



Mapping Experiences of Pathological Demand Avoidance in Ireland



Executive Summary

25th January 2020



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IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn



Institiúid Oideachais
Institute of Education



The Irish Research Council has funded this research under the Government of Ireland 'New Foundations' Scheme. Responsibility for the research (including any errors or omissions) remains with the Researchers. The views and opinions contained in this report are those of the authors and do not necessarily reflect the views or opinions of the funding body.

Founded in 2014, PRISM DLR (Parents, Resources, Information and Support, Meeting needs) addresses significant gaps in supports for families within the Dun Laoghaire Rathdown catchment area, a Dublin region with a population of circa 220,000 inhabitants. In April 2017, PRISM DLR set up a subgroup called PRISM PDA Ireland to provide practical advice, support and guidance to individuals and families supporting individuals who present with autism and anxiety-based demand avoidance. The organisation was registered as a charity in 2018 and is run entirely on a voluntary basis. There is a dearth of research examining this profile within the autistic spectrum, but findings suggest uncertain health, education, and life outcomes for children, young people and adults. Consequently, PRISM DLR commissioned this investigation with the purpose of capturing and contextualising PDA in Ireland.

January 2020

ACKNOWLEDGEMENTS

Alison Doyle and Neil Kenny would like to thank the Steering Committee for assisting with the management of this research study.

Joanne Banks Trinity College Dublin
Samantha Holman Prism DLR
Cillian Murphy Dublin City University
Stuart Neilson Autism researcher and writer

We also express sincere thanks and appreciation for the time and expertise provided by our Advisory Panel on evidence-based good practice:

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Rachel Neale Colley Parent
Paula Prendeville Enable Ireland Cork
Michael Ryan Peace of Mind
Muriel Weekes Scoil Chiaráin CBS, Donnycarney
and to our Research Assistant, **Finbar Horgan**

A special word of thanks and acknowledgment to individuals with PDA, parents, carers, guardians, and education and healthcare professionals, who gave so generously of their time to share their experiences.

The researchers would like to acknowledge the Irish Research Council, who funded this study.


GLOSSARY OF TERMS

AET	Autism Education Trust
AON	Assessment of Needs
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Services
DES	Department for Education and Skills
DSM-5	Diagnostic and Statistical Manual 5
EDA	Extreme Demand Avoidance
EDAQ	Extreme Demand Avoidance Questionnaire
EPSEN	Education for Persons with Special Educational Needs
FE	Further Education
FETE	Further Education, Training or Employment
HE	Higher Education
HSE	Health Service Executive
IEP	Individual Education Plan
IU	Intolerance of Uncertainty
ICD	International Classification of Diseases
ICF	International Classification of Functioning
MDT	Multi-disciplinary Team
NCSE	National Council for Special Education
PDA	Pathological Demand Avoidance
WHO	World Health Organisation

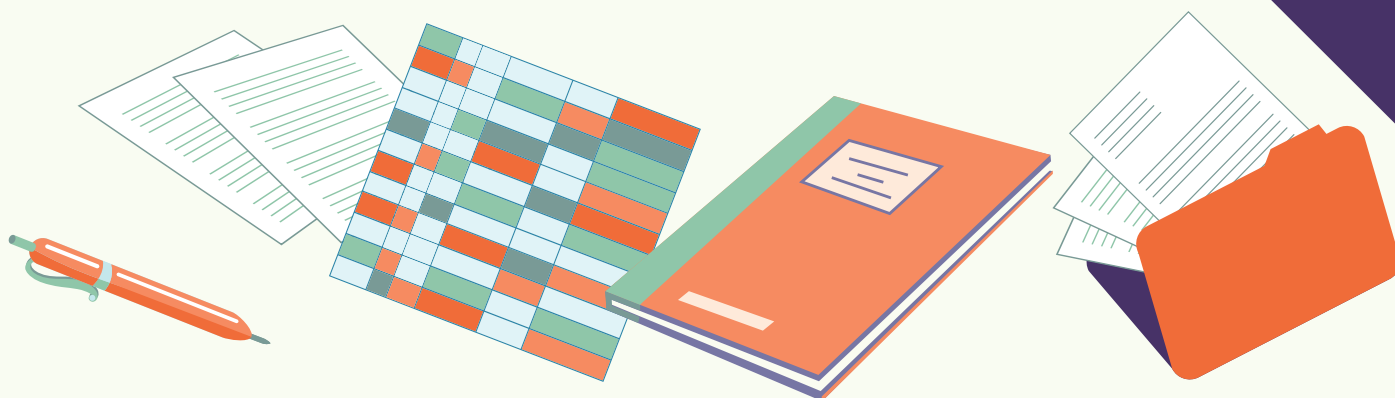


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EXECUTIVE SUMMARY



Background

In 2018, the Pathological Demand Avoidance Society (PDA) UK published the report *Being Misunderstood*, which presented the results of a national survey completed by almost 1500 individuals. There is a comparative lacuna of research exploring incidence or lived experience of PDA among individuals on the autism spectrum in Ireland. Recent investigations into school exclusion and reduced timetables (ASIAM, 2017; Barnardos Ireland, 2018; Inclusion Ireland, 2019) imposed on families of autistic children, highlight a practice which results in interrupted education, and at worst the cessation of meaningful engagement with schooling.

This situation has the potential to have a lifelong impact on educational achievement, access to further education and training opportunities, participation in future employment, potential life income levels, and overall community inclusion in the long-term. Increasingly, Irish health and education practitioners are seeking advice and guidance on strategies for supporting adults and young people with complex profiles or who require adapted support to access services in schools and clinics. Additionally, there are significant numbers of families seeking assessment, diagnosis and intervention for extreme anxiety-based demand avoidance. Therefore, a national investigation of autism, anxiety and extreme demand avoidance manifested as PDA, has the potential to benefit individuals, families, and practitioners in Ireland.

The aims of the *Mapping Experiences of Pathological Demand Avoidance in Ireland* research study were to:

- ◆ Determine levels of knowledge, recognition, and understanding of PDA in Ireland.
- ◆ Explore current pathways to assessment and diagnosis of PDA in Ireland.
- ◆ Capture experiences of access to education and healthcare services as described by families supporting individuals living with PDA in Ireland, viewpoints of professionals in health and education settings, and adults identifying as PDA.
- ◆ Determine impact on families and individuals across the lifespan.
- ◆ Identify key areas of concern for these stakeholder groups which can inform strategies for supporting individuals presenting a PDA profile in Ireland, and act as a focus for further research.

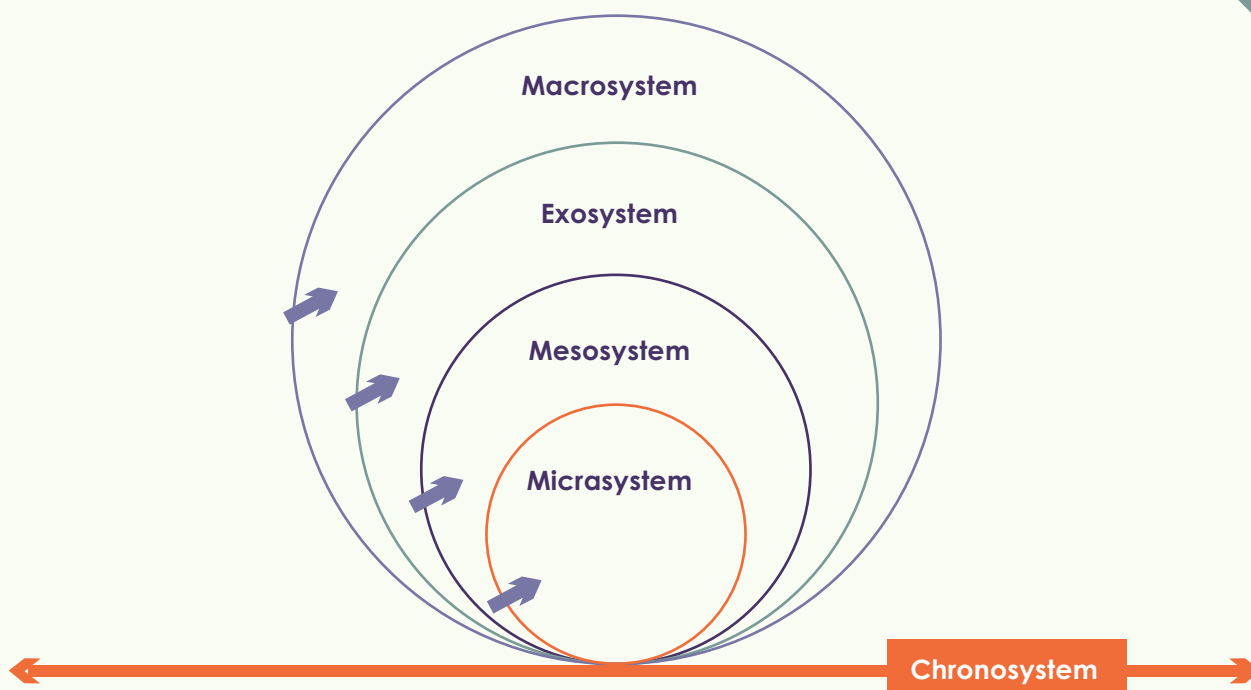
In pursuit of these aims, the following objectives were identified by the researchers, in consultation with relevant stakeholders:

- 1** Conduct a national survey to establish the degree of prevalence of PDA and the extent of access to diagnosis, support services, or educational and clinical intervention opportunities for individual or their families.
- 2** Use semi-structured individual interviews or focus groups to capture the lived experience and impacts of PDA from the perspective of individuals, families and supporting professionals.
- 3** With reference to the emerging data, develop evidence-informed advice for supporting individuals experiencing PDA, their families, and professionals working in this domain.
- 4** In collaboration with PRISM PDA Ireland, convene a conference on PDA in Ireland to raise awareness regarding PDA and foster collaboration across the networks of stakeholders.
- 5** Disseminate findings and raise awareness through 3 – 4 public seminars across Ireland regionally.

Theoretical Framework

This study takes as its conceptual framework an adapted model of bioecological systems theory (Bronfenbrenner, 1993; Bronfenbrenner & Morris, 2006) to illustrate how the relationship between systems can and does impact on education and health - and by extension - life outcomes, for the autistic community in Ireland (Figure 1). By mapping PDA onto these contexts, it is possible to more clearly understand how and why pathways to assessment, diagnosis, suitable education placements, and appropriate interventions may be complex, interrupted, circuitous, or suspended. There is an international trend towards compartmentalising conditions such as autism and separating service provision into “specialist” discrete service teams for diagnosis and support (Gillberg, 2010). This can lead to lengthy diagnostic journeys for some individuals who present with complex profiles, or where there is co-morbid diagnosis with psychiatric conditions (Green, Absoud, Grahame, Malik, Simonoff, Le Couteur, & Baird, 2018; Gillberg, 2013). Examining school exclusion and autism from a holistic nested systems perspective illustrates the very real difficulties encountered by families in pursuit of an education for their children, and for mental health services to address the outcomes of extreme anxiety. It also provides a method for scrutinizing lifelong experiences of people with PDA (sometimes referred to as PDAers). Given the complexity of this phenomenon and the nuanced reality of the interlined Irish health, education and social protection services, such a holistic and ecological approach was deemed most appropriate.

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 partner's 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. Adult PDAer



Macrosystem

Legal frameworks and definitions e.g. UNCRC, CRPD, EPSEN, Disability Act, School Admissions, Autism Bill, NCSE and HSE policies, directives from teaching unions, teacher training standards, resourcing of multi-disciplinary teams, separation of diagnoses e.g. autism and mental health

Exosystem

Primary and secondary education: physical infrastructure, sensory environments, autism units / autism classes, reverse inclusion, NEPS Continuum of Support, models of resource allocation, role of SNAs, importance of CPD, delays in Assessment of Need and service statements, under-resourcing of autism expertise

Mesosystem

Availability and utilisation of SNA support, school ethos, autism awareness-acceptance-understanding, IEPs, home-school communication, management of transitions school policies e.g. uniforms and homework, supported transitions, local provision and geographical restrictions, private or public healthcare

Microsystem

Feeling valued and accepted, opportunities to participate with peers, individualised approaches to facilitate achievement, relationships with peers, implementation of sensory diet, access to therapies, parental resources and input, idiosyncratic autism profile, dual exceptionality, availability of services and school placements

Chronosystem

Physiological, emotional and cognitive development; social and cultural thinking; economic booms and recessions; educational and medical approaches; research; activism

Impact events:

Changes in personal circumstances e.g. funding, housing; changes in / additions to autism diagnosis e.g. mental health; change in medication; changes in support teams e.g. new teachers, clinicia; management of micro (between classes) and macro (between education placements) transitions, child services to adult services.

Figure 1. Bioecology of autism, education and healthcare in Ireland



Brief review of the literature

The incidence of autism within the population of Ireland is currently estimated to be 1 in 65 (HSE, 2018), and although there is a distinct lack of scientific study into the prevalence of PDA, it is suggested that an occurrence of 1 in 5 within the autism community, may be likely (Gillberg, Gillberg, Thompson, Biskupsto, & Billstedt, 2015). The emphasis in recent years on clarity in the operationalised diagnosis of autism based on frameworks such as the DSM V (American Psychiatric Association, 2013) have been hugely influential on diagnostic and service provision practice internationally and in Ireland (Sonuga-Barke, 2009). However, while this approach to emphasising the construct validity of autism (Green et al, 2018; Woods, 2019) is based on the observation that many “subtypes”, or different profiles, within autism often lack consistency or empirical coherence (Woods, 2019). This approach has also been suggested to under-estimate the complex reality of neurodevelopmental diversity across the autism spectrum (Gillberg, 2010; Embracing complexity, 2019). For example, one study found that 70% of children on the autism spectrum had a comorbid psychiatric presentation, and 41% had two or more (Simonoff, Pickles, Charman, Chandler, Loucas, & Baird, 2008). Rogers (2019) points out that between 22% and 84% of autistic children and 35% to 77% of adults report anxiety, with 50% of children describing this as impacting on daily life. In the context of a system led by an emphasis on discrete separate diagnoses, and more worryingly, segregated “specialised” services, there may be obvious challenges in engaging appropriate services to support individuals with complex neuro-diverse profiles and their families (Green et al, 2018).

PDA was first proposed as a specific subtype of autism in a seminal paper by Newson, Marechal and David (2003), based on observational assessment and parent data for children attending the Child Development Research Unit (later known as the Early Years Diagnostic Centre) at the University of Nottingham. Two studies based around clinical observation captured an atypically autistic constellation of behaviours which include a more nuanced presentation of social behaviour, an obsessional avoidance of everyday demands, and the need for absolute control over tasks and environments, including the actions of others. Newson et al (2003) argued for the recognition of PDA as a distinct, qualitative difference within ‘pervasive developmental disorder’, describing this as a profile that is ‘pathological’ in its extremity and permeation of all aspects of life both within the family context and the wider social environment. Defining features are summarized by O’Nions, Gould, Christie, Gillberg, Viding, & Happe (2016) as:

- ◆ Continues to resist ordinary demands with strategies of avoidance that are essentially 'socially manipulative' e.g. distraction, diversion or socially shocking behaviour.
- ◆ Surface sociability, but lack of sense of pride, shame, responsibility or social identity – e.g. behaviour viewed as irksome by peers, tendency to identify self with authority figures.
- ◆ Lability of mood, impulsive, led by need to control – e.g. domineering, sudden switches from loving to aggressive behaviour.
- ◆ Comfortable in role play and pretend – e.g. adopts borrowed roles (e.g. relating to peers as a teacher).
- ◆ Obsessive behaviour – evident in quality of demand avoidance, and in obsessions with particular people, who are loved or hated.
- ◆ Passive early history, language delay, neurological involvement.

Although PDA is not currently included in diagnostic criteria (e.g. ICD-11; DSM-V), the past five years has seen increased discussion and growing acknowledgement of PDA as a distinct entity through reference by international entities such as the National Autistic Society (2019), the Autism Education Trust (2017), and the Cooperative Research Centre for Living with Autism [Autism CRC] (2019). It should also be noted, however, that there remains debate and differing perspectives regarding whether PDA is a phenomenon within the autism spectrum or whether it is more effectively understood as an external "co-morbid" condition related to heightened anxiety (Woods, 2019) or an outcome "symptom" of other underlying conditions (Green et al, 2018). The emphasis in diagnosis and case formulation in more recent years has moved towards a focus on the individual presentation of each person (Bolte, 2019; Green et al, 2018; Gillberg, 2013), perhaps in recognition of the reality that most individuals with autism present with a spectrum of co-occurring diagnosable conditions (Gillberg, 2010; Embracing complexity, 2019). Given that most autistic persons have indicated their preference for research to focus on provision of better services and support rather than focusing on discrete labels (Pellicano, Dinsmore, & Charman, 2014), an emphasis on flexible and individualised assessment and services provision is therefore advisable, allied with raising understanding and awareness regarding PDA.

Assessment and diagnosis of autism is achieved through referral to professional psychiatric or psychological services, most typically in Ireland via the Health Service Executive (HSE) and CAMHS, although increasingly parents are seeking private assessment due to significant waiting lists attached to the Assessment of Need (AON) process (Disability Act, 2005) via the HSE. There are significant delays in accessing an AON which are geographically dispersed across Community Health Organisation (CHO) areas (Joint Committee on Health, 2019). Furthermore, "even after the delay in assessing a child, there were often further waiting times of several years to access additional services ... families are not given sufficient information on the intervention pathways needed" (p. 30).

Recent changes to the DSM-5 (American Psychiatric Association, 2013) and the ICD-11 (World Health Organisation, 2016) mean that Autism Spectrum Disorder (ASD) is the overarching term used to describe profiles of autism, however, it is acknowledged that apart from the specific diagnostic criteria described at three levels, individual

profiles can be observed. PDA is increasingly, but not widely, understood and accepted as one of these dimensions with varying degrees of nuance within its features. The principal argument for recognition of this profile is not the establishment of a new symptomology or alternative diagnosis, but awareness that this particular set of behaviours requires a flexible and different method of management and support in the home and school settings. While some researchers have emphasised that the strategies suggested as being “unique” to PDA also align with many approaches suggested for those on the autism spectrum (Woods, 2019; Milton, 2013), it has been observed that much of the most frequently provided advice can be counterproductive for supporting those meeting the PDA profile (Christie, 2007). Other regularly suggested approaches, such as structured teaching may be used effectively, but only with recognition of the need to provide high levels of choice and self-direction for the individual due to high levels of anxiety or need to control for uncertainty. Such adaptations to commonly used autism supports underlines the need to raise awareness and understanding, as this may not always be clear for educators or clinicians (Milton, 2017). This foregrounds the important awareness of the impacts of accurate assessments and awareness of individualised presentations across the autism spectrum. Therefore, an initial exploration of the presence of a PDA profile may logically be incorporated into an Autism assessment, and not necessitating a separate or additional assessment for “PDA”.

The relationship between experiences of school and the mental health of autistic children and young people, for whom extreme anxiety creates avoidance of demands, is well documented. School avoidance behaviour is reported to be higher in students with autism as compared to typically developing students (Munkhaugen, Gjevik, Pripp, Sponheim & Diseth (2017) possibly connected to academic under-performance relative to ability, and difficulties with maintaining attention and regulating emotion and behaviour in the school environment (Ashburner, Ziviani, & Rodger, 2010). Across 40 studies, White, Oswald, Ollendick, and Scahill (2009) note an incidence of anxiety in young people with ASD in a range between 11 and 84% of this population and there are links between interrupted schooling and anxiety related issues. Children and young people on the autism spectrum are at increased risk of school exclusion (Brede, Remington, Kenny, Warren, & Pellicano, 2017). Interview data from secondary school students and their parents captured wholly negative experiences of school, framed around unmet needs and unsuitable strategies for managing demand avoidant behaviour, resulting in exclusion from school.

Method and Data Collection



In 2018, the PDA Society UK granted permission to the researchers to replicate their survey in Ireland, for comparative purposes. Some small amendments were made to the survey to reflect differences between systems in the UK and Ireland. The survey data was augmented in the current research with qualitative data collected from in-depth semi-structured interviews with self-selected individuals living with PDA, life partners of individuals living with PDA, practitioners diagnosing and supporting children and adults, and parents, carers or guardians of children and adults with PDA.

Plain Language Statements and Consent Forms were designed, tested and submitted for ethical approval to the Ethics Research Committee, Dublin City University. A review of the literature was conducted through academic databases such as PubMed, PsycInfo, ERIC, CINAHL, Scopus, and Google Scholar. The review encompassed research published between 2003 and 2019, using the keywords 'autism spectrum disorder', 'intolerance of uncertainty', 'demand avoidance', 'extreme anxiety', 'Pathological Demand Avoidance', 'school avoidance', and 'school refusal'. Full-text articles, written in English, were extracted from peer reviewed publications, and a search of relevant publications from national and global policy was also completed.

Data was collected from an online survey administered through SurveyMonkey via an open invitation to the autism community, and completed by parents / carers / guardians of individuals with PDA (n=264), life partners supporting Adults with PDA (n=4), individuals presenting with PDA (n=14), and professional practitioners in education or healthcare settings (n=54). Thirdly, semi-structured interviews were conducted with a self-selecting cohort of parents (n=19), adults identifying as PDA (n=2), and practitioners (n=2). An interview schedule was developed to capture experiences across six inter-related themes:

- 1 Awareness, acknowledgement, acceptance, and understanding PDA
- 2 Journeys to assessment and diagnosis
- 3 Access to education and health services
- 3 Approaches and interventions for management and support
- 5 Education, health, and life outcomes
- 6 Triumphs and challenges

Descriptive statistics were extracted from a quantitative analysis of survey data using a statistical software package (SPSS); open-ended survey responses were also themed and quantified to record prevalence of experiences and viewpoints.

A qualitative analysis of open-ended responses from the survey and interview transcripts was undertaken using coding software (NVivo). Subsequently, transcripts were thematically analysed, categorised and re-categorised on three separate occasions. Data from individual interview transcripts is also used to illustrate individual pathways and outcomes for some children and their families and are presented as vignettes in the Appendices of this report.

KEY FINDINGS



Data collated here is extracted from statistical information and open-ended responses to the survey, interspersed with interview testimony. Additionally, the Appendices present five stories which illustrate the life journey of children and adults with PDA. Data is presented, firstly according to the demographics of the respondents, thereafter under the six thematic areas.

Demographics

Survey responses were received from across the island of Ireland, with the greatest concentration in the Dublin area.

Parent data indicates that the majority of respondents have children in primary school (60%), and a further 25% have students attending secondary school. Smaller numbers are reported for early years education and post-school settings. Gender profile of the children and young people (CYP) described in the survey indicates that almost 70% are male and 30% female. The four life partners who completed the survey indicate an age range for supported adults spanning 21 to 50 years, all of whom were male, and all bar one living at home with family.

Survey participants identifying as PDA (N=14) spanned an age range of 18 – 60+ years, most respondents identifying as within the age range of 26 to 50 years, the majority (N=12) being female. The two interview participants were both female and aged between 45 – 60 years of age.

In terms of practitioner profile, the majority of respondents (85.4% cumulatively) were closely associated with education placement or contexts, with only 12.2% working

within clinical and diagnostic contexts. Two interview participants one male and one female were working as a psychologist and post-primary teacher respectively. Practitioner profiles indicate that 71% work or have worked with CYP or adults who present with a PDA profile, or traits of Extreme Anxiety-based Demand Avoidance, with the remainder stating that they have done so on occasions. For the most part practitioners work or have worked with primary school age children (66%) and post-primary school age children (49%), less than 25% reporting that they work with Early Years or Adult populations.

1 Awareness, acknowledgement, acceptance and understanding

Collating responses from all cohorts, parents, life partners and PDA adults were in agreement when describing barriers to awareness, acceptance, and understanding, principally associated with communication with education and health professionals. Levels of awareness were reported to be low, with most parent / carer respondents (63%) believed that professionals were “rarely” or “never” aware of PDA. Commentary from parents alluded to the challenges of establishing understanding in school, with an emphasis on directional / instructional approach very often advised/utilised. Such unsuccessful and inappropriate strategies run counter to clinical advice:

They could see there was nothing they could really do, we couldn't force him to go to school, it was a case of, well, if you see him, good, if you don't see him, don't comment. It was a case of, leave him alone and welcome him if he's there but that's it, don't comment. That was our instinct. The advice of CAHMS was the opposite, it's usually “Oh you have to make him go to school, or you have to do this” (PDA Adult A, interview).

Parents often report being the focus of clinical intervention / diagnostic interviews, with participants reporting poor parenting skills (45%) and attachment issues (27%) being identified to them by clinicians. A consequence of this is that parenting programmes or courses are often the first line response to challenging behaviour or school avoidance, with: “A focus on helping me ‘cope’ instead of getting my son the services he needs.” One parent, whose son subsequently received a PDA diagnosis via a HSE team, describes this experience in terms of a personal criticism:

School had told me I needed to see a counsellor, and could I get somebody in to monitor things at home, like a super nanny, but not a super nanny. That's what they thought of my parenting. I've been advised to go on parenting courses many, many times, I've done them all (Parent, survey).

More helpful, are courses that focus on identifying strategies and approaches appropriate to the individual child. This emphasis on the need for a flexible and individualised approach rather than generic “autism” advice or a sole focus on “parenting” was seen as beneficial by some parents:

Have done a course with psychologist around reducing demand and giving child more self-control and changing wording in talking with child. Reduce expectations. This course was named Collaborative Problem Solving which includes finding source of breakdown where child behaviour escalates. Going back to see what skills are missing and to problem solving around this (Parent, survey).

Parents supporting adults report similar experiences which extend beyond childhood and adolescence. However, as exemplified in the literature, in the absence of awareness and understanding, and without comprehensive, multi-faceted assessment, the consequences can be dire. Misunderstanding of an individual's presentation or delivery of inappropriate or unhelpful intervention can escalate a problematic situation, leading to chaotic and unstructured service provision. Recent cases in the UK draw attention to the incarceration of vulnerable autistic adults, and PDA Adult B describes their own experience at age 15 years:

The social services area psychiatrist who had seen me for about 20 minutes some three months prior to signing the [involuntary section] 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.

PDAers are clear about the manifestation of their own anxiety and demand avoidance: "It's anxiety driven, it's out of our control, it's who we are, it's not a choice being the way we are, and it's difficult to live with" (PDA Adult A, interview). PDA adults report significant barriers to creating greater awareness and understanding of PDA; being unable to describe, discuss and explore their experiences means that PDAers are prevented from receiving support to develop self-awareness, self-determination and self-advocacy, resulting in lifelong impacts on self-esteem and self-perception:

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. Feeling worthless all the time is hard and it stops me from being as good at things as I know I could be.

Parental participants also reported feeling the need to advocate for their young people in the face of a perceived lack of understanding among clinicians. "I can see that my son is not belligerent or ODD (which one report classified him). The next step would be for our family to get training in how to help him and also health professionals to explore this profile"

(Parent, survey). Most importantly, awareness, acknowledgement and acceptance within the autism community and PDA groups in particular provide an affirmation for parents and partners that is essential for their own mental health and well-being.

Interestingly, from the practitioner perspective almost 37% of professionals believed that they had a good understanding of the presentation of PDA, with a further 32% stating that they had some understanding, and 22% no understanding of this profile. The principle challenge for practitioners in acknowledging and accepting PDA appears to be connected to a lack of formal recognition via diagnostic tools such as the DSM-5 and the ICD-11.

Although some practitioners refer to this profile as Oppositional Defiance Disorder (ODD) and Conduct Disorder, arguably demonstrating a lack of understanding of the underpinning argument for PDA, 83% use PDA terminology, and 34% use a diagnostic terminology associated with mental health. Other practitioners use functional assessment and associated terminology to describe behaviour rather than diagnostic labelling or describe challenging behaviours as being “consistent with a diagnosis of Pathological Demand Avoidance, which is a specific form of ASD characterized by...” followed by a statement of key features.

Practitioners indicated that professional training and development was essential to working with children, young people, and adults in education and healthcare settings, and that the lack of same – irrespective of whether PDA is a recognised diagnostic category – is fundamental problem. Findings draw attention to the dearth of resources and information, and an over-reliance on informal channels: according to 30% of practitioners, formal information avenues and training opportunities are currently accessed through charitable institutions (PDA Society [UK]; Prism DLR [Ireland]), 20% through ‘Googling’, and 20% state that they have not had access to resources. Unsurprisingly, this considerable shortfall in professional knowledge impacts on awareness and understanding, and practitioners repeatedly referred to the need for avenues for professional discussion and collaboration, due to the complexity of the PDA profile:

More than other diagnosis, I find PDA very challenging professionally. I am torn knowing absolutely that the child with PDA needs adults to adjust the demand dial in the moment to match the child's coping dial in the moment but there are serious short and long term consequences if we lower expectations too low too often and equally there are consequences if we place the demand dial too high too often. I guess my question is do other professionals struggle with this - trying to do right by the child for their childhood and for their adulthood. Are other professionals concerned that we might not get the right balance and the child may be denied learning opportunities (academic, life skills, behaviour, emotional management) that he/she is able for, or we may ask too much of the child to his/her detriment.

Final note - It was such a relief to discover PDA and have explanations for children with highly complex needs. It has enhanced my professional life significantly.

Two final questions in the survey asked practitioners to express: i) the type of support and training that they felt practitioners needed, and ii) outcomes from the research

study that would be helpful. The most important requirements as determined by frequency were continuing professional development, input from multi-disciplinary teams, and more understanding from colleagues.

2 Journeys to assessment and diagnosis

The process of accessing assessment or diagnosis was reported as being fraught and challenging by parental participants. Only 25% of parents who reported that their child presented with a PDA profile, even to some degree, had received a formal diagnosis, and of those 98% were experiencing barriers to support, with the most frequent barrier being lack of understanding and / or awareness of PDA (70%), and a lack of acceptance of PDA as a profile within the autism spectrum (50%).

Lengthy waiting lists across the country are a significant barrier to timely assessment and diagnosis leaving parents to work in a vacuum: "The OT said he was demand avoidant and sensory issues etc. 18 months now till psychology start seeing him and he potentially gets support. They said 2 yrs wait now for assessment" (Parent, survey) Consequently, parents feel forced to travel outside of the country to obtain a diagnosis, in itself a cause of difficulty: "Because the SENO's excuse now is that "Oh well, the diagnosis was made in Northern Ireland, we don't know what to do with it" (Parent, survey) A lack of awareness or expertise in PDA means that this can occur haphazardly:

CAMHS now ... actually found about PDA completely by accident, the day after they gave us the diagnosis of ASD and Asperger's and I said, that doesn't fit, he still doesn't tick the boxes, that doesn't explain everything. So, the next day, pure chance the psychologist heard another psychologist talking about that profile, and completely recognised [him], phoned us saying "Have a look at this", and it was like, bam, you know lightbulb coming on. (Parent, focus group)

Provision of services to CYP are siloed between Disability Services and CAMHS, meaning that autism and anxiety are treated as separate conditions requiring intervention from different entities. This was reported repeatedly by all participants and viewed as the most significant barrier to achieving accurate, multi-dimensional diagnosis that would ensure support and intervention for all aspects of a child's profile: "the anxiety that comes with autism, fits into mental health, but autism fits into the disability team, there is no specific in-between version in autism mental health, so, you know, the child doesn't fit neatly into a box" (Parent, focus group). This is also problematic where there is disagreement between professionals working within quite different settings; the complex presentation of PDA means that anxiety and response to demands can be context specific, and thus practitioners may encounter or observe quite different presentations.

Despite the battle to access assessment and diagnosis, receiving formal confirmation does not necessarily pave the way to improved access to services whether that be within educational placements or clinical environments: "Like everything else in this country, there's no help really, it's the same kind of way, when you're down the road of autism you're kind of given an autism diagnosis and sent on your way" (Parent D, interview).

Life partners describe the relief of identifying a profile which explains heightened levels of anxiety and intolerance experienced by their partners: "At first I was horrified but then I kept listening to people who blogged and it made so much sense to me. I have told him that this could be same as him, but he does not want to know. But it is so helpful for me" (Life partner, survey). Adult PDAers believe that the ability to point to a specific diagnosis can assist with greater understanding in social contexts:

I realized by about 2003 that I probably had an atypical variant on Asperger Syndrome ...I got the diagnosis to cover me so I didn't have to live in fear of someone getting the bright idea of forcing me to live nearer to people or taking away my disability allowance because I "looked OK to them"... 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. I got the second diagnosis two years ago for the same reason as the first ... just to protect me from being forced to be among people so I could relax and get some peace in life. (PDA Adult B, interview)

Almost all diagnoses of PDA reported by parents and PDAers had been accessed through private assessment, very few survey or interview participants reported this being provided via the HSE. Of these private assessments, most had been sourced from one particular entity in Northern Ireland. Participants acknowledged the contested nature of PDA, but also that perception is multi-layered rather than absolute: "PDA is a really controversial topic, and I think, part of it is to do with that it challenges particular views or perspectives we have on how we can interact with people with autism ... I think sometimes, the diagnosis challenges people's fundamental values" (Professional B, psychologist, interview).

3 Access to education and healthcare services

While the majority of participants were accessing school placements, the vast majority of parents/carers reported barriers to accessing services. Satisfaction with service provision (once accessed) was also very poor.

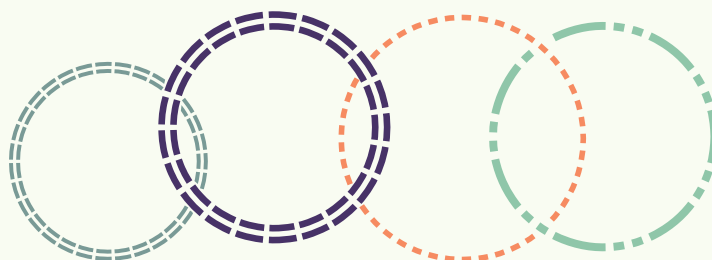
Almost 60% of children were attending mainstream education, and 8% are educated at home via Department of Education Home Tuition scheme. N=5 parents stated that their child was home educated by choice (N=4 primary age, N=1 post-primary age), however, N=16 parents stated their child was home educated as there was no other choice of educational placement (N=13 primary age, N=3 post-primary age). A greater number of respondents were caring for children in pre-school and primary school (63% of survey respondents), however, there was no significant difference in accessing supports between primary age versus older children/young people, nor was there a difference in satisfaction between age groups.

N=165 parents and carers (90% of respondents who answered the question around supports for PDA) reported barriers to accessing services for their children. Significantly, 98% of respondents whose child had received a PDA diagnosis, also experienced barriers to services, suggesting that even where a diagnosis of PDA has been secured, access to appropriate and timely services is not a given.

The most frequently cited barrier was a lack of understanding regarding PDA and its behavioural presentation (70% of respondents), with 51% of parents reporting a lack of acceptance of PDA as a valid profile, and 46% of parents a failure to discuss or listen to their individual and family experiences of PDA.

Long waiting lists and a regional lack of staffing or expertise means that CYP are not in receipt of services: "HSE/ASD unit have advised she requires supports but in reality they have advised that they will not be in a position to provide any supports" (Parent, survey) forcing parents to access therapies and interventions privately, whether or not they can afford it. Parents also expressed dissatisfaction with the quality of reporting and feedback particularly through private practitioners: "So I had an assessment done privately ... she said to me 'he's clearly extremely bright .and quirky. And then she sent me a report ... there was no follow up. Unless I paid for this privately there was no follow up, there was no meeting to go through that report I was just sent the report" (Parent, interview).

Of those families who did access services, almost two-thirds of respondents (61.2%) reported that this had little or no effect on challenging behaviour, with engagement with CAMHS reported low levels of satisfaction. PDA adults indicated that intervention and support was accessed through the GP (25%), adult mental health services (25%), or mental health inpatient or hospital care (25%).



4

Approaches to intervention and support

The results that emerged regarding impact of intervention were concerning: 82% of parents / carers (N=184) reported accessing some type of intervention or support for their child, however, almost two thirds of respondents (61.2%) reported that these were "not so" or "not at all" effective.

The most frequently cited support was a Special Needs Assistant (SNA) in school (N=114, 51%), followed by Occupational Therapy (OT) (N=107, 48%) and Speech and Language Therapy (SALT) (N=75, 33%). Children who were reported to have communication difficulties were significantly more likely to be availing of SALT and children who were reported to self-harm were significantly more likely to be availing of CAMHS support.

Of the N=173 respondents who answered the question regarding educational provision, 88% had received educational supports for their child (68%). Cross-tabulation of survey data indicates that the bulk of intervention occurred during primary school years, with decreasing levels of support throughout post-primary education. Most significantly, once individuals have transitioned into adulthood, intervention and support for autism or PDA dissipates to extremely low levels. This is of concern given the complexity of transition into adulthood for autistic people, a critical period as individuals are exited from child services into uncertain futures. These findings illustrate where gaps in support might compromise already vulnerable individuals.

Occupational therapy, Speech and Language therapy and Play therapy were the most frequently accessed intervention and were also stated to be the most successful or effective of all supports. In terms of whether supports or interventions provided in education or healthcare settings positively affected their child, 29% of parents believed that they were not so effective, and 33% not at all effective. Of the N=207 parents who responded to a question on efficacy of medication, only 17% noted an improvement, with 33% indicating no improvement.

Appropriate management and support can only be provided where there is an accurate understanding of specific aspects of the PDA profile. One of these is being "comfortable in role play and pretence, sometimes to an extreme extent" (NAS, 2019); this strategy is utilised to maintain situational control thereby avoiding demands. Play behaviour exhibited by children with PDA is intense, directive, controlling, and immersive, therefore less socially engaging for other children:

He will pretend that he is a velociraptor and when you try to call his name, and get him out of that pretence, you can't. Like you're trying to say 'Right come on now T' and he'd be like barking at you, and you know like he's biting you and things like that, to an extreme extent ... he just takes it to this whole new level of obsession. (Parent E).

Many parents acknowledged the efforts made by schools to accommodate individual needs and to try to find the right approach, but accepted that for those individuals for whom demands are intolerable, the school environment may never work:

I can't even tell you how much reaching out they've done already, absolutely stunning amount of support from them, I've had loads of phone calls, if they were bending any more backwards, they'd break themselves trying to help me, to get him in there ... even now that they're doing their absolute best for him, so, if it doesn't work, it's got nothing to do with them.

These good intentions are often sabotaged in post-primary school by whole school considerations, such as changes to teaching staff, slow uptake or recommended strategies, or failure to pass on information to teachers in subsequent years, or to transmit information from one school to another. Sometimes, however, the solution is an alternative pathway that diverges from the 'one size fits all'.

So, working with external support and with school, we kind of developed, an alternative learning programme, if that's what you want to call it, and that learning plan involved him leaving school, funnily enough in 5th year. It was a plan to help him develop his interests and his skills, build a portfolio, and go down the PLC route, which is what he did, but, strictly speaking that doesn't fit in the term IEP.

Of note, much of the interview testimony from parents specifically stipulated that well known and frequently provided advice for “good autism practice” strategies did not work for their children. For example, advice regarding use of routines, to use of visual resources such as schedules and charts:

I don't use visuals, I don't have anything like that because I think they have a awkward effect ... I think the typical autism strategies, if anything made my child worse, because I was letting him know what was expected of him ... what to be stressed out about. I can't prepare, I have to spring things on him, which is far better, if he knows he's a doctor's appointment coming up, he will, you know, start losing sleep, or start wetting the bed, he won't be eating, when I spring it upon him, and make it in to a really fun thing, like, 'oh look, we're just going to pop in here now and ask for' he doesn't have that time to worry (Parent B, interview).

This was emphasised by adult PDAers who described such approaches as sometimes “counterintuitive”. There is safety in solitude, so attempts to force PDAers into social situations are viewed as “threatening and bewildering” as are task specific instructions or demands, when in fact “what I need is full information so I can get stuck in.” Commentary draws attention to the general acceptance that one size needs to fit all as far as possible, and that this pursuit of integration is “toxic to us”.

One important point is that seeking information, support etc 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.

Reflecting on understanding and supporting the underlying fear and anxiety that feeds into demand avoidance, PDAers were specific in their dissection of appropriate care and support: “We even learn better alone – I can't learn in a classroom at all, because the classroom setting and the teaching **IS** the insurmountable barrier for me.”

Children and young people with highly specific needs are at risk within a model of support where no formal diagnosis is necessary. The detail provided from professional assessment and observation, is crucial to individual, person-centred, education and health care intervention:

I also think it depends on the resources that are available ... I would be teaching in a very big school ... our hands are tied in that sense, and people are trying to do everything that they possibly can on the ground, but there is a problem getting resources. If there isn't a diagnosis and if there isn't a report coming from the primary school. (Practitioner, focus group interview)

Despite these challenges, in both survey and interview, practitioners demonstrated not only awareness and understanding of PDA, but imagination and creativity in their approach to intervention and support (Figure 2).

5 Education, health and life outcomes

Parent / carer reports of challenges experienced by CYP (N=182 of 224 participants) are illustrative of the diversity and complexity often experienced by those who present as having PDA. A significant and complex interplay between sensory / cognitive / behavioural factors emerged which require further investigation. For example, the relationship between sensory issues (81.42%), need to feel in control (81.82%), and severe anxiety (78.26%) may be impacting difficulties with daily routine (67.59%), school attendance / refusals (52.57%), and problems sleeping (56.52%).

Significantly, children who had a greater need for control were significantly more likely to have school avoidance issues. Girls were more likely to experience difficulties in daily routines (71%) than boys, and older girls (77%) were significantly more likely than older boys (52%) to experience difficulties in daily routines.

There are also significant differences in the type of challenge experienced by children depending on their age. The age variable was recoded in order to investigate experiences of specific challenges for children from preschool through to end of primary school (ages 3 - 12 years) (N=142) compared to older children (13 – 18 years) (N=82). Younger children (from preschool through to end of primary school) were significantly more likely to experience sensory issues (89%) than older children (68%), to have a greater need for control (88%) than older children (70%) and to be more exhibit challenging behaviours (85%) than older children (68%). As children became older, gender difference increased, with older girls being increasingly more likely than boys to experience difficulties with daily routines. Younger children were significantly more likely to experience challenges with sensory issues, a greater need for control, and were more likely to present with challenges than older children. Younger children also demonstrate more behavioural challenges and associated issues than older children, perhaps indicating a lack of sufficient early intervention.

Within this present study, there was no evidence of large-scale school absences across the school age cohorts, that being said, the majority of participants indicated that their children were of primary age, and it is possible that significant difficulties with attending school may be triggered by the move to post-primary education. However, those individuals who did report absences described the school environment as presenting a hostile and impenetrable barrier for those with extreme demand avoidance:

Leave our kids out of school, because they can't cope with all of that, the expected demand of the structure, or the expected demand of, well now you will do this, and then you'll do this, and then you'll do the other, and all of a sudden then, there was kids that maybe, possibly, might have been trying to get through school, counting on, getting the door anymore, because, all of this, and very rigid approach that's put in place, which, for a lot of the kids, it's just a disaster, it certainly is in our case.

Parents of adult children describe lifelong impacts as a result of lack of care and support, that have resulted in poor outcomes and restricted life skills:

He was diagnosed as having Asperger's as a teen and also was taken into residential care due to extreme behaviour that could not be managed at home. Was being assessed for other mental health issues but disengaged from assessment and treatment when given the choice by medical professionals at age 16. He has never kept a job for more than a few weeks and his refusal or inability to engage with any official bodies and services means he is treated as unemployed, not having a disability, and so receives no money or financial support. He is supported entirely by me because I cannot see him homeless and I cannot get help from any State bodies. It has put me in a situation where I feel there is a good reason, he cannot engage enough to support himself but at the same time has left me suffering severe financial and emotional strain as I cannot not support him.

There is an existing literature suggesting that parents of children with a PDA profile experience high levels of challenge, stress and impact (Green et al, 2018; Woods, 2019). In terms of family health and well-being, N=162 parents and carers answered the survey question on the impact of supporting a family member with PDA. Of this sample, 69% reported an impact on their wellbeing, 86% an impact on their emotional and mental health, 78% reported a negative impact on their sleep, and 59% indicated impact on physical health. Regarding relationships, 78% of respondents indicated a negative impact on relationships between parents/carers, and 85% stated that this also impacted on family dynamic. Those parents and carers who reported a negative impact on emotional wellbeing were significantly more likely to also report that supports for PDA were ineffective. Further investigation reveals this relationship to the perceived effectiveness of supports to apply to parent's emotional health in particular.

Examining the potential relationship between challenges experienced by CYP and parental wellbeing, we found a significant relationship between extreme anxiety and sensory issues in children, and parental wellbeing; this was related to children's age, with a greater proportion of parents of older children reporting an impact on their wellbeing. Tentatively, this also seems to be the case for older children who experience extreme anxiety, suggesting that while sensory and anxiety issues are more prevalent among younger children in the study, where these are experienced by older children, they have a greater impact on parental wellbeing. The impact on wellbeing seems to be related to: i) the quality / effectiveness of supports received, ii) the type of specific challenges experienced by the child, and potentially iii) the age of the child. Parents who reported a negative impact of their child's PDA on their wellbeing were significantly more likely to also report that supports for PDA were ineffective.

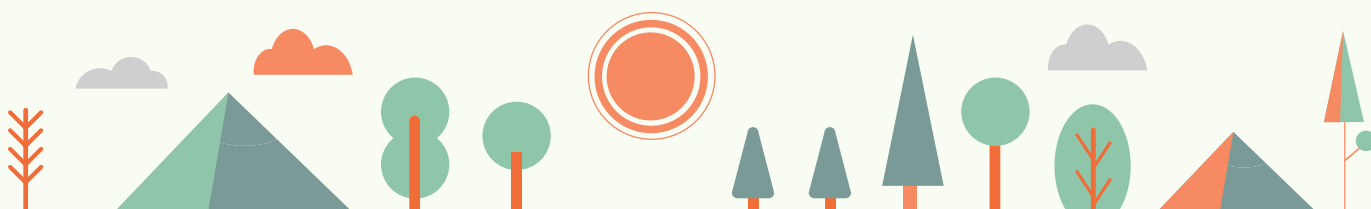
The effects of poor parental mental and physical health, together with the requirements to support vulnerable and distressed children, also has an economic effect on the family, where 35% of parents stated that they had left their job as a result of the impact of caring responsibilities, or had reduced working hours, (18%), or taken a less challenging job (11%). Despite this significant impact on household income, 66% of families are not in receipt of Carer's Allowance.

Life partners report significant challenges in providing care and support, emphasising the urgent need for health professionals to acknowledge the lifelong stress of coping:

It was so difficult to cope, I thought I was going mad. The arguments went on and became very intense. He has not had a steady job since we got married, until now, and still he constantly talks about leaving the job, and he flares up if I argue back. At first I was horrified but then I kept listening to people who blogged and it made so much sense to me. I have told him that this could be same as him, but he does not want to know. But it is so helpful for me. He is a very good person, who has high morals and I know he does try his best. (Life partner, survey).

- ◆ Failure to discuss / listen to your experiences
- ◆ Lack of understanding of what 'demand avoidance' means in practice
- ◆ Lack of acceptance of PDA as a valid profile
- ◆ Suggestions of attachment issues and poor parenting being a key cause
- ◆ Refusal to fund or provide a service with PDA expertise
- ◆ Difficulties with explaining challenges or asking for help

Data from PDA adults suggests that these barriers do not dissipate over the lifespan and the results of a lack of acceptance and understanding have a lifelong effect at an individual level.



6 Triumphs and challenges

On a positive note, 25% of parents stated that enjoying their child's unusual and quirky personality and company was rewarding, as was observing progress through achievement of previously unmanageable tasks, the development of self-awareness and self-management, and learning from their child resulting in improved understanding of their perspective. Furthermore, practitioners provided a wealth of advice for strategies that work (Figure 2).

Parents, carers and life partners identified lack of awareness, recognition, understanding and support as their most significant difficulty, as did PDA adults. Parents also referred to managing their own exhaustion and stress, dealing with violent and aggressive behaviour, getting through daily life, the effects on siblings and other family members, and getting their child into school. Practitioners identified challenges to working with individuals with PDA as understanding the underlying cause of anxiety and avoidance, utilising strategies that run counter to typical approaches, emotional dysregulation, unpredictability and mood swings, and lack of understanding - and a willingness to try alternative approaches - from colleagues.

Relationship building. Pick your battles. Acknowledge and validate emotions. Calm voice. Non-threatening body language, down on one knee below their eye level, ask them what the next procedure is give them control.. like when entering a class, you ask them what happens next, let them suggest they need to take out their books and tools for the class.

Relationship work led by child. Developing strategies to manage anxiety and coping skills providing choice within activities keeping activities fun whilst working on skills.

Allowing the student to take ownership of their support and allow them to set a time limit on how much support they need. This can be a long process of relationship building and trust.

Enthusiasm, play, vocal change and being able to accept that we have to adapt our presentation of work.

Using "I wonder"... rather than direct requests. Referring to the law/ external rules for the child having to do things (rather than me personally expecting the child to do something). Seeming to ignore the child.

Giving choices and discussing the outcomes/consequences of choices and behaviours during calm periods.

Building very strong relationships. Giving a fresh start at various points during the day. Using language where child is asked to help - I wonder if this would be a good idea - working alongside the child and allowing them to join in at their own pace rather than demanding them to join in - choosing what rules you must enforce and what you can be flexible with.

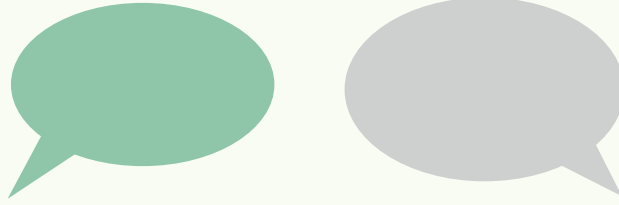
Rephrasing what we want him to do, from facts like 'it's time to wash your hands for lunch' to a conversation about being hungry, would you like to help me tidy up, tidying up makes my hands feel dirty, I'm going to wash my hands now, I love how the soap and water makes my hands feel and smell nice.

Low-demand approach with lots of flexibility. Encouraging parents to take time to practice strategies. Encouraging teachers to evaluate the level of demand placed on child. Really beneficial to encourage a school and parents to adopt a team approach.

Fortunately, I work in a service where I can take as long as needed to build a rapport, and I think that helps. Clear boundaries, some motivational interviewing techniques, reduce anxiety by being clear about what is happening etc.

Figure 2. Practitioner responses: Useful strategies for supporting PDA

DISCUSSION



The guidelines that are successful with autistic children need major adaptations for PDA children if any progress is to be made; these children hate routine and thrive best on novelty and variety. If perceived as ASD children, the wrong advice will be given: PDA children suffer a high exclusion rate if educated on autistic guidelines, as do young adults. (Newson, Marechal and David, 2003, p. 596)

Quantitative and qualitative findings from the survey and in-depth interviews provide substantial evidence to support the need for an individualised approach to supporting people with PDA, in all aspects of human life (personal, social, educational, health). PDA adults repeatedly emphasised the need to accept the way that they experience and view the social world, and to rethink the rationale for imposing rigid structures of support:

What if we started to explore the strengths of people with PDA while using high levels of support as a transitional bridge to greater independence than the norm, rather than less as at present? With all due respect, however well intentioned, and however good a purpose they serve, every carer you impose upon us is also an obstacle between us and functionality, let alone the achievement of our full potential.

Within the wider discussion of inclusion for people with disabilities, there remains work to be done on reframing difference and deficit in terms of diversity. Within the bioecological model of autism, it is the systemic influences on education and healthcare services, and society in general, that have a lifelong impact. Education and healthcare practitioners – be they teachers, psychologists, therapists, psychiatrists – must engage in the skilful use of professional tools to identify the most appropriate solutions, as they apply to the context and community of the individual. Utilising a reflective practice approach, collaborating with colleagues through sharing knowledge, and modelling acceptance of diversity which recognises that not all interventions or supports are appropriate for all individuals is in line with contemporary best practice. Our findings suggest that a flexible, informed and individualised approach to assessment and service provision for individuals presenting with this particular profile is very important. Many participants reported that the very particular strategies and approaches reflected in previous investigations by academic researchers and entities such as the PDA Society UK, are often very helpful. In addition, an approach in which there is close collaboration and ongoing communication between clinicians, professionals and parents is also very important.

In order to progress awareness, acknowledgement, acceptance and understanding, assessment and diagnosis procedures need to be clarified and streamlined to: i) provide

a clearer diagnostic pathway, and ii) to avoid driving parents towards costly private assessment processes that do not guarantee access to intervention or support. The reported disconnect in the Irish system between assessment and consequent support or intervention is a very important finding in the present study. Currently, a PDA diagnosis is available [anecdotally] via one or two HSE services in specific areas in Ireland, and from a small number of private practitioners principally in Northern Ireland. Greater recognition of the duality of autism and mental health is required by CAMHS, and that bouncing parents and individuals between disability services and mental health services, is distressing and exhausting for parents and their children.

The International Classification of Functioning, Disability and Health (ICF) provides a comprehensive and universally recognised framework to describe functioning, disability and health. Collaboration between WHO and the ICF Research Branch has resulted in the Comprehensive and Brief ICF Core Sets for a range of disability and health conditions. The ICF Core Set for Autism Spectrum Disorder (ASD) offers a tool to describe the lived experience of a person with ASD through a comprehensive and standardized method, including all of the categories of the ICF, together with specific characteristics of the child. There needs to be consensus that, as a profile, recognition of PDA does not require a separate diagnosis where autism has already been confirmed. Professionals are equipped with the competencies to note the presentation of anxiety and extreme demand avoidance and to signpost parents and educators towards appropriate support, intervention, services and educational placements. The focus on PDA as a separate 'syndrome' is controversial and contested and diverts attention away from the very real needs of individuals.

Education and healthcare services need to be accessible to all parties on a comparable basis, irrespective of geolocation in Ireland, and should be provided with input from multi-disciplinary teams. The upskilling of education practitioners and health providers in the knowledge and understanding of atypical profiles within autism, is both essential and critical. Community support groups currently provide much of the knowledge to practitioners and supports to families across the country, with little or no funding or recognition. Practitioners who are knowledgeable and skilled in working with individuals with a PDA profile must be encouraged to share that expertise.

A different way of educating children and young people who cannot function within rigid educational structures is urgently required; leaving parents to identify suitable teaching professionals to deliver a very specialised and unique education programme, within a limited timeframe dictated by the Home Tuition Scheme, is intolerable. Parents, carers, guardians, teachers, education and health professionals, need to work together to provide a brighter and better future for children and teenagers who experience PDA. This requires society to listen to the voices of adults and children and to adopt an approach which is not premised upon a culture of blame. We must recognise that when individuals exit children's services and formal education placements, they are largely abandoned to an uncertain, disparate, and isolated existence. Findings from this study illustrate the struggles of adults with PDA as a consequence of being misunderstood and marginalised, and the lifelong nature of these experiences.

RECOMMENDATIONS



A comparison of findings from this current study and a review of the literature suggests a number of recommendations pertaining to education, healthcare, and adult settings. These are framed as evidence-informed advice for best practice within specific contexts, with the purpose of creating an open dialogue between individuals with PDA, their families, practitioners and clinicians, to identify person-centred solutions to the unique challenges of autism and extreme demand avoidance.

Evidence-informed Advice for Best Practice in Supporting Pathological Demand Avoidance reflects elements of good practice in the support of autism, anxiety, and extreme demand avoidance. Advice pertaining to specific contexts and users has been sourced from experts by experience, for example, advice for parents is provided by parents of children and young people who present with a PDA profile. Similarly, good practice in clinical / educational settings or in adult services, is suggested by practitioners in those fields. There are a wealth of resources for practitioners and families produced by the PDA Society UK, who continue to be instrumental in raising awareness and supporting individuals and families. The evidence-based practices provided here are supplementary to this material and reflect guidance relevant to education and health contexts in Ireland.

- ◆ Advice for Parents by Parents to Support Children and Adults with PDA
- ◆ Supporting Pupils with PDA in Primary School
- ◆ Supporting Students with PDA in Post-Primary Settings
- ◆ Supporting Students with PDA in Further and Higher Education
- ◆ Supporting Individuals with PDA in Adult Services: Advice for Clinicians
- ◆ Working with CYP and Adults with PDA in Clinical Settings
- ◆ Working with Individuals with PDA in Adult Services: Advice for Support Workers

It is eight years since Michael McCarthy TD presented the Autism Bill – number 90 of 2012 to the Dail Eireann. After a second reading in March 2013, the Bill subsequently lapsed. It is three years since the Autism Spectrum Disorders (ASD) Bill requesting that the Minister of Health develop and implement an Autism strategy, passed all stages of the Seanad in July 2017. At the time of writing this report, this Bill has still not progressed to the Dail.

“All we need carers for is, obviously, to protect us from the limitations of childhood, to protect us from our own volatility until we can learn techniques for coping and containing it, and to desensitize us to at least a degree of co-operation and interaction with others. Instead of aiming that care toward the negative and disabling goal of lifelong care in the community, why not target lifelong independence as the final goal as soon as we can prove we are ready for it?”

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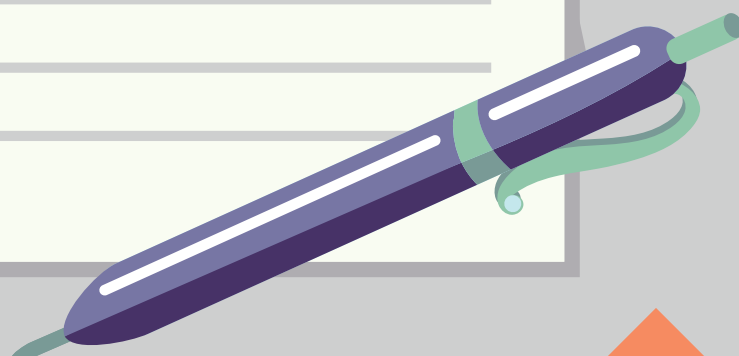
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Tommy's Story

Tommy is six years old and lives at home with his mother and grandparents. Tommy is linguistically very advanced for his age, although he did not begin to speak until the age of 18 months, when he did start speaking his language was very sophisticated. Tommy enrolled in a pre-school context at the age of 2 years but was removed from this setting after 3 months for violent behaviour towards the teacher. Tommy's mother then waited 10 months for a referral from the GP for an Assessment of Needs. Over the space of two months he received assessments by Speech and Language, Occupational Therapy, and an ADOS assessment conducted by a Psychologist. During this latter assessment Tommy became very agitated and sat under a chair screaming for the assessor to leave him alone. He received a diagnosis of Autism however due to his young age it was decided that he would be re-assessed for ADHD and ODD at the age of six years.

Tommy spent the next 12 months at home, prior to attending an ASD specific preschool from November 2017 until July 2019. He was assigned to the Early Intervention Team (EIT) at the age of 4 years however this interaction has been limited to meetings with the Specialist Nurse, as Tommy refused to engage with therapy. His mother was obliged to attend a parenting course. Due to continuing extreme violent and dangerous behaviour Tommy was referred for an assessment with CAMHS at the age of 5 years. Typical behaviours include smashing windows, attempting to exit a moving vehicle, destroying personal property including his own computing equipment and areas of the family home.

Six months after the referral his mother received a letter from the EIT stating that he had been removed from the waiting list as it was full. Tommy's mother later met with the Specialist Nurse and mentioned PDA, and soon afterwards received an appointment for a psychological assessment. At this meeting arrangements were made for a home and school visit but the EIT also informed Tommy's mother that they were discharging Tommy from their services because he was almost 6 years old and would no longer meet the criteria of early intervention: "So our early intervention was exactly no intervention at all."

Tommy's mother re-applied to CAMHS and was offered an emergency appointment on the strength of Tommy's behavioural challenges and he subsequently received a diagnosis of PDA. The assessment also observed that he would have benefitted from early intervention in the form of a sensory diet, CBT and occupational therapy, and access to a school environment specialising in challenging behaviour.

Paul's Story

Paul is a primary age pupil who has a diagnosis of ASD (Asperger Syndrome), ADHD and ODD and whilst his parents believe that he meets the Pathological Demand Avoidance profile of Autism, they acknowledge that they "don't know enough to know whether my son has it." They do not feel that there has been any awareness and understanding from professionals, and a major barrier to accessing relevant support has been a failure to discuss / listen to their experiences. They describe supports as being somewhat effective, however: "CAMHS will always say they don't deal with ASD", and in response they were offered, and completed, a parenting course.

Paul experiences significant challenges with sensory issues and challenging behaviour, resulting in school exclusion, lack of friendships, academic progress and self-esteem. In terms of intervention he has a Special Needs Assistant in school, a Family Support / Social Worker, and has attended an Occupational Therapist which has made a significant difference but has been funded privately by his parents over an extensive period of time.

Whilst Paul has an IEP, not all of the goals / recommendations are implemented, and he has been on a reduced timetable for the past 2 years. He struggles with getting into and staying in school some of the time, and whilst PDA has never been discussed, the school would provide appropriate supports with a diagnosis, and the class teacher has implemented strategies to support PDA as a profile of ASD. The family are very aware that they need support but do not know what is available or who to contact.

Paul's parents describe the experience of managing and supporting him as affecting emotional and mental health, relationships and the family dynamic, and his mother had to give up work because of the impact of caring responsibilities. The family do not receive Disability or Carer's Allowance. They describe their greatest challenge as "Trying to stay upbeat and positive for our son and his siblings, fighting school for understanding is tough, fighting SENO for SNA hours is hard. Every situation from a family get together to holidays to days out are challenging, sometimes it's easier just to stay at home." However, they also draw attention to qualities that may rarely be seen or acknowledged outside of the home: "He's the funniest, happiest loveliest boy. He has a wonderful zest for life when he's happy doing what he loves best."



Michael's Story

Michael is a 12-year-old boy enrolled in, but not currently attending, first year of secondary school. He lives at home with his parents and siblings and experiences significant challenges in terms of sensory issues and communication difficulties. His challenging behaviour is a result of the need to feel in control which affects daily routine e.g. morning / bedtime, complying with meal times, and school attendance. Consequently, he lacks friends or indeed any social engagement, has a low level of self-esteem, problems with sleeping, and severe anxiety. Michael was excluded from primary school as he left the premises without permission and the school felt unable to manage his behaviour for health and safety reasons, although Michael did not have access to a Special Needs Assistant at that time.

Michael attends the Child and Adolescent Mental Health Service (CAMHS) and has received intervention from a Speech and Language Therapist and Occupational Therapist, however, Michael's parents believe that these were ineffective. He has also received support through mentoring and guidance, and social skills programmes. Michael is prescribed Sertraline, an antidepressant in a group of drugs called selective serotonin reuptake inhibitors (SSRIs), and Melatonin to manage sleep.

Michael benefitted from a Special Needs Assistant for a short while in secondary school before withdrawing from school altogether due to his inability to cope with the structure and routine demands. His parents report that his anxiety has reduced since he was removed from the school environment and home schooled for 2 – 3 months but are not sure if this could also be attributed to the commencement of medication. His parents believe that he fits the Pathological Demand Avoidance profile of Autism, having been diagnosed with High Functioning Autism, Sensory Processing Disorder and Generalised Anxiety Disorder. They have only recently become aware of PDA but feel that it is too late for their son to return to school as he now presents with extremely negative aversion.

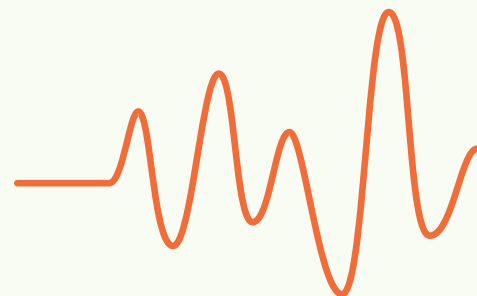
Barriers to accessing relevant support are identified as the suggestion of attachment issues being a key cause of school avoidant behaviour, and of poor parenting as being a key cause of behavioural difficulties. No suggestion of PDA has been forthcoming and although Michael's parents encountered PDA information on the Internet, they feel that they need support but do not know what is available in terms of challenging behaviour, or whom to contact. Managing PDA and supporting their son has negatively impacted on parental well-being having "a huge impact on us personally, professionally and financially and by extension the rest of our family, particularly our other children...

I have reduced my hours because of my caring responsibilities."

Despite this reduction in working hours, the family do not receive a Carer's Allowance. Michael's parents describe the challenges of PDA as being "constant unpredictability" which is "relentless" and where they "live in a constant state of alertness." However, they also acknowledge that "He has taught us to be humble, compassionate and to think in alternative ways."



Matthew's Story



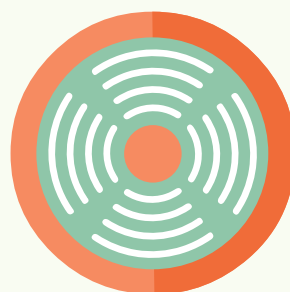
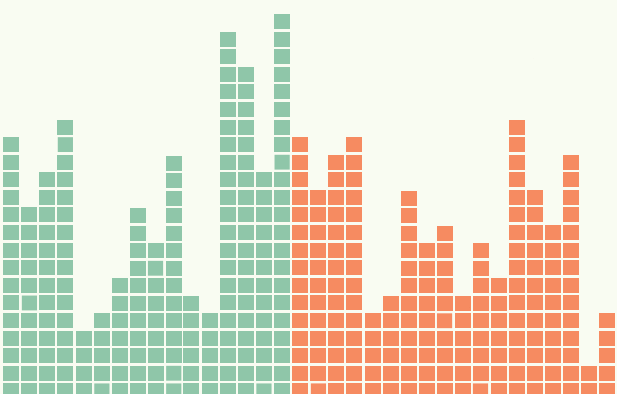
Matthew is a young man of 17 years who presents with Asperger's Syndrome, Dyspraxia, ADHD, and who also experiences Sensory Processing difficulties. He attended CAMHS from the age of 8 years for treatment for anxiety and Depression and was also assessed for PDA. Anticipatory Anxiety remains a significant challenge.

Historically, Matthew exhibits a pattern of managing school attendance in the early weeks and months of the school year, followed by occasional absences escalating to extended absences. Matthew began post-primary school in September 2013, however by November he was absent from school for an extended period, culminating in home tuition provided through the Department of Education. In May 2014, Matthew transferred to a new secondary school and completed the Junior Certificate School Programme in third year. By April 2016 Matthew had been hospitalized with severe anxiety and depression, and underwent a second hospital stay between November 2016 and January 2017.

Despite these challenges, Matthew attended the Centre for Talented Youth in Ireland programme, in Dublin City University, and engaged in the Early University Entrance programme one day a week, taking courses in Constitutional Law and American Politics. Matthew has worked as a cadet with the St. John's Ambulance First Aid Brigade, for a number of years, and is also a youth mentor with Coder Dojo. He enjoys playing and recording music and completed a number of summer courses in sound engineering and production.

Matthew identified his challenges as absorbing new academic content where there is little or no prior knowledge of the material, processing complex language such as expository text information in science, history, or geography. He also finds it difficult to complete tasks that require self-regulation or which have a timed component or a high intrinsic cognitive load, for example, those that require integration of information or the maintenance of multiple ideas at the same time. Sensory processing of background and peripheral noises and sounds, particularly in large group settings is stressful, and in turn affects management of anxiety and panic attacks within the school environment, resulting in sensory overload and feelings of loss of control.

In 2018 Matthew engaged with specialist mentoring and career guidance and withdrew from formal secondary school education. With the support and understanding of a local FE college – despite having a limited Junior Certificate – Matthew enrolled in a QQI Level 5 course in Sound Production. He was provided with reasonable accommodations in the form of additional support for Maths, personal assistance, and exam accommodations. Matthew achieved a Distinction in all modules and was subsequently offered a place on a level 8 undergraduate degree course in Sound Engineering.



Sinead's Story



Sinead is 61 years old, has limited mobility, and is in poor health. She lives a secluded life in a rural setting. There is significant family history of autism and mental health: a younger brother has a diagnosis of Asperger Syndrome and has a 'frightening compulsion to control' and her son has a formal diagnosis of PDA. Sinead remembers that, even as a small child, she hid from people, hated school with a passion and was an easy target for bullies. Sinead was recognised as being exceptionally able as a young teenager, but at the age of 15 years was involuntarily sectioned for 28 days; this experience left her fearful of medical professionals and reluctant to seek out treatment.

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. Fear has crippled everything... and unfortunately it is not usually irrational fear. I have no way to gauge the potential impact or backlash from anything I do... I literally hide here, find ways to pass the time and reasons to get up in the morning...that is my life...hiding here because there is literally nothing else that would be safe or within my ability to cope...

Sinead received an autism diagnosis in the early 2000s and describes this as being helpful in understanding her difficulties, and ensuring that "I didn't have to live in fear of someone getting the bright idea of forcing me to live nearer to people or taking away my disability allowance because I "looked ok to them."

Poor social and communication skills compromise access to the more personal aspects of healthcare and education, and Sinead reflects that "the only coping skill I ever discovered was to run away and STAY THERE, however much it hurt, however much I wished I could stick around...the skills just were not there..." With respect to education, Sinead believes that providing the tools for learning, a practical objective, a purpose, and leaving individuals to engage in their own learning, is key. PDA children need a 'concrete reality that is safe for the foreseeable future' before they are in a position to learn.

Sinead believes that the most important response to managing PDA is to provide a safe, secure environment that permits the individual to be completely independent. For example: "Support is always seen in terms what do you need people to help you with... most autistics need extra money to help them avoid people. They will pay for a companion to travel with you, but they won't pay for a car so you can travel in isolation. They lock us up in isolation to contain us, but nobody has ever tried leaving us alone constructively." What improvements in education and healthcare can help? Sinead suggests:

- ◆ Services need to accept that vulnerability and capability are NOT mutually exclusive.
- ◆ Allowance must be made for the fact that trust does not come naturally to Autistics and PDA
- ◆ Sometimes isolation is a much healthier choice particularly for those with PDA
- ◆ Some PDA is reactive and totally justified.
- ◆ One size probably does fit most, but the outliers are still worth investing in.