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A phenomenological exploration of the lived experience of adults experiencing pathological demand avoidance

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Abstract

This study explores the lived experiences of adults with Pathological Demand Avoidance (PDA) in Ireland. There is a paucity of research exploring the experience of those living with PDA in Ireland which impacts levels of awareness and understanding of anxiety-based demand avoidance and its intersection with autism. As lifelong conditions, this has implications for adults who can struggle to access services or appropriate supports or can be isolated in the transition from Child and Adolescent services. This paper extracts data from a national study, *Mapping Experiences of Pathological Demand Avoidance in Ireland*, and examines the lived experience and personal histories of adults with a diagnosis of / self-identifying with PDA and autism, consisting of statements extracted from open-ended survey responses, and in-depth interviews. A deductive approach to the analysis of their testimonies discovered four superordinate themes: (1) Bidirectional social challenges, (2) Life experiences, (3) Trust and safety and (4) Accepting our truth. Subordinate leitmotifs describe: Pervasive anxiety, Challenges negotiating life demands and Flexibility in education settings. This paper reveals the interplay between PDA, autism and mental health for these participants combined, leading to significant challenges in daily life. To support better life quality and flourishing, participants advised greater autonomy and flexibility of support across all aspects of life and more awareness of PDA across society.

Lay abstract

This study delves into the everyday experiences of adults living with Pathological Demand Avoidance (PDA) in Ireland, a topic that has been underexplored in research. Pathological Demand Avoidance is a lifelong phenomenon which often intersects with those diagnosed as autistic and can involve high levels of anxiety and very significant challenges navigating everyday demands or challenges. Limited research in Ireland has affected understanding and awareness of this condition, especially for adults transitioning from Child and Adolescent services. The study draws from a national survey and in-depth interviews, uncovering four key themes: (1) Bidirectional social challenges, (2) Life experiences, (3) Trust and safety and (4) Accepting our truth. Subordinate leitmotifs were Pervasive Anxiety, Challenges negotiating life demands and Flexibility in education settings. Participants' stories highlight the challenges faced due to the combination of PDA, autism and mental health issues, emphasizing the need for increased awareness and support from society and service providers. Participants stressed the importance of autonomy and flexible support to improve their quality of life.

Keywords

PDA, autism, education, mental health, adults

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Introduction

Autism and pathological demand avoidance

Pathological demand avoidance (PDA) has been a contested and evolving construct or profile since it was first described by Newson et al. (2003) from observations of a sample of young people with complex profiles attending her clinic in Nottingham (UK). Their proposal argued for the recognition of PDA as a distinct, qualitative difference within the then available 'pervasive developmental disorder' diagnostic classification (PDD-NOS). Defining features include resistance to both pleasurable and stressful activities using socially manipulative, avoidant behaviour; impulsive, unpredictable and volatile mood changes and obsessive focus on particular people, both negatively and positively. However, given the range of changes in diagnostic criteria and guidelines to clinicians since this initial description, and specifically the folding of 'subtypes' such as PDD-NOS into the single diagnosis of 'autism spectrum disorder (ASD)' category within the updated *DSM-V* manual in 2013, PDA as a construct remains contested (Green et al., 2018; Kildahl et al., 2021; Woods, 2019).

Although PDA is not currently a profile included within diagnostic tools (e.g., *ICD-11*; *DSM-V*) recognition of PDA as a distinct entity is increasing (Guldberg et al., 2019; Cooperative Research Centre for Living with Autism [Autism CRC]; Whitehouse et al., 2018). However, opinions differ as to whether PDA is a phenomenon within the autism spectrum or whether it is more effectively understood as an external 'comorbid' condition related to heightened anxiety (Woods, 2019) or an outcome 'symptom' of other underlying conditions (Green et al., 2018). While the conceptual framework that informed its framing as a developmental disorder within PDD-NOS (Newson et al., 2003) has evolved, others have suggested it is a rare profile among autistic individuals (Gillberg et al., 2015; Stuart et al., 2020).

The incidence of autism within the population of Ireland is currently estimated to be 1 in 65 (HSE, 2018), with the Health Department in Northern Ireland reporting a prevalence rate of 5% (Rodgers & McCluney, 2023), potentially indicating the degree of diversity of approach regarding diagnosis of autism itself on the whole island. A longstanding emphasis on clarity in the operationalised diagnosis of autism based on frameworks such as the DSM-V (American Psychiatric Association, 2013) focus on identification of individual 'disorder' and 'impairment' but have been hugely influential on diagnostic and service provision practice internationally and in Ireland (Sonuga-Barke, 2009). The emphasis on diagnosis and case formulation in more recent years has moved towards individual presentation (Bölte, 2019; Gillberg et al., 2013; Green et al., 2018), perhaps in recognition of the reality that most autistic individuals present with a spectrum of co-occurring diagnosable conditions (Gillberg, 2010; Embracing Complexity, 2019). It has also been suggested that clinical practice or a categorically based approach underestimates the complex reality of neurodevelopmental diversity across the autism spectrum (Gillberg, 2010; Embracing Complexity, 2019). In recent years, the increasing influence of the work of autistic researchers and theorists has revolutionised understandings of autism as a construct (e.g., Botha & Frost, 2020; Milton, 2012; Murray et al., 2005).

Critics of the purported link between PDA and autism note PDA is not currently recognised within guidelines for clinicians for assessment of autism (e.g. NICE, 2020) due to the lack of evidence meeting their threshold for consideration. A key concern for some autistic researchers is that existing research and theory fails to consider the perspectives of individuals identified as presenting with PDA or as 'demand avoidant' (Milton, 2012; Woods, 2019). Underpinning this emphasis on the need for standpoint epistemology in theory construction of diagnostic phenomena is a concern regarding protecting individual agency and a need to consider how environmental factors may contribute to challenges on the part of the individual (Milton, 2012; Woods, 2019). This view aligns interactionist perspectives within a neurodiversity paradigm (and some diagnostic frameworks, such as the ICF-10) and emphasises how external factors such as sensory discomfort, social expectations and/or contexts may induce anxiety on the part of the person perceived to be 'demand avoidant' (Milton, 2012; Kildahl et al., 2021). Some researchers have expressed concern that the concept of PDA may contribute to a lack of focus on contextual, social or environmental factors (e.g., see Green et al., 2018) while others have criticised the quality of existing research exploring links between PDA as a construct and autism (e.g., see Kildahl et al., 2021 for discussion). On balance, however, *most* participants within the existing PDA literature also identify as autistic (Hollocks et al., 2019; Kerns et al., 2021; Rosen et al., 2018), and Kildahl et al. (2021) report significant life challenges for those with PDA, emphasising the need to conduct further research in partnership with this cohort. Such research does not preclude or foreclose differing perspectives on, or understandings of, PDA as a phenomenon.

Pathological demand avoidance in adults

Egan et al. (2019) make the point that there is a dearth of research into PDA in adult populations, in part due to the absence of diagnostic tools but also that research has focused on combined PDA and autism, rather than the combination of PDA traits and a broad autism phenotype. The Gillberg et al. (2015) study of PDA amongst a population of 15–24-year-olds indicated a prevalence of PDA with ASD in just under 0.2% of adolescents/adults in the study context (Faroe Islands) and highlighted the necessity for recognising the support needs of adults who are extremely demand avoidant; Eaton and Banning (2012) discuss the ramifications of a failure to recognise autism and PDA in childhood and thus further research into PDA in adults is crucial. The PDA Society publishes adult PDA viewpoints on managing life, education, health, work and relationships; these opinion pieces offer valuable insights and draw attention to the subtle differences within PDA, for example, the preference for sameness and routine for autistic individuals, and the advantages of variability and variety. In terms of managing everyday life, autistic individuals who identify with PDA prioritise interests and less so daily life tasks; they emphasise the need for acceptance, recognising a demand and when it needs to be reduced or disguised, being aware of masking, and the importance of self-awareness (triggers) and self-acceptance. They also point out that coping strategies are essential to developing good mental health, which might include medication, and highly individualised therapeutic approaches are needed in recognition that accessing regular therapy, in itself is a demand.

Experiences of PDA in Ireland

The dearth of PDA research in Ireland and awareness and understanding of anxiety-based demand avoidance in general, arguably impacts on pathways to assessment and diagnosis, which in turn determine access to support in education and healthcare settings, and ultimately influence life outcomes. The original mixed methods study from which these findings are drawn, *Mapping Experiences of Pathological Demand Avoidance in Ireland* (Doyle et al., 2019; Doyle & Kenny, 2023), collected quantitative data from an online survey complemented by thematic analysis of open-ended survey questions and in-depth, semi-structured individual interviews and focus groups. A self-selecting probability sample of 335 individuals participated in the online survey comprising of parents ($N = 264$), life partners of autistic individuals who experience PDA ($N = 6$), autistic individuals self-identifying as experiencing PDA ($N = 11$) and education and healthcare practitioners ($N = 54$). This data was augmented by life partners of individuals living with PDA, practitioners diagnosing and supporting children and adults with PDA ($N = 2$; and parents, carers or guardians of children and adults with PDA (individual interviews $N = 5$; focus group participants $N = 4$).

The survey, interview schedule and final report were premised upon five inter-related a priori themes: i) awareness, acknowledgement, acceptance and understanding PDA, ii) journeys to assessment and diagnosis, iii) access to education and health services, iv) approaches and interventions for management and support, iv) education, health and life outcomes and v) triumphs and challenges. Findings indicated a lack of awareness and recognition of PDA, and substantial long-term waiting lists as a significant barrier to assessment and diagnosis (Ombudsman for Children, 2020), affecting access to health and education services particularly as autism and anxiety are treated as separate conditions requiring differentiated intervention from Disability Services and CAMHS.

This current paper presents qualitative data extracted from the original study *Mapping Experiences of Pathological Demand Avoidance in Ireland* (Doyle et al., 2019; Doyle & Kenny, 2023) voicing the lived experience of pathways to assessment and diagnosis, education and healthcare services and encounters with professionals in health and education services. This study also presents their individual viewpoints on support needs within society and factors that would improve social inclusion and flourishing, and life outcomes, providing rich insights into the impact of PDA on life outcomes as a function of both intrinsic and extrinsic factors, adding depth and detail to our understanding of the PDA experience.

Method

Participants

A purposive sample of $n = 13$ adults identifying with autism and/or PDA completed the original survey (Table 1). Access to participants was achieved through an open/public request for participants shared via social media (Facebook / Twitter) and third-party dissemination by autism support groups, to complete an anonymous online survey. A final question invited participants to self-select for participation in a semi-structured in-depth interview or focus group.

The two interview respondents who are the focus of this paper both have dual autism / PDA diagnoses; commentary from participant responses to open-ended survey questions is also included (see Table 2 for an outline of open-ended survey questions). Two autistic adults who did not complete the original survey contacted the researchers independently and expressed a desire to tell their stories. Aoife (pseudonym) is a 61-year-old female living alone; Breda (pseudonym) is a 52-year-old female living with her husband and three adult children, all of whom have a spectrum of diagnoses including autism, ADHD, PDA and dyslexia. Neither of the participants had a formal diagnosis of PDA, but self-identified after years of reflection, discussion with others and consulting PDA and research literature. Both participants had parents/siblings with diagnoses of autism, specific learning disability and mental health conditions. Both participants described themselves as intellectually gifted.

Data collection

Interview participants were contacted by telephone and expressed a preference for this medium for interview. A convenient day and time for the call was agreed and Aoife and Breda were emailed a framework of themed questions (Table 3). Interviews lasted between 45 and 60 min and were digitally recorded; transcripts were approved by participants. Additional material was gathered from Aoife via email as she expressed a preference for this medium.

Table 1. Demographic data for participants identifying with PDA (survey).

ID	Age	Gender	Domicile	Highest qualification[a]	Employment	Additional medical conditions
P1	31–40 years	Female	Independently on my own	Leaving Certificate	Salaried employment	
P2	31–40 years	Female	With a life partner	Undergraduate Degree	Salaried employment	Dyslexia
P3	26–30 years	Female	At home with parents, carers or guardians	Undergraduate Degree	Student	Asthma, Dyslexia Dyspraxia, ADHD, depression, dissociation, autism spectrum disorder, sensory processing disorder, menstrual OCD, GI issues
P4	Over 50 years old	Female	With a life partner	Undergraduate Degree	Retired	Fibromyalgia
P5	41–50 years	Male	Independently on my own	Leaving Certificate	Unable to work	
P6	31–40 years	Female	With a life partner	Postgraduate degree	Homemaker	ADHD
P7	31–40 years	Female	A combination of settings	Leaving Certificate	Unable to work	Fibromyalgia, Hypermobility syndrome, arthritis, OCD, PTSD
P8		Male	At home with parents, carers or guardians	Leaving Certificate	Student	
P9	41–50 years	Female	With a life partner	Postgraduate degree	Student	
P10	26–30 years	Female	At home with parents, carers or guardians	Post-Leaving Certificate / QQI award	Out of work and looking for work	PcDH19 Epilepsy, IBS, menstrual problems
P11	41–50 years	Female	Independently on my own	Undergraduate Degree	Out of work but not currently looking for work	ASD adult diagnosis, Rheumatoid arthritis, history of depression and anxiety for over 20 years
P12	21–25 years	Female	In a mental health unit or hospital	Postgraduate degree	Out of work but not currently looking for work	
P13	26–30 years	Female	Renting room	Postgraduate degree	Out of work and looking for work	Dyspraxia

[a] Leaving Certificate is the equivalent of A levels (UK).

Data analysis

A hybrid approach to thematic data interpretation (Fereday & Muir-Cochrane, 2006; Swain, 2018) was adopted to examine interrelated themes. Initially, transcripts were examined against the a priori themes from the main study and subsequently, this text corpus was analysed and coded manually for emerging superordinate and subordinate themes using IPA, to illustrate individual histories. This involved reading and rereading both transcripts several times to establish familiarity with the data, with

Table 2. Open-ended survey questions.

What has been the biggest challenge in life for you as an autistic person who experiences PDA?
What has been a barrier to accessing support?
What factors affect your daily life?
Have the challenges of managing PDA affected your work life?

notes and comments recorded by both researchers. Emerging superordinate and subordinate themes were noted for each interview transcript and merged, collapsed and expanded during the analysis phase, and open-ended survey comments integrated into this hierarchy (Figure 1).

Results

Results report illustrative excerpts from survey responses and interview transcripts together with the researchers' interpretations.

Bidirectional social challenges

Open-ended survey responses highlighted significant challenges faced by females aged 30–50 years of age with PDA. These individuals indicated 'huge anxiety' and attempted to socialise online or via text leading to 'feeling drained or depressed'. These individuals indicated unsuccessful attempts to socialise online or via text, which were experienced negatively, and reinforced a sense of being dismissed by others. There was also a more generalised sense of mistrust of social situations, related to 'being too trusting', having been let down by others, and 'all the contradictions and [social] rules that make no sense'.

One participant, Aoife, noted that: 'like any autistic, hierarchies mean nothing to me' and she rejects the notion of interacting with society through the prism of 'the pecking order', with group dynamics being 'pointless, primitive and a bit disgusting'. She acknowledged a 'fundamental need of most people' for tribes or group identities in society but felt they created barriers for autistic individuals like her. She suggests that these structures operate as a social barrier to the participation of autistic people and those with PDA, who '… can't make sense of it … I can't read people's feelings or intentions towards myself, even with my life on the line'.

Aoife clearly recognised a bidirectional miscommunication (Milton, 2012) which underpins the double-empathy problem understanding of social interaction differences between autistic and non-autistic individuals. Another participant, Breda, frequently felt misunderstood, and often perceived as rude despite her genuine attempts to explain her behaviour due to PDA. This response often baffles and frustrates Breda who feels misunderstood, but she believes her diagnosis of PDA can offer others an explanation that she doesn't 'mean to be rude' but 'now I have an explanation for why I appear rude or aggressive'.

Aoife expanded on Breda's point by describing her perception that she was negatively perceived and responded to by others due to the complexity of her profile. She uses the

Table 3. Interview themes.

Theme 1: Journey to assessment	Can you tell me about your journey to assessment and diagnosis? Was there anything that was positive or helpful? Can you give me an example? Were there any aspects which you feel could be changed?
Theme 2: Experience of education and healthcare	Tell me about your experiences of education and health care in relation to PDA. Have you had positive experiences? What were they? Have you experienced any challenges in your interactions with services? Can you give me some examples? Were there any aspects of services that you feel need to change?
Theme 3: Supports for life skills	What supports are needed to help young people, and adults in their management of everyday life? Can you give some examples? Are these supports available? Which ones? Have you experienced any barriers to accessing such supports? Please explain.
Theme 4: Future developments	From a PDA perspective, how do you see your future? Why do you see it this way? Are there any supports or changes that you feel would have an impact on your views for the future?
Theme 5: Knowledge about PDA	PDA is a less well-known aspect of the autism spectrum, what are the key things that people need to know about this condition? Why did you choose these? What effect would greater awareness have had on your experience with PDA?

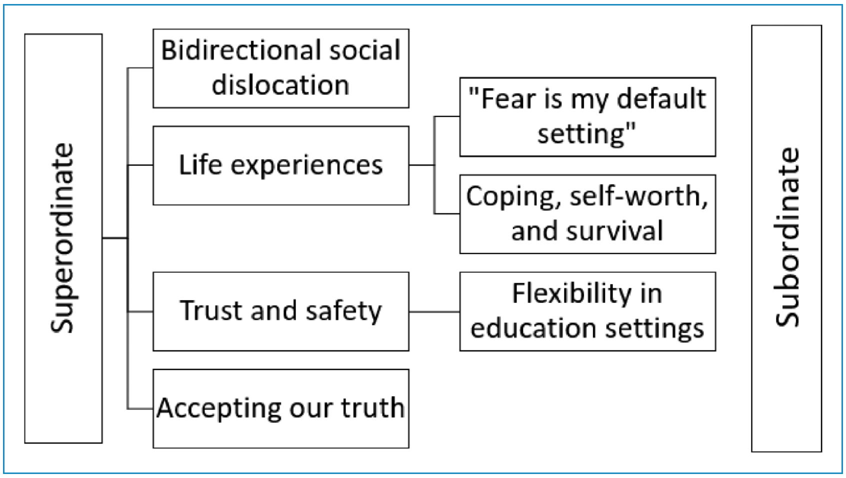

Figure 1. Superordinate and subordinate themes.

term ‘wrong kind of victim’ to describe herself as she is both very intelligent and able, while also having significant areas of support needs simultaneously. This relates to the stigma faced by autistic people like her, who are twice exceptional, having a high IQ and being Autistic. Vasquez (2023) discusses the reality that ableist language, within the discourse of average, can often act to stigmatise both disability and gifted populations and is especially detrimental to the identity of twice-exceptional individuals. According to Aoife, this kind of profile confuses others, who then respond negatively towards her:

> … the idea of vulnerability and capability being mutually exclusive. Highlight someone’s capability and their vulnerability vanishes from sight … but not from their needs. Highlight someone’s vulnerability and their capability vanishes from sight … but not from their nature. … . In practical terms in my own life people only accept me at all until they see my intelligence in action …

Aoife emphasized the challenges faced by autistic individuals through how others perceive twice exceptional autistic people who, she feels, are viewed through outdated and stigmatising lenses regarding disability and disorder. Autistic people bear the burden of this stigma, medical model-based views of autistic disability, which impacts access to services and accommodations in educational/social settings:

> As soon as people know you are autistic, they either infantilise you or treat you as a threat …, there is not a level on which people can perceive an intellect like mine AND make lawful accommodation for my disability,

Aoife also clearly expresses the reality that it is often the autistic person who bears the brunt of the social consequences for this social breakdown. Her approach was to keep her distance from others following repeated failure to access required services or rejection within social settings with neurotypical individuals. In her case, Aoife blames herself for the inflexibility and rejection she experienced:

> That interactive blindness … gets in the way of communicating with a plumber, or applying for an allowance, let alone the more personal aspects of healthcare and education, and it gets worse, not better with familiarity as expectations rise and the social skills in play become more complex …

This account is also a clear example of the tangible impacts of how minority stress (Botha & Frost, 2020) impacts on autistic individuals in society owing to their status as the social other who differs in important social facets from the majority who surround them. Lifelong complexity and volatility impacted relationships across all aspects of both individuals’ lives. Participants perceived themselves as having difficulties relating to others, including autistic people without a PDA profile, which had contributed to their experiences of being bullied at school and experiencing exclusion in their adult lives. Aoife’s account indicates she has internalised this stigma and blame for her social challenges, leading to a personal negative self-perception regarding her ability to relate to other effectively. She concluded that she was ‘fundamental incompatibility with people (including autistics) that is no more my fault than it is theirs’.

This account aligns with prior research with autistic cohorts which showed increased experiences of bullying and victimisation (Paul et al., 2018; Trundle et al., 2023) and high levels of heterogeneity across presentation and experiences of victimisation within autistic populations

(Trundle et al., 2023). These accounts also emphasise the importance of social networks of support for autistic or otherwise neurodivergent (Crompton et al., 2023) and access to flexible, tailored mental health supports to manage negative impacts on well-being or self-esteem from experiences of marginalisation (Brede et al., 2022). However, while it is important to recognise that this evidence relates to autistic participants, it is interesting to note that Aoife also perceives her own social experience, social presentation and coping needs as differing from other autistic people: 'the gulf between me and other high function autistics is as great as the gulf between autistic and 'normal' people, they are far more socially competent than I beyond the most superficial level, and they are also much more social'. This account indicates the sense of social disconnection for participants and the burden to camouflage PDA experiences among others, and even among the autistic community, indicative of heterogeneity within the autistic community or of divergences between those living with PDA and autistic individuals.

It should be recognised, however, that this perspective reflects the social experiences of these participants, but may not reflect the experiences of others. The research shows that autistic individuals present with a spectrum of co-occurring diagnosable conditions (Gillberg, 2010; Embracing Complexity, 2019), leading to high levels of diversity in profile and experiences across the autistic community. In addition, PDA has a less well-developed research foundation, thus suggesting that dual diagnosis of autism with PDA would likely imply high levels of diversity in presentation across individuals (Gillberg, 2010; Embracing Complexity, 2019). These accounts may be highly individual to those participants in this study.

Life experiences

Participants in this study discussed their experiences of life as being both challenging and difficult. Seven of the survey respondents identified low self-esteem as affecting their everyday life and in particular noting: 'understanding why this happens and trying not to hate myself' was an important part of accepting her experience, forgiving herself '… for being utterly useless' sometimes and unable to keep up her 'high achiever' standards, living 'constantly fearing failure and being found out' creating a sense of 'feeling like I am not integrated and sure of myself'. A key strength that emerged across the accounts from both participants interviewed was self-awareness, curiosity and resilience in the face of challenges and past significant trauma.

Breda described a long history of masking her difficulties across adulthood, often feeling misunderstood and 'out of place' where: 'I felt, all my life, I felt, a fraud, I felt, not belonging, and, with a, a dark secret in my myself, and I couldn't explain why'. Demonstrating keen self-awareness and ability to reflect on her own experiences, she described her need to 'mask enough' to be accepted by others but this led to her consequently feeling 'depressed'. Having the opportunity to disclose and talk about her experiences with other people validates her sense of self. Similarly, Aoife describes her perception of self as: 'I was more able to function socially when I was younger, but I was never normal, even as a small child I hid from people, hated school with a passion and attracted bullying like a magnet'.

Breda and Aoife also discussed their clear awareness of their own differences from those around them, and an urge to understand or explain why. Breda felt she 'shouldn't have any shame of conditions we didn't choose', illustrating the ability to reflect objectively on her own experience and support her resilience and ability to survive. The seeking to understand was a long-term and important aspect of Aoife's experience also:

> From 1987 on I spent years searching the internet to try and understand what made that difference and fix it … I realized by about 2003 that I probably had an atypical variant on Asperger Syndrome that probably stood on the cusp of psychopathy … it took everything I have and then some to come to terms with that but at the end of the day, given the rigid control conscience and honour impose on my life … (I am MUCH less social than most Aspies and can only learn from my own observations and abide by my own code of morality).

This illustrates how both participants sought to explore a range of diagnoses or consider different profiles as pathways towards self-understanding, self-acceptance and self-preservation. Breda received diagnoses of dyslexia, autism and PDA. Aoife discussed being diagnosed with Autism (Asperger's syndrome) 'adolescent schizophrenia', 'empty sella syndrome' and PDA across her life from a range of different clinicians and services. The discovery of PDA had an impact on both participants, with Breda saying that her diagnosis '… just makes sense. It just explains everything'. However, the tone of their accounts, and how they relate to these various diagnoses is negative in its language, and coloured by their past experiences of trauma, social isolation and rejection. This is indicative of the internalisation of stigma, minority stress associated with social rejection and struggles for self-acceptance and overcoming trauma.

Pervasive anxiety. Participants describe clear emotional impacts in terms of how they saw themselves. Aoife expressed and described the relationship between anxiety, fear and coping as features of everyday life:

> I cannot gauge anxiety … fear is my default state. Fear, denial of fear, or very, very rarely this crystal clear 'battle

> mode' I feel now …. I have no way to gauge the potential impact or backlash from anything I do.

This searing description clearly outlines her experience of life as being fraught and existentially dangerous. She described her life as feeling like 'making a perilous climb to a dizzying height, and one slip, at any step', would lead to serious harm or death. This pervasive feeling of anxiety has led Aoife to feel her best course for living her life is '… hiding here because there is literally nothing else that would be safe or within my ability to cope …'

Close management of the physical and social environment allows her to gain a sense of perspective and understanding in life. Being able to predict her own responses or the response to them from those who surround her is important. A recent study from Buckle et al. (2021) illuminated the concept of autistic inertia as a 'widespread and often debilitating difficulty' which the authors state has been under-researched; one survey respondent described the impact of autistic inertia in their testimony:

> I have to pace my working/study week and finely balance my family caring duties (I have 2 children, one also has autism) and other commitments or I experience burnout – if there are too many demands I shut down and avoid people, find it impossible to start or complete tasks or figure out ways to deal with what seem like insurmountable tasks (from writing a report to taking a shower). If I have pushed beyond my limit I experience headaches, palpitations, skin-itching, extreme fatigue, and a rushing/buzzing sensation in my head and torso. I want to hide from the world and just about manage to cope with taking care of my kids. My anxiety builds and affects normal sleep and makes inertia harder to break. My partner helps but must work full time as I cannot.

This pervasive experience of heightened anxiety contributed to a very challenging experience of life, typified by Aoife discussing feeling a lack of control or predictability which made her feel 'vulnerable on the edge of helplessness'. These perspectives align with previous accounts which reference a need for predictability (Doherty et al., 2023) and intolerance uncertainty (Johnson & Saunderson, 2023) in accounts of those with PDA which led to 'approach-avoidance' behaviour patterns (Johnson & Saunderson, 2023). An anxiety regarding unpredictability in the responses of others and trauma from past negative social interactions lead many with PDA to experience high levels of anxiety regarding socialising with others (Johnson & Saunderson, 2023). In her account, Aoife views her social presentation as 'a tall lady with a cut glass Brit accent' was negatively perceived by others, leading to their negative responses towards her in her life.

Challenges negotiating life demands.

Seven of the survey respondents identified low self-esteem as affecting their everyday life. Major life challenges expressed by participants included 'living', 'losing everything I have ever enjoyed as I have sunk deeper into not coping with life', 'feeling worthless all the time', no 'motivation to do work like study', worries about future 'transition from school to college and finding a job', were some of the perspectives shared. This led to negative self-assessments on the part of many participants. For example, Aoife said she '… was ashamed … I always have been deeply ashamed of being unable to support myself, buy my own home, live a useful life – and all that shame came to the surface'. This was echoed by the accounts of survey respondents who stated: understanding why this happens and trying not to hate myself for being utterly useless. On good days I know I am good at what I do and objectively can see that I am a high achiever, but I also know that I am barely keeping things together and constantly fear failure and being found out as useless.

> having to relinquish control to other adults for some aspects of my life. I find it hard to reduce demands.

Breda described a long history of masking her difficulties across adulthood, often feeling misunderstood and 'out of place' she felt like a 'fraud'. Having the opportunity to disclose and to talk about her experiences with other people validates her sense of self. However, she qualified this by observing that therapy would not be useful 'because that would imply you know, being mentally ill' but preferably 'counselling with somebody who understands and knows about PDA'.

Open-ended survey responses indicated 'huge anxiety' and attempted to socialise online or via text leading to 'feeling drained or depressed'. Seven respondents indicated that managing work tasks and managing self-care impacted on daily life and serious and significant impacts of demand avoidance on everyday life – including home and work contexts – were described by females aged 30–50 years:

> I am not coping at all. Everything I have loved over the years has slipped away from me. They are all demands that I cannot cope with. I rarely leave the house, usually to just switch between my partners and my mother's. I am scared and ashamed of what is wrong with me, and I have no idea who to turn to. PDA is too difficult to understand for most people and after a life of emotional abuse I have learned to read people very well, most people dismiss my problems because they cannot conceive that

> this could actually be a thing. I struggle with most daily tasks and at my worst will just sit stimming and pulling my hair because everything is just too much.

Aoife also expressed and described the relationship between her recognition of her vulnerability and support needs and also her levels of ability and capacity. She describes her experience of starting '… to disintegrate involuntarily … at an alarming rate' when she is 'trapped among people'. She supports herself by isolating herself from others because '… in isolation, I am in a different frame of mind with a different level of functionality … different abilities … and that creates different possibilities and options'. This account echoes the experiences of other individuals with PDA who recounted feeling others were unpredictable and feeling a source of deep anxiety (Johnson & Saunderson, 2023). These findings echo the mismatch of salience proposed by Milton's (2012) Double Empathy Problem, with the consequences impacting the lives of autistic people.

Trust and safety

A fundamental barrier to accessing support is the mismanagement of first-line responses and misunderstanding of the interplay of autism, anxiety and PDA. This is reflected in Aoife's experience of receiving an involuntary section order under the Mental Health Act (UK) at the age of 15 years:

> This was decided and signed by the Social Services area Psychiatrist who had seen me for about 20 min some three months prior to signing the order, and never saw me again until after it was signed. A young locum General Practitioner who had seen me in considerable distress for no more than half an hour the night before. A social worker who had only met me once in his life, six months before when he was called out over Christmas to bring me from one place to another place, he had then passed the journey by subjecting me to considerable personal abuse in front of his two small daughters who were on the back seat.

The impact of this for Aoife was the development of a complete lack of trust in doctors or medical or social support services. 'As a direct result of that experience, I have been terrified of doctors and anything connected with them since. …. I learned, for my own protection, to hide any trace of distress or "instability" from a Doctor as a natural default'.

Breda experienced her own challenges in engaging with clinicians, but through the medium of seeking diagnosis for her children. She reported that the psychologist was 'very clear that they were accusing us as being responsible' but in an indirect manner. For a year and a half, both she and her husband engaged with psychologists who implied but were '… not very subtle in trying to say to us, it's you, it's your fault. And, you know, blaming the attachments between myself and [son]'. This viewpoint relates to the lack of clarity regarding how PDA is conceived and understood, with some proposing that PDA is a form of Attachment Disorder (Christie, 2007; McElroy, 2016; Milton, 2017). Perhaps such a viewpoint would suggest that parent–child relationship challenges or lack of atunement would be explored by clinicians who held this viewpoint. However, given that Breda and her child both had autism diagnoses, such an approach may be viewed as using outdated 'refrigerator mother' (Bettelheim, 1967) understandings of autism within clinical engagements with autistic family systems. This experience was echoed by one 26–30-year-old female survey respondent who received suggestions of attachment issues being a key cause of PDA, or upbringing as a function of poor parenting. While some have suggested the evidence base for PDA being within the autism spectrum is poor (Kildahl et al., 2021; Woods, 2019), there is very poor evidence supporting the proposal PDA is a form of attachment disorder.

Breda's experiences with the clinicians led to a breakdown of trust between her family and the psychological services which impacted the quality of the advice or guidance she felt she received from the clinicians. 'So you see, we were locking horns all the time. So CAMHS latched on to that big time, like, you know, oh, well, it's, it's your problem. It's your problem, you're parenting wrong, that sort of thing'. The real-world impacts of this interaction were the Breda and her family were unable to access support or appropriate services.

Breda's perspective should be balanced with the perspective of psychologists in recent research which explored their views regarding the utility of the PDA as a profile during the assessment aspect of their practice (Haire et al., 2023). The participating psychologists reported not finding foregrounding PDA profile descriptors as being useful within the diagnostic process, finding its terminology medicalising and unhelpful. They preferred focusing on early identification of individualised profiles of strengths or vulnerabilities to support access to appropriate support services. They employed various methods to collaborate with the adults in children's environments, emphasising transactional interactions and embracing diversity. Because of their focus on systemic approaches, psychologists are adept at integrating neurodiversity into their practice (Haire et al., 2023). This approach is potentially at odds with the emphasis Breda put on using the PDA profile formulation as foundational within the diagnostic process, but the psychologist's preferences do echo the recommendations for individualised profiles with assessment (e.g., see Kildahl et al., 2021).

Aoife stated clearly that she wanted to access a diagnosis of autism as an important step in allowing her to live in a way that facilitated coping. To provide her with 'cover' so 'I didn't have to live in fear' of social or welfare services removing 'disability allowance' or dictating where she would live. Breda discussed the difficulty of achieving a PDA diagnosis as an adult, describing initially a lack of first-hand knowledge from the psychiatrist; however, on further exploration of the condition, she received a tentative diagnosis verbally but with a refusal to provide this in writing. She also stated that an adult son with Asperger Syndrome and self-identified PDA was in the process of seeking formal diagnosis to ensure appropriate supports in college. This, she expressed, was necessary in the absence of widespread understanding of PDA and effective strategies and interventions:

> [for our son] they give us a diagnosis of mild autism with Asperger's for [name] but … they send it by post and the psychologist [name] wrote by hand a little note saying, 'I can't … I cannot put it in writing or something, but please find attach a diagnosis of Autism' that's really so telling that she's telling us verbally, she's telling us in with her handwriting that it is PDA or she, you know, she acknowledges that it is she sees is PDA but she cannot at this point in time, you know, formally diagnose PDA because it's not in the manual, basically.

Some participants identified the failure of clinicians to discuss or listen to personal experiences, difficulties with explaining challenges or asking for help, a lack of understanding of what 'demand avoidance' means in practice and of PDA as a valid profile, together with a refusal to fund/provide a service with PDA expertise. Within this context, challenges in accessing appropriate diagnosis, support and advice for PDA are perhaps understandable.

Flexibility in education settings. Aoife believes that trust and safety are fundamental to managing PDA within the education system: '… we do not know enough about PDA autism to start thinking about educational strategies yet, because our ability to learn and function depends on eliminating the fear, and where normal kids can feel safe on reassurance alone, a PDA kid needs a concrete reality that is safe for the foreseeable future before his mind is even open to learning'. The implications and necessity for a holistic approach whereby flexibility within the education system would support the engagement of young people with PDA was clearly outlined by Breda, reporting that her son: 'couldn't go to school' attending '40%' of the time while also experiencing 'deep depression'. While she indicated that his school listened to the family and was prepared to be flexible, this was only partially effective. 'When he got his diagnosis, [the school] stopped putting pressure on him, which was good'. They were very understanding. Unfortunately, Breda felt that the overall education system place requirements on individual schools and the lack of available resources meant '… there was nothing they could do really'. This is indicative of the importance of appropriate provision of support and accessible services for autistic people with demand avoidance profiles. This account serves as a clear contrast to previous data which was indicative of the negative outcomes for Autistic adults who identified with PDA when they were not appropriately supported or felt unable to engage with educational or social services.

Reflecting on the role of support in the lives of PDA individuals, Aoife considers that: 'independence is not just an abnormal need it is also our greatest strength … we need passive support, active support is just pushing us into our limits and crippling us'. Furthermore, accessing information and support 'should never be dependent on interacting with a person at all, because the more stress we are under, the more likely that interaction, in itself, and the mechanics of it are to be an insurmountable obstacle … pressing an alarm button is easy for us … figuring out the dynamics of calling a person on the phone for assistance can easily be a secondary crisis'.

Accepting our truth

The participants in this study were clear that a lack of understanding regarding their experience, and regarding PDA more generally was a significant barrier across their lives. Indeed, one of the biggest impacts of discovering PDA for many for these participants was access to greater self-understanding and acceptance. Interestingly, both Aoife and Breda reported seeking multiple diagnostic assessments over their lives to understand their experience of difference. This aligns with past research regarding positive experiences post-assessment for many autistic individuals with regards to self-understanding, accessing support and membership of a minority community (Botha & Frost, 2020; Crompton et al., 2022).

One of the chief motivations for both interview participants to take part in this research was to raise awareness of their situation and the impacts or features of PDA more generally. Aoife's perspective focused on the potential impact of sharing her experiences and reflections: 'Ideally, nobody must ever be allowed to live a life like mine again on any excuse. It has been a totally unnecessary kind of hell'. However, this needs to be considered with the recent research which reported that use of PDA profile formulation within assessment was not useful for them in developing an individualised assessment and recommendations for clients. Aoife's perspective emphasises the impacts of not being supported or able to access the kind of support or networks of appropriate services across life. It foregrounds the importance of individualised and flexible service models tailored to the specific needs of the person.

In an email, she offered a number of 'improvements' which she suggested would be useful for those wishing to support people living with PDA. These recommendations aimed to help others understand the experiences or perspectives of those, such as herself, who had a dual diagnosis of PDA and autism. These recommendations focused on both individual and societal understandings of support, provision of services and understanding of vulnerability. They are as follows:

- The whole phenomenon of 'the wrong kind of vulnerable' needs to be explored and demolished for good.
- Somehow services need to be geared to accept that vulnerability and capability are NOT mutually exclusive.
- Some PDA is reactive and totally justified.
- Sometimes isolation is a much healthier choice particularly for Autistics and PDA.
- Allowance must be made for the fact that trust does not come naturally to Autistics and PDA.
- There are two kinds of distrust, one is moral, the other is qualitative, and, particularly, but not exclusively, in the case of high IQ autistics is a red flag that should never be ignored.
- Special needs kids from dysfunctional families need constructive access on demand to Guardian Ad Litem or we haven't got a prayer.

Breda also emphasised the need for greater awareness across staff or service providers in education, clinical services and social services regarding PDA and demand avoidance. In addition, 'Some kind of … counselling with somebody who understands about PDA would probably be useful' to support self-awareness, self-acceptance and positive life outcomes. She was not aware of such resources being available at present in Ireland.

Conclusion

These first-hand accounts of the experiences, perspectives and recommendations of this under-researched cohort indicate significant, and sometimes extreme, social marginalisation and isolation. All participants expressed clear accounts of bidirectional social dislocation, accompanied by a ready awareness of being misunderstood leading to high levels of anxiety, fear and challenge. These clear outcomes of minority stress (Botha & Frost, 2020) reported by the participants are augmented by their perception that there is a general lack of awareness regarding extreme, anxiety-based demand avoidance across society. In the case of Aoife, this lead her to live in voluntary social isolation and poverty. The accounts of participants regarding victimisation and experiences of bullying align with research on the experiences of autistic cohorts (Paul et al., 2018; Trundle et al., 2023). However, a novel finding related to the lack of perceived attunement or understanding with other autistic individuals may be indicative of differences between those with PDA and autistic others, or aligning with evidence of high heterogeneity in presentation and experiences within autistic populations (Trundle et al., 2023). This contributed to experiences of social marginalisation and experiences of isolation, often also associated with masking or camouflaging in the presence of others (Pearson & Rose, 2021). Distrust and a consequent lack of engagement with health, mental health, social and educational services, together with poor experiences of the diagnostic process, were also clear. High levels of ability allied with significant support needs led to participants being perceived negatively by others and consequently not receiving timely and necessary support. However, this point is also balanced by Breda's experience of her child (who is also Autistic and identifies with PDA) who experienced a flexible and responsive response from their school. This contrasts with Breda's experiences with mental health services, indicating the important positive outcomes of tailored and empathetic service provision for this cohort of autistic people in Ireland.

Participants in this study emphasised the need to support independence and agency among those with PDA. Access to resources or services, while essential, needs to be provided on the individual's terms (without being dependent on social interaction or restrictive requirements), and key to this is increased awareness and understanding of PDA and demand avoidant profiles. Recognition that access to individualised assessment, flexibility in service provision to reflect the profiles and preferences of individual people and respect for the views of those presenting with demand avoidant profiles is key. A move away from using diagnostic categories to gate-keep access to support services and greater acceptance of the lived experience of those identifying with PDA can amplify the voices of individuals who are still not heard.

Limitations and future recommendations

The small number of interview participants and survey respondents who self-identified as a PDA cohort in the study *Mapping Experiences of Pathological Demand Avoidance in Ireland* (Doyle et al., 2019*;* Doyle & Kenny 2023) prevent generalisation of their experiences, and certainly does not provide evidence of PDA being a 'sub-type' within the autistic community, nor for it being a separate phenomenon. However, we would argue that the depth, richness and urgency of their testimony, and the exemplars of the significant impact of bidirectional social dislocation, emphasise the need for continued exploration. Acceptance, support and listening to the individual are fundamental to social inclusion and appropriate service provision.

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