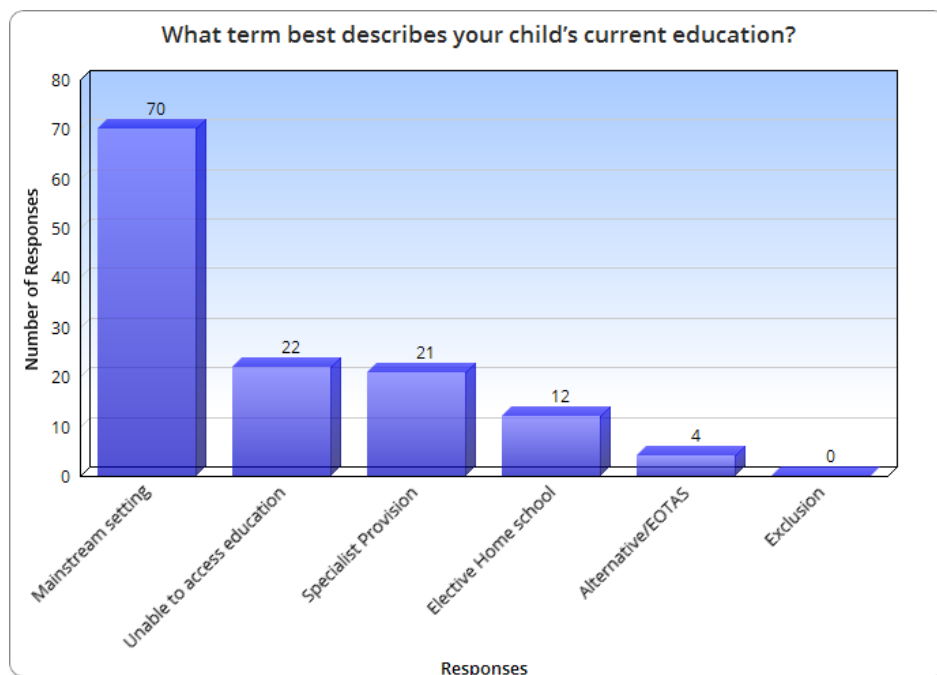
The analysis revealed that children have encountered education-related obstacles such as exclusion and limited alternative options. As a result, some parents opt for home schooling to prioritise their child’s mental well-being. One parent emphasised:

*“My child has been signed off school for 10 months now, in burnout having experienced school trauma”.*

Figure 13 reveals that, while some parents (n=38) believed their child was receiving an adequate education, a significant number (n=75) expressed dissatisfaction. This highlights the

necessity for further investigation and support in educational settings. Figure 14 shows that only 37% of respondents (n=48) felt supported by health and education professionals, while 45% (n=58) reported not feeling supported. This emphasises the importance of coordinated support plans (CSPs) and child plans (CPs), which ensure clarity among the multidisciplinary team regarding their involvement and ensures that actions and outcomes align with the child's needs.

Figure 15 Current Education Description of Children



The analysis revealed (Figure 15) that 54% (n=70) of participants' children were registered in a mainstream setting, with smaller numbers in specialist provision (n=21). Some were unable to access education (n=22) or electively home educated (n=12) or in Education Other Than at School (EOTAS) (n=4). The aim of EOTAS is to ensure that all children have access to education, even if they cannot attend traditional school settings, EOTAS is not available in Scotland.



Figure 16 Existing School Accommodations or Adjustments in Place

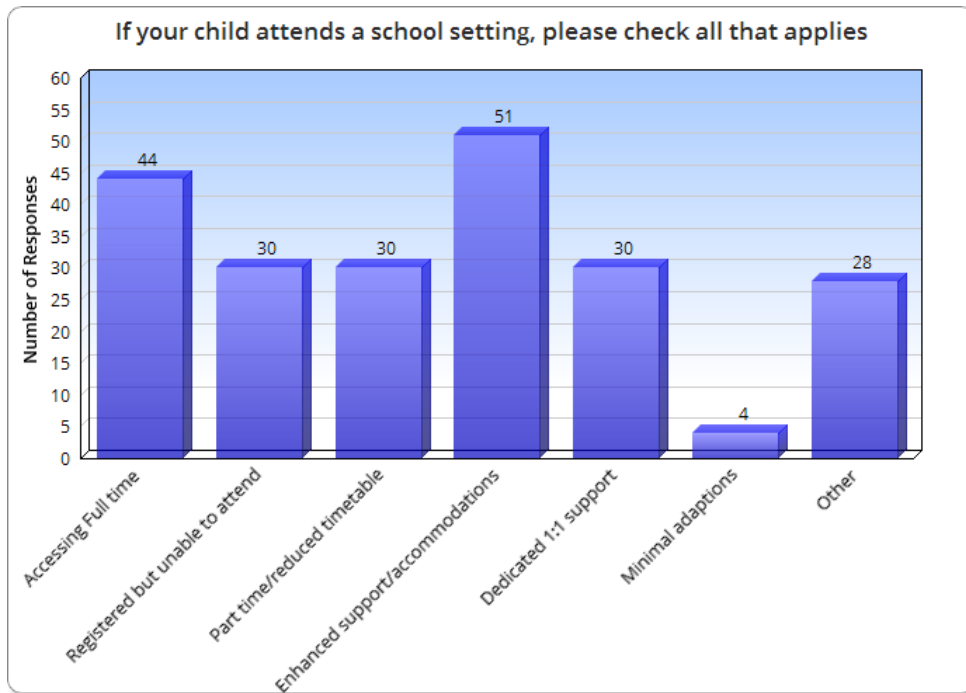


Figure 16 shows that, out of those currently registered at a school setting (n=91) only 48% (n=44) were accessing full time education, whilst 32% (n=30) were on a part time timetable. Fifty-six percent (n=51) have enhanced support and 32% (n=30) receive one-to-one support. Among the four responses reporting minimal adaptations, two were already attending enhanced provisions, while the other two were in mainstream education but unable to attend full-time. These findings indicate that PDA children require enhanced support and accommodations to successfully access education.

Figure 17 Concern for Social Perception.

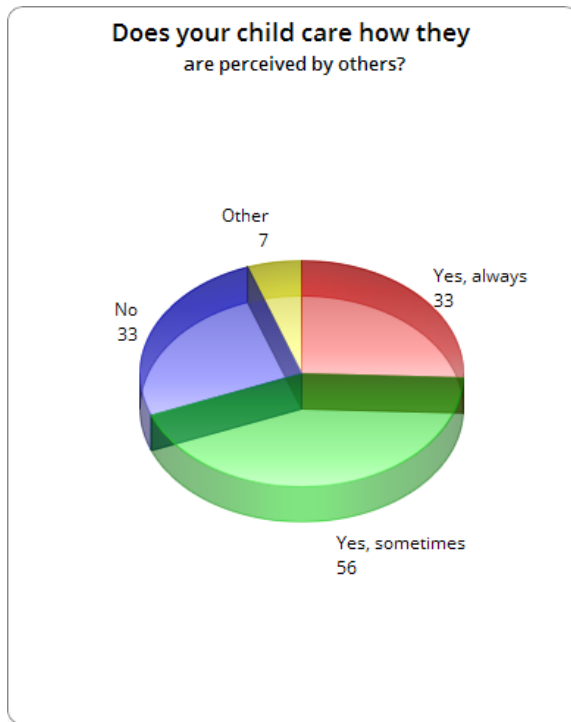
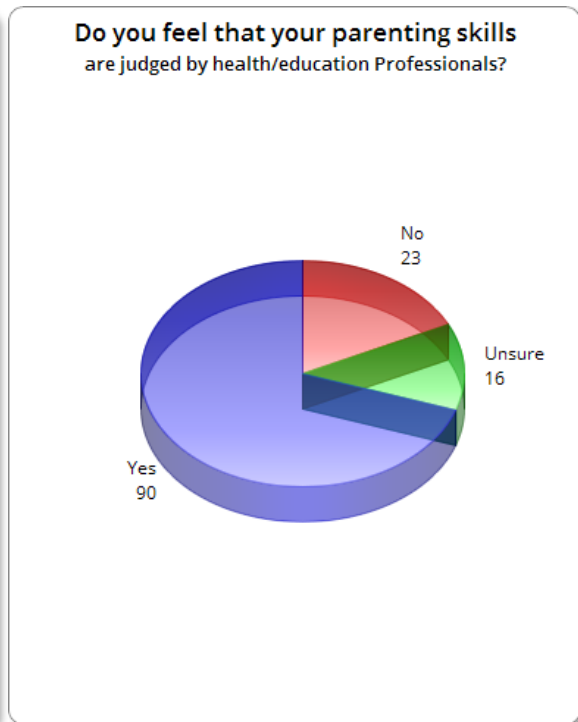


Figure 18 Judgment of Parenting Skills



It is noteworthy (Figure 17) that eighty-nine individuals expressed concern about how others perceive them. It may have been more beneficial to include this question before and after experiencing heightened states to gain specific insights. Figure 18 shows that most parents are hesitant to collaborate with professionals due to fears of being judged based on their children’s behaviours, which impacts their parenting abilities. Seventy percent of parents reported feeling judged (n=90), which can increase stress and hinder caregiving. This highlights the importance of creating a supportive and non-judgmental environment for parents to empower them throughout their parenting journey.

One parent commented:

*“Professionals implied that my child was being wilfully defiant, and our parenting was the cause. Doctors have said that we aren’t trying hard enough.”*

Another said:

*“CAMHS has eluded that we have created and/or contributed to our son’s behaviours. She could not understand that how everything she suggested did not work and, hence, we must be doing something wrong.”*

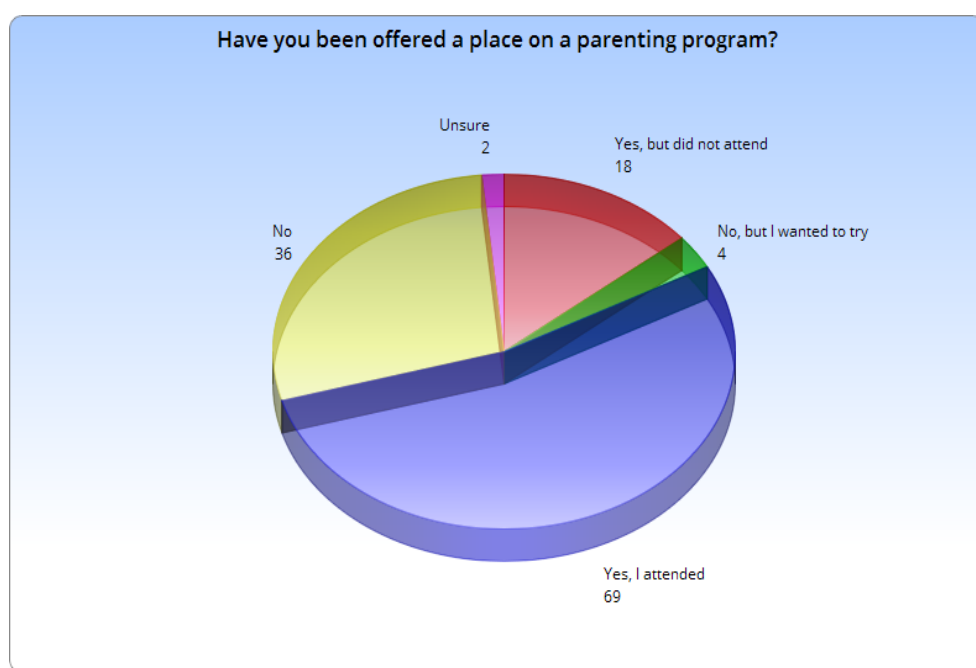
Of those that did not feel judged (n=23) one parent said:

*“They tend to accept what I tell them rather than give other reasons for behaviours. This may be because I work in education and have read a lot around PDA.”*

Another said:

*“I have identical twins, so it works to my advantage. They can clearly see my parenting works with his brother so clearly that’s not the issue!”*

Figure 19 Offer of Parenting Program

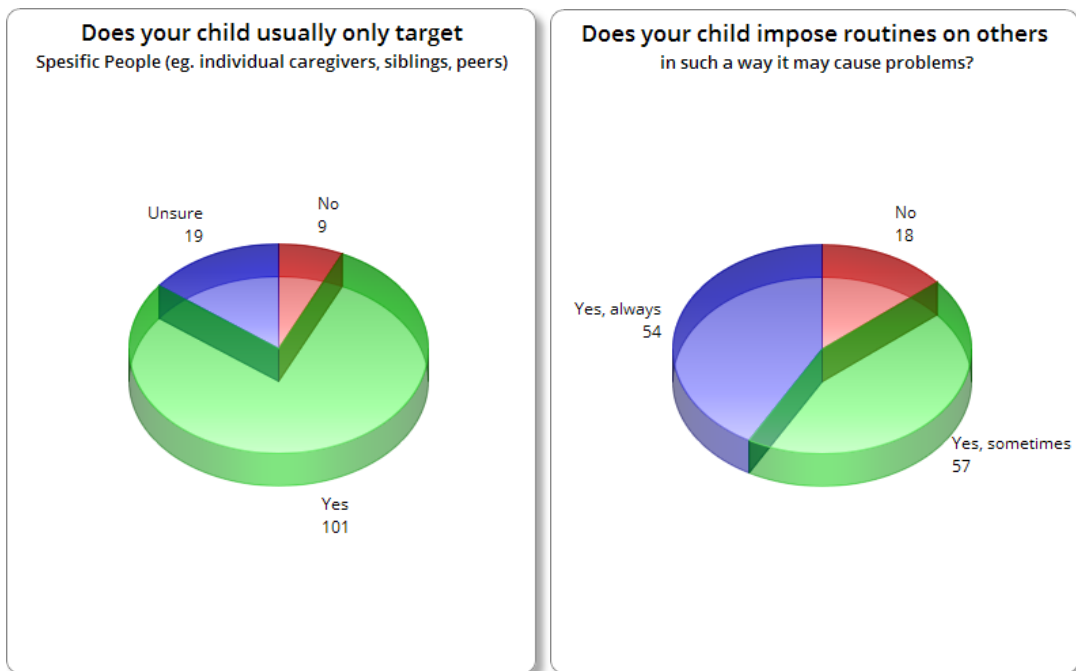


It was discovered (Figure 19) that 68% of parents have been offered a parenting program (n=87) by the NHS. Of those, only 14% (n=18) refused to attend which suggests that most parents are keen to engage in anything that may help their child. One parent reported:

*“I have been sent on numerous parenting courses, with conflicting strategies, referred for counselling and CAHMS offered me Dynamic Interpersonal Therapy which is aimed at looking at me and how I relate to others and my personal relationships. I felt that even though my son presented with the same behaviours everywhere, they were very much of the impression that my poor mental health was the issue and not that my mental health was poor as I was dealing with so much and with no support”.*

Figure 20 Preference for Specific Individuals.

Figure 21 Imposition of Routines Causing Problems



PDA can manifest in obsessive behaviours, often focused on other people, as a way of avoiding social situations or following instructions. However, this behaviour may be considered manipulating and controlling. Among the respondents (see Figure 20), 78% (n=101) shared that their child tends to single out specific individuals. One parent remarked:

*“My child tends to target children he perceives to be a threat; he can be very harsh with his words and sometimes physical.”*

Additionally, 86% of parents reported (see Figure 21) that their child imposes routines on others, aiming to gain control over the situation and escape ordinary demands or social interactions. For example, one parent mentioned:

*“He will only go to the lunch hall if he is permitted to sit opposite one particular child.”*

Figure 22 Dominant Emotion Displayed by Child

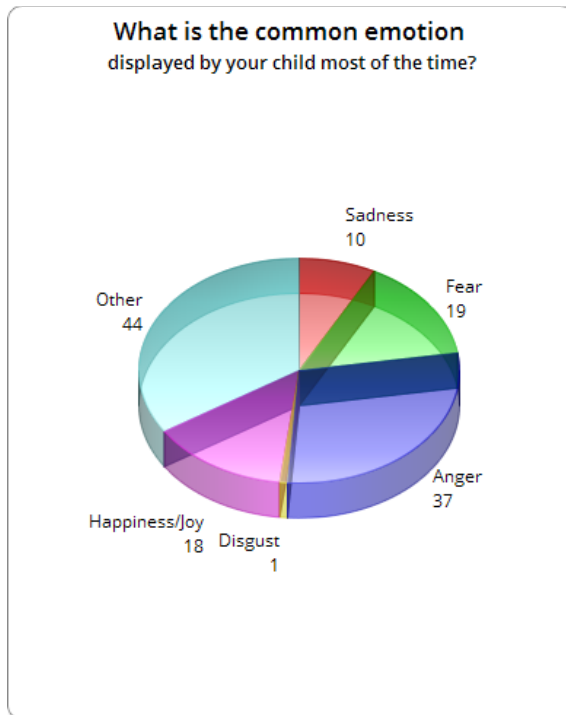
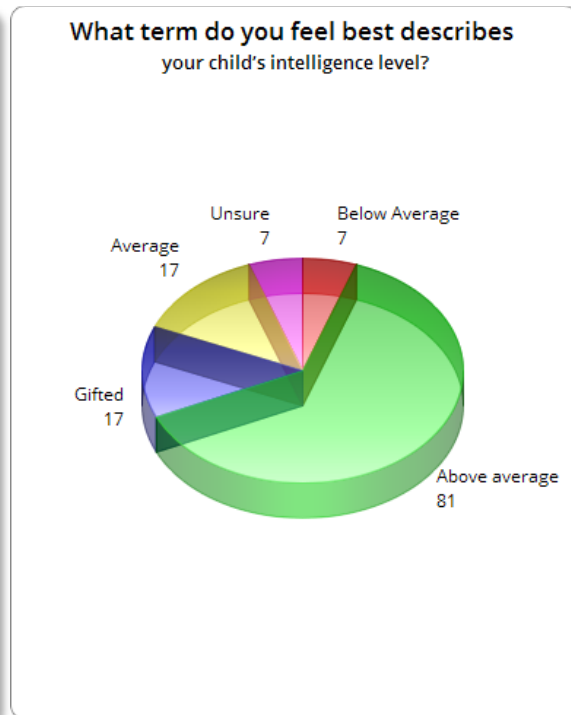


Figure 23 Intelligence Level Description of Child



The children surveyed displayed the most common emotions as anger (n=37), fear (n=19), and happiness (n=18), with an additional forty-four responses noting rapid mood swings from anger to happiness. Despite 76% of these children being identified as above average intelligence (n=81) and gifted (n=17), with only 5% (n=7) reported as below average intelligence (Figure 23), they were not thriving academically. This highlights the need to address the isolation and exclusion experienced by these children. Educators should recognise the significance of control, autonomy, anxiety, and stress in PDA children to develop effective strategies for support. By fostering collaboration among parents, educators, and professionals, tailored early interventions and accommodations can be implemented to promote the children’s well-being and academic success.

#### 4.2 Survey: Identified Themes

This study used open-ended questions in a questionnaire to explore how parents address the educational, psychological, and emotional needs of PDA children for their overall

development. Data was analysed using thematic analysis (Braun and Clarke, 2006) to examine parent responses. The themes identified provide valuable insights into the behavioural responses of PDA children and how parents manage these challenges. The three main themes identified were: the significance of control and autonomy, rigid thinking, and the impact of anxiety and stress.

#### 4.2.1 Need for Control and Autonomy

The first theme, the significance of control and autonomy, emerged as a prominent finding from the parental questionnaire. The results indicate that PDA children consistently express a strong inclination to have control over various aspects of their lives, including daily routines, activities, and the behaviour of others. However, this behaviour often presents challenges for parents, as everything must align with the child's rules, resulting in increased stress and strained relationships with educators, peers, and family members. This excessive need for control may be attributed to the children's underlying anxiety and their need for a sense of security in their environment.

For instance, one parent highlighted:

*“My child must be in control of everyone and everything. It gives them some control when they make lots of demands on me.”*

Another parent echoed this, saying:

*“She wants things done her way all the time. It's a constant struggle to negotiate even the smallest decisions.”*

The parents' responses demonstrate that PDA children necessitate complete control over their lives and decisions. Absence of this control causes considerable anxiety, resulting in intensified PDA characteristics and behaviours. The strain of this affects both the child and those around them.

#### 4.2.2 Rigidity of Thought

The second theme arising from the analysis was rigidity, which was expected given that all children were ASC diagnosed and 54% diagnosed ADD/ADHD. These neurodevelopmental differences lead to distinct thinking and information processing patterns, often resulting in a preference for consistency and predictability. Autistic individuals may have inflexible thinking, struggle to shift perspectives, or consider alternative viewpoints. They may also face challenges with abstract or hypothetical concepts, gravitating towards concrete and literal thinking. According to 72% of parental responses, children's behaviour escalates when specific things do not align with their motivations. For example, one child insists on a particular seat despite it being occupied, while another insists on a specific classmate seating arrangements. Parents noted that PDA children prefer specific activity timings, task orders, meal choices and outing destinations. Deviations from routines cause significant distress, leading to verbal and physical behaviours. As a result, parents and teachers often adhere to these routines to minimise anxiety, create predictability, and allow for some flexibility to facilitate inclusion.

The response from a parent highlights the difficulty of raising a PDA child due to rigidity and need to control:

*“My child controls our routine, what I do and when. I had to give up my full-time career, I don't schedule anything before 11am because I never know how difficult it will be to get my child to school.”*

Another parent further explained the extent of the challenge:

*“If we have to change the routine unexpectedly, it completely throws him off, and he becomes extremely anxious and agitated.”*

The behaviour of the child would prove challenging to navigate, further aggravating their PDA. In contrast, some participants reported that their children struggle to follow day-to-day routines at school and/or at home unless they align with their own agenda, with one highlighting:

*“Routines are seen as a demand, they increase anxiety, he finds routines boring and is persistently on high alert ready to refuse to engage in any routine which is expected, he needs persistent excitement and spontaneity, everything needs to be his idea, or he will either refuse to participate or forcefully alter the request until it aligns with his agenda”.*

#### 4.2.3 Anxiety and Stress

The third theme that emerged is the impact of anxiety and stress on the behaviour of PDA children. Participants reported that their children displayed increased control-seeking behaviours, particularly after experiencing stress, such as at school, with some refusing to attend. The need for control may serve as a coping mechanism to manage anxiety, providing a sense of stability and predictability in their environment.

One parent mentioned that their child would change to a new routine to regain control:

*“He seems to do it after a stressful experience, more, after school. It is like a need to be in control. He seems to subtly alter a routine, and then that very quickly becomes the new routine.”*

Another parent agreed with the notion of control, stating:

*“When she feels anxious or overwhelmed, her need for control becomes even stronger, she becomes hyper-focused on trying to control everything.”*

Imaginary friends and fantasy worlds are another way that children cope with the stress and anxiety they experience in a mainstream school setting, where they may feel a loss of control. Thirty nine percent of parents reported that their child engages in fantasy and role play (n=131), with 18% (n=62) reporting that their child did so when younger but appeared to have either grown out of or masked this behaviour. One parent highlighted:

*“My child identified as catboy for a year, as he matured, he started to adopt more believable personas such as 9-year-old John from Australia; every persona had a well-versed back story that’s never forgotten.”*



PDA Children display emotional challenges and significant fluctuations in mood and behaviour, which can be challenging for parents. These difficulties negatively impact on the child’s health and well-being, underscoring the need for specialised support and interventions that address their comprehensive development.

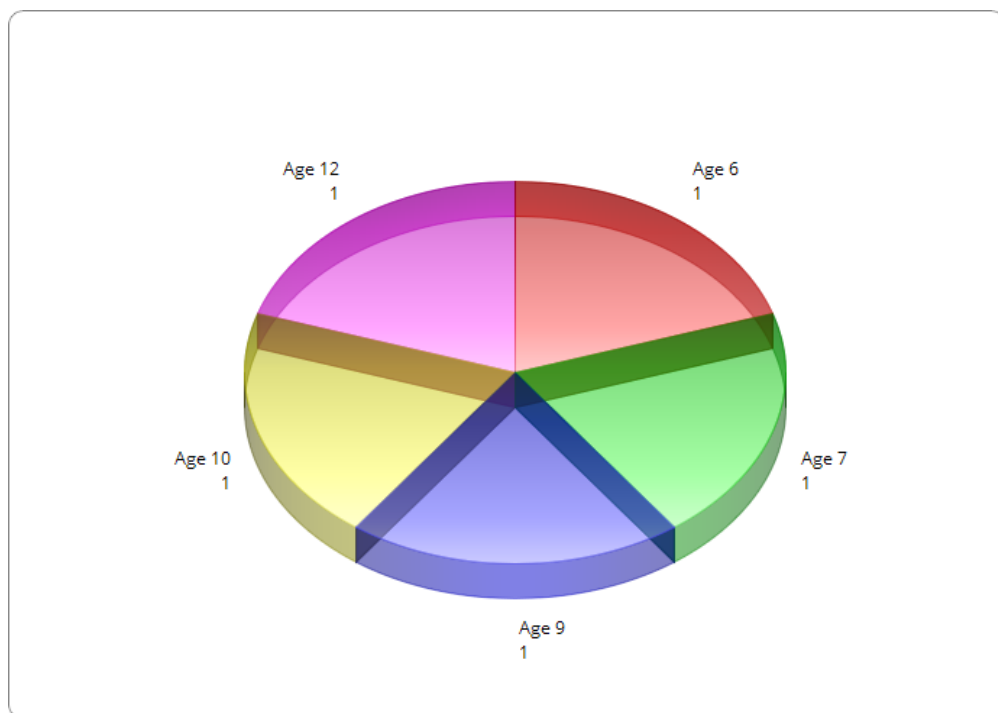
### 4.3 Analysis of Interviews

Interviews were conducted with five participants who had children diagnosed with a PDA profile to gain insights into their behaviour and the support provided by the education system.

#### 4.3.1 Demographic Information

Twelve participants were contacted and five responded. The average age of their children was 8.8 years. The chart (Figure 24) displays the distribution of the demography:

Figure 24 Age of Child



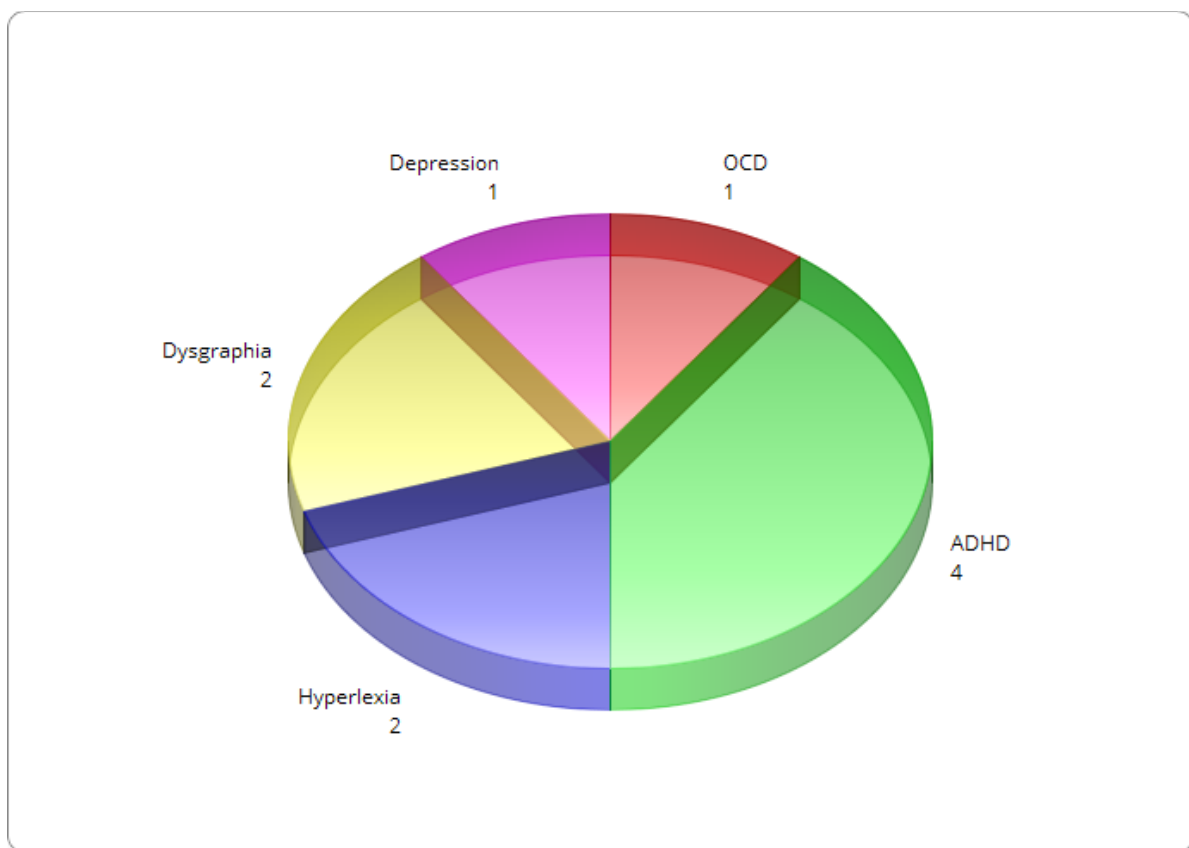
#### 4.3.2 Background Information

Participants had children who received a mix of mainstream schooling (n=3) and home education (n=2). The home-educated children were previously enrolled in mainstream

schools. Of the children in mainstream education, one attended full-time while the other two attended part-time. All children experienced difficulties attending school and showed signs of VCB. Four participants had to give up their careers to address their child's challenges. Additionally, four participants felt isolated, and all children had previously experienced rejection and exclusion from social events. Currently, four children still face rejection.

All participants reported that their child had co-occurring conditions (See figure 25): ADHD (n=4), Hyperlexia (n=2), Dysgraphia (n=2), OCD (n=1), Depression (n=1).

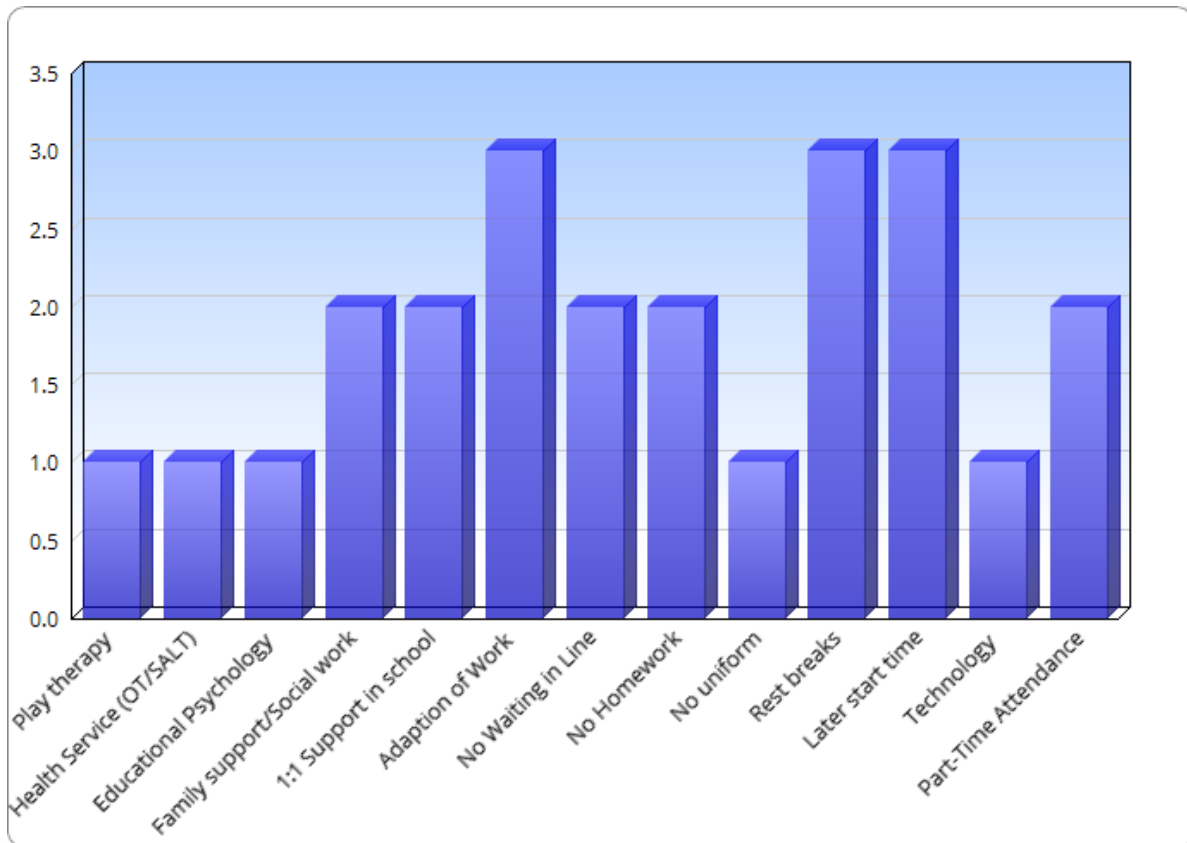
Figure 25 Co-occurring conditions



Interestingly, the one participant without a dual diagnosis of ADHD observed sporadic bursts of excitement in their child, which could be comparable with ADHD traits. Despite high intelligence, all children encountered difficulties with authority and structured hierarchical environments. According to participants, children derived enjoyment from independent learning through the internet.

The graph below (figure 26) shows accommodations currently provided in school or, in the case of those now home educated, accommodations provided while they were at school.

Figure 26 Accommodations/Reasonable Adjustments



Participants emphasised the significance of various accommodations and supports that have played a vital role in facilitating school attendance and minimizing harmful behaviours. These adjustments including having adaption of work (n=3), later start times (n=3), rest breaks (n=3), one-to-one support in school (n=2), part time attendance (n=2), no homework (n=2), family support (n=2), no waiting in line (n=2), no uniform (n=1), technology (n=1), play therapy (n=1), health services (n=1), and educational psychology (n=1). Participant A said:

*“They gave him access to a quiet space and wasn’t forced to take part in lessons because they knew it just makes him angrier”.*

Participant C commented:

*“They try to ensure that his voice is heard during class discussions, when he displays harmful behaviours it is very often because he feels frustrated about the environment or the people in it”.*

All participants had concerns about the competence of educational staff in supporting their child. Four participants mentioned that teachers showed limited interest in participating in Continuing Professional Development (CPD). Four out of five participants believed that staff frequently blamed them for their child's behavioural challenges. All participants were offered parenting courses.

Participant E said:

*“They blamed me, not always outrightly but I could tell that this is what they were implying”.*

Participant D said:

*“It is insulting to keep having parent training offered when I know they have no background in PDA and all their suggestions are just counterproductive.”*

#### 4.4 Interviews: Identified Themes

The interview data was analysed using the Six Steps of Data Analysis (Braun and Clarke, 2006) (see Appendix 7). The following themes emerged.

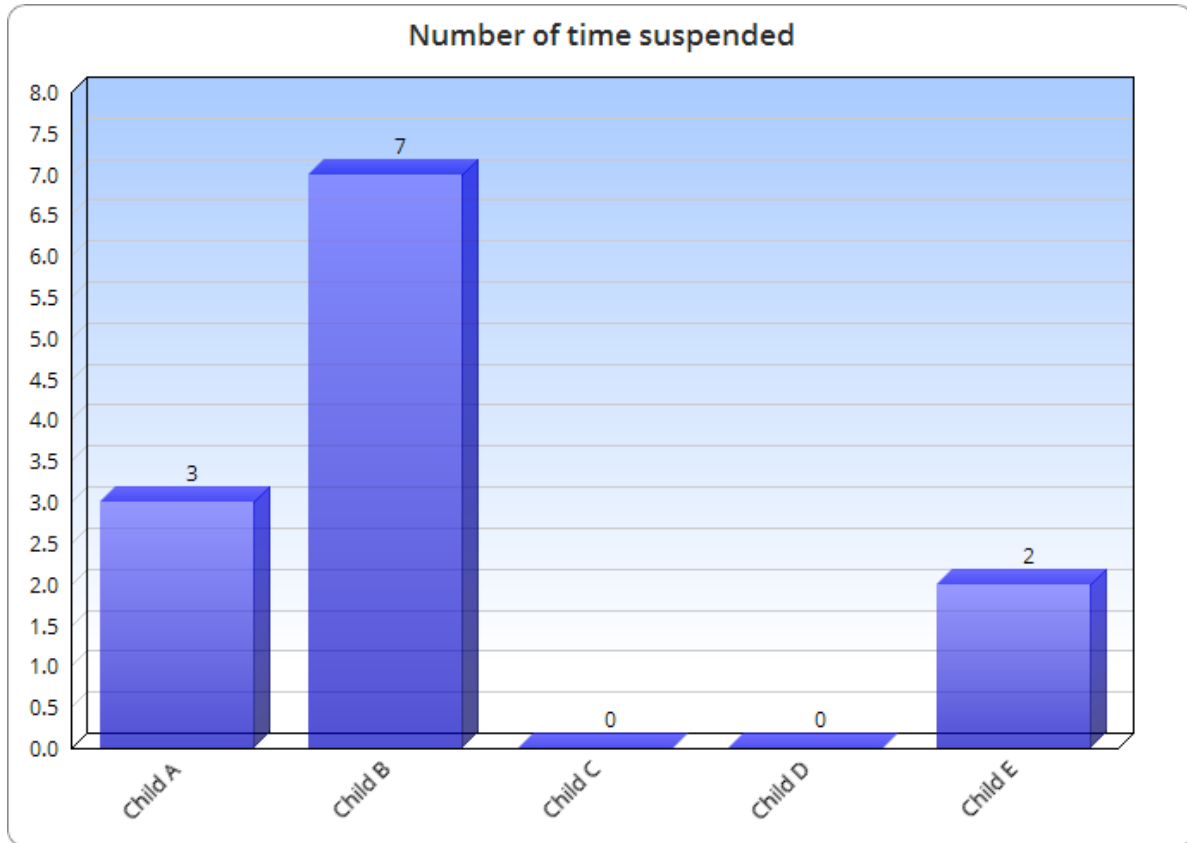
##### 4.4.1 Impact of Anxiety and Stress and Explosive Behaviour

All five parents reported that their children exhibited fight or flight response behaviours when faced with uncomfortable situations. Participant C indicated that when her child is dysregulated, he needs to use more “shocking” language to communicate when shouting “no, stop, go away” isn't taken seriously. Participant B shared that their child's fight response led to suspension from school on seven separate occasions (Figure 27):

*“They forced her into school even though she was kicking and screaming every day, she is traumatised by the experience, and it affected her mental health.”*

This response represents the way PDA has greatly impacted the education of children with the condition.

Figure 27 Number of Times Suspended from School



#### 4.4.2 Desire for Control and Autonomy

The second theme that emerged was the importance of control and autonomy. Parents have made compromises to balance safety while enabling their children to have more independence in daily routines and choices. For instance, Participant A has made concessions to establish a harmonious home environment for herself and her older child, allowing their PDA child to determine mealtimes and bedtimes based on personal preferences. They explained:

*“When he was suspended, they didn’t give any help to my family, it was really hard on his brother because the kids at school were bullying him because of his brothers shocking behaviour.”*

Furthermore, the other participants also emphasised the importance of prioritising safety for their child, themselves, and others by accommodating the child's preferences. For example, Participant C's child would cooperate well when anxiety levels were low, often impersonating cartoon characters to encourage participation in specific tasks. These concessions were crucial in preventing behaviours that might disrupt effective interaction or hinder motivation to complete assigned tasks.

#### 4.4.3 Parent-Child and School Relationships.

The interviews also revealed that the children had difficulty associating with others. Some participant's children (A, B, and E) had never been invited to parties, while participant D mentioned rare invitations to whole class parties. Participant C's child previously experienced isolation due to parental reluctance to allow interactions owing to unpredictable and harmful behaviours. Additionally, participants noted that although their children expressed interest in playing with peers, they often tried to control and change the rules of games, leading to tensions.

All participants reported difficulties getting the school to effectively engage their children in meaningful learning opportunities. They attended parent courses that did not focus on PDA, and which provided advice they believed to be harmful to their children. Parents expressed frustration with the school system, and legal action was required in the case of participant C to ensure their child's needs were met. After legal intervention, participant Cs child was placed in a suitable out-of-catchment school with full-time one-to-one support, which resulted in positive behavioural patterns and engagement with other children.

Three participants expressed a lack of support from the education system, leading to significant challenges for them and their children. Four participants had to leave employment to provide appropriate care. Participants A, B, and D stated that they faced segregation from other parents due to their child's unpredictable harmful behaviours, resulting in significant isolation. All Participants mentioned that their children could learn independently using technology to pursue their own interests. The interviews also revealed that, except for Participant C, none of the participants were aware of any existing peer support groups within their community.

The interview results align with the questionnaire findings, particularly regarding how PDA children respond to uncomfortable situations with a fight or flight reaction to anxiety. Both the survey and interview results highlight the segregation experienced by parents and their children. Autistic learners typically need structure, routine, predictability, and rewards, whereas PDA learners require novelty, spontaneity, control, trust, and autonomy (Kerbey, 2023, p. 14). The interviews also demonstrated that educational institutions, despite their varying provisions, did not offer sufficient support.

#### 4.4.4 Technology

The fourth theme identified focused on technology. All participants reported that their children devoted a significant amount of time to gaming or engaging in online platforms. Participants highlighted that their children relied on technology as a means of accessing desired information. Moreover, participants mentioned that their children possessed a high level of proficiency in using technology, allowing them to pursue their interests. However, Participant D noted that their child utilised technology as a coping mechanism, often isolating themselves indoors while playing games.

#### 4.4.5 Professionals and Collaboration

The theme of engagement with trained professionals also emerged as an important issue. Several participants expressed difficulties in getting the school to effectively engage their children in meaningful learning opportunities. Participants A, B, D, and E, all felt that educational staff lacked understanding and knowledge about PDA, leading to despair and feelings of being unsupported. Participant E was not even aware of PDA until after their child had left school. Participants A, B, D, and E also mentioned being blamed for their child's behaviour without receiving helpful advice or seeing any improvement in staff suggested approaches. In contrast, participant C reported a more positive experience, noting that educational staff had some awareness of PDA and were willing to work collaboratively to find solutions. The school in participant C's case sought support from external health and education professionals. This collaborative partnership resulted in positive outcomes, with participant C's child attending school full-time with necessary adjustments and accommodations, including one-to-one support.

#### 4.5 Conclusion of Findings

The interview findings align with the questionnaire results, indicating that PDA children often display flight or fight behaviours when experiencing anxiety or stress. These behaviours stem from their desire for control and autonomy, potentially resulting in explosive anger and frustration. Participants made daily sacrifices to care for their PDA children and sought professional assistance to diagnose their children, which is essential for adaptation in an educational environment. Nevertheless, parents also play a significant part in promoting positive behaviour in their children. For instance, Participant C sought professional help to ensure their child received support for modelling and encouraging communication and positive behaviours. Understanding their child's needs and motivations is vital for parents to facilitate engagement with others and task completion. Parents are responsible for identifying triggers and avoidance behaviours exhibited by their children, which, coupled with knowledge on how to support them, can help foster positive behaviours. Therefore, parents have a central role in ensuring their children receive appropriate support and care, with parents and educational institutions both having a crucial role to play in promoting engagement and support for PDA children.



## Chapter 5: Discussion

This chapter provides discussion on the challenges faced by PDA children in school, supporting existing evidence that PDA is often identified in childhood (Gilberg, 2014). Recognising PDA traits allows for early intervention during critical child development stages.

Thematic analysis revealed recurring themes of control, hyperactivity, intelligence, anxiety, and stress in PDA children. Exploring these themes aims to enhance understanding of the unique challenges faced by PDA children and their caregivers. This understanding may contribute to interventions promoting successful education and inclusion of PDA children in mainstream schools.

### 5.1 Valuing Lived Experience

Recognising the value of lived experience is important in academia as it enhances research, promotes inclusivity, empowers marginalised individuals, connects theory and practice, informs policymaking, and upholds ethical responsibilities (Lewis and Hasking, 2019). Including diverse perspectives and engaging with individuals who have first-hand knowledge can generate more comprehensive knowledge and achieve meaningful outcomes, which improves the quality and credibility of findings and provides unique insights and a deeper understanding (Taylor and DaWalt, 2020). Validating and comparing findings with lived experiences adds further legitimacy research and has the potential to positively impact people's lives.

In this study, the real-life experiences of two adults, Julia Daunt and Harry Thompson, who were diagnosed PDA in childhood (Fidler and Daunt, 2021; Thompson, 2019) were examined and compared, alongside the documented experiences of a parent raising a child diagnosed with PDA named Mollie (Shewin, 2015). Julia was described as polite and courteous, but her behaviour with other children was unpredictable, causing fear (Fidler and Daunt, 2021, p26-p27). Similarly, Thompson (2019, p54) recalls being seen as “*strange and unpredictable,*” exhibiting sudden shifts from being loud to quiet and from being “*polite to rude*”. These accounts align with the metaphor of a “*Jekyll and Hyde*” character (Milton, 2013; Keenan, 2018) and support the experiences shared by parents in this research study, who reported rapid mood variations in their children. The literature review highlights the challenges of

raising PDA children, exacerbated by insufficient support from the education system (Gore Langton and Frederickson, 2015; Kerbey, 2023; Mavir, 2023; Truman, 2021). Inadequate support and a lack of flexibility in the curriculum for PDA children contributes to stigma and may worsen their circumstances. Educators require support to address challenges when working with PDA learners, as identified by Doyle and Kenny (2022). These challenges include understanding the causes of anxiety and avoidance, implementing unconventional strategies, managing emotional dysregulation, dealing with unpredictability, and facing a lack of support from colleagues for alternative approaches, which is crucial for educators in navigating these obstacles effectively.

## 5.2 Control, Freedom, and Independence

The findings of this study are consistent with the existing research (Christie et al., 2012; Gore Langton and Frederickson, 2015; Truman et al., 2021), highlighting the crucial role of control and autonomy for PDA children and how it significantly impacts their families. Parents often find themselves accommodating their children's demands, making sacrifices in their careers and personal lives. These findings are consistent with research conducted by Connolly and Mullally (2023) and Doyle and Kenny (2022), which highlight various aspects of parents' experiences, such as dealing with fatigue and stress, addressing aggressive behaviour, managing daily activities, considering the impact on other family members, and supporting their child's education. This notion is supported by Moh (2012), who provides insights into the difficulties encountered by parents in their attempts to establish authority in such situations. Thus, it is imperative to recognise and acknowledge the inherent necessity of autonomy in order to design interventions that can effectively enhance emotional well-being and facilitate adaptive responses within educational environments. Examination of the interview data revealed that 70% of parents reported feeling judged or blamed for their child's actions. The findings align with the research conducted by Running and Jata-Hall (2023) who reported a greater percentage of blame (87.8%). Likewise, Julia shared that her mother faced continuous blame until she was hospitalised at twelve for self-harm and referrals were made for assessment (Fidler and Daunt, 2021, p38-p61). Elizabeth Newson described Julia's parents as

*“A major source of strength for Julia at great emotional cost to themselves.”* (Fidler and Daunt, 2021, p61).

This underscores the need for empathic and supportive assistance for parents in their caregiving role. The findings suggest that PDA children become more resistant as expectations increase, with a peak in avoidant behaviours occurring around school starting age which is consistent with Truman et al., (2021).

This study emphasises the substantial influence that the need for control plays in the expression of PDA, shedding light on how it contributes to demand-avoidant behaviours. According to Fidler and Daunt (2021, p27, p88), Julia displays a significant dislike for unpredictability and anything outside of her control. According to her mother, *“right from the start, it was her way, or all hell broke loose”*. Sherwin (2015, p73) explains that everything had to be either avoided or done on her child’s own terms. Similarly, Thompson (2019, p24, p62) explains his inherent desire for freedom rather than a compulsion driven by a lack of control emphasising that need is so strong that *“even death”* is often considered a more favourable option than obeying orders.

The findings from the survey and interviews indicate that a dearth of customised environments and resources for PDA children has a role in the misinterpretation of their behaviour and upbringing. The need for control plays a significant role in the lives of PDA children, as it enables them to effectively navigate potentially distressing circumstances and successfully acclimatise to various social environments. A study by Newson et al, (2003) revealed that all children exhibited demand avoidance through social manipulation. These findings are bolstered further by PDA adult Thompson (2019, p 32) who recalls:

*“In my most unhinged moments as a child I thought if I tried hard enough that I could manipulate and get my own way with the entire universe.”*

This is also consistent with the findings of this study, where 90.7% of participants reported using negotiation tactics to avoid demands. Sherwin (2015, p. 78) also noted that her child's lack of control outweighs their ability to prioritise the needs of others.

According to Green et al. (2018), PDA children have a strong internal drive but are influenced by their avoidance of demands. Contrary to previous beliefs (O’Brien, Frick, and Lyman, 1994; O’Nions and Eaton, 2020), my observations suggest that instantly gratifying rewards can motivate PDA children when they align with their intrinsic motivations. To

capture their interest, it is important to strategically present stimuli and experiences that cater to their strengths and interests, while always being mindful not to exploit them. Julia agrees that, despite the challenges of her PDA, she finds motivation in a supportive online community where she can relate to and help others (Fidler & Daunt, 2021, p. 57). It is noteworthy that PDA children often utilize a blend of fantasy and reality as a coping mechanism to navigate overwhelming aspects of daily life. For instance, one participant reported effectively overcoming challenges by utilizing their child's passion for online streaming by helping them create and review content. They further enhanced their learning by accessing resources for editing and producing videos.

### 5.3 Anxiety and Stress

This research also indicates that PDA children may exhibit explosive anger or engage in risky behaviours when experiencing anxiety or stress, which aligns with Christie's (2012) observations. Furthermore, the findings reinforce the notion that PDA children display avoidant behaviours and demonstrate flight or fight patterns, consistent with existing reports (Dundon, 2021; Eaton, 2018; Fricker and Fidler, 2022)

According to Greene (1998), explosive behaviours in children are not deliberate choices but a result of delayed development in flexibility and frustration tolerance skills. Identifying the factors that hinder the acquisition of these skills is crucial when cognitive capacity exceeds ability to handle demands. The study findings support the existing research in highlighting high exclusion rates (Gore Langton and Frederickson, 2015). In Scotland, the Scottish Government has established national policies and procedures that regulate school exclusions (Scottish Government, 2017). The primary focus is on fostering inclusion, tackling challenging behaviour, and aiding learners who may be susceptible to exclusion. Schools are obligated to the Education (Additional Support for Learning) (Scotland) Act 2004. This law outlines the rights and responsibilities surrounding support for children with additional needs. Newson,(2003) also highlighted challenging behaviours and high rates of suspensions in schools. Both Fidler and Daunt (2021, p37) and Thompson (2019, p109, p111) had a history of suspensions, and Sherwin (2016 p28, p39) reported multiple suspensions for violent outbursts and property destruction. Once diagnosed, Sherwin (2016) received improved support and experienced collaborative efforts that resulted in the elimination of the need for

suspension, whilst Julia became more settled within a pupil referral unit after diagnosis (Fidler and Daunt, 2021 p38-p49).

A PDA individual may display behaviours that go against society's core moral values. The survey revealed 95% of parents reported that their child says things that may be considered tactless or socially inappropriate. This aligns with the experiences of Sherwin (2015, p22) who explains that her child "*shocks others with complete lack of boundaries*". Thompson (2019, p53) also highlights that he goes to extreme lengths to get a reaction of "*sheer gobsmacked awe or shock*", whilst Daunt (2021, p18, p109) would incorporate shocking topics in conversations in attempts to dominate discussions. Research indicates that swearing can effectively alleviate stress (Vingerhoets et al., 2013; Stephens and Umland, 2011) and my conversations with participants support the idea that swearing serves as a coping mechanism. Swearing and verbal insults may act as a deterrent, preventing the child from physically harming others. Participant D indicated that when her child is getting dysregulated, they use more "*shocking*" language to communicate when shouting "*no, stop, go away*" isn't taken seriously. Greene (1998) explains swearing is usually a sign that the child doesn't currently have the linguistic skills to express frustration adaptively, highlighting that when a child's triggers are identified, explosions will become highly predictable. This pattern of behaviour frequently arises from feelings of inadequacy and insecurity, especially in social settings where the child may experience anxiety about their performance.

#### 5.4 Hyperactivity and Intelligence

Through thematic analysis, another theme emerged, highlighting the relationship between hyperactivity and intelligence among PDA children. Interestingly, the study found that 76% of the participants children exhibited high levels of intelligence and intense focus on areas of interest, often utilising technology to explore their passions. This corresponds with the research conducted by Doyle and Kenny (2023), where both of the PDA adults involved in the study were recognised as intellectually gifted.

According to Daunt (2021, p62), Julia is described as "*intelligent but not particularly academic*", This could be attributed to the rigid and methodical nature of academia, which may pose challenges with demand avoidance. Thompson (2019, p43-48), who is an

autodidact and self-proclaimed PDA extraordinaire, further supports this viewpoint by describing the school system as a meaningless and futile process.

Additionally, there was a significant association between PDA and ADHD. Over half of the participants (54%) in this study reported comorbid ADHD, with four out of five interviewees reporting diagnosed ADHD and the other reporting the presentation of related traits. This aligns with the experience of PDA adults Julia and Harry (Fidler and Daunt, 2021, p24; Thompson 2019 p75) and Mollie (Sherwin, 2015 p179) all of whom also have comorbid ADHD diagnoses.

It is important to differentiate between traits of giftedness and ADHD, as confusion often leads to misdiagnosis or overlooked recognition of giftedness (Kennedy et al., 2011 p16). ADHD is a clinically recognised disorder with specific diagnostic criteria, while Dabrowski's Overexcitabilities, which relate to intensities in individuals with advanced developmental potential, are not formally recognised as a diagnosis but provide a framework for understanding intelligence and intense personal development (Daniels and Piechowski, 2009). Furthermore, Alias et al. (2013) found that 88% of gifted learners possess at least one high level of overexcitabilities.

## 5.5 Exploring the Connection between Dabrowski's Overexcitabilities and PDA

Dabrowski's theoretical framework encompassed five distinct overexcitabilities, namely psychomotor, sensual, intellectual, imaginal, and emotional (Daniels and Piechowski, 2009). These overexcitabilities are indicative of heightened sensitivities and pronounced reactions to specific stimuli and potentially impact upon an individual's personality and behaviour. Several studies have explored the correlation between ADHD and Dabrowski's overexcitabilities, shedding light on their potential interplay. However, none of the existing research specifically explores the connection between Dabrowski's overexcitabilities and PDA. The survey revealed that 76% of the children had above-average or gifted intelligence and also revealed the presence of autodidact and abilities to hyperfocus on areas of interest.

### 5.5.1 Psychomotor Overexcitability

PDA individuals often exhibit high levels of psychomotor activity, characterised by restlessness, competitiveness, and enthusiasm in areas of interest, coupled with bursts of impulsivity. This was also highlighted by interview participants (Appendix 6). Both PDA and psychomotor overexcitability involve intense responses to external stimuli (Daniels and Piechowski, 2009; Moore, 2020). Misinterpretation between strong aversion or anxiety towards demands or requests and heightened physical and motor responses to stimuli may exist, suggesting a positive association between PDA and psychomotor overexcitability and indicating a potential overlap in symptomatology.

### 5.5.2 Sensual Overexcitability

Sensual overexcitability relates to heightened sensitivity to sensory stimuli, including sound, touch, taste, and smell. Sensory sensitivities are commonly observed in PDA individuals as highlighted during parental interviews. (Appendix 6), leading to avoidance or aversive responses to sensory stimuli (Green et al., 2018; Malik and Baird, 2018; O’Nions et al., 2017). Studies have highlighted the presence of sensory sensitivities in individuals with overexcitabilities, although more research is needed to fully establish a link between sensory overexcitability and PDA.

### 5.5.3 Intellectual Overexcitability:

Intellectual overexcitability is characterised by a fervent enthusiasm for learning, intricate thinking, and a desire for intellectual stimulation. The results of this study indicate that 76% of the participants children showed above-average or gifted intelligence. Additionally, these children were noted to be self-directed learners, drawing a potential link between PDA and intellectual overexcitability. According to O’Nions et al. (2013), 46% of identified PDA children demonstrated superior intelligence, while 34% had average intelligence. Sherwin (2015, p29 p55) reported exceptionally high intelligence, with an IQ of 135 (99th percentile) at three years old and 123 (94th percentile) at eight years old. Despite Participant Cs PDA preventing him completing all sections of the Wechsler Intelligence Scale for Children (WISC), he was considered 88th percentile. Participant D was identified as gifted, and Participants B and E exhibited extensive knowledge within their areas of interest. The results discussed in this study align with the research carried out by Doyle and Kenny (2023), whose findings indicated that one participant displayed exceptional reading skills, resulting in their

advancement to the next grade. Additionally, another participant was assessed as being within the top 2% of ability at school and received a scholarship to attend a prestigious institution in the UK.

#### 5.5.4. Imaginational Overexcitability

Imaginational overexcitability entails vivid imagination, rich fantasy life, and creative expression. Role Play and fantasy are a key criterion of PDA and the research findings show that 56% of the participants' children possessed this trait, with an additional 17% seeming to outgrow it. This suggests that PDA individuals possess heightened imaginative abilities as they navigate away from demands. Julia, a PDA adult, explains that as a child her:

*“Lines between reality and fiction were frequently blurred...”* (Fidler and Daunt 2021, p 37)

This is further explained by Sherwin, (2015, p80):

*“[S]he appears to use fantasy to reduce the stress imposed on her by the outside world at times she can become so involved in her imaginary role play, the edges of fantasy and reality appear blurred”.*

#### 5.5.5 Emotional Overexcitability

Emotional overexcitability involves heightened emotional responsiveness, intense empathy, and a strong emotional connection. Eighty-six percent of parents reported that their child imposes routines on others. They also reported that their children struggled with managing and expressing their emotions. The intense emotional reactions associated with overexcitability can lead to negative responses and a tendency to avoid demands.

#### 5.6 Dabrowski's overexcitabilities and PDA

While research linking Dabrowski's overexcitabilities and PDA has not been studied, a study by Smith et al. (2016) found a significant correlation between higher levels of giftedness and increased avoidance behaviours. Johnson's (2009) Achievement Avoidance Theory suggests



that gifted individuals may engage in avoidance when faced with challenging tasks, highlighting the need for a supportive learning environment that reduces anxiety. Sensory sensitivities, emotional dysregulation, imaginative tendencies, and a desire for autonomy and control are common aspects of both overexcitabilities and PDA. Further research exploring the relationship between these concepts could improve our understanding of PDA individuals' unique characteristics and needs. Recognising the potential interaction between Dabrowski's overexcitabilities and PDA can contribute to a more comprehensive understanding of PDA and facilitate more effective interventions and support for individuals with this profile.

## 5.7 Discussion Conclusion

This study aimed to assess how parents evaluate the quality of educational provision for their PDA children in mainstream schools. The focus was on understanding parental perceptions of their children's educational experiences, exploring the impact of these experiences, and identifying strengths and challenges associated with educational provision. The results emphasised the importance of teaching effective strategies for managing stress and anxiety in PDA children through open communication, joint problem-solving, and accommodations, such as flexibility in the curriculum and rest breaks. By doing so, flight or fight behaviours can be reduced. Incorporating the children's interests into their learning can also prove beneficial in enhancing their educational experiences, promoting a sense of calmness and reducing VCB. However, caution should be exercised to avoid exploiting these interests as manipulative means of control. The literature review indicated widespread challenges for PDA children in accessing education, but this study found a smaller number of affected children than expected. It is crucial to note that all participants' children already had a diagnosis of Autism with a PDA profile, which provides legal safeguards against discrimination. The Equality Act (2010) ensures that autistic individuals are safeguarded from unfair treatment based on their disability and appropriate accommodations in educational settings. Parenting training offered to 68% of participants in this study proved inadequate, as trainers had no knowledge of PDA. As discussed by Gore Langton and Frederickson (2015), insufficient parental training and a lack of understanding in the education system hinder the intellectual development and positive outcomes for PDA children in society.

## Chapter 6: Implications, Limitations and Recommendations

This chapter discusses the implications, limitations, and recommendations derived from this study and provides suggestions for future research. It will also discuss the significance of the study and its potential impacts for PDA children in education.

### 6:1 Implications of the Research Study Findings

The research findings uncovered several key insights that are crucial for informing the education sector on supporting PDA children. Firstly, they highlight the importance of employing professionals with expertise in PDA within educational institutions. These professionals play a critical role in tailoring the curriculum to meet the specific needs of PDA children, as well as enhancing the understanding of PDA among staff and parents. This collaboration between professionals, schools, and parents is essential in ensuring a smooth transition for PDA children from home to school (Kerbey, 2023 p 124).

Additionally, the research emphasises the vital role parents play in identifying their child's condition and in facilitating integration into society. By offering appropriate guidance and support, parents can contribute significantly to their child's overall development and wellbeing. These insights underscore the significance of collaboration among professionals, educators, parents, and the development of tailored strategies to ensure adequate support for PDA children (Fricker and Fidler, 2022; Gore Langton and Frederickson, 2015)

### 6:2 Limitations

The research also contains some limitations. One limitation is that the research solely relied on interviews with parents to assess their children's experience and progress at school. While the survey questionnaire and interview process produced meaningful results, it is important to acknowledge that they may have been influenced by the respondents' personal biases (Braun, Clarke and Gray, 2017). Another limitation is the lack of involvement from educational institutions, which means that the research primarily represents the parents' perspective on PDA-diagnosed children. The study is qualitative and therefore focused on understanding subjective experiences, meanings, and interpretations rather than obtaining quantifiable data (Sharp, 2012).

## 6:3 Recommendations

PDA poses challenges for both parents and educators in ensuring that children receive an adequate education. The research suggests that the current system falls short in meeting the needs of PDA-diagnosed children. Therefore, it is crucial to reassess the situation and ensure that parents, children, and educators work together to provide appropriate attention, care, and support. Educational institutions should therefore consider creating inclusive environments that cater to the unique needs of PDA children in line with Getting It Right for Every Child (GIRFEC) (Scottish Government, 2022); a framework implemented in Scotland, supporting children and young people's well-being and development. GIRFEC prioritises a holistic understanding of needs, addressing them comprehensively. SHANARRI, a key component of GIRFEC, consists of indicators (Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, and Included) to assess and promote children's wellbeing. Attention to GIRFEC and consideration of SHANARRI helps provide appropriate care, support, and opportunities for children to thrive (Coles et al., 2016). Additionally, collaborative efforts between parents, educators, and professionals are recommended for implementation of tailored interventions (as discussed in chapter 5) and accommodations that promote the wellbeing and academic success of PDA children. In doing so, the dissatisfaction parents have expressed with the education system's treatment of their children and themselves can be addressed.

Furthermore, further research should be conducted to understand the challenges faced by educational institutions in providing support to PDA children. This research will be vital in finding solutions to alleviate these challenges, ensuring that PDA children receive the care and support required for an education equivalent to that of their non-PDA peers.

This study highlights the importance of carefully evaluating critical aspects of PDA and aligning the education system to meet the unique needs of PDA children. By gaining a deeper understanding of the challenges these children face, this research offers insights that can inform the development of customised strategies and interventions to support educational journeys and overall wellbeing. Successfully educating PDA individuals necessitates a multifaceted approach that considers their specific needs in terms of recognition, individualised support, flexible classroom environments, communication, sensory considerations, emotional well-being support, collaboration, and inclusive practices. This can

be achieved through increased awareness, training, and advocacy services, leading to a more inclusive and nurturing learning environment.

#### 6.4 Reflection and Conclusion

This research explores the reasons for poor educational outcomes in PDA learners and emphasises the need to recognise and address the impact of anxiety on their well-being and functioning. Poor educational outcomes for PDA learners are often influenced by a lack of recognition and understanding among educators and professionals. Insufficient training and information about PDA can lead to inadequate support and strategies in educational settings. The inflexibility associated with traditional educational environments can have significant consequences for PDA children because the absence of adaptability contributes to heightened levels of anxiety and manifests in behavioural challenges that hinder both academic advancement and social relationships.

In order to develop an appropriate curriculum, it is imperative to implement tailored educational policies and procedures that are informed by individuals who possess direct experience of PDA. The provision of training programmes for educators and parents, in conjunction with the active participation of professionals with expertise in the field, has the potential to augment the level of support available to PDA children. Obtaining professional guidance and parental acknowledgement of triggers are essential for ensuring the provision of suitable support. Here, collaboration is key and care should therefore be taken to avoid a breakdown in trust between home and school. Understanding the causes of poor educational outcomes for PDA learners is vital for developing effective strategies and support systems, including tailored accommodations, flexible environments, enhanced teacher training, and inclusive practices. These interventions would enhance the education system's ability to support PDA learners.

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## Glossary

**Allistic:** A person who is not autistic.

**Inerta:** difficulty in starting and stopping tasks,

**Monotropism:** *An attention that focuses on a narrow range of interests.* (Dinah Murray, 1992).

**Neurodivergence:** Cognitive functioning which is not considered "typical". For example, autistic, dyslexic, and dyspraxic people.

**Neurotypical:** The opposite of Neurodivergent. *"Neurologically typical"* - within the typical (average) range for human neurology.

## Abbreviations

ADHD: Attention Deficit Hyperactivity Disorder

AO: Autism Outreach

ASB: Antisocial Behaviour

ASC: Autism Spectrum Condition

ASD: Autism Spectrum Disorder

ASL: Additional Support for Learning

ASN: Additional Support Need

BPD: Borderline Personality Disorder

CAMHS: Child and Adolescent Mental Health Services

CBT: Cognitive Behavioural Therapy

CD: Conduct Disorder

CfE: Curriculum for Excellence

CP: Childs Plan

*CPD: Continuing professional development*

CSP: Coordinated Support Plan

DCM: Diagnostic and Statistical Manual of Mental Disorders

EHCP: Education and Health Care Plan (England)

EP: Educational Psychologist

EOTAS: Education other than at school

FII: Fabricated or Induced Illness

GIRFEC: Getting it Right for Every Child

ICD-11: The International Classification of Diseases (11th revision)

IED: Intermittent Explosive Disorder  
IEP: Individualised education programme  
LA: Local Authority  
MP: Member of Parliament  
ND: Neurodivergent  
NHS: National Health Service  
NICE: National Institute for Health and Care Excellence  
OCD: Obsessive Compulsive Disorder  
ODD: Oppositional defiant disorder  
PDA: Pathological Demand Avoidance  
PCRA: Pupil Centred Risk Assessment  
PP: Perplexing presentation  
PTSD: Post Traumatic Stress Disorder  
RDA: Rational Demand Avoidance  
RAD: Reactive Attachment Disorder  
SAR: Subject Access Request  
SEN: Special Educational Needs (England)  
SEND: Special Educational Needs and Disabilities (England)  
SENCO / SENDCO: Special Educational Needs Co-ordinator (England)  
SHANARRI: Wellbeing Indicators (Safe, Healthy, Achiving, Nurtured, Active, Responsible, Respectful, Included)



## Appendices

### Appendix 1 Ethics Form

#### Committee for Research Ethics & Governance in Arts, Social Sciences & Business

#### Application Form for Ethical Approval of Research for Undergraduate & Postgraduate Taught Research Projects

##### Project details

**Title of Project: ED506A (2022-23): Masters Project/Dissertation** - Parent perceptions on their pathologically demand-avoidant child's experience of school.

**Name of Principal Investigator: Linda Lumsden**

**Project Start Date: January 2023**

**Additional Research staff (if applicable):**

##### Recruitment procedures

###### **IMPORTANT NOTE:**

The University has a duty to safeguard all children and vulnerable (protected) adults at risk, including visitors attending University events; potential students met off-campus; students, staff and volunteers who are part of the University; or others who come into contact with University staff, representatives, or students in the course of their work.

If your research involves any of the above-mentioned groups, please provide the following confirmation:

*I will comply with the requirements of the [University's Safeguarding Policy](#).*

**Please tick the box to confirm**

		Yes	No	N/A
<b>1</b>	Does your research activity involve persons less than 18 years of age? If yes, please provide further information below.		<b>X</b>	
Gathering data concerning primary school aged children from their parents/caregivers				

		Yes	No	N/A
<b>2</b>	Does your research activity involve people with learning or communication difficulties? ( <b>Note:</b> all research involving participants for whom provision is made under the Mental Capacity	<b>X</b>		

		Yes	No	N/A
	Act 2005 must be ethically reviewed by NHS NRES). If yes, please provide further information below.			
<p>Given that the research is concerning neurodivergent children, there is a high probability that one or both of the parents interviewed are also neurodivergent. It will be taken into consideration whether interview questions should be given to participants in advance. It may also be acceptable to offer participants more time and to rephrase and break down questions with prompting. To make sure I have understood their viewpoints, I will also recap by summarising in my own words which will also provide further opportunity for clarification. I can inquire in advance if there are any other specific accommodations that should be taken into account.</p>				
		Yes	No	N/A
3	Is your research activity likely to involve people involved in illegal activities? If yes, please provide further information below.		X	
		Yes	No	N/A
4	Does your research activity involve people belonging to a vulnerable group, other than those noted above? If yes, please provide further information below.	X		
<p>The Equality Act (2010) legally protects people from discrimination (both direct and indirect discrimination as well as harassment and victimisation), and applies to the following protected characteristics: Age, Race, Sex, Gender reassignment, Disability, Religion or belief, Sexual orientation, Marriage or civil partnership, Pregnancy and maternity. I have familiarised myself with the legislation and I will inquire in advance if there are any specific accommodations that should be taken into account.</p>				
		Yes	No	N/A
5	Does your research activity involve people who are, or are likely to become your clients or clients of the section in which you work? If yes, please provide further information below.	X		
<p>I am a full-time volunteer of a charity group supporting neurodivergent children and their families with various extra-curricular activities and peer support. I claim no financial reward for my work.</p>				
		Yes	No	N/A
6	Does your research activity provide for people for whom English is not their first language? If yes, please provide further information below on how this support will be provided, or if it will not be provided, please explain why not.		X	
		Yes	No	N/A
7	Does your research activity require access to personal information about participants from other parties (e.g. teachers, employers), databanks or files? If yes, please explain below how you will ensure that use of this data complies with data protection legislation.		X	
<p>The research will involve parental accounts</p>				
		Yes	No	N/A
8	Do you plan to conceal your own identity during the course of the research activity? If yes, please provide further information below		X	

		Yes	No	N/A
	(e.g. that this is necessary for the nature of the research, whether subjects will be contacted directly after the period of observation).			

**Consent Procedures**

<b>9</b>	Please provide details below of the consent procedures that you intend to use for obtaining informed consent from all subjects (including parental consent for children). You should provide details of how you will let subjects know that participation is voluntary and that they can withdraw at any time. You should also provide details of the processes for giving potential subjects adequate time for considering participation and for obtaining written consent. If research is observational, please advise how subjects will provide consent for being observed. If any of these issues are not applicable to your research or if you do not intend to address them for reasons of research methodology, please provide further information.
<p>Participants will be given an information sheet and consent form outlining the objectives of the study being conducted and how the data will be used before completing the questionnaire. All data will be anonymised, indirect identification of a participant will not be possible and parents details will be held in strictest confidence and they are permitted to opt out at any time which is clearly stated on both the information sheet and the consent form. Participants will be required to affirm their willingness to fill out the survey and to say whether they are open to taking part in any follow-up interviews. There will be no direct observations of children, the research will only involve parent perceptions of their children’s experiences.</p>	

**Possible Harm to Researchers/Participants**

		Yes	No	N/A
<b>10</b>	Are there any safety issues for you in conducting this research? If so, please provide details below of what these might be and how you intend to address such issues.		<b>X</b>	

		Yes	No	N/A
<b>11</b>	Is there any realistic risk of any subjects experiencing either physical or psychological discomfort or distress? Or any realistic risk of them experiencing a detriment to their interests as a result of participation? If so, please provide details below of what this might be and how you intend to address such issues.	<b>X</b>		
<p>There is no risk the participants’ interests will suffer as a result of their participation, but there is a chance that talking about sensitive and private matters surrounding their children could result in slight psychological discomfort. As it can be easy to become blind to the positives when one is experiencing negative daily situations, I will try to emphasise the positive aspects and traits of a PDA presentation in order to lessen the impact on the participants and encourage a shift in mindset. (PDA positive traits include being: honest, independent, charming, imaginative, determined, passionate, intelligent, charismatic, unique, loving, brave, justice orientated, bright, witty and talented)</p>				

**Data Protection and Security**

**IMPORTANT NOTE:**

The General Data Protection Regulation imposes a number of obligations for the use of **personal data** (defined as any information relating to an identified or identifiable living person), or including the use of personal data in research.

If you are using personal data, you should consider whether your research requires a Data Protection Impact Assessment and complies with the University Data Protection policy.

If you are, you now need to see the [Data Protection Checklist for Researchers](#)<sup>1</sup> for guidance.

If you then feel that a DPIA may be required or you need data protection advice, then you should contact the Data Protection Officer [dpa@abdn.ac.uk](mailto:dpa@abdn.ac.uk).

Please provide the following confirmation:

*I have read the above guidance and have met the relevant data protection obligations.*

**Please tick the box**

**In addition**, you should also check the requirements for a Data Management Plan (DMP) in the [Research Data Management Policy](#) and [Guidance](#).

**Once checked, please confirm the requirement by ticking one of the following:**

**No requirement for DMP**

**DMP required and this is attached**

Please see [here](#) for guidance on creating a DMP. For further support, contact [digitalresearch@abdn.ac.uk](mailto:digitalresearch@abdn.ac.uk)

<b>12</b>	<p>Please provide details below of how you intend to ensure that data is stored securely and in line with the requirements of the Data Protection Act and the General Data Protection Regulations. Please refer to the <a href="#">University's Data Protection guidance for researchers</a>, and in particular, the <a href="#">Data Protection checklist for researchers</a>.</p> <p>Please give specific consideration to whether any non-anonymised and/or personalised data will be generated and/or stored and what precautions you will put in place regarding access you might have to documents containing sensitive data about living individuals <b>that is not publicly available elsewhere</b>? If your research relates to the latter, please consider the consent of the subjects including instances where consent is not sought.</p>
<p>The participant's name will appear on consent forms and questionnaires; interview transcripts will be anonymised, with participants identified by a code.</p> <p>Transcripts of interviews as well as consent forms and printed surveys will be kept in a locked cabinet, electronic data will be stored on a password protected USB.</p> <p>Upon study completion, all generated records will be forwarded for secure waste disposal and all electronic data will be deleted after the examination process and degree awarded. All findings of the study will be released anonymously.</p>	

**IMPORTANT NOTE:**

Please confirm if your research requires you to **travel outwith the UK?** **NO**

<sup>1</sup> Click on 'Guides' to find the checklist

If YES, please provide the following confirmation:

*I will comply with the requirements of the [University's Overseas Travel Policy](#), including obtaining permission to travel (where required by the policy), completion of a [risk assessment](#) and will obtain [University travel insurance cover](#).*

Please tick the box to confirm

**It is the responsibility of all researchers to ensure that they follow the University's various policies designed to ensure good research practice.** This includes providing appropriate participant information sheets and consent forms and ensuring confidentiality in the storage and use of data. Any significant change in the question, design or conduct over the course of the research activity should be notified to your School Research Ethics Officer and will require a new application for ethics approval.

**Please attach the following to this form:**

- **Full proposal of relevant research project.** In order to speed up the process of review, applicants are advised to pay particular attention to those areas for which a 'Yes' has been ticked in the following form, either by providing an account of the procedures or training to be employed to ensure ethical practice, or an academic justification for the research strategy employed (or both).
- **Participant information sheet and consent form (where appropriate).** Please note that the Participant information sheet must include a weblink to the ['Privacy Notice for Research Participants'](#).

**Applicant Name:** Linda Lumsden

**Signature:** *Linda Lumsden*

**Date:** 19<sup>th</sup> December 2022

**Supervisor:** Approved/

Notes:

Signature                     *Jackie Ravet*                    

Date                     14/9/23

## Appendix 2 Questionnaire

How do the parents of children with PDA evaluate the quality of educational provision available to their children in mainstream schools?

### **Introduction**

Autism and pathological demand avoidance (PDA) have an impact on the lives of children who have been diagnosed, but it also has an impact on their peer relationships, teachers, and the larger school community. The proposed study will look at how the parents of children with PDA evaluate the quality of educational provision available to their children in mainstream schools.

### **Description**

The following questionnaire is seeking feedback from Parents of children with PDA. If you decide to take part in this study, you will be asked to complete a 21-question survey. Your responses will be collated and analysed as part of a University of Aberdeen research study to provide an insight into how children with PDA experience education. Participation is completely optional, and your confidentiality is safeguarded. While it is most beneficial to the study if you complete the entire process, you may withdraw from the study at any time.

### **Privacy**

This notice is being distributed in accordance with the General Data Protection Regulations (GDPR). We will take the following steps to protect your personal information. This survey is anonymous. Once the data has been transferred into an electronic system for analysis, it will be stored on a password-protected USB drive, which will also be kept in the locked file cabinet.

Your participation in this research is entirely voluntary. All responses will be permanently erased when the research has been completed and marked.

1. How old is your child?

2. Please indicate whether your child has ever received one of the following Autism

**Spectrum Disorder diagnoses:**

- Autism Spectrum Disorder (ASD)/ Autism Spectrum Condition (ASC)
- Asperger's Syndrome/Disorder
- Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS)
- No Diagnosis

3. Please indicate whether any professional agrees that your child has PDA:

- Yes, PDA profile is documented on their Autism diagnosis
- Not diagnosed but medical professional(s) agree
- Not diagnosed but educational staff agree
- No, behaviour only presents at home

4. Has your child been diagnosed with, or are you in the processes of obtaining a

**diagnosis of, any of the following specific learning disabilities/ difficulties?**

- Mild Learning Disability
- Moderate Learning Disability
- Severe Learning Disability
- Attention Deficit (Hyperactivity) Disorder (ADD/ADHD)
- Dyslexia
- Dysgraphia
- Dyscalculia
- Dyspraxia
- None

**5. What term best describes your child's present education**

- Mainstream setting
- Specialist Provision
- Elective Home school
- Unable to access education
- Exclusion/No alternative provision offered

**6. If your child attends a school setting, please check all that applies**

- Registered but unable to attend
- Accessing Full time
- Part time/reduced timetable
- Dedicated 1-1 support
- Enhanced support and accommodations
- Minimal adaptations

**7. How old was your child when you first discovered that their demand avoidance was**

**more than what would be deemed usual for age/stage of child?**

**8. Does your child have a passive early history?**

- Yes
- No
- Unsure



**9. What is the common emotion displayed by your child most of the time?**

- Happiness/Joy
- Sadness
- Fear
- Anger
- Disgust

**10. What term do you feel best describes your child's intelligence level:**

- Gifted
- Above average
- Average
- Below Average
- Unsure

**11. How do they usually avoid demands? (select all that apply)**

- Verbally refuses (saying no)
- Physical refusal (Scream, hit, bite or kick)
- Attempts to negotiate better terms
- Complains about illness or physical incapacity when avoiding
- Invents fantasy worlds and acts them out.
- Pretends to be an animal/or other character
- outrageous or shocking behaviour
- Unsure

**12. How is your child's verbal communication?**

- Still non-verbal/minimal functional words
- Initial Speech delay but fast catch up
- Typically developing
- Unsure

**13. Do you feel that your child is receiving an adequate education?**

- Yes
- No
- Unsure

**Why/Why not:**

**14. Do you feel you and/or your child are supported by Education and Health professionals?**

- Yes
- No
- Unsure

**Why/Why not:**

**15. Do you feel that your parenting skills are judged by health/education**

**Professionals?**

Yes

No

Unsure

**Why/Why not:**

**16. Does your child spend a lot of time pretending (e.g. pretending to be a superhero, roleplay)?**

Yes

No

Unsure

**17. Does your child say things that may be considered tactless or socially inappropriate?**

Yes, always

Yes, sometimes

No

Unsure

**18. Does your child make eye-contact?**

Yes, always

Yes, sometimes

No

**19. Does your child have and repetitive movements? (e.g. spinning, flapping, finger flicking, tapping etc.)?**

Yes, always

Yes, sometimes

No

**19. Does your child impose routines on others in such a way it may cause problems?**

Yes, always

Yes, sometimes

No

**20. Does your child care how they are perceived by others?**

Yes, always

Yes, sometimes

No

**21. Does your child recognise people in position of authority? (e.g. Head Teachers, police)**

Yes

Yes, but doesn't respect them

No

Unsure

## Appendix 3 Questionnaire recruitment and responses

A recruitment poster was created and posted on the social media pages of Early Intervention, The PDA society, and reshared 135 times by organizations and families on all PDA support forums including The PDA Parent space and Pathological Demand Avoidance (PDA) Support Group which has over 35,000 members.

---

**Early Intervention**

16 February · 🌐

...

👉 Research Opportunity for parents of children aged 4-14 with Pathological Demand Avoidance (PDA)

👉 <https://forms.office.com/Pages/ResponsePage.aspx...>

No official diagnosis is required to take part, however, we are looking for parents of children who meet the Key features of a PDA profile.... **See more**

---

👍❤️ 17

5 comments 56 shares

---



PDA Society

9 March · 🌐



Linda Lumsden (a postgraduate student) at the University of Aberdeen is inviting parents of PDA children (age 4-14 years old) to take part in a research study which aims to understand the educational experiences of PDA children from a parental viewpoint. An official diagnosis isn't required to take part but the researcher is looking for parents of children who meet the key features of a PDA profile.

Initial participation involves completing a confidential, anonymous question... [See more](#)

**RESEARCH OPPORTUNITY**

**1495 UNIVERSITY OF ABERDEEN**

**For parents of children aged 4-14 with Pathological Demand Avoidance (PDA)**

**PDA in Education: Parents Voice**

*This study aims to understand the educational experiences of children with pathological demand avoidance (PDA) from a parental viewpoint. It is anticipated that the study will aid in improving the understanding of a PDA presentation and provide relevant parties with tentative suggestions for supporting children within education.*

*Parent Volunteers will be asked to complete a confidential and anonymous questionnaire, which should take no more than 20 minutes. You may also be invited to participate in an interview on Microsoft teams, which may last up to 60 minutes.*

**For Further Information:**

Contact Linda Lumsden: [llumsden.21@abdn.ac.uk](mailto:llumsden.21@abdn.ac.uk)

The study is being undertaken at the University of Aberdeen for a Masters degree in Education.

88

34 comments 79 shares

A total of 337 individuals responded to the survey and completed the questionnaire.

## The educational experience of children with pathological demand avoidance (PDA):

**337**  
Responses

**51:01**  
Average time to complete

**Active**  
Status

### 1. Parent/Carer Permission Request

■ Yes

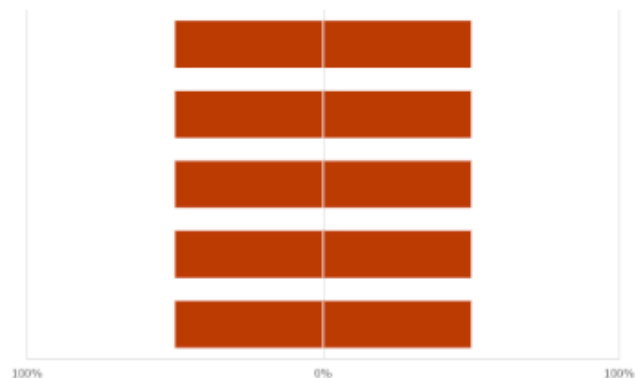
I confirm that I have read and understood the attached informatio

I understand that anonymity and confidentiality will be protected at al...

I understand that participation is voluntary and that I have a right to

I understand that information arising from the study will be stored in a...

I consent to participate in this study.



However, for the purpose of this study, the responses were carefully analysed and reduced to a final sample size of 129 participants who had a clinical diagnosis of a PDA profile of ASC/ASD.



The educational experience of children with pathological demand avoidance (PDA):

129 Responses      64:25 Average time to complete      Active Status

View results

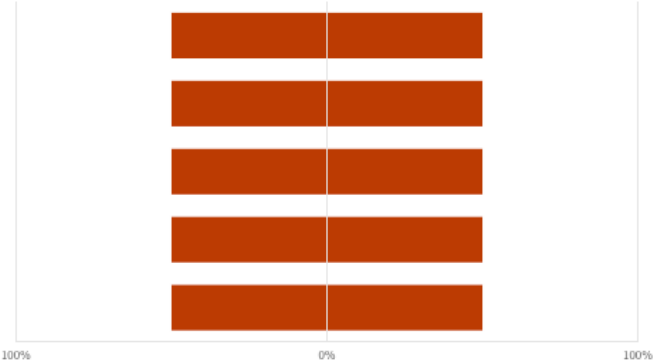
Open in Excel \*\*\*

1. Parent/Carer Permission Request

[More Details](#)

■ Yes

- I confirm that I have read and understood the attached information sheet for the study.
- I understand that anonymity and confidentiality will be protected at all times.
- I understand that participation is voluntary and that I have a right to withdraw from the project at any time.
- I understand that information arising from the study will be stored in a password safe, secure computer. I understand that my personal details will be kept...
- I consent to participate in this study.



2. Anonymity Code: Please provide an anonymity code. Eg your initials followed by the any two numbers (LL10)

## Appendix 4 Interview Participant invitation email

### Invitation Email

Dear xxxxx,

I hope this email finds you well. My name is Linda, and I am currently pursuing my Post Graduate studies in Education at the University of Aberdeen. As a mother to a child with a PDA profile, I have a personal experience that has sparked my interest in researching how parents evaluate the quality of educational provision available to their PDA children in mainstream schools.

I am reaching out to kindly invite you to participate in an interview for my research study. Your unique perspective and valuable insights would immensely contribute to my understanding of the educational experiences of PDA children and their parents, as well as the impact these experiences have had on them.

To ensure convenience, the interview will be conducted through a video call on Microsoft teams and is estimated to take approximately up to 60 minutes of your time. During our conversation, we will explore your experiences regarding your child's educational journey and how these school experiences have influenced both you and your child. By exploring these aspects, I aim to identify strengths and weaknesses within the current educational system for PDA children.

Please note that your participation is entirely voluntary, and you may withdraw at any point. Rest assured that all information shared during the interview will be treated with the utmost

confidentiality, and your identity will remain anonymous unless you indicate otherwise.

If you are willing to participate, please let me know your availability between now and 10th September. Once I receive your response, I will promptly reach out to schedule a convenient date and time for our interview, I understand how challenging it can be to arrange a specific time and can be very flexible. If you have any specific preferences or concerns, please feel free to share them, and I will do my best to accommodate them.

Your involvement in this research would be greatly appreciated and significantly contribute to the advancement of knowledge in this field. Should you have any further questions or require additional information, please do not hesitate to contact me.

Thank you very much for considering this invitation. I look forward to the opportunity of speaking with you.

Warm regards,

Linda Lumsden

Post Graduate Student

University of Aberdeen

## Appendix 5 Interview Schedule

1. How has school impacted your child?
2. Has your child been excluded from school?  
If Yes, how long for and were any suitable alternatives offered?
3. Do you feel educational staff understand (or are willing to learn) about PDA and demand avoidance?
4. Do you believe that teachers have provided needed educational support for your child?
5. Has your child's level of ability/academic performance been assessed?
6. Do you feel like the school setting has helped in improving your child's interest in their studies?
7. What (if any) accommodations have been offered?  
Do you feel they are beneficial?
8. What are some of the improvements you would suggest would help?
9. Do you and your child feel supported by the rest of the school community?
10. How do you overcome demands at home?
11. Does your child find it easy to interact with other children and join peers play games easily?

12. Does your child attend playdates/invited to parties?
  
13. Do you feel included by your child's peers parents? (e.g. included in class parent social media communication/acknowledgement during pickup/dropoff, playdate/party invites for your child)
  
14. Have you or your child attended any support groups with other neurodivergent children/parents. If yes does your child present differently in this environment?

## Appendix 6 Interview Transcripts

### Participant A

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Participant B

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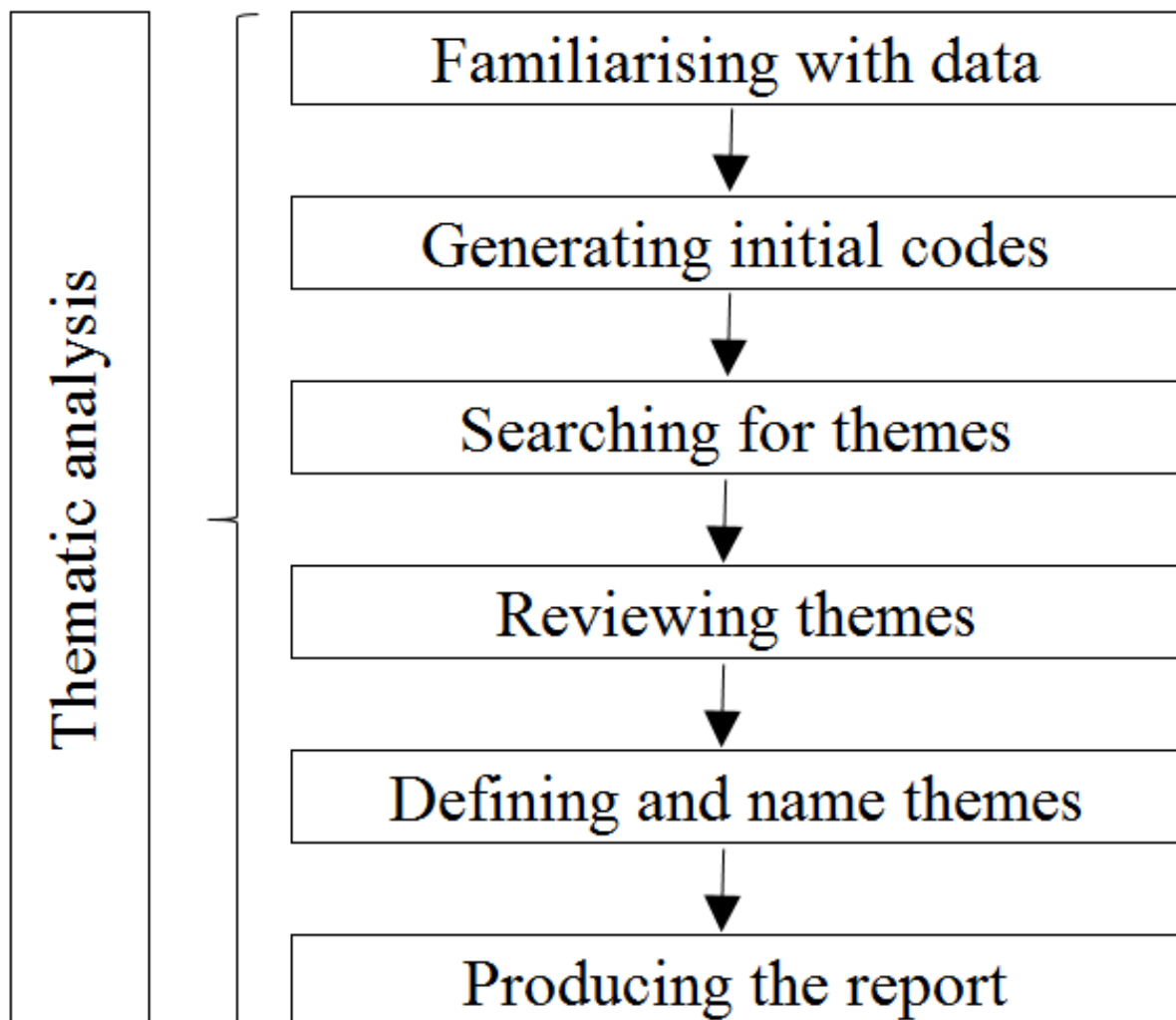
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## Appendix 7: Six Step Data Analysis Process

The process of data analysis follows a systematic approach, which involves selecting the appropriate method to extract valuable insights from raw data. In this research study, both an interview questionnaire and a survey questionnaire were utilized to collect data. To ensure high-quality and comprehensive analysis, the six essential steps outlined by Braun and Clarke (2006) was followed. These steps were implemented to optimize the utilization of the collected data and uncover meaningful information.

The six steps are as follows:



### **Step One: Familiarization of Data**

Once data had been collected, the gathered information was examined. This process of familiarization aims to gain a comprehensive understanding of the data and allow researchers to become more acquainted with the subject matter. It also helps in generating potential insights that the data may suggest, aligning with the research questions that were posed. In this particular study, the focus is on investigating the support provided by the educational system for children diagnosed with PDA and their parents. Therefore, the data analysis will concentrate on identifying relevant factors and recurring themes, ultimately aiming to provide answers to the research question and refining the study's focus.

### **Step two: Generation initial Codes**

After familiarizing with the available data, the research study proceeds to identify recurring patterns and topics that align with its focus. These identified patterns are then linked to the research data through the use of codes, enabling the study to address the research questions. The coding process involves assigning different labels to the responses, uncovering recurrent themes, patterns, or concepts. By using the interview responses, the study demonstrates the identified patterns and topics. Ultimately, the coding process provides clearer and more concise information on the research questions presented to the participants.

### **Step three: Searching for Themes**

The third stage of data analysis involved consolidating the codes into themes. By examining the identified codes, recurring topics and patterns are identified, forming cohesive themes. These themes provided a more targeted overview of the insights revealed in the interview responses, related to the research study. These themes were elaborated further in relation to the research study.

### **Step Four: Reviewing Themes.**

Once the themes were identified, they were carefully examined in conjunction with the research aims and objectives, utilising the interview responses to provide additional clarity on the themes. Further exploration of the themes were conducted to gain deeper insights into the findings derived from the data collected. This process also validated the identification of the themes based on the collected data.

**Step Five: Determine and define the themes.**

In this stage, the identified themes were evaluated in relation to the research study questions and objectives. This process enables the assessment of the importance of the thematic findings in relation to the achievement of the research objectives and hypothesis. The significance of the identified themes to the research study was addressed and a connection between them established.

**Step Six: Reporting of Findings:**

The sixth step entailed reporting the identified themes and their correlation. This step provided valuable insights into the identified themes, the established connections, and their relevance to the research study. Additionally, it involved interpreting the results in the context of the research objectives and drawing meaningful conclusions that addressed the initial questions.

In conclusion, the six steps of the data analysis process offer a structured approach to extracting valuable insights from interview data. Beginning with defining the research objective and concluding with result interpretation, each step contributed to a comprehensive and meaningful analysis. Customizing the steps to fit the interview context ensuring effective data gathering, organization, and analysis, enabling the derivation of insightful conclusions and contributing to the respective field of study or practice.