

“There’s some controversy around it”: An exploration of Educational Psychologists’  
perspectives on pathological demand avoidance

Fay Johnson

A thesis submitted for the degree of Professional Doctorate in Child, Community and  
Educational Psychology

Tavistock and Portman NHS Foundation Trust

University of Essex

May 2024

## Abstract

**Background:** Pathological demand avoidance (PDA) is a term which is being increasingly used to describe a particular presentation of behaviours. However, it is not presently recognised as a formal diagnosis and there is contention around the application of this term. Previous research into Educational Psychologist (EP) involvement with PDA is currently limited. This research explores EPs' perspectives on PDA, including their views on working with the term PDA, and how they communicate and give advice around PDA.

**Methods:** Semi-structured video interviews were facilitated with eight EP participants, and the dataset was analysed using reflective thematic analysis (RTA) (Braun & Clarke, 2021).

**Findings:** Five main themes were generated: 'Look at the Bigger Picture', 'Challenges are Prevalent', 'Different Labels, Different Places', 'We Need to Work Together' and 'Adapt to Accommodate'. Eight subthemes were also highlighted within these themes.

**Conclusion:** PDA is a complex, controversial concept in EP practice, considering the challenges associated with this presentation and the national disparities in recognition. The role of the EP in the identification of PDA was mostly refuted, and it was suggested that use of the term PDA should be approached thoughtfully. The importance of comprehensive, holistic assessment and individualised, integrated support are acknowledged as part of professional involvement. Implications include the generation of inductive thinking models (Figures 6, 8 and 9) in conjunction with principles for EP practice (Table 8). Directions for future research have also been discussed.

## **Acknowledgements**

A massive thank you to the EPs who reached out with interest to support my research, and to those who participated. Your thoughts, insights and experiences have propelled my passion for this topic and truly made pursuing this research a meaningful journey.

Another big thank you goes to my supervisor Nikki Collingwood for guiding and containing me throughout this process, and for working above and beyond to meet me wherever I was at. A special mention also goes to Jude Mortell, my first research supervisor; thank you for understanding and believing in my research.

I am incredibly grateful to my family and friends for recognising the demands (no quip intended) of the doctorate over the last three years and allowing me the space and flexibility to navigate my way through training however I needed. A hugely important thank you also goes to my partner Bradley for keeping me motivated and always supporting me, no matter how many compromises we've needed to make!

Finally, I want to give mention to the individuals and families who are exploring or have accepted PDA into their world. Amongst the controversies, with increasing voices and research, the conversation will continue to thrive.

## Table of Contents

Abstract .....	2
Acknowledgements .....	3
List of Tables.....	10
List of Figures .....	11
Abbreviations .....	12
Terminology .....	13
Chapter One: Introduction.....	14
1.1 Chapter Overview .....	14
1.2 Pathological Demand Avoidance .....	14
1.2.1 The Genesis of PDA.....	14
1.2.2 Syndrome or Symptoms? The PDA Debate.....	15
1.3 Demand Avoidance and Autism .....	16
1.4 Theoretical Models of PDA .....	18
1.5 Considerations for Terminology .....	20
1.6 Executive Functions and PDA .....	21
1.7 National Context and the EP Role .....	22
1.8 The Function of Labelling.....	23
1.8.1 Issues around Labelling.....	24
1.8.2 Impact of Self-Diagnosis.....	25

1.9 Current Research .....	26
Chapter Two: Literature Review .....	28
2.1 Chapter Overview .....	28
2.2 Search Techniques .....	28
2.3 Critical Appraisal for Selection of Studies.....	32
2.4 Approach to Literature Review .....	32
2.4.1 Conceptualisation .....	33
2.4.2 Identification .....	38
2.4.3 Intervention .....	41
2.4.4 Experiences (including EP Involvement).....	41
2.5 Evaluation of the Current Literature .....	47
2.5.1 Methodological and Topical Critique .....	47
2.5.2 Culture and Identity.....	48
2.5.3 Biological Frameworks .....	49
2.5.4 Implications for EPs.....	51
2.6 Summary and Rationale for Current Research.....	52
Chapter Three: Methodology .....	54
3.1 Chapter Overview .....	54
3.2 Research Paradigm.....	54
3.2.1 Theoretical Frameworks.....	54
3.2.2 Ontological and Epistemological Orientations .....	55
3.3 Research Purpose and Aims .....	56

3.4 Research Methodology and Rationale .....	57
3.5 Research Participants .....	59
3.5.1 Participant Information .....	59
3.5.2 Recruitment .....	61
3.5.3 Sample .....	61
3.6 Data Gathering .....	63
3.6.1 Semi-structured interviews.....	63
3.6.2 Virtual Interview Facilitation .....	63
3.6.3 Pilot Interview .....	65
3.6.4 Interview Procedure .....	65
3.6.5 Reflections on Interviews.....	66
3.7 Transcription .....	67
3.8 Data Analysis .....	67
3.8.1 Stage 1: Data Familiarisation .....	67
3.8.2 Stage 2: Data Coding .....	68
3.8.3 Stage 3: Generating Initial Themes.....	69
3.8.4 Stage 4: Developing and Reviewing Themes .....	69
3.8.5 Stage 5: Refining, Defining and Naming Themes .....	70
3.8.6 Stage 6: Write Up.....	71
3.9 Quality Criteria.....	71
3.10 Ethical Considerations .....	72
3.10.1 Informed Consent and Right to Withdraw .....	73
3.10.2 Confidentiality and Data Protection .....	73
3.10.3 Respect, Dignity and Relationships .....	74

3.10.4 Power Balance .....	74
3.10.5 Social Responsibility .....	74
3.10.6 Maximising Benefit and Minimising Harm .....	75
3.10.7 Reflexivity .....	75
3.10.8 Relevance and Impact .....	75
 Chapter Four: Analysis .....	 77
4.1 Chapter Overview .....	77
4.2 Thematic Map and ‘Findings’ .....	77
4.3 Theme 1: Look at the Bigger Picture .....	80
4.3.1 Subtheme 1.1: Unpicking the Context .....	80
4.3.2 Subtheme 1.2: Unpicking the Biological Factors .....	83
4.3.3 Subtheme 1.3: Unpicking the Psychological Factors.....	86
4.3.4 Subtheme 1.4: Unpicking the Socioenvironmental Factors .....	89
4.4 Theme 2: Challenges are Prevalent.....	92
4.5 Theme 3: Different Labels, Different Places .....	95
4.5.1 Subtheme 3.1 Recognition of PDA.....	95
4.5.2 Subtheme 3.2: What’s in a Name? .....	98
4.6 Theme 4: We Need to Work Together .....	101
4.6.1 Subtheme 4.1: Multidisciplinary Support .....	101
4.6.2 Subtheme 4.2: Child-Adult Partnerships.....	104
4.7 Theme 5: Adapt to Accommodate .....	106
4.8 Summary of Findings .....	110
 Chapter Five: Discussion .....	 111

5.1 Chapter Overview .....	111
5.2 RQ1a: What are EP’s views on working with the term PDA?.....	111
5.2.1 Consistencies and gaps in the conceptualisation of PDA .....	111
5.2.2 The PDA concept should be approached holistically.....	114
5.2.3 Controversy in PDA: Diverging from or enhancing the ‘script’?.....	118
5.2.4 School provisions have a key role.....	121
5.2.5 Incongruencies in labelling should be considered sensitively .....	123
5.3 RQ1b: How do EPs communicate and give advice when PDA is raised?.....	125
5.3.1 Promoting multisystemic collaboration .....	125
5.3.2 Caution around using the term PDA .....	126
5.3.3 Relationships Make a Difference .....	128
5.3.4 Adopting the PANDA .....	129
5.4 The Story of the Data .....	131
5.5 Reflexivity.....	132
5.5.1 A Reflection on Social Graces .....	135
5.6 Strengths and Limitations .....	137
5.7 Summary of Discussion .....	140
5.8 Implications.....	140
5.8.1 Recommendations for EP Practice.....	140
5.8.2 Suggestions for Future Research.....	142
5.9 Dissemination Strategy .....	144
5.10 Conclusion.....	145
References .....	146



Appendices .....	165
Appendix A: Summary of Studies included in Literature Review .....	165
Appendix B: Critical Appraisal of Literature Review Papers.....	170
Appendix C: Extreme Demand Avoidance 8-item measure .....	175
Appendix D: Ethics Application .....	176
Appendix E: Recruitment Advert Posted on EPNET .....	195
Appendix F: Interview Schedule.....	196
Appendix G: Initial Familiarising and Coding by Hand.....	198
Appendix H: Coding Extract from NVivo .....	199
Appendix I: Visual mapping during Stage 1 of RTA .....	200
Appendix J: Grouping Codes in Stage 3 of RTA.....	201
Appendix K: Initial Code Group Names in Stage 3 of RTA .....	202
Appendix L: Visual Mapping during Stage 3 of RTA.....	203
Appendix M: Codes Mapped Against Themes in Microsoft Excel .....	204
Appendix N: Codes Grouped by Theme .....	205
Appendix O: Reflexive Diary Extracts .....	210
Appendix P: Linked BPS competencies and HCPC Proficiencies .....	212

**List of Tables**

Table 1.....	31
Table 2.....	40
Table 3.....	45
Table 4.....	59
Table 5.....	62
Table 6.....	78
Table 7.....	129
Table 8.....	141

**List of Figures**

Figure 1 .....	16
Figure 2 .....	20
Figure 3 .....	30
Figure 4 .....	58
Figure 5 .....	78
Figure 6 .....	115
Figure 7 .....	117
Figure 8 .....	122
Figure 9 .....	132

### **Abbreviations**

ADHD	Attention Deficit Hyperactivity Disorder
ASC	Autism Spectrum Condition(s)
BPS	British Psychological Society
CYP	Child(ren) and/or Young People/Person
DISCO	Diagnostic Interview for Social and Communication Disorders
EDA-Q	Extreme Demand Avoidance Questionnaire
EF/EFs	Executive Function(s)
EHC	Education, Health and Care
EP/EPs	Educational Psychology/Educational Psychologist(s)
GCSE	General Certificate of Secondary Education
HCPC	Health and Care Professions Council
IOU	Intolerance of Uncertainty
LA	Local Authority
NAS	National Autistic Society
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
ODD	Oppositional Defiant Disorder
PDA	Pathological Demand Avoidance
PDD	Pervasive Developmental Disorder
RTA	Reflexive Thematic Analysis
RQ	Research (Sub)Question
SEND	Special Educational Needs and Disabilities
UK	United Kingdom

## Terminology

Throughout this thesis, the researcher has elected to refer to *autism* or *autism spectrum condition (ASC)* in favour of autism spectrum disorder, recognising autism as a neurodevelopmental difference and aspect of identity rather than a medicalised disorder (see Monk et al., 2022).

Furthermore, the researcher has consistently chosen to refer to *pathological demand avoidant (PDA) presentations, characteristics, features, behaviours etc.* This is to reflect the ambiguity of how PDA is conceptualised within the literature and provide space to explore these ideas curiously in line with the research aims, rather than assuming a position. Where considered appropriate, the researcher has also identified PDA as a *label*, since diagnostic manuals do not currently classify PDA as a diagnosis (DSM-V, American Psychiatric Association, 2013; ICD-11, World Health Organisation, 2018).

## **Chapter One: Introduction**

### **1.1 Chapter Overview**

The number of families in the United Kingdom (UK) seeking identification and labelling of pathological demand avoidance (PDA) for their children has significantly increased over the past ten years (Green et al., 2018; Stuart et al., 2020). Congruently, it has been acknowledged that some clinicians and educators are using the term PDA more frequently (O'Nions et al., 2014b). However, there has been continuous debate as to whether PDA should be regarded as a standalone diagnosis or if it more accurately describes features of other conditions, since the term was first conceived approximately 40 years ago (Newson et al., 2003) (Gillberg, 2014). This chapter introduces the concept of PDA, exploring potential underlying theories linked to the term and how it could be explained. Additionally, this chapter explores the relevance of the term PDA in the current context of educational psychology (EP) practice.

### **1.2 Pathological Demand Avoidance**

#### ***1.2.1 The Genesis of PDA***

In the 1980s, Professor Elizabeth Newson, a consultant child psychologist in the UK, first coined the term PDA (Newson et al., 2003). As joint directors of Nottingham University's Child Development Research Unit, Newson and her husband facilitated a specialised clinic for the diagnostic assessment of children and young people (CYP) presenting with complex communication and developmental difficulties (Christie, 2007). Over time, it was observed that many of the CYP seen within this clinic were considered "atypically autistic" (Newson et al., 2003, p. 595). These CYP were noted to share two central characteristics: "a degree of sociability that allowed social manipulation as a major skill" and "an obsessional avoidance of the ordinary demands of everyday life" (Newson et al., 2003, p. 596). Furthermore, it was also observed that equal numbers of males and females

were displaying these traits; this counters current knowledge of gender ratios in autism as 3:1 with a higher prevalence in males (Loomes et al., 2017). PDA was subsequently proposed as a "separate entity within pervasive developmental disorders (PDDs)" (Newson et al., 2003, p. 595) through a culmination of further studies and publications, and the following diagnostic criteria were described:

- passive early history in first year
- continues to resist and avoid ordinary demands of life
- surface sociability, but apparent lack of sense of social identity, pride, or shame
- lability of mood, impulsive, led by need to control
- comfortable in role play and pretending
- language delay, seems result of passivity
- obsessive behaviour
- neurological involvement (p. 597)

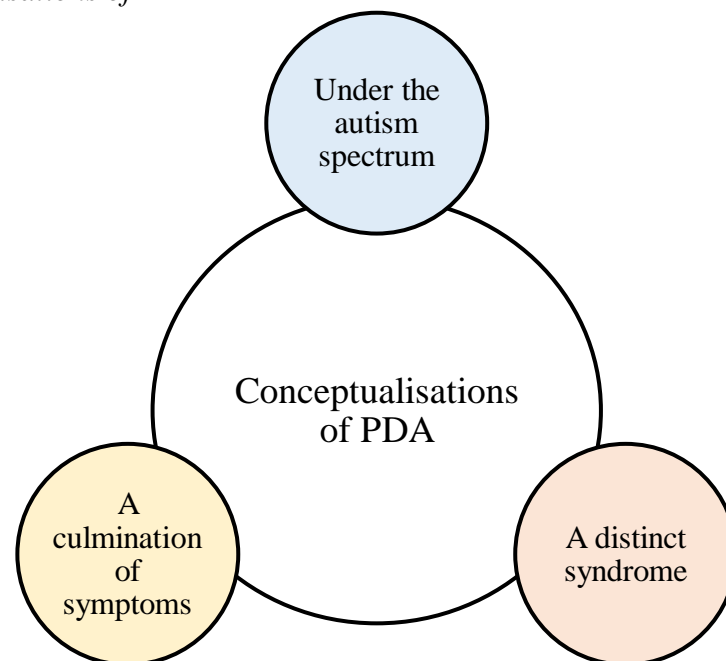
### ***1.2.2 Syndrome or Symptoms? The PDA Debate***

Since Newson and her colleagues (2003) first proposed PDA as a distinct syndrome, the concept has generated notable controversy within the research literature. PDA is not classified as a diagnostic category in the International Classification of Diseases (ICD-11) (World Health Organisation, 2018) or the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013). In addition, several authors express concern about the scarcity of research around PDA (Green et al., 2018; Woods, 2020a). Explicitly, there is disagreement as to whether PDA is disparate from other conditions, or if the characteristics exist across a variety of other diagnoses (Gillberg, 2014). Malik and Baird (2018) discussed the overlap of features between PDA and other existing disorders, including oppositional defiant disorder (ODD) and conduct disorder, but suggest that PDA traits may have a different underlying basis. It has also been suggested that some

PDA features are similar to those of borderline personality disorder (BPD) (Eaton, 2017). From comparing differing CYP profiles, O'Nions et al. (2014b) found that CYP identified with PDA displayed behaviours comparable to CYP diagnosed with conduct disorder, as well as autistic traits similar to CYP diagnosed with autism. It was also observed that CYP identified with PDA displayed more emotional difficulties than children diagnosed with conduct disorder or autism. PDA has thus been described as a "triple hit" of anxiety, conduct problems, and autism (Gore Langton & Frederickson, 2018, p.17). The graphic in Figure 1 demonstrates the researcher's conceptualisation of PDA within the current literature.

**Figure 1**

*Different conceptualisations of PDA*



### **1.3 Demand Avoidance and Autism**

Despite ongoing debate, PDA is now more widely recognised as a behavioural profile under the umbrella of autism spectrum conditions (ASC) (Truman et al., 2021). Indeed, some local authorities (LAs) and National Health Service (NHS) Trusts have issued formal position statements acknowledging a 'PDA profile of autism' which can be described in diagnostic reports of autism assessments (see PDA Society, n.d.-b). Although the prevalence of PDA is



difficult to investigate due to a lack of agreement on its status, one study suggested that one in every five people with autism may exhibit PDA features during childhood, and that less than 0.2% of the population could be described as having autism and PDA traits (Gillberg et al., 2015). It has been noted that while PDA was first proposed as a distinct category within PDDs, autism and PDDs are now more commonly seen as synonymous, with PDA thus being viewed as part of the autism spectrum (Christie, 2007). In accordance with this, the National Autistic Society (NAS) have released information on the history and debates surrounding PDA, and alongside this, note that demand avoidance “has been characterised as the key characteristic of a proposed condition or profile of autism” known as PDA (n.d.-a, Relationship to autism and other neurodivergences). Furthermore, PDA is understood as being part of the autism spectrum by registered charity PDA Society, which was founded in 1997 as a contact group for parents of CYP identified with PDA (n.d.-a).

Whilst diagnostic manuals do not include PDA, clinical guidelines from the National Institute for Health and Care Excellence (NICE) list demand avoidance behaviour, or "unusually negative response to the requests of others" as a possible feature of autism in CYP under the age of 19 (2011, p. 34, 37, & 41). The PDA Society's guidelines, however, note the importance of differentiating between demand avoidance in PDA, in autistic individuals and as a normal human trait (n.d.-e). Additionally, it is stated that although marked demand avoidance is thought to be the most important characteristic of PDA, it is not the only characteristic. The PDA Society (2022) have revised Newson and colleagues' (2003) original proposal to name six key features of a PDA profile:

- resists and avoids the ordinary demands of life
- uses social strategies as part of the avoidance
- appears sociable on the surface, but lacking depth in understanding
- experiences excessive mood swings and impulsivity

- ‘obsessive’ behaviour, often focused on other people
- appears comfortable in role play and pretend, sometimes to an extreme extent (this feature is not always present) (p. 7)

Notably, mention of “passive early history in first year”, “language delay” and “neurological involvement” (p. 597) are absent from this amended list of features. Although ‘neurological involvement’ can be linked to the PDA Society’s recognition of PDA as part of the autism spectrum, it is unclear whether these traits are still considered prevalent in PDA. However, this list of features could also be viewed as more of a behavioural overview, compared to Newson’s suggestions of clinical criteria. Nevertheless, this demonstrates how conceptualisation of PDA has somewhat evolved over time, but with many of the fundamental features remaining consistent.

#### **1.4 Theoretical Models of PDA**

Both within assumptions of PDA as a distinct “pervasive developmental disorder” (Newson et al., 2003, p. 595) or as a profile of autism, PDA is commonly viewed through a neuropsychological lens (Ogundele, 2018), where the presenting behaviours are thought to be due to biological factors within brain processes (BPS 1.4, Appendix P). Neurodevelopmental conditions such as autism are traditionally understood through a medical model, with the associated behaviours viewed as “deficits” or “impairments” (Moore, 2020, p. 42). Milton (2018) acknowledges this dominant narrative, and advocates for moving away from a medical model of understanding PDA behaviours. Notably, there has been increasing movement for autism to be considered as a neurological difference and an aspect of identity, as opposed to a clinical disorder (Monk et al., 2022). By instead aligning with the social model of disability, these ‘impairments’ are seen to impose social and systemic barriers on the autistic community due to interactions between their neurodivergent characteristics and the environment (Gillespie-Lynch et al., 2017; Pellicano & den Houting, 2022) (BPS 3.6,

Appendix P). Within its relationship to autism, PDA could also be viewed through this model and seen as a 'rational' response to over-conformity (Milton, 2013) within the social world.

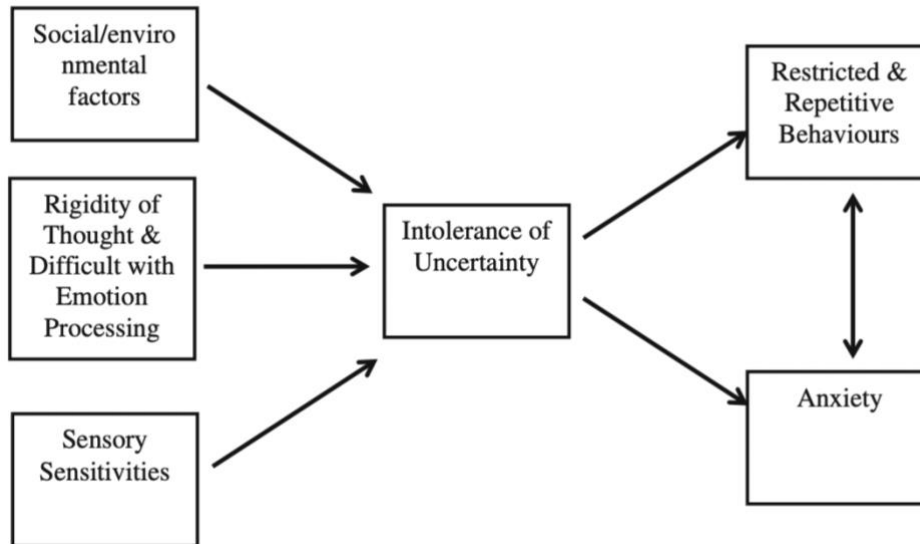
Countering the biological perspective, Woods (2020c) has suggested that the behaviours associated with PDA could be associated with trauma and environmental factors, due to the lack of evidence for “diagnostic biomarkers” (para. 4). They suggest that PDA behaviours are seen in non-autistic individuals and note that some research indicates PDA can be explained by co-existing conditions (Green et al., 2018) which can be associated with adverse experiences and childhood trauma. This view was similarly considered by other academics following a systematic review of PDA literature (Kildahl et al., 2021). Linked to trauma, PDA can be understood through polyvagal theory (Porges, 2011) in which states of fight, flight and freeze are triggered in response to stress, with this increase in arousal impacting on social engagement (BPS 1.1, Appendix P). It is possible that in the context of PDA, demands can be viewed as 'threats' (PDA Society, n.d.-c), and therefore rouse an individual into moving from the ventral vagal state to a sympathetic or dorsal vagal state (Porges, 2011). Exploring the application of this theory, PDA blogger Sally Cat writes that whilst polyvagal theory can explain how demands trigger neuroception, it does not consider why a ‘perceived demand’ may also trigger this response (2023b).

PDA behaviours have recently been suggested to be underpinned by an intolerance of uncertainty (IOU) and anxiety (Stuart et al., 2020). Corresponding with the notion of PDA presenting within the autistic population, IOU has been proposed as a framework for understanding anxiety in CYP with autism (Boulter et al., 2014) (see Figure 2). Within this model, IOU is established as a key risk factor in the development of anxiety, which is predisposed by autism related characteristics and the challenges faced by autistic individuals. It also considers that the presence of restricted and repetitive behaviours in autistic populations may represent attempts to make life as predictable as they can, when faced with a

wealth of uncertainty. This framework could be applied to provide an understanding of PDA through cognitive processes (BPS 1.1, Appendix P).

## Figure 2

*A proposed model of anxiety in autism*



*Note.* Cited from Boulter et al. (2014)

### 1.5 Considerations for Terminology

The name ‘PDA’ was assigned by Newson and her colleagues within their 2003 proposal, as it was felt that this was descriptive of the degree of demand avoidance presented for these CYP. Although they indicate that the label is advantageous for professionals who encounter CYP displaying these features, they also note that this term was chosen under the pressure of a forthcoming lecture (Newson et al., 2003).

Within ongoing controversy surrounding the characterisation of PDA, others have suggested a change in language or terminology. To reflect individual perspectives that avoidance of everyday demands may appear appropriate, although perceived as disproportionate to others, some have proposed using the term ‘extreme’ demand avoidance (EDA) rather than ‘pathological’ (Gillberg, 2014). In a similar vein, some autistic scholars have contended that demand avoidant behaviour is inherently rational, and therefore this

profile is best understood as rational demand avoidance (RDA) (Milton, 2013; Woods, 2019). The preferred term Demand Avoidance Phenomena (DAP) has also been suggested by Richard Woods, a frequent contributor to the PDA debate (2019). Additional descriptors located in the literature include demand avoidant behaviour, autism with PDA traits and Newson's Syndrome (Brede et al., 2017; Woods, 2020b). While many professionals consider the word 'pathological' to be unhelpful and derogatory (Eaton, 2017), there has been opposition to the use of terminology that is not a recognised descriptor in the literature (Eaton, 2020, as cited in Woods, 2020b).

Although not formally published, neurodivergent activist Tomlin Wilding posted an online article stating that they prefer the name 'pervasive drive for autonomy' as an alternative abbreviation of PDA (2020). Identifying as an adult 'PDAer', Wilding discussed their objections to the use of the word 'pathological' as this can imply illness or disease; this aligns with the Oxford English Dictionary definition (2023). They argue that the key feature of PDA is an "intense and pervasive need for personal freedom and self-determination" (Wilding, 2020, What would we change it to?), and it is the strive for autonomy that characterises their presentation. Wilding's article follows a blog post by Sally Cat, another adult identifying with PDA, who discusses contention in the PDA community over the term 'pathological demand avoidance' and how it is felt this misrepresents the condition (2019) (BPS 2.5, Appendix P).

## **1.6 Executive Functions and PDA**

Execution functions (EFs) refer to higher level cognitive skills including cognitive flexibility, inhibition and working memory (Diamond, 2013) which are required for thinking and doing (Dawson & Guare, 2018). EFs are often seen as areas of difficulty for CYP with neurodevelopmental conditions, including autism (Costescu et al., 2023) conduct disorder (Fairchild et al., 2009) and attention deficit hyperactivity disorder (ADHD) (Diamond, 2005;

Lui & Tannock, 2007) and are also often associated with behavioural and emotional regulation (Gioia et al., 2010) (BPS 1.4, Appendix P). Furthermore, research has suggested that anxiety may impair EFs, whilst anger does not (Shields et al., 2016). Given that PDA is widely considered to be neurodevelopmental in nature and related to experiences of mood lability (Newson et al., 2003), it seems likely that challenges with EFs could be prevalent. Acknowledging the previous lack of consideration for the cognitive profile of PDA, the relationship between EFs and PDA behaviours in CYP with autism was explored within a clinical psychology thesis (Goodson, 2018). It was found that overall, EFs were significantly related to PDA traits, and CYP with autism and PDA features presented with more EF deficits than CYP without autism. These deficits were also predictive of non-compliance behaviours and emotional dysregulation. The author therefore proposes that EF skills should be considered for assessment of CYP with demand avoidant presentations.

### **1.7 National Context and the EP Role**

Some parents and clinicians have stated that, despite the lack of a formal or universal understanding, PDA identification and labelling is necessary to receive appropriate educational support (Sherwin, 2015, as cited in Truman et al., 2021). Crucially, it has been contended that traditional strategies for supporting CYP with autism are ineffective or less effective for CYP with PDA traits (Duncan et al., 2011; Newson et al., 2003). Additionally, studies have shown that CYP who have been identified with PDA appear to face high rates of school exclusion and placement breakdown (Gore Langton & Frederickson, 2016). Given these difficulties, it is very likely that CYP whose needs may be associated with PDA will be involved with EPs. This may be especially prominent given EPs' statutory contributions to Education, Health and Care (EHC) plans, which are essential for CYP in need of specialised education provisions (Children and Families Act, 2014; SEND Code of Practice, 2015).

Outside of statutory responsibilities, the function of EPs in assessing, formulating, and providing support for special educational needs and disabilities (SEND) is additionally reflected in professional practice guidelines published by the British Psychological Society (BPS) Division of Education and Child Psychology (2002) and Health and Care Professions Council (HCPC) (2023) (BPS 2.2, Appendix P). However, there may be conflicts between what schools are looking for from EP involvement compared to what EPs would like to offer (Kelly & Gray, 2000). As many families and teachers may strive for identification of PDA in support of appropriate school provision, it is possible that tensions may arise where EPs or EP services may have opposing positions on PDA, and whether this is something that they can label.

### **1.8 The Function of Labelling**

Although debates concerning the conceptualisation and semantics of PDA are prevalent, contention around the value of labels for SEND in general is equally significant for this topic area. The number of CYP diagnosed with disorders or disabilities has increased significantly through ongoing revisions to diagnostic manuals, such as the DSM and ICD (Frances & Batstra, 2013). According to Arishi et al. (2017), labelling has become inextricably linked to obtaining funding for LAs, and many individuals find labels or diagnoses useful in understanding certain behaviours or characteristics. However, it is also taken into consideration whether a 'blanket label' could mask the individual needs of CYP and run the risk of social categorisation within educational environments. Furthermore, the medical model of labelling may lead to the perception of 'within-child' deficits, which generates the possibility of optimistic expectations for CYP being lowered (Lauchlan & Boyle, 2007) (BPS 2.5; Appendix P). In previous research exploring EPs' perspectives on the assessment and treatment of ADHD, wider consideration of contextual factors was advocated for over the medicalisation of CYP's behaviour (Hill & Turner, 2016). These deliberations

draw attention to the potential conflicts that may arise for EPs when attempting to promote inclusive and equitable education through labelling.

EP practice is often associated with labelling and diagnosis of SEND (Lauchlan et al., 2017). However, there is regular discussion within the EP community around whether obtaining a label or diagnosis for means of additional support, including EHC plans, is necessary (BPS, 2022). For EPs who are therefore involved in discussions centred on seeking labels, such as PDA, it is arguably pertinent for them to consider how they approach these. Norman (2017) describes three choices psychologists can make surrounding diagnostic labels: reinforcing the utility of the label, reframing the conventions of labelling, or removing the label through concerns of detrimental impact. However, limited literature regarding EPs' historical and current views on labelling is available. Within positioning around labelling, EPs may also consider who the label is for, and what impact this may have.

### ***1.8.1 Issues around Labelling***

As well as PDA, controversies also exist around the labelling of other conditions. Gibbs and Elliot (2020) address concerns around labelling dyslexia, noting that like PDA, there are no universally agreed criteria for dyslexia and varying definitions. In addition, factors associated with parental socioeconomic status have been found to be significant predictors for diagnoses of dyslexia in CYP (Knight, 2019), indicating that the labelling of dyslexia may be biased within more affluent populations (BPS 3.3, Appendix P). Similar influences may be seen in the labelling of PDA, with Moore (2020) noting an increasing emergence of private practitioners offering a diagnosis of autism with a PDA profile, where positions from NHS Trusts on labelling PDA may vary across the UK.

Another contention in labelling is whether conditions can be mislabelled, due to the complex overlapping of presentations across diagnoses. For example, research has examined the commonality between autism and BPD (May et al., 2021), ADHD (Mayes et al., 2012;



Taurines et al., 2012) and attachment disorder symptoms (Davidson et al., 2022; McKenzie & Dallos, 2017). To support clinicians in differentiating autism and attachment difficulties, Heather Moran (2010) created the Coventry Grid interview. With PDA gaining wider acknowledgement, the Coventry Grid was later adapted to include items which may support the identification of CYP with a demand avoidant profile (Eaton et al., 2018). Nonetheless, given the debate around whether PDA is disparate from other several existing conditions (Gillberg, 2014, Egan et al., 2019), it is possible that there is risk of mislabelling PDA when assessing need.

With recognition to the consistent overlap in diagnostic criteria, there has also been a growing movement towards using transdiagnostic approaches in understanding and supporting neurodevelopmental (Astle et al., 2022) and mental health conditions (Newby et al., 2015). When employing a transdiagnostic model, the underpinning processes or mechanisms which contribute to an individual's presentation are considered over diagnostic labels (Harvey et al., 2004). Astle and colleagues argue that this approach captures the heterogeneity of the neurodivergent population, allowing for greater understanding of CYP's individual needs and bespoke guidance when providing support. For queries surrounding PDA, this could mean addressing a CYP's specific behaviours and experiences related to avoiding demands, without seeking to label them. This approach can also be seen to align with the CYP-centred contribution of EP practice (Baxter & Frederickson, 2005), as supported by Cameron (2006) who stipulates that the role of an applied psychologist is not to 'label people', but to understand the "complexity of human experience" (p. 301).

### ***1.8.2 Impact of Self-Diagnosis***

Due to thriving media platforms and internet communities, research has steered a recent focus to examining 'self-diagnosis' through digital access of information. For CYP, media consumption of TV shows depicting autistic characters was found to have a significant

correlation to self-diagnosis of autism (Mittmann et al., 2023). Within the realm of social media, Gilmore et al. (2022) found numerous online posts relating to CYP's self-diagnosis of ADHD after viewing related videos on the online forum TikTok. A recent review noted that there has been an increase in adults who are self-identifying as autistic, through reports that they struggle to access a formal diagnosis (Overton et al., 2023). Whilst self-belief of being autistic is respected by the NAS (n.d.-b) in accessing their online community and resources, they additionally suggest that a formal diagnosis may help those with a 'demand avoidant profile' to be recognised by others as 'autistic'. Although self-verifying autism has often received support through the concept of 'self-expertise', there are also some contentions around the validity of this practice (Sarrett, 2016). Overton et al. (2023) express concerns that renegotiating one's identity through self-diagnosis can generate psychological difficulties such as anxiety and depression (see Lewis, 2016) which may not be appropriately supported without formal recognition.

Whilst avenues for professional PDA identification are likely to be inconsistent based on the variable positions of NHS Trusts and LAs across the UK (see PDA Society, n.d.-b), it is highly probable that some are choosing to self-identify with the PDA label (NAS, n.d.-a) or indeed, apply this label for CYP. This has likely been through the influence of online forums, such as PDA Society (n.d.-a) and Sally Cat's blog (2023a), raising awareness of the PDA concept. For EPs who encounter 'informal' identification of PDA, either from CYP themselves or applied by others, it is arguably pertinent to value the pupil voice whilst also maintaining open curiosity as to the function of the assumed PDA label.

## **1.9 Current Research**

Social and professional awareness of the term PDA has continually increased since its initial conception, provoking varied and contentious narratives. It is important to acknowledge that regardless of these debates, PDA is a term that is more regularly being

applied within both the UK health and education systems (O'Nions et al., 2014b) and is therefore relevant to the context of the EP role. The next chapter presents a critical literature review of existing research to ascertain how PDA has been understood and supported in relation to CYP. Subsequently, this thesis explores EPs' perspectives on working with the term PDA and how they communicate and give advice when PDA is raised. The researcher explores their personal motivations towards the PDA topic and the axiomatic implications in greater detail within the discussion chapter.

## **Chapter Two: Literature Review**

### **2.1 Chapter Overview**

This chapter presents a review of the current literature related to the question ‘how is PDA understood, assessed and supported for CYP?’. The sub-question ‘what are the implications for EP practice?’ is also considered within this review. A systematic search and review were undertaken to synthesise and evaluate the current research pertaining to these questions (Grant & Booth, 2009). The systematic review of the literature was conducted using the Preferred Reporting Guidelines for Systematic Reviews and Meta-Analyses (PRISMA, Moher et al., 2009) (see Figure 3), providing an evidence-based checklist for the items which should be reported within this type of review (Page et al., 2021). The identification and evaluation of this existing research base then informs the direction of the current research.

### **2.2 Search Techniques**

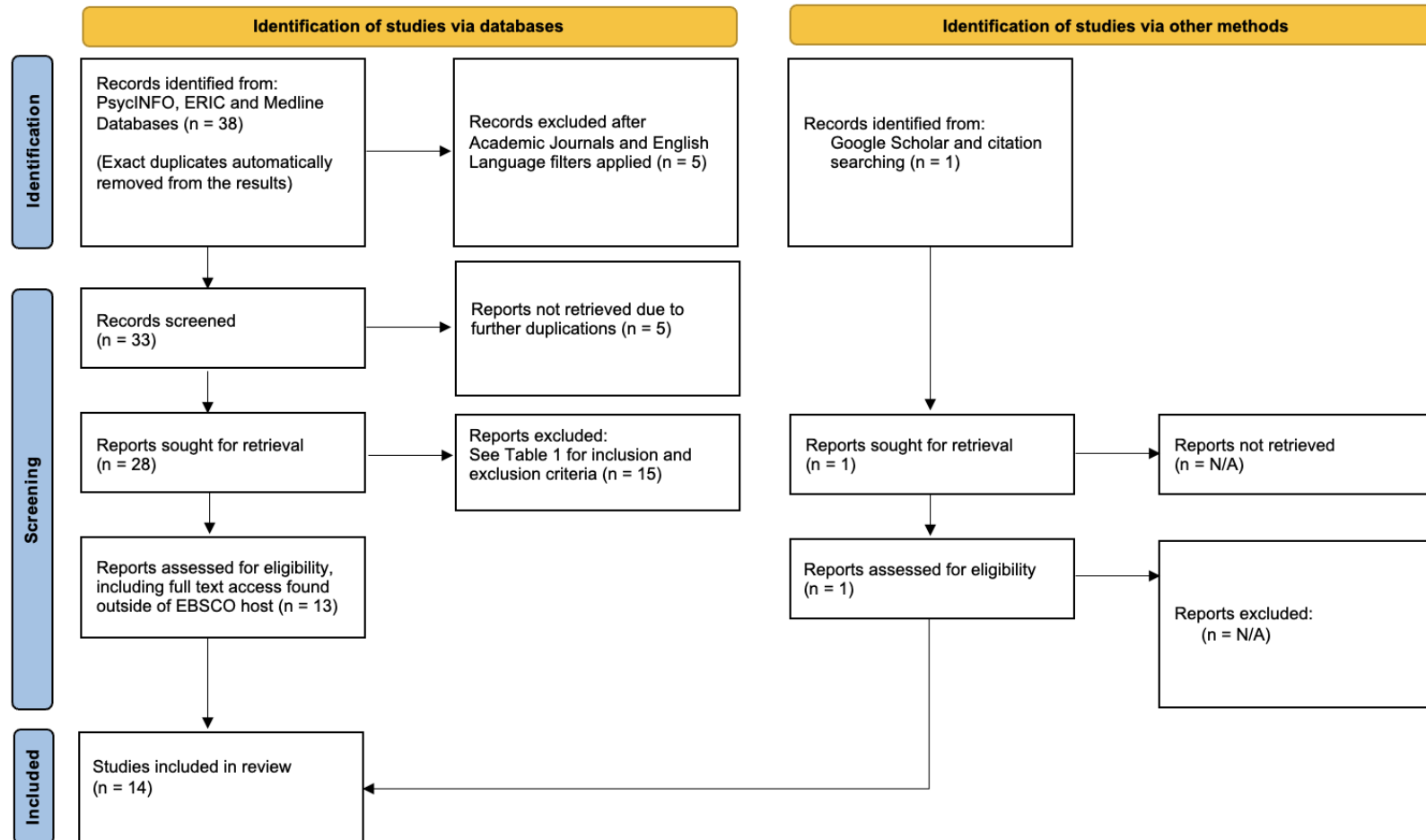
A systematic literature search was conducted between August 2023 and January 2024 using an EBSCO search of the term “pathological demand avoidance” on three databases: PsycINFO, ERIC and MEDLINE. These databases were surveyed as initial literature scoping indicated that PDA is researched across psychological, educational, and medical professions. The initial search generated 47 results, with exact duplicates removed. These results were then limited to academic journals, with linked full text, which had been published in English and examined for further duplicates. Subsequently, the titles and abstracts of the remaining articles were examined against the inclusion and exclusion criteria for the literature search (see Table 1), of which 12 papers were selected for review. As the term ‘extreme demand avoidance’ was seen in several of the papers’ titles, an additional search of this term using the same criteria was carried out, and no other articles were identified. Lastly, supplementary searches using Google Scholar and chaining techniques through references cited in the

previously selected papers were then carried out to identify any further relevant papers. An additional 2 papers were identified, totalling 14 papers for review. A final search was carried out in April 2024 before completion of writing to ensure more recent literature was identified; no further articles were found, however one of the papers originally selected through chaining later emerged using the EBSCO search, as the linked full text limiter was not applied in this instance.

In July 2024, another literature search using the acronym “PDA” was initiated on the same three databases of the EBSCO host. Once limited to academic journals and the English language, the number of results remained at 38,399, which was deemed an unmanageable number for further screening. Furthermore, most of the results appeared to pertain to several alternative topics which also use the ‘PDA’ acronym, including “polydopamine”, “pancreaticoduodenal artery” and “patent ductus arteriosus”, which were not appropriate for this literature review. Therefore, a supplementary search using the search term “PDA [AND] pathological demand avoidance” was employed (see Figure 3), firstly generating 38 results. With the same limiters applied, this produced 28 results for screening against the inclusion and exclusion criteria (see Table 1). Following this supplementary search procedure, and further scoping searches, it was deemed that no further articles of interest had emerged.

Figure 3

## PRISMA Flow Diagram for Systematic Review



Note. Adapted from Page et al. (2021)

**Table 1***Inclusion and Exclusion Criteria for the Literature Review*

	Inclusion Criteria	Exclusion Criteria	Rationale
Study Design	Empirical research studies of either quantitative or qualitative data, which took place in any location over the last 20 years.	Commentaries, responses, position, and review papers were excluded. Books and book reviews were also excluded.	The aim of the literature review was to establish how PDA is being explored through research, as opposed to gathering information on viewpoints.
Study Focus	Empirical research studies describing PDA/EDA in CYP from the perspective of any participant.	Studies which did not explicitly focus on PDA/EDA within their title or abstract were excluded.  Studies solely concerning PDA/EDA in adults were excluded.	Several papers generated through the search focused broadly on ASC. The aim of the literature review was to examine PDA/EDA as a primary concept, as some research suggests that this presentation may exist outside the autism spectrum (Gillberg, 2014).

Study Quality	Empirical research studies published in peer-reviewed academic journals.	Unpublished sources (including theses) were excluded due to the absence of peer-review.	PDA is recognised as a controversial topic, and many sources available focus on the opinions of their authors. Peer-reviewed, published studies ensure quality and credibility of the papers.
---------------	--	---	---

### 2.3 Critical Appraisal for Selection of Studies

The papers selected for review were screened to identify the different types of studies (see Appendix A). For ensuring quality assessment of the literature, a selection of critical appraisal tools from the Joanna Briggs Institute (JBI) were used (see Appendix B). JBI tools use comparable checklists across different types of study and have been evaluated favourably as appraisal instruments for systemic reviews (Hannes et al., 2010; Zeng et al., 2015). Consequently, quality assessment was guided by the JBI checklists for analytic case reports, cross-sectional studies (Moola et al., 2020) and qualitative research (Lockwood et al., 2020).

### 2.4 Approach to Literature Review

The papers selected for systematic review have been grouped and discussed using a thematic approach. It is recognised that the review of the literature could have been presented chronologically to examine development of the PDA topic over time, with consideration to differing theoretical perspectives or of varying research methods. However, it was deemed most helpful to understand where the emphasis on current PDA research has been, in determining what is currently known and where there might be gaps for future research



(Grant & Booth, 2009). Therefore, identifying themes which capture the focus of these papers was considered appropriate for structuring the review. The themes identified among the papers were: conceptualisation, identification, intervention, and experiences (including EP involvement). The review of the literature is then summarised and discussed with reference to limitations and possible future directions.

#### ***2.4.1 Conceptualisation***

A significant proportion of the current literature has sought to conceptualise PDA by exploring the associated needs and investigating the aetiology and prevalence of its presentation (Gillberg et al., 2015; Newson et al., 2003; O’Nions et al., 2014b; 2018; Reilly et al., 2014; Stuart et al., 2020).

As previously stated in chapter one, Newson et al. (2003) first introduced the concept of PDA and published their proposal for this to be recognised as a distinct syndrome, following a series of studies. Between 1970 and 1994, Newson and colleagues noted that numerous CYP referred to their diagnostic clinic were “puzzling” and not “typical of autism” (p. 595). After six years, a cohort of 21 CYP were given a diagnosis of “atypical autism” (p. 595), whilst also presenting as typical to each other regarding a degree of sociability that allowed for social manipulation, obsessional avoidance of ordinary demands of life and symbolic play. Over time, the population of CYP referred with this presentation reached 150, totalling 75 males and 75 females between the ages of 4 and 16. To investigate the parameters for a differential diagnosis, Newson and colleagues examined two separate samples. Firstly, 50 CYP who had received a “clear cut” diagnosis of PDA were randomly chosen and compared in a functional analysis against 20 CYP diagnosed with “classical autism” and 20 CYP identified with Asperger’s syndrome (p. 596). Furthermore, investigation into the data associated with the defining criteria for these CYP was also undertaken. Lastly, a sub-sample of 18 CYP from this cohort were subject to an additional

study examining outcomes in early adulthood. Through this research, PDA was proposed with the rationale that it provided status for many people who would have otherwise been diagnosed with a “pervasive developmental disorder not otherwise specified” (p. 598) and had reportedly been useful for paediatricians, psychiatrists, and psychologists in ensuring that accurate diagnosis supported appropriate educational intervention. Whilst Newson and colleagues describe a variety of behaviours and prospective causes for these within their proposal of PDA, the process in which the criteria were developed or refined is unclear (Kildahl et al., 2021). Furthermore, since the ‘PDA’ and ‘non-PDA’ groups were defined by the researchers, their analysis may be circular, and therefore lack validity (Green et al., 2018). As a result, additional studies which seek to replicate and verify these findings would be crucial to endorse the conceptualisation of PDA.

Over a decade later, seeking to explore the behavioural profile of PDA, O’Nions et al. (2014b) compared parent reports of CYP labelled as having PDA (n=25), CYP with ASC (n=39) and CYP with conduct or emotional difficulties (n=28). It was found that CYP identified with PDA displayed comparable autistic traits and peer problems to the CYP diagnosed with autism, as well as anti-social behaviours comparable to CYP diagnosed with conduct disorder. It was also noted that children identified with PDA displayed higher levels of emotional difficulties than children diagnosed with autism or conduct disorder. Aligning with the researchers’ extreme demand avoidance questionnaire (EDA-Q) development study (O’Nions et al., 2014a) which will be discussed in more detail later in the review, there is likely to have been inconsistency as to how PDA was identified for the participants in this research. Variations in recruitment methods for each of the groups and a small sample size were also noted as limitations. Whilst the findings of this study support the notion that CYP with PDA traits also present with autistic characteristics alongside conduct and emotional concerns, it is additionally highlighted that these CYP present with differences in social

imagination and cognition from those with ‘typical’ autism. In consideration of advancing the exploration of this behavioural profile, the authors discuss the potential influence of neurocognition on the PDA presentation and suggest this as a direction for future research.

In the same year, Reilly et al. (2014) examined four case studies of CYP with epilepsy, who scored above the threshold on O’Nions et al. (2014a)’s EDA-Q screening measure for significant traits of PDA. All four of the CYP were deemed to have cognitive impairment and met the criteria for ADHD. They had also all experienced their first seizure before the age of 5. Three of the CYP met the criteria for ASC and developmental coordination disorder, and two met the criteria for ODD. Reports from the CYP’s parents and schools indicated that these CYP experienced functional impairments and management concerns, particularly when responding to everyday demands. The authors therefore recommend that PDA features should be considered when examining co-existing neurobehavioural conditions in CYP with epilepsy. They also propose that ‘EDA’ may be a more acceptable term to describe this presentation. Whilst demand avoidance was indicated across both parent and teacher reports, it is also considered that use of the EDA-Q only with parents/caregivers may have limited the understanding of these behaviours across contexts. Nonetheless, the findings from these case studies provide basis to suggest that examination of other conditions in relation to PDA may be beneficial in determining what underpins this presentation, and whether it is distinct from other diagnoses.

Due to the frequency of PDA being referenced within clinical settings, Gillberg et al. (2015) sought to investigate the prevalence of PDA within the population of the Faroe Islands. A cohort of 15 to 24-year-olds were initially screened against the diagnostic criteria for autism, of which 67 individuals met the criteria. Parents of 50 of these individuals were then interviewed using the Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al., 2002), a measure which reportedly contains 15 items specific to PDA.

For these individuals, 9 were reported to meet the criteria for a “possible clinical diagnosis of PDA” (p. 981). This indicated that almost 1 in 5 of the participants had indications of a PDA presentation alongside autism in their childhood, however, only 1 of the participants met the full criteria for a prospective diagnosis between the ages of 15-24. The authors therefore discuss that the general outcomes for CYP with these presentations are likely positive, as the criteria for PDA are unlikely to be met in later adolescence or early adult life. They also stipulate that it is important to recognise CYP who are extremely demand avoidant, as they may need adjustments to interventions more typically recommended for those with autism. Although intended to represent the general population of the Faroe Islands, this study constituted a small sample size, and no comparison of PDA presentations in non-autistic populations were made. Furthermore, as the PDA-specific items of the DISCO had not been validated, these findings should be considered cautiously. Regardless, this research indicates that PDA appears to be relatively common in those with autism.

In 2018, O’Nions and colleagues explored parental perspectives on dimensions of difficulty in CYP with an autism diagnosis and features of PDA/EDA. From an initial sample of 82 parents who completed a screening using the EDA-Q, 29 of the parents reported that their CYP had PDA features and subsequently took part in semi-structured interviews. Responses from these interviews were then coded against the PDA indicators identified from the DISCO (O’Nions et al., 2016), of which 26 of the interviews met the cut off. These interviews were then analysed inductively, and several themes, including control over situations and others’ activities, emerged. Avoidant behaviours presented in this sample were also suggested to be ‘strategic’, as opposed to ‘manipulative’. Furthermore, a multitude of factors including negative emotional response to demands, phobias, sensory sensitivities, and uncertainty were deemed to have a role in triggering these behaviours. Interestingly, novelty was also seen to exacerbate demand avoidance, although this was previously reported as a

helpful approach (Newson et al., 2003); a suggested explanation is that rigidity may allow CYP to feel in control of what is happening. The authors subsequently advise that identifying these dimensions is important in developing targeted interventions. As with previous research, this study constituted a small sample size and did not pursue detailed information on the overall picture for CYP, including any differential diagnoses. Furthermore, there is likely a participant bias from the parents who elected to take part in the study, towards those who had already encountered information on PDA/EDA. To address these limitations, the authors proposed that observational research from a greater cross-section of families may support representation in the future.

Based on the emergence of other evidence in autistic populations, Stuart et al. (2020) proposed IOU and anxiety as underlying the behaviours associated with PDA. A quantitative, online survey was completed by a sample of those with a PDA diagnosis (n=69) and those with features of PDA identified by parents (n=151). 11 of these participants then completed telephone interviews to obtain qualitative data. Their analyses of the data indicated that demand avoidant behaviour could be partly conceptualised as an attempt to “increase certainty and predictability to alleviate increasing anxiety” (p.59). Furthermore, strategies employed by CYP to manage their IOU included control behaviour, meltdown, and withdrawal into fantasy. Whilst all these behaviours were predicted by IOU, only meltdown was shown to be mediated by anxiety. Overall, these findings support the premise that anxiety and IOU may contribute to PDA related behaviours, which offers implications in ascertaining how these behaviours can then be supported. As in previous research relating to PDA, the lack of formally agreed diagnostic criteria or assessment instruments created limitations in determining the participant sample for this study, particularly for the inclusion of CYP where PDA was ‘suspected’. This can be seen as a fundamental issue in seeking to conceptualise PDA, and therefore further exploration or verification may be necessary.

### **2.4.2 Identification**

Three papers published by O’Nions and colleagues focused on developing and refining clinical tools for the assessment and identification of PDA (2014a, 2016, 2021).

Seeking to promote consistency in the description of PDA, O’Nions et al. (2014a) developed the EDA-Q, which intended to measure PDA characteristics using data reported by parents or teachers. Their validation study constituted data from 326 parents, allocated into 6 groups: typically developing CYP (n=102), CYP with ASC without disruptive behaviour (n=36), CYP with ASC with disruptive behaviour (n=48), CYP for whom their parents suspected PDA, irrespective of other diagnoses (n=67), CYP who had been identified as having PDA, irrespective of other diagnoses (n=50) and behavioural concerns without suspected/identified ASC or PDA (n=23). The findings suggested that scores on the EDA-Q for CYP previously identified with PDA were significantly higher compared to all the other comparison groups, with good sensitivity and specificity. In addition, females were found to score higher on the EDA-Q than males; this counters gender prevalence ideas from Newson et al.’s (2003) clinical observations. The authors suggested the potential for the EDA-Q to be used in future research, however, it is also acknowledged that diagnoses reported by parents were not verified, and therefore it is possible that they may not have been correctly grouped. In addition, given the disparity on whether clinicians will provide a ‘diagnosis’ and the lack of information gathered on parents’ insight into PDA, allocations across the groups may have had limitations. Finally, the number of CYP in group 6 was relatively small in comparison to the other groups, and therefore may not have had sufficient representation for validation.

Following their EDA-Q development study, with recognition that there is no established clinical instrument for identifying PDA presentations, O’Nions et al. (2016) examined the Diagnostic Interview for Social Communication Disorders (DISCO) and initially identified 17 items which were deemed characteristic of PDA. This stage was

informed by the findings of their EDA-Q study (2014a) but is also noted to contradict the 15 DISCO items which were identified for Gillberg's (2015) study. Subsequently, data from 153 individuals who had been assessed for autism using the DISCO was scrutinised, deeming that 11 of the originally derived PDA items had low endorsement rates in a generalised autistic population. The authors suggest that these rates may offer meaningful indicators of a PDA subgroup, outside of typical autism. Finally, using the selected 11 DISCO items, the sample was analysed again, and 27 individuals were identified as having high levels of PDA features. This allies Gillberg et al.'s (2015) findings on the prevalence of PDA, as this equates to approximately 1 in 5 from the sample. Furthermore, only 1 of these 27 individuals did not meet the criteria for a diagnosis of autism. It is important to acknowledge that this sample was purely inclusive of individuals where social communication differences had been suspected, and this therefore may not represent the occurrence of PDA features outside of those with autistic traits. In addition, since the cut offs used for the PDA items from the DISCO were determined pragmatically, these may not have been an appropriate measure of the degree of functional impairment experienced. Therefore, it is indicated that a lower or a higher threshold of PDA features may have been more beneficial.

Since the development of the EDA-Q, its authors have aimed to refine the measure (O'Nions et al., 2021) using principal components analysis and item response theory analysis on data from parent/caregiver reports of 334 CYP with ASC. They found 8 of the items from the EDA-Q were discriminating indices of PDA/EDA features and showed good internal consistency and validity with other measures; the collation of these items was henceforth referred to as "EDA-8" (p. 276) (see Table 2 and Appendix C for the formal measure). As a result, the authors suggest that the EDA-8 may be useful in identifying PDA/EDA traits in children with ASC. Like previous studies by O'Nions and colleagues, this study is limited by a lack of in-depth information about the CYP, obtained by only one parent/caregiver. As this

research team have been involved with a series of studies focusing on PDA/EDA, they acknowledge that their self-selective sample may overrepresent CYP with these features. Furthermore, it is discussed that the EDA-8 only explores demand avoidance for a limited period, and that further research would benefit from looking at the maintenance of PDA/EDA traits across the lifespan. This would further the findings of Gillberg et al. (2015), which suggested that PDA features may diminish through late adolescence and into early adulthood.

**Table 2**

*EDA-8 items*

Item Number	Item
1	Obsessively resists and avoids ordinary demands and requests
2	Is driven by the need to be in charge
3	Tells other children how they should behave, but does not feel the rules apply to him/herself
4	Has difficulty complying with demands unless they are carefully presented
5	Seems unaware of the differences between him/herself and authority figures (e.g., parents, teachers, police)
6	Mood changes very rapidly (e.g., switches from affectionate to angry in an instant)
7	Uses outrageous or shocking behaviour to get out of doing something
8	Has bouts of extreme emotional responses to small events (e.g., crying/giggling, becoming furious)

*Note.* Adapted from O’Nions et al. (2021)



### **2.4.3 Intervention**

At present, it appears that only one paper has sought to examine the interventive strategies involved in supporting PDA (O’Nions et al. 2020).

Recently, O’Nions et al. (2020) explored the structure of their newly developed Parenting Strategies Questionnaire, intended to quantify behaviours related to managing behaviours that challenge for children with autism. From a sample of 222 parents residing predominantly in the UK, of whom their child had a diagnosis or significant traits of ASC, they examined relationships between CYP behaviour and parenting using data from this questionnaire. Three parenting subscales were revealed from the analysis: accommodation, reducing uncertainty and reinforcement approaches. Furthermore, accommodation and reducing uncertainty were deemed to be linked to CYP behaviour that challenges. CYP factors were found to predict some variance in parenting, with ‘socially inflexible’, ‘non-compliance’ and ‘IOU’ cited as the strongest predictors. However, CYP factors bore no relationship to reinforcement approaches. As a result, the authors suggest that longitudinal studies are needed to examine these relationships further, with recognition that direct causal influences between parenting and CYP behaviour could not be determined from their findings. This study presents with several limitations, namely the influence of social desirability bias from solitary parent respondents, of which the majority were mothers. Therefore, it is unclear whether these findings can be generalised to parents/caregivers of CYP with ASC more broadly across the UK, and future research should gather data from multi-informants and include any additional caregivers.

### **2.4.4 Experiences (including EP Involvement)**

Four papers were published in relation to experiences of PDA. Of these studies, two sought to explore the educational experiences of CYP identified as having demand avoidant behaviours, through parent questionnaires (Gore Langton & Frederickson, 2016; Truman et

al., 2021). Another explored parents' experiences of professional involvement (Gore Langton & Frederickson, 2018). Notably, it also appeared that these were the only three papers from the literature review to explicitly mention EPs within their findings and as part of their qualitative discussions. Although Doyle and Kenny (2023) had recruited one EP as part of their practitioner sample for their research, which explored experiences of PDA in Ireland, their distinct viewpoint was not documented.

In the initial research of Gore Langton and Frederickson (2016), parents were invited to participate if they considered their CYP to have PDA, with additional screening using the EDA-Q and other measures then taking place to inform the inclusion criteria. This resulted in a sample of 42 parents. Responses from parents indicated that their CYP displayed significant behaviour that challenges in school, as well as receiving high levels of SEND support and involvement from professionals. Despite this, these CYP reportedly experienced high rates of placement breakdown or exclusion, with 48% of them accessing mainstream education. Within the findings, it was noted EPs had sometimes been one of the professionals involved in identifying CYP as having PDA. In addition, it was reported that 88% of these parents had an EP involved with their child. The researchers suggest that this high level of EP involvement may reflect EPs' statutory duties in assessing SEND (BPS 7.2, Appendix P). Whilst the present study offers helpful groundwork for considering the educational needs of CYP identified with PDA, the participant sample was limited due to its relatively small size and notable predominance of families with higher socioeconomic statuses, as determined by the educational attainment of the parents. Furthermore, CYP who did not attend school full-time were not included in the sample. Therefore, it is possible that these findings may not be representative for a larger population of CYP who are thought to display PDA traits.

Truman et al.'s (2021) recent study examined the educational experiences of CYP with autism who presented with EDA behaviours versus those who did not. PDA is therefore

recognised as part of the autism spectrum within this study. Online questionnaires were filled out by 211 parents, to gather both quantitative and qualitative data. Using the EDA-Q, the parents were further divided into groups according to whether their CYP had been labelled as having PDA, displayed EDA behaviours, or neither. The findings indicated that while school exclusion rates did not significantly differ between the groups, CYP with EDA presentations showed higher levels of behaviour that challenges; this was particularly elevated for the PDA group. Furthermore, the qualitative findings indicated that CYP with EDA behaviours had incredibly negative school experiences, leading to anxiety and mental health difficulties. The parents of these CYP ascribed these experiences to misunderstanding of their CYP's diagnoses and a lack of targeted support; they also reported feeling that their CYP may be masking their difficulties at school. However, the parent perspectives gathered in this research may not align with those of educators or the CYP themselves, as acknowledged by the authors. It is also considered that if a CYP had negative educational experiences, their parents may have been more likely to have taken part in the study. Although professional involvement is discussed, it is unclear whether EPs' role is included as they are not named in the article beyond a sole quote from a parent. This study raises the question of whether it is possible to improve the educational experiences of autistic CYP through identifying distinct behavioural profiles, like PDA.

Following their prior research, Gore Langton and Frederickson later explored parents' experiences of professionals' involvement for CYP who were identified as having EDA (2018). Screened for inclusion using the EDA-Q, as before, a sample of parents to 42 CYP completed questionnaires asking about professionals who had been involved with their CYP and how beneficial they thought their involvement had been. Parents reported a high level of professional involvement for their CYP, and most of these experiences were deemed to be helpful. Themes pertaining to input which was perceived as helpful included the skills and

qualities of the professionals, enabling access to resources and services and providing assessment and strategies.

The involvement of EPs was explicitly identified and described in this study. The families within the sample reported a notably high level of EP involvement, as similarly found in Gore Langton and Frederickson's earlier research. 57% of these involvements were said to have been beneficial. Additionally, it was found that after clinical psychologists, EPs were mentioned the second most frequently as the most beneficial professional involved. However, 29% of the parents did not specify a specific professional as being the most helpful. The authors also included the following parent comments about EPs within their data analysis:

The educational psychologist made the best assessment of my child's educational needs and her assessment carried sufficient weight to get those needs included in his statement.

The school educational psychologist wrote a clear and insightful report.

The educational psychologist has observed my son in class and brought PDA up and I feel that has made more sense than anything else.

The educational psychologist's excellent report has been copied word for word into the statement (p. 20)

Like the previously reviewed articles, it is thought that the study's sample may not accurately reflect the general experiences of families whose CYP exhibit PDA characteristics. Additionally, there is a suggestion that parents who were recruited for this study might have been more inclined to participate because they were more likely to be familiar with the terms 'PDA' and 'EDA'. The authors provide recommendations for how professionals can effectively support "children with PDA and their families" (p. 23) based on the findings of their study (see Table 3). Although this guidance provides professionals with a useful and

accessible reference point from the perspective of parents, it could be argued that some of the suggestions may fuel contention. For example, where PDA is not recognised within diagnostic manuals or perhaps at certain service levels, “supporting families to obtain a diagnosis” could become potentially problematic. Then, it would seem beneficial to investigate the support professionals are currently offering.

**Table 3**

*Effective professional support for “children with PDA” and their families*

Making sure to...
<ul style="list-style-type: none"> <li>• Listen to parents from a no-blame perspective</li> <li>• Be willing to learn more about PDA</li> <li>• Allow families to build relationships and receive continuity of care</li> </ul>
Staying outcome-focused by...
<ul style="list-style-type: none"> <li>• Carrying out comprehensive assessment of children’s needs</li> <li>• Communicating our formulations clearly</li> <li>• Offering direct interventions to improve children’s day-to-day lives</li> <li>• Giving practical strategies and advice to help family life run more smoothly</li> <li>• Keeping the wellbeing of the whole family in focus</li> </ul>
Opening doors by...
<ul style="list-style-type: none"> <li>• Supporting families to obtain a diagnosis which reflects their child’s needs</li> <li>• Helping families to navigate the special educational needs system</li> <li>• Referring to and liaising with other services which can meet families’ health and care needs</li> </ul>

*Note.* Adapted from Gore Langton & Frederickson (2018)

More recently, Doyle and Kenny (2023) sought to gather perspectives on different groups' experiences of PDA. Using a mixed methods approach, a sample of 264 parents, 54 practitioners, 9 life partners and 6 individuals identified as experiencing PDA first completed an online survey. Within the practitioner sample, one EP was described. The data from these surveys was then supplemented through semi-structured interviews with 2 of the individuals identified as experiencing PDA, 2 life partners and practitioners and 5 parents or guardians. A focus group with 4 parents or guardians was also facilitated. The findings suggested that a flexible, transdisciplinary, and cohesive approach to service delivery and assessment is crucial across social, educational, personal, and health care and support. It was noted that education and healthcare professionals should use their professional tools skilfully to determine which solutions are best for each person's situation and community. In line with best practice, it was reported that using a reflective practice approach, working with colleagues by exchanging knowledge, and realising that not all interventions or supports are suitable for every individual are appropriate in supporting those identified with PDA. Overall, these findings suggest that it is critical to take an individualised and flexible approach to assessment and service delivery for people who present with a PDA profile.

A key strength of Doyle and Kenny (2023)'s research was that the perspectives of individuals who identify with having PDA were included, as well as viewpoints from teachers, partners, and other professionals, where earlier studies had focused primarily on parent voice. However, although these perspectives were gathered, it remained that the sample of the quantitative data was predominantly constituted of parents by a significant margin. Like critiques of the research by Truman et al. (2021), it should be considered that the parental views may have been biased, as they may have been more likely to participate in the research if they had perceived their CYP to have had negative experiences. Nonetheless, as the experiences are presented discretely between-groups within the findings, this study

provides crucial insights into the considerations of how PDA characteristics can be best supported.

## **2.5 Evaluation of the Current Literature**

### ***2.5.1 Methodological and Topical Critique***

Overall, the current literature indicates that there is a notable occurrence of CYP presenting with significant demand avoidant characteristics, commonly although not exclusively (e.g., Stuart et al., 2020) seen in autistic CYP. However, despite a high focus on identification, the root of these behaviours remains unclear. As previously discussed, Newson et al. (2003) do not specify how their initial criteria for PDA were defined. This subsequently presents credibility issues for all later studies which have been at least somewhat built on their proposal.

A pertinent consideration within the literature is that maintenance of PDA-related behaviours over time appears inconsistent. In support of the initial proposal of PDA as a neurodevelopmental condition (Newson et al., 2003), it is anticipated that these specific characteristics would remain present throughout the lifespan. Whilst Doyle and Kenny (2023) discuss differences in needs between younger and older CYP and identify a lifelong impact for adults with PDA presentations, Gillberg et al. (2015) and O’Nions et al. (2016) consider that demand avoidant behaviours may not persist in later life for some individuals (see also Kildahl et al., 2021). It could be deliberated whether some adolescents or adults learn how to better navigate challenges with demands as they mature, which may explain why these avoidance behaviours are seen less. Nonetheless, it is likely that research pertaining to PDA in adults would provide greater insight into how these behaviours might manifest or change over time, however this was not the focus of this literature review. Furthermore, this should also be considered in the context of whether PDA associated traits may exist outside of a pervasive, neurological difference.

It is important to recognise that most of the reviewed studies were dependent on information provided by parents or caregivers as part of their methodology, in turn increasing the likelihood of confirmation bias surrounding the identification of PDA (Green, 2020; Kildahl et al., 2021). In addition, the limited scope of research facilitated with individuals who identify with PDA themselves may result in misrepresentation of their experiences. Given the controversy surrounding PDA, future directions should include gathering the views of CYP given this label, to aid in providing a person-centred perspective on this issue.

### ***2.5.2 Culture and Identity***

A key consideration in the evaluation of the current literature is that most of the studies selected for review took place in the UK, and all were derived from geographic locations in western Europe. As PDA is a term which originated in the UK, with research surrounding this gradually increasing, it is possible that other countries may have less awareness or application of this term. Nonetheless, this presents implications for recognising whether there may be cultural differences in how demand avoidant behaviours are viewed and understood, given previous literature has acknowledged cultural differences in language use and attitudes towards learning for pupils of diverse ethnic groups (Seifert & Sutton, 2019) and differences in how emotional competence is conceptualised across cultures (Friedlmeier et al., 2011; Raval & Walker, 2019). Similarly, aspects of participant identity which are not associated with pre-existing diagnoses, such as ethnicity and religion, were not gathered in any of the reviewed studies. Therefore, the possible intersection of culture with the presentation of these behaviours are not addressed, and it is unknown whether labelling of PDA may be over or underrepresented among certain social groups (BPS 3.7, Appendix P).

Despite an existing narrative that PDA features are independent of autism, most of the studies comprised participants who were autistic; this was also sometimes part of the sample criteria (see Appendix A), which may in turn restrict the scope of exploring PDA



presentations in research. In fact, only two studies sought to directly examine PDA traits in other groups of individuals (O’Nions et al., 2014a; 2014b). Likewise, though PDA has also been suggested as existing as a culmination of symptoms (Gore Langton & Frederickson, 2018), only four of the studies appeared to report the co-existence other neurodevelopmental or mental health conditions with PDA (O’Nions et al., 2021; Reilly et al., 2014; Stuart et al., 2020; Truman et al., 2021). It would be beneficial for future research to consider and address a greater breadth of factors in relation to participants’ background and social graces (Burnham, 2018), to increase consideration of how different lifestyles, values and characteristics may impact upon the presentation of demand avoidant behaviours, as well as how these are perceived and addressed within different cultural systems. Whilst the current research does not directly seek to explore individual CYP presentations and the interactive factors which may contribute to these, it is possible that this could be discussed in relation to EPs’ perspectives of PDA.

### ***2.5.3 Biological Frameworks***

The published literature surrounding PDA has been consistently informed by an understanding that the associated behaviours exist due to innate, neurological differences which occur ‘within’ the CYP. As such, although it is not empirically recognised, many researchers have regularly adopted a positivist position in viewing PDA from a biological or medical perspective and seek to determine or detail its existence. This framework is additionally reflected in the few studies which have focused on experiences for CYP who present with these behaviours (Doyle & Kenny, 2023; Gore Langton & Frederickson, 2016, 2018; Truman et al., 2021), as they continue to recognise PDA as a pervasive entity. Although Stuart et al. (2020) suggest an explanatory framework of anxiety and IOU for conceptualising demand avoidant behaviours in PDA, they advocate for PDA having clinical and diagnostic status as a ‘disorder’ (p.60), hence continuing to align with the medical model.

Whilst understanding of PDA is still in its infancy, these polarised positions generate limitations for the consideration of how other factors, such as adverse childhood experiences or trauma (Kildahl et al., 2021; Woods, 2020c), could be contributing to or maintaining demand avoidant presentations.

Notably, there appears to be limited consideration of cognition and learning processes within the conceptualisation of PDA, and how this may impact the development of demand avoidant behaviours. Several studies reported variable ‘intellectual abilities’ among their PDA-identified participants (O’Nions et al., 2014a; 2016; 2020; 2021; Truman et al., 2021), and Reilly et al. (2014) described all the CYP in their case studies as having a ‘cognitive impairment’. However, relationships between PDA presentations and cognitive profiles in peer-reviewed research (excluding the thesis of Goodson, 2018, discussed in chapter one) are unclear; this is reflected in O’Nions et al.’s (2014b) advocacy for future research to explore the influence of neurocognition on the PDA presentation. Interestingly, Gillberg et al. (2015) excluded participants with “severe intellectual disabilities” (p. 981) from their analyses, with the rationale that they did not envisage that these individuals would present with a PDA profile, which seems to somewhat counter the participant demographics and subsequent findings in other studies.

It could be argued that taking alternative perspectives to PDA research, such as a cognitive or a socioenvironmental perspective, may provide alternative insights into the factors which contribute to and maintain demand avoidant behaviours. As such, a constructionist lens is taken for the current research, in seeking to explore the development of EPs’ perspectives of PDA and their approaches to this term in their practice.

#### ***2.5.4 Implications for EPs***

The research on PDA in EP practice is currently limited, but the existing findings seem to suggest that EPs play an important role in working with CYP presenting with PDA features, providing a high level of involvement and helpful support for families. According to current studies, some EPs are identifying PDA and using the term PDA in their practice (Gore Langton & Frederickson, 2016, 2018). It is unclear, though, how EPs conceptualise and understand this term. Also, previous studies have indicated that EPs are among the professionals most likely to work with CYP who have been identified with PDA (Gore Langton & Frederickson, 2016, 2018). While assessment purposes are occasionally referenced, little is known about how EPs tailor their involvement more generally. It could be argued that there is insufficient information to provide a detailed description of the role of the EP, as research frequently relied on questionnaire data and parental perspectives. Furthermore, only one study seems to have explored educators' perspectives or experiences relating to PDA (Doyle & Kenny, 2023) which is critical to informing the EP role, given that a high proportion of EPs' involvement is directly with schools. There are still questions as to how EPs are describing the PDA-related needs of CYP, including whether they believe using the term PDA can be beneficial. It is also unclear what advice and support EPs are offering to schools and families regarding these needs.

It has already been acknowledged that professional opinions on PDA may differ (Gore Langton & Frederickson, 2018; O'Nions et al., 2014b). Though research on professional involvement with PDA indicated that EPs were among the most helpful compared to other professionals, it remained that just over half of the EP involvements were felt to have been helpful (Gore Langton & Frederickson, 2018). This suggests that more research on PDA in EP practice is necessary, to ensure collaborative efforts are employed in providing meaningful support where the term PDA is raised. This should be considered for

EPs in conversation with families, teachers, and other school staff, recognising their key roles in identifying and supporting the educational needs of CYP.

## **2.6 Summary and Rationale for Current Research**

Although the research base is not yet well established (Green et al., 2018), PDA has attracted growing attention in the literature, with many authors contributing varying perspectives on how it should be conceptualised (Eaton, 2017; Gillberg, 2014; Gore Langton & Frederickson, 2018; O’Nions, 2014b; Woods, 2020). Nonetheless, most prevalent is that the underlying PDA presentation is felt to be neurodevelopmental in nature. The EDA-Q, developed by O’Nions and colleagues (2014a), has often been applied as a screening tool for PDA identification and participant selection, however it appears that other approaches to understanding, assessment and support are somewhat limited. Whilst there is currently no formal consensus on the categorisation of PDA, the characteristics and behaviours associated with PDA can be seen to pose significant challenges for CYP within education (Gore Langton & Frederickson, 2016; Truman et al., 2021), and for their families (Gore Langton & Frederickson, 2018). Hence, the current research recognises that it is critical that these difficulties are acknowledged and considered within EP involvement.

Since prior research indicates a high likelihood of EPs working with CYP whose needs are associated with PDA, it appears pertinent to contribute further literature from the EP perspective, as there is currently limited research providing this view. This is especially true where the aetiology of PDA has been the primary focus of existing research. Although many academics seek to uncover and define ‘what PDA is’, it is important to recognise that this term will likely carry different meanings for different individuals and organisations, and professional’s responses to and willingness to use this term may vary (Gore Langton & Frederickson, 2018; O’Nions et al., 2014b). This may also be influenced by the rise in favouring a transdiagnostic approach (see chapter one) to understanding and supporting

neurodevelopmental needs, and through the various debates of labelling. As such, a more systemic approach aligned with EP practice may offer helpful challenge to the medical focus on PDA, and further open the debate for broader considerations around the PDA concept.

With the upsurge of online PDA forums (such as Cat, 2023a; PDA Society, n.d.-a) and families and schools increasingly using the term PDA (Green et al., 2018; O’Nions et al., 2014b; Stuart et al., 2020), it is possible that tensions can arise where different positions on PDA are taken; notably, parents have reported feeling judgement or blame in relation to their CYP’s behaviours (Truman et al., 2021). As a key professional involved with CYP, it is important to explore the positions that EPs are taking on PDA, how they are navigating conversations surrounding this and what they are recommending to schools and families in supporting CYP. Therefore, this research aims to explore EPs’ perspectives on PDA, encompassing their views on working with the term PDA, and how they communicate and give advice when PDA is raised.

## **Chapter Three: Methodology**

### **3.1 Chapter Overview**

This chapter describes the theoretical and philosophical positions which have been adopted for this research, and how these inform the research purpose and aims to generate the research questions. The rationale for the chosen research design is also discussed, including procedures for participant recruitment, data collection and the analytic processes employed. Finally, ethical considerations and the steps taken for quality assurance are addressed.

### **3.2 Research Paradigm**

#### ***3.2.1 Theoretical Frameworks***

As previously discussed in chapter two, a positivist, biological perspective (Cherry, 2021) has consistently shaped a large portion of earlier literature regarding PDA, which seeks to explain distinct patterns of behaviour arising from neurodevelopmental factors. Likewise, previous studies which have focused on the experiences of CYP who present with PDA-related behaviours are consistent with this understanding of PDA. In contrast, the current research adopts a constructionist lens to explore how EPs' perspectives on PDA have developed and how this informs their professional practice. Constructivism, as a theory of learning, suggests that new meanings are created when new environments or ideas interact with existing knowledge, and recognises that understanding is a shared cultural experience (Bélanger, 2011). This research extends the constructivist perspective by further considering a social constructionist viewpoint, which stipulates that knowledge is created through social interactions and engagements, such as shared projects. The ontological and epistemological positionings of the researcher further reflect and describe this theoretical framework.

### ***3.2.2 Ontological and Epistemological Orientations***

Within a research paradigm, Guba and Lincoln (1994) describe that ontology, epistemology and methodology influence how the research is designed and implemented. The ontological position of a researcher is influenced by their philosophical assumptions on the nature of ‘reality’ and existence. This position aids the researcher in knowing how to approach their research questions and make sense of the data collected. Correspondingly, the epistemological position of a researcher considers the basis of knowledge and whether ‘truth’ is constituted by factual evidence or lived experiences.

Rejecting a positivist orientation, this research takes a relativist ontological position, viewing reality as a subjective experience (Guba & Lincoln, 1994). While a critical realist perspective would be taken into consideration if one were looking to discover the ‘truth’ about what PDA is, the focus of this research is on how EPs conceptualise, view and work with the term PDA; this considers the semantic nature of PDA as terminology used within educational systems. As a result, adopting a relativist stance is appropriate in acknowledging the possibility of differing ‘truths’ and experiences with PDA, especially where prior publications have highlighted varied opinions regarding the terminology and its meaning.

This research employs social constructionism as its epistemological position. Burr (2015) outlined four key assumptions about social constructionism: knowledge is historically and culturally specific, goes together with social action, is sustained by social processes, and challenges the idea that knowledge is derived from objective observation. This research is focused on the premise that PDA is a term which has been socially constructed to characterise a specific set of observable behaviours, regardless of whether it is understood as a syndrome, a set of symptoms, or otherwise. This research also considers that social interactions build assumptions about PDA, such as the premise that PDA exists as part of the autism spectrum. This perspective aligns with EP practice, since it can be acknowledged that

interaction with academic tutors, supervisors, colleagues, and service users informs professional development (BPS 2.10, Appendix P). However, as further research is pursued, there is also potential for existing knowledge and understanding of PDA to evolve. Furthermore, whilst empirical evidence bases for supportive strategies are ideal, these are currently lacking in PDA research (Green et al., 2018). As a result, it can be argued that approaches to support in this domain are predominantly socially constructed. Overall, it is befitting for this research topic to acknowledge that EPs' perspectives on PDA exist through socially constructed knowledge.

### **3.3 Research Purpose and Aims**

The purpose of this research is exploratory, aiming to generate a greater understanding of PDA in EP practice, an area where it seems that not much is currently known. Exploratory studies are also typically used to gather rich, detailed information about views and experiences, which aligns with the relativist, social constructionist positionings previously outlined. From the literature review, it emerged that there is currently little known about how EPs conceptualise and support PDA-associated needs within their involvement. This directed the development of the research aims, which were to explore EPs' perspectives on PDA, including their understanding and views of the term, and what advice and support they offer within their involvement.

Given the aims of the research, an overarching research question and two sub-questions are employed. The overarching research question is 'what are EPs' perspectives on PDA?'. Sub-questions were then designated as it is deemed valuable to understand both EPs' views on PDA and how EPs address the topic of PDA in their practice, without making assumptions that one may directly influence the other. The sub-questions are therefore:

1a) What are EPs' views on working with the term PDA?

1b) How do EPs communicate and give advice when PDA is raised?



### 3.4 Research Methodology and Rationale

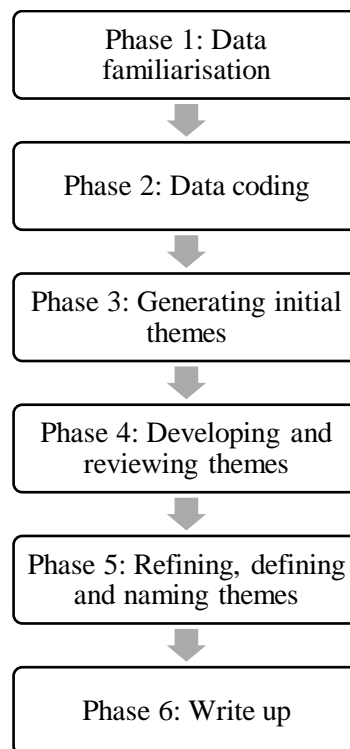
This research employed a ‘big Q’ qualitative design, due to its exploratory purpose and the philosophical positions adopted. Qualitative research provides scope for deeper complexity and nuance in the data collected (Braun & Clarke, 2021), which is valuable in considering individuals’ thoughts and experiences. The term ‘big Q’ describes research which tends to be interpretative and subjective (Clarke & Braun, 2013), as opposed to ‘small Q’ research which is more greatly concerned with implementing a structured approach to reduce bias in the research process (Braun & Clarke, 2021). Reflexive thematic analysis (RTA), an approach developed by Braun and Clarke (2019) from their initial 2006 thematic analysis model, was used to analyse the data. The RTA process is comprised of six phases, as illustrated in Figure 4, enabling the identification and generation of common themes while simultaneously acknowledging the unique viewpoints and experiences of each participant. Braun & Clarke (2021) describe four domains to RTA which provide a flexible framework in how the researcher may approach their analysis, which has been described below.

- Orientation to data: A more inductive approach was taken, as the coding and development of themes were driven by the dataset, rather than being shaped through an existing theoretical lens, which is considered a ‘deductive’ approach.
- Focus of meaning: Both semantic codes which summarise content and latent codes which captured meaning within the data were created during the analysis.
- Qualitative framework: The research questions informed an experiential framework to the analysis, as it aims to explore individuals’ own understandings and perspectives on PDA.
- Theoretical frameworks: As previously discussed in reference to ontology and epistemology, the analysis aimed to unpack individual insights and experiences which were expressed using relativist and constructionist frameworks.

Recognising the subjectivity and biases of the researcher is a key aspect of RTA. Practicing reflexivity helped to identify whether the researcher's opinions or beliefs could have influenced the data analysis. The importance of using a reflexive approach in this study is covered in more detail under the ethical considerations section.

#### Figure 4

*The six phases of reflexive thematic analysis (RTA)*



*Note.* Adapted from Braun and Clarke (2020).

In developing the research design, it was considered whether discourse analysis (DA) may be an appropriate approach to data analysis. DA is centred on examining how people use language (Harper & Thompson, 2011), which could have been implemented in the current research as aspects of the research questions focus on the use of PDA terminology. However, by only looking at EPs' discourses surrounding PDA, this may not have captured the rich picture of their views on the PDA concept and how they address this in their practice, which embodies an important purpose of this research. Furthermore, DA would not have addressed

the potential bias that the researcher brings to the data analysis process, which is highly valuable given the researcher's own experiences with PDA, discussed later in this thesis. Other methods of analysis such as Interpretative Phenomenological Analysis and Grounded Theory were not contemplated for this research, as it sought to explore commonalities amongst EP participants and consider the implications for wider practice, rather than examine individual lived experiences (Smith & Fieldsend, 2021), or generate explanations through theory development (Charmaz & Henwood, 2017) respectively. Therefore, RTA was determined to be the most appropriate approach to data analysis (BPS 9.4, Appendix P).

### **3.5 Research Participants**

#### ***3.5.1 Participant Information***

For this research, the population of interest were EPs who were registered with the HCPC and currently practising in the UK. Participants were chosen using purposive sampling according to inclusion and exclusion criteria pertinent to the research questions (see Table 4).

**Table 4**

*Inclusion and Exclusion Criteria for Participation*

Inclusion	Exclusion	Justification
Qualified EPs (private or LA employed, including main-grade, senior, principal etc.).	Trainee EPs, Assistant EPs or other professionals. Trainee and Assistant EPs are not considered to have an extensive level of autonomy, experience, or training to discuss views and experiences of PDA in depth.	The research aims to explore how EPs approach the term PDA within their practice, so the perspectives of other professionals are not considered to be relevant.

---

		Both LA employed and private EPs were invited and selected to participate to represent a broader scope of perspectives and approaches.
Registered with the HCPC and currently practising as an EP in the UK.	EPs practising outside of the UK.	The EP role and the use and understanding of the term PDA may vary across other countries.
EPs who have encountered the term PDA during their practice and can reflect on their thoughts and experiences of this.	EPs who have not encountered the term PDA within their practice.	The researcher recognises that participants may have varying understandings, views, and experiences of the term PDA in their practice.

---

The aim was to recruit between six to eight participants. Braun and Clarke (2022) discuss that statistical models for determining sample sizes and the concept of ‘data saturation’ are problematic when pursuing thematic analysis, and instead invite researchers to reflect on the ‘information power’ (Malterud et al., 2016) within their dataset, and how this marries with the purpose of the research. This number of participants was deemed appropriate for this research as it allowed for the rich, individual data to be valued, whilst also accounting for feasibility of transcribing and analysing the data within a certain timeframe. Data collection was ceased after eight participants had taken part in interviews, as at this point, the

data collected was deemed sufficient in providing a “rich, complex and multi-faceted story” (Braun & Clarke, 2021, p211) in response to the research questions.

### **3.5.2 Recruitment**

The participants for the interviews were recruited through EPNET; an online, public forum for those working within the field of educational psychology (JISC Mail, n.d.). This approach meant that the researcher was able to recruit EPs who are employed across different contexts nationally, to additionally account for whether service positions or policies may inform perspectives and approaches to PDA. As well as posting a recruitment advert on EPNET (Appendix E, also see Appendix D for poster version), information about the research was also shared with EPs the researcher was familiar with.

After expressing an interest in the research over email, the EPs were provided with an information sheet and consent form (see Appendix D) to read, sign, and return if they still wanted to take part. At this stage, the EPs were also invited to ask any questions they might have about the research. Lastly, they were informed that if they were no longer interested in taking part, then they did not need to respond to the email.

### **3.5.3 Sample**

Seventeen EPs responded to the recruitment advert to express their interest in the research. Four of these EPs did not respond further after being sent the information and consent forms. One EP was unable to sign the consent form digitally. Recruitment was ceased after the first eight digital consent forms were received chronologically. After the recruitment sample was achieved, one further consent form and two emails of interest were received. The EPs were informed that the recruitment sample had been achieved, but that the researcher would be able to send them a summary of the findings once the research is complete.

Eight HCPC registered EPs took part in the research. During the interview process, they were asked to provide some information about the context that they work in (see Table

5). In addition, one EP shared that they had completed their training outside of the UK. The participants have been referred to by pseudonyms.

**Table 5**

*Participant Information*

Participant	Current role and work context	Time working in current context	Geographic location of work in the UK
Alex	Main grade EP, LA employed	4 years	North
Beth	Main grade EP, LA employed	5 months	North
Charlie	Principal EP, LA employed	4 years	North
Georgia	SEN school and private EP	7 years	Midlands
Jamie	Main grade EP, LA employed	5 ½ years	South
Kate	Private EP and expert witness	3 years	National (predominantly South)
Lucy	Senior EP, LA employed	16 years	Midlands
Taylor	Private and locum senior EP	7 years	South

## **3.6 Data Gathering**

### ***3.6.1 Semi-structured interviews***

Semi-structured interviews were used to gather data for this research. This method enabled participants to discuss their experiences and thoughts regarding PDA more generally while also providing specific information on their perspectives (Fylan, 2005). This was especially appropriate given the exploratory design of the research (Willig & Rogers, 2017), as it provided depth in its contribution to a presently limited literature base. Although focus groups would have provided a forum for discussion and debate, semi-structured interviews were thought to be a more valuable approach as they gave participants the freedom to share their opinions and practices in greater detail without outside influence or concerns about potential conflict or judgement. Similarly, interviews offer greater confidentiality and anonymity, which allows participants to feel able to speak more openly (Longhurst, 2003). In addition, facilitating focus groups would have created pragmatic difficulties in bringing participants from across the country together to one location, or in running group discussions online. By developing a semi-structured interview protocol which considered appropriate probes to address the research questions, the impact of researcher bias was also reduced (Harrell & Bradley, 2009).

The duration of the interviews ranged between 12 and 50 minutes. The researcher followed a semi-structured interview schedule (see Appendix F) comprised of six key questions, including an open question for sharing anything of interest to the topic area at the end.

### ***3.6.2 Virtual Interview Facilitation***

The semi-structured interviews were facilitated using the video conferencing platform, Microsoft Teams. It was determined that carrying out online interviews provided greater scope for recruitment of EPs from across the UK, as the desired participant sample.

Furthermore, Microsoft Teams was identified as a secure platform for carrying out and recording the video interviews compared to other platforms such as Zoom, as this was associated with the researcher's University Microsoft Office account and was password protected. Once the participants had returned the consent forms and an interview time and date were agreed, the researcher emailed them a link for a Microsoft Teams meeting discreetly titled 'Research Interview'. Where most correspondence with the participants took place approximately two months before the interview date, a follow-up email with the Microsoft Teams link reattached was often sent nearer the time of the interview.

Whilst face-to-face interviews have historically been favoured in qualitative research, the emergence of the Coronavirus pandemic in 2020 and subsequent social distancing resulted in greater exploration of alternative methods (Saarijärvi & Bratt, 2021). As such, a systematic literature review by Thunberg and Arnell (2022) examined the strengths and barriers to using digital interviews across a series of qualitative research studies. Their findings indicated that using video interviews can be more cost-effective, as well as increasing participation from greater geographical distances. They also found that the richness of data pertaining to sensitive topics was often greater in online interviews compared to in-person methods. However, the risk of technical difficulties was highlighted as a potential limitation for impacting the quality of the interview. Furthermore, it was acknowledged that as computer cameras only capture the upper body of the participants, it can be harder to read body language or other visual cues. Overall, the authors discuss that digital interviews can be just as good or in some respects even better than in-person interviews, assuming that ethical issues are considered, and the internet connection is robust.

For the purposes of this study and to meet the recruitment preferences, it was considered that the benefits of virtual interview facilitation would outweigh the potential drawbacks. Nonetheless, in seeking to ensure that technical difficulties would not interfere



with the interview, the researcher checked at the beginning of the interviews whether the participants and the researcher were both able to see and hear each other clearly. One participant was unable to get their camera working despite several attempts to resolve this. However, they were still able to see the researcher on camera, and verbal communication between the researcher and participant appeared undisrupted. This interview had been rearranged at short notice due to unforeseen circumstances conflicting with the participant's availability, and it had been difficult to co-ordinate a suitable time to reschedule. Therefore, the researcher determined that it was acceptable to continue with the interview if they were comfortable with this, as only the audio data was required for analysis, and the researcher would ask the participant to clarify any responses that were unclear without the support of visual cues (BPS 10.11, Appendix P).

### ***3.6.3 Pilot Interview***

To review the quality of the interview schedule and to ensure that the interviews could be facilitated successfully using Microsoft Teams, the researcher conducted a pilot interview with a qualified EP colleague prior to the formal interviews. This included testing the recording features and evaluating whether the interview questions were effective in eliciting rich, detailed responses. The feedback from the colleague who took part in the pilot also supported the researcher to consider the information that would be helpful to share both at the beginning and the end of the interviews, such as reassuring the participants that there were no right or wrong answers, and that all views and experiences were welcome.

### ***3.6.4 Interview Procedure***

The researcher began facilitating the eight formal interviews approximately two weeks after the pilot interview, and these took place across a two-month period. On joining the Microsoft Teams call, the researcher welcomed the participants by introducing themselves and reiterating the purpose of the research interview. The researcher asked

whether the participants were comfortable and ready to proceed with the interview and invited them to make a drink or use the facilities before getting started if they wished. The researcher advised the participants that they were wearing headphones and facilitating the interview within a private space to protect their confidentiality. The researcher indicated that the interview proceedings were anticipated to last for up to an hour, and enquired if they would be happy to continue if the interview went beyond this time. The researcher talked through key details from the information sheet they had been provided with, to ensure that their informed consent was still valid, and asked if the participants had any questions before beginning the recording.

Video recordings of the interviews were made using Microsoft Teams' recording feature. Flexible application of the semi-structured interview schedule allowed for some alteration based on the participants' responses. For example, the prompt "can you tell me more about that?" was delivered to support the collection of rich data. The participants were thanked for sharing their views and experiences at the end of the interview and provided with an opportunity to ask questions or discuss any thoughts or feelings raised. The researcher then explained that they would be looking at themes in the data, and that the participants were still able to withdraw from the research up until the point that the data had been analysed. The researcher also reiterated that the participants' identity would be protected on the records stored by use of pseudonyms. Finally, the participants were invited to contact the researcher via email if they wished to follow up with anything from the interview at a later point.

### ***3.6.5 Reflections on Interviews***

As part of maintaining reflexivity during the data gathering stage, the researcher kept a reflexive diary which they wrote immediately after each interview to document their thoughts and feelings about what had been spoken about in the interview, as well as comments on their own facilitation of the interview (see Appendix O). Any queries the

researcher had pertaining these reflections were shared and discussed with their research supervisor. Reflections on the whole research process are discussed further in chapter four (BPS 10.2, 10.5, Appendix P).

### **3.7 Transcription**

The video recordings were downloaded from Microsoft Teams onto OneDrive, converted into audio recordings, and stored on an encrypted laptop. The audio recordings from the interviews were then transcribed into Microsoft Word and anonymised, with all identifiable information either changed or omitted. Transcription of the interviews was done ‘verbatim’ (Clarke & Braun, 2013) which included stammers and significant pauses within speech. During the process of listening to the recordings, there were a few incidences when a word or short phrase used by the participant was unclear. In these few cases, a term deemed the best match to that heard in the audio data was transcribed and highlighted so that the researcher could bear this in mind during the data analysis.

### **3.8 Data Analysis**

As aforementioned within the research methodology, data analysis was carried out using Braun and Clarke’s (2020) six stage process of RTA. Although this is presented as a chronological process, each stage was followed and revisited as required.

#### ***3.8.1 Stage 1: Data Familiarisation***

During this stage, the researcher immerses themselves in the data by listening to the audio recordings, critically reading the transcripts, and starting to identify any patterns that may be emerging. The researcher initially elected to print their transcripts and use highlighters in starting to identify key concepts which they noticed were arising as they read through the dataset (see extract in Appendix G). Through this process, the researcher began to map some initial ideas both pertaining to individual data items, and of the whole dataset, in relation to the original research questions (see Appendix I).

### ***3.8.2 Stage 2: Data Coding***

This stage comprises working through the dataset systemically and thoroughly to identify segments which appear meaningful and relevant to the research questions and apply code labels to these. Although the researcher had initially elected to begin analysis of the dataset using printed copies of the transcripts, they quickly acknowledged that they would find it difficult to manage the breadth of data coding in this manner. Therefore, the researcher decided to move to using NVivo, computer-based software for qualitative data analysis, to keep track of the increasing number of codes (see extract in Appendix H). Although NVivo was suitable for generating a comprehensive codebook from the analysis, the researcher found that reviewing the coded extracts within the transcripts was often difficult to navigate using this software.

The researcher started coding the transcripts in chronological order and at the semantic level, by looking for very explicit references or meanings from the data. The researcher noticed that they were often naturally making connections within the data, and this meant that some of the codes were readily compiled together. As the researcher became increasingly familiar with the dataset and their coding developed, they progressed onto applying latent codes to more conceptual ideas. To ensure that the order had not influenced their coding, the researcher then reviewed the transcripts in the opposite order to check their existing codes and identify any other detail that could be coded. The researcher found that the longer interviews were more difficult to code, as they pondered with whether some of the information or experiences shared in depth were pertinent to the research questions.

After thoroughly reading and coding the transcripts, a total of 210 codes was generated. The researcher initially queried whether this was enough codes, although Braun and Clark (2021) describe that there is no guideline on the number of codes deemed appropriate for RTA. The researcher considered that many concepts coded within the data

were quite similar, which may have influenced the breadth of unique codes generated. Furthermore, it was acknowledged that as the researcher became more familiar with the dataset, they would more instinctively relate some extracts to pre-existing codes. It was also considered that the length of the interviews may have also reflected the amount of information gathered from some of the participants, which in term may have restricted the quantity of unique ideas available for coding. Additional reflections on the interview lengths are discussed later in chapter five.

### ***3.8.3 Stage 3: Generating Initial Themes***

This stage is centred on beginning to identify shared patterned meanings across the whole dataset. The researcher began this process by exporting the codes from NVivo into Microsoft Word, then printing them onto paper, cutting them out and collating them onto coloured pieces of card (see Appendix J). The researcher elected to initially cluster the codes using this visual, tactile approach, as it allowed ease of beginning to see and group the codes flexibly. Clusters of codes were compiled if they appeared to share core ideas, such as ‘Challenges of PDA Presentation’ or ‘Recognition and Labelling of PDA’, which the researcher correspondingly documented in a colour-matched table (see Appendix K). The researcher then reviewed and refined these groupings and considered how these clusters could offer a possible ‘answer’ to the research questions. Once the researcher was content with the coding clusters, they began creating a visual map of the broad themes considered to be representative within and across these groups (see Appendix L).

### ***3.8.4 Stage 4: Developing and Reviewing Themes***

This stage involves assessing how initial themes fit to the data, and determining whether the overall analysis is viable. Once the researcher had created their initial thematic map, they revisited the dataset and examined whether the themes made sense based on the codes they had allocated, and to establish whether the themes were highlighting important

patterns from the dataset in relation to the research questions. For ease of tracking the codes against the themes that were being developed, the researcher transitioned away from the paper cut-out codes and again exported the original codebook from NVivo into a Microsoft Excel document, adding a supplementary column for the corresponding themes; these were adjusted during the refining phase of the analysis (see Appendix M). During stage 4, the researcher also focused on generating the subthemes which they felt provided useful detail and clarity to their initial themes. This supported the researcher in ensuring that the codes in the dataset were considered in their entirety. The researcher revisited this stage during the ‘write-up’ phase of the analysis, to ensure that the number of themes and subthemes they had were clearly and coherently capturing the data they were describing.

### ***3.8.5 Stage 5: Refining, Defining and Naming Themes***

This stage is centred on refining the analysis to ensure each theme is clearly defined and named concisely. The researcher examined the themes and evaluated whether they were clear, distinct, and meaningful in relation to the research questions. The researcher also reflected on how these aligned with their initial ideas from stage 1 of RTA. It was considered whether the themes were affiliated to the overarching research question, and how some themes could be relevant to either or both sub-questions. Thenceforth, the researcher began selecting quotes and extracts from the dataset which were deemed to compellingly demonstrate the varying analytic concepts which constituted each theme and considered how the themes fit into the “story about the data” (Braun & Clarke, 2021, p. 36). The researcher also revisited this stage during the write-up, as when pulling the data together under the themes, they felt that further redefining or renaming some of these themes would provide an improved communication of their impression of the analysis. A table displaying which codes constitute each of the final themes can be found in Appendix N.

### **3.8.6 Stage 6: Write Up**

Braun and Clark (2021) describe that writing up is a “key component of the analytic process” (p. 118) and recognise that much of this may have already taken place in the scribing of other sections of a research report which help to ‘set the scene’ of the findings. In the instance of this research, the introduction, literature review and most of the methodology chapters had been written in draft prior to the data analysis taking place. However, in conjunction with the RTA process, this final stage entails pulling together the analytic narrative from the dataset through writing and editing, to present the overall story of the data (Braun & Clarke, 2021). The complete analysis and subsequent ‘findings’ have been reported in the next chapter, which includes a figure of the thematic map as well as a table summarising the main themes.

The presentation of the analysis includes both descriptions and interpretations of the raw data, which aligns with the initial focus of coding being both latent and semantic in nature. The themes are discussed by weaving together the extracts from the interview transcripts identified in stage 5 and providing an interpretation to the patterns emerging. These themes are further connected with the applicable research questions, and in relation to other themes or subthemes within this chapter. Subsequently, the analysis is then scrutinised within the discussion chapter, where the research findings were explored in relation to previous literature, theoretical frameworks, and other published materials. This phase of the write up crucially includes commentary on how reflexivity was practiced during the analysis.

### **3.9 Quality Criteria**

Validity in qualitative research is established through confirmability, dependability, credibility, and transferability (Lincoln & Guba, 1986). Yardley (2000) proposed four principles to ensure the quality of qualitative studies, which were taken into consideration for addressing any potential issues in this research. Because of their theoretical flexibility and

broad applicability, these quality criteria were considered valuable when using RTA (Braun & Clarke, 2020). These four principles are detailed below:

- **Sensitivity to Context:** Participants' professional contexts are documented and considered within the analysis, as well as reference to personal context where this has been voluntarily shared. The meanings generated within the data were carefully considered through a robust RTA process, with any preconceived ideas discussed and challenged through self-reflexivity and research supervision.
- **Commitment and Rigour:** The data was collected and analysed thoroughly using credible methods, and the careful selection and application of RTA has been justified earlier in this chapter. Due to the social constructionist nature of this research, it is considered that knowledge is produced through human practices, and therefore analysis is more concerned with its implications than its objective truth (Braun & Clarke, 2021). Hence, interpretations of the data and learnings from the analysis were reviewed with the researcher's supervisor throughout the process.
- **Transparency and Coherence:** A clear, coherent argument has been presented in the write-up of this research. An audit trail of the analytical process including a coding sample and the organisation of code print outs have also been included to demonstrate how the themes were generated.
- **Impact and Importance:** The research findings have both theoretical and practical applications. They will present a distinct viewpoint on EPs' perspectives of PDA and offer written illustrations of PDA in applied EP practice.

### **3.10 Ethical Considerations**

This research follows guidelines set out by the BPS Code of Human Research Ethics (2021) and the HCPC Standards of Conduct, Performance and Ethics (2016) (BPS 2.1, Appendix P). To ensure these requirements were established for this research, an application



for the ethical approval for this research was submitted to the Tavistock and Portman NHS Foundation Trust Research Ethics Committee (TREC) on the 1<sup>st</sup> of February 2023 (see Appendix D). This application was approved on the 17<sup>th</sup> March 2023.

### ***3.10.1 Informed Consent and Right to Withdraw***

All EPs who expressed an interest in the research were provided with an information sheet outlining details of its purpose. The information sheet also explained how the information from the research would be used and stored. Participants were given a consent form to review and sign, outlining their right to discontinue participation at any time and to have their data destroyed in accordance with legal requirements (Data Protection Act, 2018). Prior to the formal recordings of the interviews, the information sheet was verbally reviewed with the participant to confirm that they understood what to expect, and they were invited the opportunity to ask any clarifying questions. The participants were advised that they could stop the interview at any time, as their participation was entirely voluntary. At the end of their interview, the participants were reminded of their right to withdraw up until the point that the data had been analysed. None of the participants chose to withdraw from the research following the interviews.

### ***3.10.2 Confidentiality and Data Protection***

Pseudonyms were used to protect the participants' anonymity. Moreover, at the time of transcription, names and places of employment were deidentified to preserve confidentiality. Additionally, careful consideration was taken to ensure privacy of any information disclosed during the interview process, including use of headphones, and planning for the privacy of the environment the interviews took place in (BPS 10.11, Appendix P). Participant details and consent forms were stored securely and separately from their interview data. All data gathered was stored securely in accordance with the Tavistock

and Portman NHS Foundation Trust's policies and the UK data protection law. Within the information sheet, all participants were advised as to when this data will be destroyed.

Participants were informed that confidentiality within the interview was subject to legal limitations, and they were reminded that disclosures indicating harm to either themselves or others would need to be shared on. Additionally, participants were informed that they might be able to identify some of the quotes they had provided during their interview, but that every effort would be taken to ensure that these could not be identified by others.

### ***3.10.3 Respect, Dignity and Relationships***

The knowledge and insights of the EP participants in this research were respected. Alongside consideration of Burnham's (2018) social graces, their individuality and cultural differences were also respected. The researcher had a professional relationship with one of the participants, and they assured them that information regarding their participation would not be shared with mutual colleagues.

### ***3.10.4 Power Balance***

As a Trainee EP conducting interviews with qualified EPs for this study, the researcher took power imbalances into account and how they might affect the dynamics of the interview process. However, they also noted that as a researcher with previous experience of working with CYP identified with PDA, they held their own epistemological power due to the opportunity for generating and disseminating knowledge (Ennsner-Kananen, 2019). Supervision was accessed to discuss any issues of power that emerged during the interviews.

### ***3.10.5 Social Responsibility***

The purpose of this research was to contribute psychological understanding and perspectives on the concept of PDA, which in turn will inform and benefit EP practice. While operating within the bounds of their professional competence (BPS 2.4, Appendix P), the

researcher also engaged in self-reflection (BPS 10.2, Appendix P) and remained open to challenges and potential outcomes related to the contributions of the research. The researcher, as a Trainee EP, was supervised by a university tutor who is a qualified psychologist (BPS 2.10; Appendix P).

### ***3.10.6 Maximising Benefit and Minimising Harm***

The aim was to maximise the study's benefits whilst minimising potential risks to participants' wellbeing or personal values (BPS 2.8, Appendix P). It was not anticipated that the research was likely to cause any discomfort. Participants were informed at the beginning of the interview that there would be time to debrief at the end to address any questions or concerns that may have been brought up. None of the participants showed signs of emotional discomfort either during or after the interview and none required any additional support.

### ***3.10.7 Reflexivity***

The researcher's personal experiences and subsequent interest in PDA led them to choose this research topic. Before commencing EP training, the researcher supported neurodevelopmental assessments where PDA was identified and labelled as a profile of the autism spectrum, in various contexts. It was therefore important that the researcher considered carefully how these experiences may have shaped their interpretations (BPS 2.9; Appendix P); this was incorporated within the RTA. Aspects of reflexivity through the research process are discussed in greater depth in chapter five (BPS 10.5, Appendix P).

### ***3.10.8 Relevance and Impact***

With an increasingly growing body of research on PDA, this study distinctly offers the perspective of EPs on this concept. Since previous research has indicated that EPs appear to be readily involved with CYP identified with PDA, this study further explores how and whether EPs are applying this term in their practice. Furthermore, this research offers insight into how PDA is understood by EPs and how this aligns with the existing range of definitions

or perspectives surrounding PDA. Although ‘PDA strategies’ have been put forth within the literature (Gore Langton & Frederickson, 2018; Woods, 2019), this study delves deeper into the specific advice and support that EPs are providing when working with families and schools in supporting CYP’s needs; these could in turn be applied in wider EP practice (BPS 9.5, Appendix P).

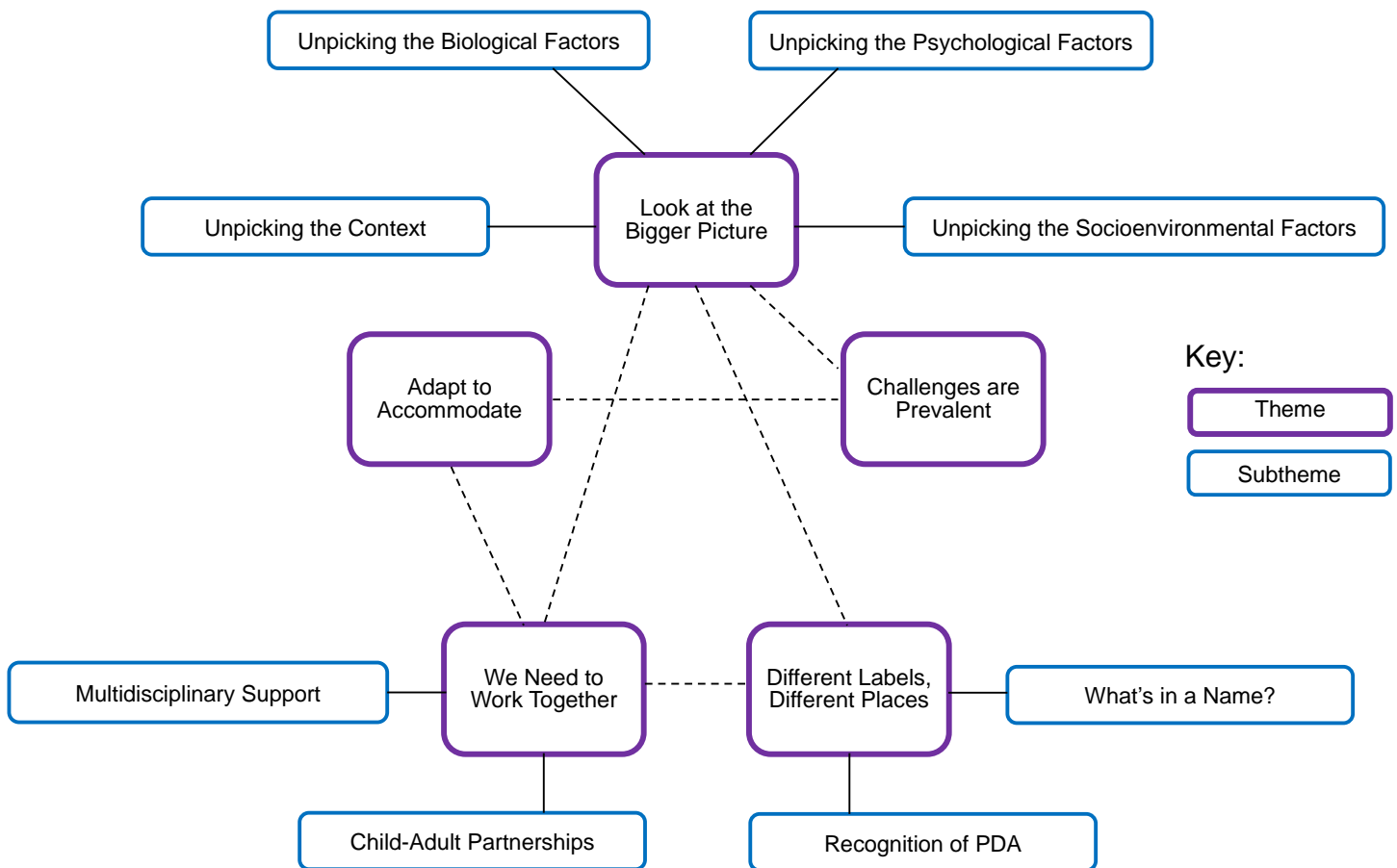
## Chapter Four: Analysis

### 4.1 Chapter Overview

This chapter presents the findings of this research through the process of reflexive thematic analysis (RTA). The findings are discussed in relation to the themes generated from the analysis. Each theme corresponds to the overarching research question ‘what are EPs’ perspectives on PDA?’ and is linked explicitly to the sub-questions ‘what are EPs’ views on working with the term PDA?’ and ‘how do EPs communicate and give advice when PDA is raised?’. Extracts and quotations from the transcribed EP interviews are referenced in support of the themes.

### 4.2 Thematic Map and ‘Findings’

Five themes and eight subthemes were generated in response to the overarching research question on EPs’ perspectives on PDA, through linking to Research Sub-Question 1a (RQ1a), which was exploring EPs’ views on working with the PDA term, and Research Sub-Question 1b (RQ1b), which was how they communicate and provide guidance when PDA is raised. The theme ‘Look at the Bigger Picture’ corresponds with both RQ1a and RQ1b and incorporates four subthemes: ‘Unpicking the Context’, ‘Unpicking the Biological Factors’, ‘Unpicking the Psychological Factors’ and ‘Unpicking the Socioenvironmental Factors’. The theme ‘Different Labels, Different Places’ also links to both research sub-questions, and incorporates two subthemes: ‘Recognition of PDA’ and ‘What’s in a Name?’. The theme ‘We Need to Work Together’ links to RQ1b and incorporates two subthemes: ‘Multidisciplinary Support’ and ‘Child-Adult Partnerships’. The other themes are presented as ‘Challenges are Prevalent’ which relates to RQ1a, and ‘Adapt to Accommodate’ which relates to RQ1b. The relationships between these themes and their subthemes are presented within a thematic map (see Figure 5). Furthermore, Table 6 presents a summary of the ‘findings’ which contributed to each of these themes.

**Figure 5***Thematic map of the data analysis***Table 6***Summary of Findings*

	Theme	Link to Research Sub- Question	Summarising Statements
1	Look at the Bigger Picture	1a and 1b	EPs' views of the need for comprehensive assessment which considers the CYP's context and the interactive factors contributing to PDA-related behaviours.

2	Challenges are Prevalent	1a	EPs' perspectives that PDA-related behaviours are challenging for those who support them. Mainstream settings struggle to meet need, and therefore specialist provisions can be sought.
3	Different Labels, Different Places	1a and 1b	Private assessments have a role in the labelling of PDA. There is a 'postcode lottery' of where PDA is recognised, with professional understanding of PDA varying. EPs may or may not use or identify the term PDA themselves.
4	We Need to Work Together	1b	EPs have a role in supporting school staff and families, including supervision and training around PDA. Multidisciplinary working around a CYP is important.
5	Adapt to Accommodate	1b	EPs recommend adjustments to accommodate CYP's individual needs. Adults should change their communication style, provide personalised curriculums and be flexible. Resources or strategies from

---

the PDA Society website are used and signposted to.

---

### **4.3 Theme 1: Look at the Bigger Picture**

This theme provides insight into RQ1a, exploring EPs' views on working with the term PDA. The theme encompasses the EPs' perspective on holistically and appropriately understanding PDA-related behaviours, including what the causal and maintaining factors may be. Through the analysis of responses, it was possible to identify different EPs' understanding of PDA, and how this can be connected to other known difficulties or diagnoses. Linked to this complexity of formulation, many of the participants also spoke about the importance of assessing CYP comprehensively. Within this theme, four subthemes which detail the areas of understanding PDA behaviours are discussed.

#### ***4.3.1 Subtheme 1.1: Unpicking the Context***

This first subtheme describes what the EPs interpret PDA to mean, and how these associated features may fit within an array of wider contextual factors. As such, an emerging narrative or explanation for the general conceptualisation of PDA was related to CYP who find demands extremely difficult to manage. For example, Georgia (see Table 5 for participant details) shared that when she thinks of PDA, "I think of young people who are resistant to demands and find demands tricky to manage" (lines 30-31). Alex outlined that these demands may not always be related to adult requests and explained "I've heard parents describe the children as struggling with the demands of their own body, like I need to go to the toilet" (lines 64-65). Alternatively, Taylor (line 27) and Kate (line 61) mention difficulty with demands being placed "on" or "upon" a CYP, and Lucy described her understanding of PDA as follows:



“it’s largely a sort of extreme avoidance of social demands effectively any situation where there may be expectation or assumption by others that you will do things in certain ways” (Lucy, lines 64-66)

Expanding on this narrative, some of the EPs referred to other diagnoses interrelated to PDA. Taylor shared their experience of their own child receiving a PDA diagnosis and explained “he already had a diagnosis of ADHD and autism, and when he started his ADHD medication, he became more and more anxious and demand avoidant” (lines 37-39). This could promote the concept of co-existing conditions but could also highlight the overlap of difficulties recognised within alternative diagnoses. On this point, Lucy discussed the Coventry Grid framework which was created to “distinguish between PDA and attachment disorder” (lines 41-42) and spoke about a CYP identified with PDA she has worked with who has “an eating disorder and is known to the local eating disorders team” (lines 136-137). Jamie also shared that they initially saw PDA as synonymous to ODD and found it “odd that this [PDA] needed to be a specific different category” (lines 114-115). These contributions address the complex nature of recognising, and distinguishing PDA among other, more established conditions.

Heavily interweaved in the deliberations surrounding identification was the premise that all possible factors for demand avoidance should be considered, prior to applying the PDA label. Lucy indicated that those involved in assessment should “get to know your families. Get to know those children within the context” (line 286) and that “there is something about ruling in, ruling out” (line 357). In addition, Jamie shared that when PDA has been suggested or identified, “I go further to investigate what that means” (line 40) as to “why are they experiencing such a high level of anxiety?” (lines 40-41).

Alex expressed strong concerns about applying the PDA label without careful thought to other possible explanations. They stated, “there’s a lot of unpicking I think needs to

happen before someone would arrive at that description” (lines 59-60) and “I worry a little about the, the ease at which it can be applied without really a thorough kind of analysis first” (lines 55-56). Alex further emphasises this point later in their interview:

“What might actually be other explanations, rather than a label which is about this child, and something that is wrong with them were rather than what are the contextual factors that might be contributing to the child struggling to cope with everyday requests?” (Alex, lines 150-153)

Aligning with the diversity of co-occurring difficulties, Alex later suggested that CYP who are thought to have PDA may have “lots of other things going on” (line 185) and indicated that this label may be inappropriately given “because it’s quicker and easier to go with a, it’s not necessarily a diagnostic label, but an explanation that is more superficial than, you know, an environmental one” (lines 185-187). These accounts suggest there is complexity in undergoing formulation for CYP presenting with demand avoidant behaviours and indicate value in ‘unpicking’ an individual’s presentation and context.

Lucy addressed limitations in the facilitation of comprehensive assessment, stating that her LA do not have the health and social care resources to do “that very thorough build-up of a child’s whole profile and presentation” (lines 363-364) and shared “I think we’ve got a way to go before there’s perhaps good practice across the board in terms of ruling in, ruling out” (lines 366-367). She also advocated that “assessment and intervention over time is the ideal” (lines 300-301). Kate shared similar aspirations for the future of PDA understanding:

“I think I would hope you know in the course of the next 10 or 20 years, we're going to really expand our knowledge and you know and understanding and yeah, hopefully, hopefully just become increasingly holistic, in my opinion, it, you know, that would be really great news in terms of understanding the whole child [...]” (Kate, lines 236-239)

Overall, the participants appeared to share similar ideas in their blanket conceptualisation of PDA and the need to ‘unpick it’, however it seemed clear that exploring the bigger picture was crucial in fully understanding CYP and their experiences, and in determining whether a label of PDA would be appropriate. The various contributing and interactive factors considered by EPs within the context of PDA identification are discussed in the further subthemes: ‘Unpicking the Biological Factors’, ‘Unpicking the Psychological Factors’ and ‘Unpicking the Socioenvironmental Factors’.

#### ***4.3.2 Subtheme 1.2: Unpicking the Biological Factors***

This subtheme considers the biological factors which were discussed by the EPs in relation to their perception of the PDA presentation. All eight of the EP participants commented on PDA having a relationship with autism. Activation of stress responses and the influence of sensory-processing experiences were also considered to be relevant to PDA.

Many of the EPs embodied a neurodevelopmental perspective in viewing PDA as part of the autism spectrum. Speaking about CYP identified with PDA features, Taylor shared “I feel that they do fall within the autism profile, but almost as like a subgroup” (lines 70-71). In addition, Charlie shared that through their LA’s research, it is suggested that “demand avoidance is a profile within ASD” (line 35) but later enquired whether the NHS have fully determined “whether it’s a profile within ASD or whether it’s a robust diagnostic label?” (lines 164-165). Similarly, Lucy described that her LA would “manage it [PDA] within the context of an appropriately validated and reliable autism diagnosis” (lines 51-52). Aligning with this view, Jamie spoke about their role in supporting others to understand autism:

“I would ensure that there's like an understanding of how like the neurodiversity and the differences in how a person with autism might be thinking about situations and understanding of social conventions.” (Jamie, lines 72-24).

Although they acknowledged an association with autism, Jamie also referenced the value of the PDA description and noted “I could see how this [PDA] would be like a more unique presentation that needed to be identified” (lines 117-118). Some of the other EPs also discussed the usefulness of recognising PDA outside of a typical autism diagnosis.

Interestingly, Lucy shared “I don't think it's entirely autism based” (line 103) and later discusses other factors which may be “sustaining and maintaining a situation” (line 111).

Beth additionally indicated that there are distinctions between autism and PDA:

“[...] it seems quite different from autism in that there's there doesn't seem to be, you know, that rigidity of routine and the predictability doesn't always sort of transcribe to young people that are demand avoidant.” (Beth, lines 115-117)

The dominant commentary of PDA's relationship to autism seems to indicate that the EPs recognise a neurodevelopmental root to the associated behaviours. It also appears the EPs feel that acknowledging PDA's differences from 'stereotypical' autism may be important, although uncertainty about the parameters of this distinction remain.

Also relating to biological functions, some of the EP participants additionally referred to PDA behaviours precipitating through CYP's stress or threat responses. This was highlighted by Taylor, who recognised that CYP with PDA presentations are “easily triggered into their stress response” (line 25) and references this being a “fight, freeze, fawn response” (line 26). Lucy also described that support for PDA-related behaviours is “about reducing anxiety and managing that heightened arousal, brain freeze stuff, which I think is probably the neurobiology of it” (lines 218-219). In a similar vein, Georgia shared that she felt PDA behaviours were “a case of more survival and not being able to manage demands rather than it being a choice” (lines 82-83). Beth discussed the impact of demands on a CYP's physiological response as follows:

“[...] there might be a demand that actually is quite desirable that they actually quite enjoy doing, but because the experience of the demand has happened, it then becomes a sort of almost like a panic attack reaction [...]” (Beth, lines 40-42)

The connection made by the EPs between the experience of a demand and the activation of a ‘fight/flight’ survival response suggest the presenting behaviours of CYP with PDA features may in fact be bodily responses to perceiving demands as ‘threats’.

Also linked to the nervous system, several of the EPs referred to the sensory-processing experiences of CYP in consideration to PDA. Taylor described that within their involvement, they would be “looking at the sensory sensitivities and whether we need to accommodate any of those” (lines 113-114). Likewise, within her ideals for assessment, Lucy stated “let’s have a look at sensory processing issues” (line 302). During her interview, Georgia shared that a CYP she had been working with found “other child and young people’s noise difficult to manage” (line 130) and that he had a concern around “cleanliness and hygiene” (line 166). Kate also spoke in depth about a CYP she had worked with and how she related PDA to their sensory experiences:

“[...] I just felt and that actually they, by overlooking the sensory processing needs, it was really missing out a really fundamental part of the puzzle for her. So, you know, in terms of helping her to be able to be regulated within her own body and to, like, develop ways of being able to self-regulate more. And I just. I just do wonder whether, with that kind of you know, with that demand avoidant profile, whether more consideration around its interaction with sensory issues is being considered enough, you know, is it is a child who is avoidant you know, avoidant of any demands is some of that avoidance related to sensory issues? Are they trying to keep you know, regulated by avoiding something that they know is going to impact upon their senses, do you see what I mean?” (Kate, lines 223-231)

Through holding the EPs' blanket perspective that PDA is associated with autism, it is unsurprising that sensory sensitivities are mentioned within the bigger picture of PDA, as this is well recognised as an autistic attribute. Kate also queried whether some avoidance presentations could be a response to undesired sensory stimuli, rather than demands. Nonetheless, it is evident that a CYP's sensory needs alongside other biological influences are often considered by the EPs within their involvements and their understanding of PDA presentations, whether this directly relates to PDA or not.

#### ***4.3.3 Subtheme 1.3: Unpicking the Psychological Factors***

This subtheme addresses attributes of CYP's personality as well as cognitive and emotional features under the umbrella of psychological factors, which the EPs had related to the PDA presentation within this study. Differences in social communication are also noted.

Describing her experiences of working with CYP identified with PDA, Lucy shared that they "often seem to be very bright, sensitive, artistic-y, creative children" (lines 379-380). This presents a distinctly positive view of PDA characteristics. Taylor additionally agreed that these CYP appear to be "very sensitive" (line 81) and felt that the PDA label does not capture this. Further to these attributes, several of the EP participants spoke about a key feature associated with PDA being a desire for control or autonomy. Georgia stated that PDA can look like "seeking control and needing control in interactions with others" (lines 31-32). Beth also described her understanding of PDA with reference to this:

"[...] the kind of a need to escape that and to regain that control, um, so kind of maybe characterised a bit by a sort of loss of control and a need to experience the control which is, the control has been removed by the demand being placed on them by somebody else [...]" (Beth, lines 42-44)

Lucy spoke about her experiences of working with one CYP where "everything has to be on the girl's terms" (lines 123-124). However, rather than talking about 'control', Lucy

described her understanding of PDA as a “a need for at all times a high level of autonomy” (lines 67-68). Aligning with this concept, Taylor identified that some individuals prefer to use the term “persistent drive for autonomy” (line 24) in place of the PDA acronym. These characteristics synonymously appear to be key to the EPs’ interpretations of why demand avoidant behaviours may emerge.

In further consideration of the contributing factors, Lucy mentions the potential influence of learning within PDA presentations. Within her reasoning of ‘ruling in, ruling out’, she wonders whether there could be “learning difficulties unrecognised” (line 202). Lucy also refers to PDA behaviours themselves being learnt: “learning a whole repertoire of behaviour that helps them avoid situations that they find difficult and stressful” (lines 187-188). Interestingly, none of the other EPs discussed cognition or learning within their interviews, and linked to Lucy’s point on unrecognised needs, this may be reflective of an overall limited area of understanding.

Related to the concept of ‘social skills’, it was also noted that PDA can be associated with social differences or difficulties. In fact, Lucy described CYP with PDA presentations as experiencing “extreme social discomfort” (lines 66-67). Jamie also suggested that they felt PDA behaviours can precipitate from “not understanding the social context” (line 52). Meanwhile, Beth discussed that CYP with PDA “might appear more sociable but lack that understanding of actually what that sociability is, and you know, those kind of nuances” (lines 36-37). This indicates that the EPs’ experiences of PDA are often of CYP who present with social communication needs, allied with significant demand avoidance.

Another topic which was prevalent within the EP interviews was the emotional experiences of CYP. Georgia regularly referenced the importance of reading a CYP’s emotional arousal level when placing expectations on them. For example, she described the involvement she has had with a CYP recently:

“So, then it's about reading the young person's arousal level to see what he can manage in that moment. So, if he's really heightened, any kind of demands, phrased in any way are going to be too much for him so the adult completely steps back and doesn't put demands in place. If he is really calm, if he's engaging with staff, if he's having a laugh with them and using humour, if he is engaged and he's learning, then staff know that they can put more demands in [...]” (Georgia, lines 171-176)

It was also noted that Georgia frequently referred to this CYP as being ‘dysregulated’ when describing the incidents experienced in their school, implying that his behaviours had precipitated through emotional distress. Whilst the other EPs did not refer to emotions more generally, there was a strong message about experiences of anxiety in relation to PDA. Charlie shared that part of their understanding of PDA was “anxiety driven high levels of distress, anxiety response to demand” (line 31). Beth similarly related this to a difference in PDA from autism, noting that CYP with this presentation have “anxiety and panic around any demands that have been placed on them” (lines 38-39) and later, “they do seem to have a significant anxiety reaction to demands” (line 64). Taylor shared that over time, their understanding has developed to think more about the CYP’s anxiety and sensitivity, rather than their demand avoidance (line 83-84). Similarly, Jamie advocated for a “growth mindset” in “exploring how we can address the underlying anxiety that is being created” (lines 42-43). It therefore appears that the EPs are regularly viewing demand avoidant behaviours as driven through high levels of anxiety and may seek to understand how these feelings are provoked.

In summary, there are key examples from the interviews to suggest that the EPs are often giving weight to affective factors in their perspective of PDA, but perhaps less examination of cognition. There may also be variation in the framing of PDA characteristics, in viewing a drive for ‘control’ versus ‘autonomy’. However, given the distinct contributions of the EP role, consideration of psychological factors surrounding PDA is clearly prevalent.



#### ***4.3.4 Subtheme 1.4: Unpicking the Socioenvironmental Factors***

Complementing the former subthemes, this final subtheme under the theme of ‘Look at the Bigger Picture’ examines the role of social and environmental factors. This highlights the possible impact of family dynamics, adverse experiences and the CYP’s environment.

Several of the EP participants shared that they would explore environmental factors within their involvement. Jamie noted that they “might also really explore the environment of the classroom” (lines 99-100) when supporting CYP presenting with demand avoidance. As previously mentioned in her aspirations for work surrounding PDA in the future, Kate additionally shared that she would like “understanding more of you know, environmental factors” (line 240) to be included within assessment. Whilst describing an education resource which had been produced within their service, Charlie mentioned a specific recommendation for supporting demand avoidant behaviours was “looking at the environmental, some of the triggers” (lines 148-149). These perspectives demonstrate that the EPs may be looking to focus their involvement outside of the CYP, rather than within.

Talking about their views on the use of the term PDA, Alex discussed their experience of delivering training centred on why CYP might struggle with receiving a request from an adult, which included “what factors are there in the environment and also including COVID and children being at home during COVID” (lines 67-68). They later discussed how the COVID pandemic had led to gaps in CYP’s development (line 169) and indicated that the demands of the curriculum may have led to CYP not being able to cope in the classroom (lines 164-167). Lucy also discussed the “very heightened monitoring of performance, which is greater now than certainly when I was a teacher” (lines 183-184) within schools and shared that she feels “the curriculum goes too far, so very young” (line 185). Similarly, Jamie felt that they previously saw this presentation in the early years but are now seeing these

characteristics more in secondary provisions, with a shared view around the impact of demanding curriculums:

“[...] I feel like I'm seeing uh these characteristics more in secondary in relation to the high pressure with tests and perhaps teachers trying to create like a sense of like urgency and commitment to academics, that just like this, underlying pressure that like we're like, you need to be doing this like, your future's on the line I, you know, I don't know this just like way off pressure but you know I think that's where I'm seeing people with autism more presenting with these characteristics [...]” (Jamie, lines 121-126)

These ideas shared by the EPs indicate that perhaps the demand avoidant presentations they are seeing are not inherent or ‘pathological’ but are instead triggered through the heightened contexts of the pandemic and academic pressures. As Lucy suggests, “I think the numbers are rising” (line 181), which may be linked to these circumstances.

Moving on to look more at the influence of social factors, a few of the EP participants contemplated the possible overlap between features of PDA and attachment difficulties. Within her advocacy for comprehensive assessment, Lucy noted that professionals should “rule out trauma” (line 310) and described a CYP with PDA features she had worked with who had experienced an “ocean of tragedy” (lines 115-116). Kate shared a similar view:

“[...] I also believe, so we've got some kids that are autistic that maybe are wrongly diagnosed, but I also believe that we do also have some kids who are autistic, and they also do have attachment difficulties [...]” (Kate, lines 220-222).

Although they did not directly suggest that PDA-related behaviours precipitated from experiences of trauma, Taylor described their recommendations as “in terms of a child who would fit what we most stereotypically see as kind of having a PDA profile, I would say like first and foremost a trauma informed approach” (lines 108-110). These views once again

highlight the complexity of shared symptomology, and whether PDA, or indeed autism, could be being misdiagnosed in place of recognising adverse childhood experiences.

Lastly, a few of the EPs gave mention to parenting style, and how this might impact a CYP's presentation. When describing a parent that she had previously worked with, Lucy described the following:

“She's very into the whole gentle parenting movement, which is fine. That's all lovely stuff and I don't have a problem with it, but sometimes maybe it's too gentle and the child is left very in control.” (Lucy, lines 246-248)

Lucy had previously discussed the CYP in question as presenting with PDA characteristics. It could therefore be implied that alternative parenting approaches are adopted in line with the CYP's needs, however, it could also be interpreted that this parenting style has perpetuated their demand avoidance. Kate shared a similar perspective:

“[...] I'm going on an incredibly anecdotal, sparse level of, you know, information from my own experience, but I know two, if not three families who've definitely been indulgent parents and I think that their children, one definitely and all of them, probably to some extent have got traits of PDA and I just... If you think about it on a psychological level, you can kind of, you can kind of potentially hypothesise that if you're.... If you're being... If you're being allowed to do what you want as a child, thus your boundaries are not, they're perhaps a little bit wider.” (Kate, lines 191-196).

Whilst Kate also outlined “I'm not taking away from the notion of kind of neurodivergence in the first place” (lines 199-200), these thoughts around parenting during those “really early formative years” (lines 201-202) continue to corroborate with the concept that external influences may contribute to demand avoidant behaviours. Altogether, it seems clear that the EPs valued the examination of the socioenvironmental context whilst ‘looking at the bigger picture’ for CYP in discussion around PDA.

#### 4.4 Theme 2: Challenges are Prevalent

The second theme continues to explore EPs' views of working with the PDA term (RQ1a) and captures the prominent narrative of how PDA behaviours are seen as challenging for those who support them, and within the context of the system. The pursuit of alternative or specialist provisions was often described, with incompatibilities between mainstream approaches and policies often named.

Recalling their experiences of having conversations surrounding PDA, Alex noted that “professionals seem to be almost like at the wits end” (line 92) and later described “I think it's one of the most challenging profiles that schools come to us with” (line 161). Similarly, Charlie shared “a recognition that demand avoidance profiles present professionals and parents with significant challenges” (lines 94-95). Beth shared that from her own experience “I've worked with children and young people who present as demand avoidant. It's difficult. It's draining” (lines 113-114). Working within a specialist setting, Georgia described a series of behaviours that challenge she has experienced with one CYP. She explained that “we've had loads of progress, but we have had some really difficult incidents” (lines 307-308) including hurting other CYP, hurting staff, swearing, shouting, throwing chairs and tables, kicking the walls, and pulling artwork off the walls. These accounts recognise an impact of demand avoidant behaviours on others around the CYP, and the experiences that EPs have had both directly and indirectly of working with these challenges.

Building on these challenges, many of the EPs spoke about how CYP with PDA presentations are struggling to access mainstream education, and therefore other provisions are being sought. Both Lucy (line 122) and Georgia (line 127) described CYP who had been home educated, and Kate spoke about a CYP who she worked with within a secure unit (lines 50-51). Reflecting on their practice surrounding PDA, Alex shared:

“[...] they are often children that so far I have found schools find it really difficult to include and will often be children that are not able to cope in the classroom and that will then be spending lots of time out of class, often with teaching assistants in corridors or alternative provisions, and then ending with going to a specialist setting or requesting specialist settings [...]” Alex (lines 162-166)

In a similar vein, Georgia shared that the previously mentioned CYP was home-schooled after their primary school placement “had broken down completely” (line 126) and “the local authority struggled to find a place that they felt would be able to support this young person’s needs” (lines 127-128). When this CYP later joined her school, she noted that “it was quite difficult for them to be in the classroom” (line 129). Meanwhile, Beth described how discussion of PDA has seemed to be a way for schools to say that a CYP’s needs are “too great for us to manage in mainstream” (line 104). She also spoke about a CYP she has worked with recently, whose school “excluded him because they’ve said that he can’t uh, they can’t meet his needs in mainstream” (line 107) and stated to her that “he needs to go to a specialist provision” (line 110). Furthermore, Charlie shared that even within the context of one of their LA’s specialist provisions, there was a narrative that they “cannot cope” (line 102) with demand avoidant behaviours and external placements are then sought (line 103). Reflecting on the difficulties faced in mainstream settings, Taylor expressed their views on determining appropriate provision for CYP:

“[...] I know some people are very sort of fixed that children with a PDA profile, you know, can't do well in mainstream schools. I don't really find a position. I'm more I'm looking at, how can we adjust any system to best suit that child's needs, whether that be home, that home education, a mainstream school setting, or a specialist setting. I thought that there's things that all settings can do to better accommodate children, and

that every child's got different strengths and difficulties, and some will do better in one setting versus another.” (Taylor, lines 114-120)

It seems apparent that the EPs feel that existing provisions are often not supportive of needs related to demand avoidance, resulting in changes in placement or isolated approaches to teaching and learning. More specifically within the realms of mainstream schooling, and alongside the demands of the curriculum previously mentioned within the subtheme ‘socioenvironmental factors’, several of the EPs further spoke about the difficulties of supporting CYP with demand avoidant behaviours within secondary schools. For example, Jamie noted that “it feels like the secondaries are not supportive of their needs” (lines 126-127). Lucy also agreed with this notion, and stated:

“[...] we're seeing some quite, what I consider coercive and unpleasant practice, particularly in high schools these days, in academy chains which are very results driven which I do believe is causing harm to the most sensitive learners and causing this rise in demand avoidant presentation.” (Lucy, lines 344-347)

Beth also addressed difficulties within secondary schools, and spoke more specifically about the limitations of behaviour policies in supporting CYP with demand avoidant needs:

“[...] there seems to be a much more rigid and sort of clinging to the need for a behaviourist sort of approach in secondary schools [...] so I try and have conversations around, right, what reasonable adjustments do we need to make to the behaviour system? You know, we can't be applying the behaviour system in the same way if the child has got all these needs that we've already discussed.” (Beth, 187-188 and 190-192)

The challenges emphasised within the EP interviews demonstrate an importance in recognising not just the experiences of the CYP, but of the system around them, and the impact that this may have on families and schools. The difficulties in effectively supporting

these CYP are also seen to exist both within mainstream and specialist settings, which indicates that further understanding of needs beyond a change in placement may be necessary.

#### **4.5 Theme 3: Different Labels, Different Places**

This theme embodies the ideas shared around the national disparity in recognition and understanding of PDA, with considerations to how the label is being applied (RQ1b) and adds to the understanding of EPs' views on the PDA term (RQ1a). Both Kate (line 86) and Charlie (line 162) referred to the "postcode lottery" of different service views on PDA, with Kate acknowledging "there's still this kind of political battle as such around, you know, the officiating the diagnosis or not. And professionals' understanding" (lines 84-85). Within this theme, two branches of concepts relating to knowledge of where PDA is or is not recognised and the EPs' opinions of the PDA label are designated as subthemes respectively.

##### ***4.5.1 Subtheme 3.1 Recognition of PDA***

Throughout the interviews, there were a variety of accounts of differing service positions on PDA and the professionals who recognise it, which are named under this subtheme. Lucy explained that PDA was recognised within her LA and described that one family moved into her local area because they would "be in a place where PDA was understood" (line 46). Likewise, Jamie shared that they had received a service training on PDA (line 24), indicating that it was recognised within their LA as well. Alex noted that they have "read from other authorities' reports where they will say PDA" (line 46-47). Kate also described her understanding that there are "statutory services in X who are saying, who are recognising PDA and using that as a, you know, template for understanding this young person's very, very extreme levels of behaviour" (lines 119-121). Although they were unsure about their LA's position on PDA, Taylor explained that their "local NHS services do" use this term (line 47). Charlie similarly shared "I know one NHS CAMHS team that, you know,

where in X there was a very high identification” (lines 160-161). These accounts suggest that there are many services within the UK who identify and accept the concept of PDA, and some who may have alternative positions.

Noting that there are differences in service recognition, and “there’s some controversy around it” (line 67), Georgia described that she is more comfortable using the term PDA with schools than she is with parents, as “I don't want to be putting another label out there that potentially then a parent can't access” (lines 103-104). Building on her perspective on this disparity, Kate appeared to advocate for greater recognition of PDA, sharing the following:

“[...] my friend in X who is going through the procedures that will go through the notion that the motion of getting her son diagnosed and she's talking to paediatrics and they're saying point blank PDA isn't recognised, we don't go there. So, you know, it's kind of creates a real kind of unequitable or, you know, unfair advantage or unfair disadvantage for certain parts of the country where people aren't recognising it and so therefore you know the perhaps the kind of the development of understanding around a child’s needs is not as thorough as it may well be.” (Kate, lines 127-132)

Further to discussions around where the term PDA is used, many of the EP participants spoke about the role of private assessments in labelling PDA. Taylor addressed the issue of socioeconomic status in labelling, stating “a lot of the time, it’s perhaps someone who has seen an independent psychiatrist” (lines 91-92) and CYP whose “parents were affording private assessments” (line 93) were receiving the PDA label. Speaking about the LA she works in, Lucy shared “I think it’s pretty prevalent now across X because of the existence of the private practitioners” (lines 180-181). Similarly, Alex described that PDA is not diagnosed in their local area, however “quite often parents want to go privately to get a PDA diagnosis” (lines 144-145). In her LA, Kate described tensions that have arisen due to a private psychologist diagnosing CYP with PDA, noting “it was riling people within the local



authority, and there've been quite a lot of pushbacks" (lines 33-34). Further explaining her local position, Kate shared that if parents want to see someone private then they can "obviously go ahead, but we can't advocate for that" (line 95).

There were differing accounts on whether identifying or using the term PDA was part of the EP role. Taylor shared that within their role, they will sometimes raise the concept of PDA to schools and parents when they feel "we need a different approach for this particular child" (lines 97-98). However, Taylor also acknowledged:

"[...] we don't diagnose anyway, so that's not our question. It's what we can learn from understanding this group of children better so that we can make better recommendations from home and school." (Taylor, lines 133-135)

Both Alex (line 26) and Georgia (lines 89-90) also shared that they do not apply the label of PDA in their practice and described that they did not feel this was part of their role. On using the term PDA, Alex explained "I don't think I'd ever have a conversation like oh it must be PDA, or I think it could be PDA or he should get assessed for PDA" (lines 106-107). They additionally shared "I'm a little bit wary of applying that label, and you know, as an EP, I don't feel I can determine that" (lines 25-26) and "whether I would use the term, is it PDA? I don't think I'd ever have a conversation like oh it must be PDA, or I think it could be PDA or he should get assessed for PDA" (lines 106-107). Jamie described that they would use the term PDA when it has been "formally diagnosed" (line 64), but further explained a shift in their practice:

"Previously, if it was just really described and the parents had been investigating it, and that is how they are seeing their child, I would use it in those terms (...) I wouldn't say... I don't personally identify that anymore, like whereas one time maybe I would have labelled a set of characteristics that way." (Jamie, lines 65-68)

As an overview, these accounts reflect an array of perspectives on the practicalities and usefulness of labelling PDA. The EPs indicate that there may be a socioeconomic skew through the private labelling of PDA, and this may not always align with wider acknowledgement of different professionals and LAs. It seems that whilst the EPs might seek to convey and support CYP's needs with reference to PDA, it is not seen that their role is to provide a label themselves.

#### ***4.5.2 Subtheme 3.2: What's in a Name?***

This subtheme builds on the recognition that there is diversity of labelling PDA to explore the EPs' views on the use of the term PDA, which included differing perspectives on the wording of the term PDA. For example, several of the EPs shared opinions which promoted the value of the PDA label. Lucy stated, "I'm comfortable with the concept for some children, some adults" (lines 100-101). Jamie felt that the PDA label can be useful:

"I feel like it's quite helpful, uh, anything that can help you understand, understand a young person better (...) I would say my views are, lean towards positive of just being able to have certain hypotheses before you see a young person, and to explore those."

(Jamie, lines 37-39)

Beth similarly shared a positive view of the PDA label:

"[...] I think in a way, if it is diagnosed and it is used in a way that helps to understand experience and helps to understand needs, I think like any diagnostic label, it can have its uses, um, you know, if it's used to understand experience, develop empathy, develop the right support. Get a real understanding of the needs and then put the right support in place. It can be very, very useful and it could also open up uh narratives around, you know, the young person understanding themselves, the family being able to understand [...]" (Beth, lines 84-89)

Whilst these views indicate that identification of PDA can help to understand CYP's needs, some of the EPs shared a more negative perception of the PDA label. Conversely to her positive perspective, Beth also discussed that she felt applying the PDA label is not always useful:

“It can be used very negatively. It can be used like I've already said to kind of say, well, well, you know, they're just naughty. Some it often feels to me like the label is used synonymously with ‘they're naughty, or they've got PDA, they're demand avoidant’, and therefore that means that they're naughty. Um, and so I think it can be, it can be unhelpful as well. Um, and I think I've also encountered it being used quite a lot as a as an excuse to not do anything, like oh ‘they're demand avoidant, what can we do?’”

(Beth, lines 94-99)

Charlie expressed strong views about the application of the term PDA, stating “I don't think it's [PDA] a great way to a great thing to label a child. I really don't. I think it's one of the most, most incongruent labels for a child we can have.” (lines 119-120). They emphasised that they had issues with the word ‘pathological’ as part of this labelling:

“I find pathological, you know, in particular, a really challenging and I think... It's a very with it offers a very within, it points to a very within child kind of explanation for difficulties, you know and with that there can be a fatalism.” (Charlie, lines 115-118)

Beth and Charlie's accounts suggest that using the PDA label could have harmful connotations around how a CYP is viewed. Like Charlie, Alex also stated “I'm not a big fan of the term pathological” (line 27). Georgia described that PDA is “not the most friendly language” (line 78) and stated that the questionable use of the term ‘pathological’ “could be interpreted as young people and children who are just being controlling” when she feels that there may not necessarily be a choice about that (lines 79-81). It therefore can be presumed

that some of the EPs' apprehensions around using the term PDA may be due to disliking the word 'pathological' in particular, rather than not recognising PDA associated difficulties.

In reference to hesitations around the use of the PDA language, several of the EPs spoke about the preferred or alternative terminology which they or their service may apply instead of the term PDA. Although they were unsure on more appropriate terminology, Taylor noted "I'm not sure whether the term best describes, uh, these children" (line 63). Alex shared that they often encounter the phrase "demand avoidant" in schools (line 30) and within their LA, they would identify a "demand avoidant profile if they make an autism diagnosis" (line 43). Similarly, Beth also described that the position of her LA would be to use language around a "demand avoidant profile" (lines 79-80) rather than PDA. Describing their understanding of the PDA concept, Taylor noted that "some prefer a pervasive or persistent drive for autonomy" (line 24) as a varied designation to the PDA acronym. Charlie conveyed a clear preference for using the term extreme demand avoidance (EDA), rather than PDA, in line with their aversion to using the word 'pathological'. They discussed the research they have done in determining the use of EDA as their service position:

"[...] our current advice is to use extreme demand avoidance and, you know, I think we've got to be very careful in terms of the labelling aspects and there is a gap in the literature. And some people, you know, come across some researchers who have said there's nothing inherently pathological about the behaviours classified as under PDA, but they are behaviours interpreted as extreme or pathological [...]" (Charlie, lines 37-41)

The perspectives shared by the EPs suggest that whilst the characteristics and behaviours associated with PDA may be recognised by the EPs, they might be named differently. Whilst advantages of pursuing the label were shared by some, there were also concerns around the negative associations which a label of PDA may have. The overarching

premise seems to be that using alternative language to PDA may be more congruent in EP practice.

#### **4.6 Theme 4: We Need to Work Together**

This theme links to RQ1b and highlights the idea that multisystemic collaboration around a CYP is important; it includes working with families, school staff and other professionals. In addition, this theme captures the role EPs have in supporting the people around the CYP. Furthermore, the criticalness of developing trusting relationships between CYP and the adults who support them is emphasised. Both ideas regarding ‘working together’ are expanded upon as part of two subthemes.

##### ***4.6.1 Subtheme 4.1: Multidisciplinary Support***

This subtheme captures the ideologies of the EPs that a team of support is required around CYP. Strongly alluding to the cruciality of this working alongside other professionals, Lucy stated “you need a professional village around a child” (line 234) and Charlie noted that in relation to PDA, there was “sensitive work being required with parents and professionals around this area” (lines 91-92). Alex noted that often her understanding of PDA had been enhanced “through reading reports from psychologists or clinical psychologists and speech language therapists as part of the autism assessments and just kind of consultation with school” (lines 45-46), which suggests that there may be a role in sharing professional insights. In further consideration of working with other professionals, Lucy advocated that speech and language therapists (SLT) are enlisted to “have a look at the language development” (lines 301-302) and that social care involvement may also be necessary:

“So, I've been ringing safeguarding bells around this for quite a long time and saying to the local authority and my advice to you is that there do need to be just occasional visits to from social care to check welfare.” (Lucy, lines 132-134)

In Lucy's later reflections on comprehensive assessment, as previously mentioned in the 'Look at the Bigger Picture' theme, she discussed the limitations in LA resourcing across services which may contribute to misinterpretation of need, alongside the potential role of the EP in tackling waiting times for neurodevelopmental assessment:

“[...] that's where we are lacking because we do not have the resource on our side or the health side or dare I say, on social care side to do that very thorough build-up of a child's whole profile and presentation.” (Lucy, lines 362-364)

“[...] shocking that NHS and education can't put their heads together. Yes, OK, it's political. You've got separate budget. We've got separate budget. But it's unethical not to say actually, this EP does already know this child. And we can already give you lots of information. Why can you not just complete the assessment based on that?” (Lucy, lines 393-397)”

Lucy's accounts powerfully indicate that there are systemic issues in establishing the appropriate recognition of need and service support for CYP and suggest that there are useful contributions that EPs can provide as part of a working as a team. She also provided an example of this earlier in her interview, describing that she was “part of a little working group within our NHS based neurodevelopmental service and colleagues from the CAMHS team where we came up with a position paper” (lines 47-49) for working with PDA. Conveying their own experience of this, Charlie described their participation in writing a PDA position paper and facing initial difficulties with this after it was “already written without any kind of real Ed Psych involvement” (lines 72-73), again promoting the valuable insight of EPs to shared professional understanding.

Further to a role in working with other professionals, several of the EPs also shared examples of the work they provide to school staff around PDA presentations. Alex described that they promote the value of supervisory spaces in schools:

“I do offer supervision often for schools. It's not always taken up, but I have done some supervision. That's something I always recommend is you know if you want, this is what how we could kind of take this forward cause I do feel it's an ongoing need supervision particularly for children with a profile like this, um, and it worries me because ultimately, it's kind of just, it's part of the sort of segregation” (Alex, lines 179-183)

Alex also shared that they have “been asked to give training to schools on PDA, which I've delivered” (lines 23-24). Georgia additionally spoke about her role in supporting staff at her school for a CYP with PDA behaviours, which like Alex, included supervision:

“[...] my role is kind of planning with staff and problem solving with staff and supervision with staff when they've had a difficult incident and it's around that kind of wider approach around our understanding of what we do to support him” (Georgia, lines 374-376)

When asked about the advice and recommendations that she makes when PDA is raised, Lucy also spoke about working with school staff, stating “obviously what we're doing is working around, you know, for the teacher. How do you approach this for the teaching assistant?”, which alludes to a key consideration of teaching assistants (TAs) often working with CYP with PDA presentations. Alex additionally addressed this notion in their interview, thinking about the potential impact of TAs' approaches on why some CYP struggle to cope with demands, saying that there are “children with special education needs being taught by teaching assistants who we know tend to use less questioning, tend to use more direct instructions to children” (lines 69-71). These accounts suggest that TAs are likely to have a crucial role in supporting CYP with demand avoidant presentations, and therefore EPs should ensure that TAs are upskilled in their work with these CYP.

In summary, it is evident that the EPs gave value to the idea of working alongside professionals, but also that EPs can support teachers and TAs to support CYP in turn. By giving attention to the people who are working directly with CYP on a regular basis, it seems that the EPs feel this would lend itself to successful outcomes.

#### **4.6.2 Subtheme 4.2: Child-Adult Partnerships**

Within the theme of ‘We Need to Work Together’, this subtheme gives emphasis to the premise of building, maintaining, and repairing collaborative relationships with the CYP themselves in effectively supporting them. As described within the name of this subtheme, Lucy explicitly describes “you’re actually a partnership with this child” (lines 221-222).

There were consistent references to the importance of building trusting relationships within the EP interviews. Taylor shared that within their practice, they would recommend “having time to establish like really trusting key relationships within their setting” (lines 110-111). Similarly, Jamie shared “I would be focusing on, you know, building that trusting relationship with a key person” (lines 82-83) and that they feel “that often is the key that leads to like, compliance with activities” (lines 84-85). Alex also suggested that exploring the CYP’s relationships with key adults would be central within their advice:

“[...] I will talk a lot about key adult relationships. I will do that anyway. That tends to be quite common theme in any conversation about a child with special educational needs, but it does seem to be the primary, kind of response that I would give is, OK, so who knows him really well and what do they feel, and do they have a good relationship with him?” (Alex, lines 130-134)

Within a trusting relationship, it was also highlighted that adults should take a non-judgemental approach to working with CYP who present with demand avoidant behaviours. Georgia shared that the staff who support a CYP with a PDA presentation in her school are “super, super patient, super, super nurturing, super fun and non-judgemental” (lines 191-192)



as “he needs to feel this sense of non-judgement from them” (lines 200-201). Kate shared that a piece of advice she would share would be “not shaming the child” (lines 156-157). She spoke about this approach in supporting a relationship between a CYP and their father, indicating the following:

“[...] it was actually just a phenomenal amount of resilience and patience and just, you know, keeping things on offer and just keeping it as kind of non-attacking or non-aggressive and non-demanding as possible for the child so that eventually, things kind of came around” (Kate, lines 160-163)

Alongside the importance of building non-judgemental relationships, Georgia also described the significance of repairing child-adult relationships when the trust has been broken. She shared that she has worked closely with one family after “the relationship had broken down not only with the young person and the (previous) school, but with the family and the school”. Interestingly, she spoke about the function of an exclusion in her school as part of facilitating relationship recovery and that “it’s repair straight away” (lines 249-250):

“[...] that fixed term exclusion is not put in as a punitive measure to teach him that it's not OK to hurt people, but it's put in as a way of giving him space and staff space for a day. So that then kind of he can recover his emotions and staff can recover their emotions. And then there can be a process of fixing things when he comes back in.” (Georgia, lines 241-244)

Building on their views around fostering trusting relationships, Jamie explained that for CYP with PDA presentations, they feel that “a lot of it is about the broken trust in a relationship from, like a perceived injustice or not understanding the social context, which makes the young person feel unsafe and causes that anxiety” (lines 51-53). When examined together with Georgia’s perspectives, giving focus to the process of relationship repair is seemingly helpful in ensuring that the CYP has meaningful educational experiences.

Further describing her explanation of a “partnership”, Lucy recommends that adults should “invite the child to work with you in that way rather than telling them what you want them to do” (lines 225-226). Kate referred to some training she had attended by a CYP who identifies as having PDA: “He said present yourself as an equal person rather than a, you know, rather than sort of in a hierarchy and humour is a great leveller, he said” (lines 151-152). Likewise, Georgia described using negotiation, collaboration and “working together” (lines 36-37) with the CYP in her school, and that there’s “constant learning with this young person” (lines 229-230). Jamie also advocated for “working alongside a young person [...] so they feel like they’re being supported alongside them” (lines 92-94). They provided an example of a Reception-aged child who was identified with PDA:

“[...] he needed like to start with learning at his time where it was like kind of a choosing time, so like the TA did like have lots of like small quick activities to do and would go around with him, to like, engage him with phonics when he was willing” (Jamie, lines 94-97)

Overall, these recommendations shared by the EPs convey a key focus on adults developing a trusting, working relationship with CYP, as an important approach in alleviating the challenging perception of demands.

#### **4.7 Theme 5: Adapt to Accommodate**

The final theme frames the clear communications provided by the EPs around their advice and support when PDA is raised, which were centred on using flexible, creative, and adaptive approaches when supporting CYP with demand avoidant presentations. This provides further understanding to RQ1b which centres around communicating and giving advice when PDA is raised. All the EP participants spoke of sharing adjustments to accommodate a CYP’s individual needs. Alex highlighted this in their strategies to support PDA behaviours:

“So, then the strategies would be more about what that person would do or what other adults would do or what they do in the environment, how they’d respond to things that they saw” (Alex, lines 134-136)

Notably, many of the participants referred to adopting a CYP-centred and needs-led approach to their advice and recommendations. Taylor noted “it still depends on the child [...] every child is unique regardless of their profile or diagnosis” (lines 104-105). Similarly, Kate shared “I guess it really depends on [...] what is being presented really. You know, and every child is different” (lines 167-168). Georgia spoke about offering a “personalised programme of support” (line 32) which is foremost based on the CYP’s interests. Speaking about her role in offering support and guidance, Beth explained:

“I think really it's just trying to get an individual picture of what the needs are and how the needs can be met in school is what I try and do as much as possible.” (Beth, lines 179-180)

These accounts from the EPs indicate that accommodations should be made for CYP, regardless of whether they present with demand avoidant behaviours. However, an important consideration in supporting CYP with PDA presentations was that typical autism strategies were not felt to be supportive. This was discussed in line with many CYP identified with PDA also having an existing autism diagnosis. For example, Alex shared “Maybe if the child’s already got an autism diagnosis. Strategies that they would use for a child with autism often don’t work” (lines 96-97). In reference to the CYP she works with, Georgia also indicated that “typical ASC strategies were not working for him” (lines 49-50). Taylor advocated for understanding when these strategies are not supportive:

“I feel that it's quite useful to think of there is this group of children that a lot of us come across where they are not responding fantastically to the most commonly used autism type strategies, so things like, having a very predictable routine, really high

visuals, really kind of like broken down tasks in terms of things like writing plans or whatever, um, and who need a different approach.” (Taylor, lines 128-132)

These views align with those shared in the ‘Look at the Bigger Picture’ theme, where identifying PDA separately to autism can inform more appropriate strategies. Among the adapted approaches associated with PDA, a key consideration shared by the EPs was around communication style. Jamie recommended “changes to how like instruction is being taught” (line 44) and Lucy suggested “using language that doesn’t, sort of say take away control, really” (lines 223-224) such as “how about if we, I wonder if you can help me” (line 224). Georgia described in detail how altered use of language has been used in her practice:

“[...] demands are never put in in terms of ‘you need to do X now’ or like ‘now is this activity, next is this activity’. It's never about that. It's always ‘OK, so you like this. I've noticed that you're interested in that. How would you feel about this?’ (Georgia, lines 233-235)

“[...] there needs to be some acknowledgement that something's happened, but it's not done in kind of a you ‘you made the wrong decision, you did this, you've hurt people’. It's very much about, OK, so this happened. So, I imagine the conversation will go something like ‘OK, so you wanted to go into the classroom and that was brilliant. And we were really proud of you for that. And you had a really successful morning and that was great. And then and then it went wrong, and we think it was a bit too much, too soon for you. And so next time you want to go into the classroom, we might just have to think about shorter bursts so that it's easier for you to manage’.” (Georgia, lines 251-258)

The EPs’ examples of how demands or expectations have been phrased in their prior experience, or believe they should be phrased, demonstrate their perceived importance when making recommendations to families and schools. Corresponding with considerations around

how an adult communicates with a CYP, the EPs also shared that demands on the CYP should be reduced. Taylor suggested that CYP should have “demand breaks and where they have opportunities for low demands” (lines 111-112), and Lucy shared that adults should “think about how we can remove the demands” (line 221). Referring to the CYP she works with at her school, Georgia described “there weren’t any demands on him. And that’s the sort of thing that we do that is, that is effective and successful” (lines 353-354). Kate additionally discussed this advice in detail:

“[...] PDA 101 advice is around reducing, reducing demands, so not making kind of explicit direct demands on children and young people with PDA, but you know instead kind of making, kind of giving options and kind of make framing, framing things within a curiosity framework or within a, you know, a kind of an open kind of question rather than direct demands” (Kate, lines 142-146)

It therefore appears that reducing or removing demands as much as possible would also sit within EP advice around PDA presentations. Lastly, most of the participants either made explicit reference to strategies from the PDA Society or described strategies which have been named by the PDA Society. Taylor shared that she would suggest that “the strategies and information on the PDA website would be really useful” (lines 95-96) for CYP with a PDA presentation. Furthermore, Lucy stated “I do use the resources from the PDA website” (line 92) and Beth explained “I’ve got some stuff from like the PDA Society that I share with parents and schools” (lines 176-177) which supports the implementation of flexible approach. Finally, Georgia shared her celebration of the ‘PANDA’ approach (picking battles, anxiety management, negotiation and collaboration, disguise and manage demands, adaptation) from the PDA Society website:

“[...] our successes have kind of reinforced that, that actually through the PANDA approach and through acknowledging that he has that kind of real need for control and

real resistance to demands and that he finds that really dysregulating, like we're having major successes with that.” (Georgia, lines 387-390)

In conclusion, there was a consensus that strategies typically advised for autistic CYP are not always helpful, and that the advice and recommendations that EPs offer seem to readily involve making adaptations around the CYP to meet their needs.

#### **4.8 Summary of Findings**

The EPs who took part in this research shared a variety of perspectives which enabled exploration of EPs’ views on working with the term PDA (RQ1a) and how EPs communicate and give advice when PDA is raised (RQ1b). Whilst there was acknowledgement by the participant EPs that PDA is known to present alongside the autism spectrum, there was also a pertinent message of ensuring that all possible factors for demand avoidance are considered or ‘unpicked’ before the identification of PDA (‘Look at the Bigger Picture’). Differences in understanding and recognition of PDA across LAs were shared, and the implications of private ‘diagnoses’ was discussed (‘Different Labels, Different Places’). There were also some concerns about the language of the term PDA (‘Different Labels, Different Places’). Nonetheless, the EPs highlighted the challenges that CYP with features of PDA present to schools, families, and professionals (‘Challenges are Prevalent’). The importance of early intervention, comprehensive assessment and multidisciplinary support were raised, and building partnerships between adults and CYP was considered crucial (‘Look at the Bigger Picture’ and ‘We Need to Work Together’). Finally, when giving advice and recommendations, the EPs advocated for flexible approaches and adapted communication styles, which held the CYP at the centre (‘Adapt to Accommodate’).

## **Chapter Five: Discussion**

### **5.1 Chapter Overview**

This chapter explores the ‘answers’ to the research questions regarding EPs’ perspectives on PDA in detail, by linking the themes to theoretical frameworks, previous literature, and other published materials. As such, an overall story of the data is presented. Analysis and themes generated in relation to the research questions and impressions of the data are considered reflexively in how the analysis may have been influenced. The strengths and limitations of this research are outlined, and the implications addressed, including recommendations for EP practice and suggestions for future research. Finally, a dissemination strategy for this research is described.

### **5.2 RQ1a: What are EPs’ views on working with the term PDA?**

#### ***5.2.1 Consistencies and gaps in the conceptualisation of PDA***

During the EP interviews, it was interesting to learn how the participants’ knowledge of PDA had developed, and how this aligned with both established and less common ideas which have been previously discussed in the literature. Centring on EPs’ understanding of PDA, it was clear that the EPs’ conceptualisation of this presentation was readily concerned with its relationship to autism and was thus described as part of the ‘Unpicking the Biological Factors’ subtheme within the main theme, ‘Look at the Bigger Picture’. This allies with the more recent and prevalent recognition of PDA as a profile of autism (Truman et al., 2021, PDA Society, n.d.-b), a concept which has been supported through the findings of earlier studies (O’Nions et al., 2014b, Reilly et al., 2014). However, there was also deliberation from some of the EPs as to whether PDA was purely part of the autism spectrum, noting discernible differences between autistic and PDA presentations, and exploring other considerations which may contribute to the presentation of demand avoidant behaviours. These portrayals and queries raised around the EPs’ understanding of PDA as a

neurodevelopmental condition appear to mirror the existing debate within the literature (Gillberg, 2014), which continues to seek clarity on whether PDA is distinct from other conditions, as originally proposed by Newson and her colleagues (2003).

Another standout contributing factor to the EPs' understanding of PDA was CYP's experiences of anxiety. It has been well acknowledged that anxiety is common in autistic CYP (White et al., 2009), and Stuart et al. (2020) suggested that anxiety may have significant relevance to understanding the behavioural features of PDA, since higher levels of emotional difficulties had been observed in CYP with PDA features, compared to those with autism (O'Nions et al., 2014b). Interestingly, although intolerance of uncertainty (IOU) has been considered as a contributing factor together with anxiety in autism (Boulter et al., 2014) and PDA (Stuart et al., 2020), this concept was not described by any of the EPs within their interviews. This may reflect the idea that the theoretical IOU concept is less well known in EP practice, and therefore may not contribute to the EPs' understanding of PDA. However, ideas surrounding a desire for control or autonomy were named, which can be viewed as means of managing uncertainty (Stuart et al., 2020).

Throughout several of the EP interviews, there was reference to demand avoidant behaviours presenting because of a CYP's stress or threat response becoming triggered. These perspectives support the application of polyvagal theory (Porges, 2011) in understanding the PDA presentation. Similarly, there was also regular description of CYP's arousal state and difficulties with emotional regulation contributing to demand avoidant behaviours. This complements previous research which has indicated there may be a predictive relationship between PDA presentations and emotional dysregulation (O'Nions et al., 2014; Goodson, 2018), and alongside the recognised experiences of anxiety, fits within the subtheme 'Unpicking the Psychological Factors'. Interestingly, under this subtheme, the associated link between EFs and emotional regulation as explored in Goodson's research,



was not named by the EPs. Although one EP (Lucy) referred to considering whether a CYP could have learning difficulties, the others did not voice ideas surrounding the possible influence of cognitive factors on PDA presentations, alongside the more explicit affective factors associated with regulatory skills. Since academics have not readily explored PDA from a cognitive perspective, it is therefore unsurprising that the EP perspectives additionally did not seem to consider these ideas, even though supporting learning is a key part of EP practice (Cameron, 2006) and is readily associated with cognition and EFs (Marques & Cladellas, 2018). This may be because ‘disruptive’ behaviours are readily seen in relation to behavioural or emotional conditions or difficulties, including PDA (Ogundele, 2018). Interestingly, from a previous case study, it was alternatively noted that behaviours that challenge were associated with learning difficulties prior to further exploration of other explanations (Young & Newland, 2002). Though the EPs in this research promoted comprehensive assessment of interactive factors, it is possible that EPs may also incur blind spots in their formulations as they may be inclined to segregate behavioural responses towards their initial perception or established labels, such as autism or PDA, as opposed to investigating the impact of other possible areas of need, such as learning or cognition.

Further exploring the landscape of anxiety in PDA, Boulter et al.’s (2014) model considers the influence of social and environmental factors on IOU in autism. The EPs in this research were additionally open to the consideration of these factors in their understanding of PDA behaviours, as depicted in the equivalently named subtheme of ‘Unpicking the Socioenvironmental Factors’. For example, the relationship between PDA features and attachment difficulties was named by two of the EPs, including explicit reference to using the Coventry Grid (Eaton et al., 2018; Moran, 2010) in supporting distinguishment between the two. Whilst it has been argued that PDA features can be explained by trauma and adverse childhood experiences (Kildahl et al., 2021; Woods, 2020c), it was noted that the accounts of

the EPs in these interviews did not necessarily seek to conceptualise PDA through an attachment lens, but rather considered that this could be part of the picture.

Overall, established ideas and theories which view PDA in relation to neurodevelopment and emotional regulatory experiences were dominantly captured within the EP accounts, as well as an alliance with some alternative but previously cited perspectives which observe PDA through an attachment lens (BPS 1.1, Appendix P). An underexplored gap in the existing literature pertaining to cognition and learning profiles of CYP who present with PDA features was similarly reflected in the knowledge portrayed in the EP interviews, and this should be considered as an important direction for future research in developing a more comprehensive understanding of PDA presentations in relation to a CYP's universal experiences.

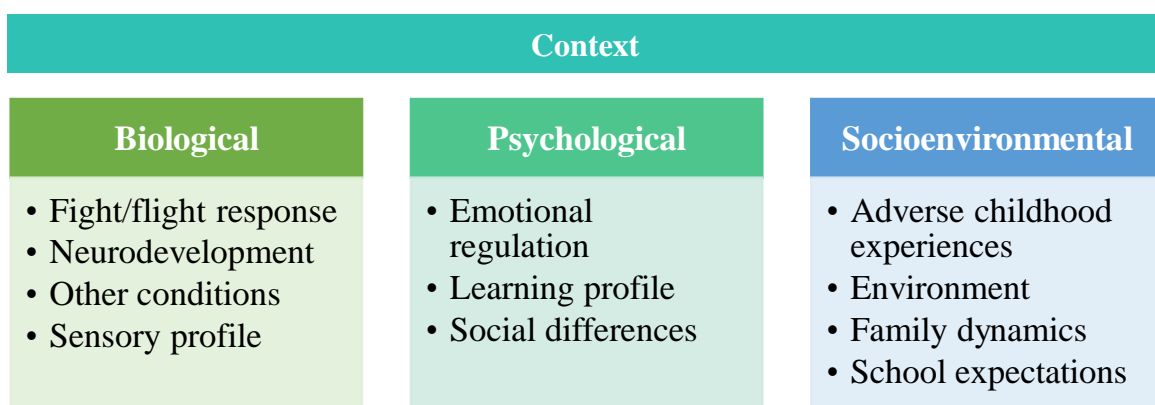
### ***5.2.2 The PDA concept should be approached holistically***

A significant element to the theme of 'Look at the Bigger Picture' was the emphasis the EPs gave to the importance of comprehensive assessment. This mirrors recommendations from Gore Langton and Frederickson (2018) in providing effective professional support (see Figure 4 in chapter two). Doyle and Kenny (2023) also suggest that a "flexible, informed and individualised approach to assessment" (p.58) is crucial in the context of how PDA-related behaviours are reported, although neither study alluded to the specifics of how the characteristics of this presentation should be explored. However, the EPs in this research described a series of factors which they attributed to their understanding and considered within their assessment of PDA, which are highlighted within the subthemes of theme 1 (Unpicking the Context, Biological, Psychological, and Socioenvironmental Factors). It is postulated that exploration of these factors provides breadth to the contribution of conceptualising PDA.

Discussing the distinct contribution of EPs, Cameron (2006) describes how human behaviour is ‘helpfully’ viewed psychologically through an eco-systemic perspective, which includes adopting an interactive view, rather than a single-factor view, and recognising that there are different layers to understanding problem situations. Whilst previous research has regularly looked at PDA as existing predominantly through a biological lens (such as Gillberg et al., 2015; Newson et al., 2003; O’Nions et al., 2014b; 2018; Reilly et al., 2014; Stuart et al., 2020), most prevalently in relation to autism as a neurodevelopmental condition, many of the EPs indicated that it is important to consider other additional or alternative factors which may be contributing to or maintaining demand avoidant behaviours, captured in theme 1 ‘Look at the Bigger Picture’ and theme 2 ‘Challenges are Prevalent’. The key factors described by the EPs as important for consideration, based on the analysis of this current research, have been outlined within Figure 6. These concepts have been organised in alignment with the biopsychosocial model, which was developed to advocate for the intersection of biological, psychological, and socioenvironmental aspects in understanding concerns pertaining to human development or health, rather than more traditional medical models (Engel, 1977; 1981).

### Figure 6

*Factors EPs consider when exploring PDA presentations, organised using the biopsychosocial model (Engel, 1977;1981)*



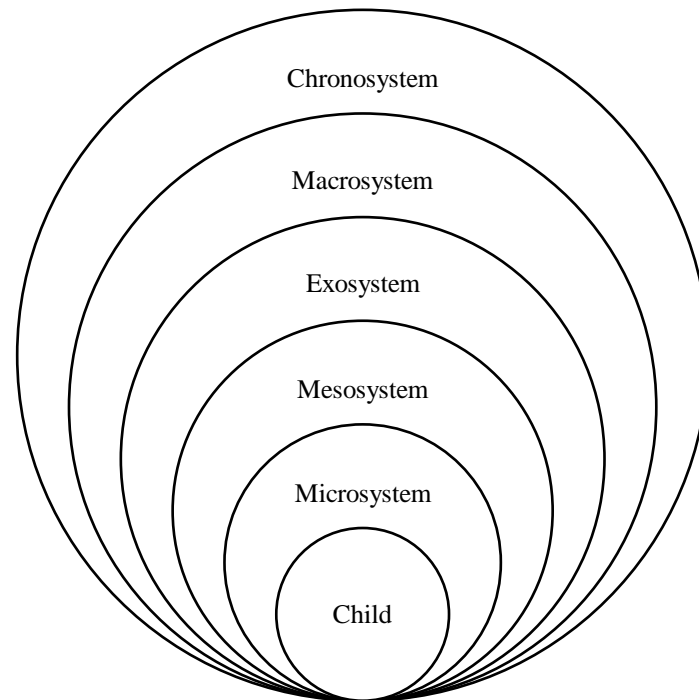
Since its introduction over 40 years ago, the biopsychosocial model has become a powerful approach to understanding health and illness, its validity widely supported and applied within clinical guidelines and research (Wade & Halligan, 2017). However, with UK health systems based primarily on biological/medical models, it has been claimed that more holistic, alternative models of understanding health and illness are not considered at the organisational and commissioning levels of service support (Wade & Halligan, 2017). Specific to the modelling of PDA, it is notable to acknowledge that autism subtypes have been removed from the DSM-V. This potentially has implications for the medical classification of PDA, as this principle would exclude PDA from the autism spectrum (Woods, 2020b), and therefore the biopsychosocial approach could be argued to be more relevant to conceptualising PDA. However, despite the achievements of the biopsychosocial model, it has also been criticised for a lack of clarity in how each of the three domains should be balanced, insensitivity to individual experience and misaligning with general systems theory, which the model was proposed to be rooted in (Benning, 2015). Although this model was not explicitly named by any of the EPs, there was a shared impression that PDA presentations should be understood by exploring the variety of possible factors which could relate to these behaviours, which were subsequently described within the subthemes of the analysis.

The consideration of demand avoidant behaviour exhibiting through complex interactions between CYP and their social contexts is also affiliated with Bronfenbrenner's (1979; 2005) ecological systems theory, which specifies that child development is influenced by a series of relational connections within and between their environments. Since its initial conception, the theory has been further developed to consider the role of biology and is therefore often known as the bioecological model of human development (Bronfenbrenner &

Morris, 2007). A graphic model of this theory and the five associated system levels is presented in Figure 7.

**Figure 7**

*The revised (bio)ecological systems model*



*Note.* Adapted from Bronfenbrenner (1979; 2005)

Ecological systems theory is a well-established and widely accepted framework in supporting holistic thinking around the power of dynamic relationships (Hayes et al., 2022). Furthermore, it promotes cultural sensitivity in practice through consideration of a CYP's wider ecological factors (Paat, 2013). Like the biopsychosocial model, this theory contests the principles of the medical model and contributes to the application of a more interactive conceptual framework in EP practice (Scottish Executive, 2002; Toland & Carrigan, 2011). It therefore seems unsurprising that the EPs in this research made regular references to interplaying factors in consideration of PDA which constitute many of these different systems, including the CYP themselves, their family and school (microsystems and mesosystems) and wider education, health, and social care services (exosystems).

Considering assessment as a key function of EP practice (Scottish Executive, 2002; see also Freeman & Miller, 2001) (BPS 2.2, Appendix P), this theme recognises the EP role in examining a CYP's profile of strengths and need. Within the context of EHC needs assessments, EPs are required to provide statutory advice (Atfield et al., 2023) based on an understanding of CYP's learning and development through factors relating to communication and interaction, cognition and learning, social, emotional, and mental health, and physical and sensory development (Department for Education, 2015) (BPS 7.2, Appendix P). The holistic nature of these assessments could be argued to influence EP approaches to understanding of need, including PDA characteristics. Much like the biopsychosocial model, assessment guides such as the interactive factors framework (Frederickson & Cline, 2002) are also implemented within EP practice to ensure consideration of a CYP's affective, biological, behavioural, environmental, and social factors when exploring hypotheses and generating formulations, whilst also enabling connection building between these factors (BPS 5.3, Appendix P). Crucially, coming alongside parental views of PDA being "misunderstood" (Truman et al., 2021, p.66), some of the EPs expressed that they would like for there to be an increased global understanding of PDA in the future, and improving current assessment practice could be suggested as a way forward for this.

### ***5.2.3 Controversy in PDA: Diverging from or enhancing the 'script'?***

As noted in the title of this thesis, PDA is known to be a controversial topic, seen both in the various debates of existing literature (such as Gillberg, 2014; Woods, 2019) and within the EP views shared in this research. This controversy was noted in differential accounts of how PDA is understood ('Look at the Bigger Picture'), discrepancies in who is providing the PDA label and to whom ('Different Labels, Different Places' and 'Recognition of PDA') and how EPs feel about using the term PDA ('What's in a Name?'). Controversy may be thought to have negative connotations or create discomfort and prevarication; however, it can also be

beneficial in generating greater consideration and developing epistemological beliefs (Schommer-Aikins & Hutter, 2002), rather than enduring blind acceptance of the PDA concept. Working ethically is fundamental to EP practice (BPS, 2021; HCPC, 2016) and is underpinned by moral principles relating to social justice, autonomy, and beneficence (Mahdi, 2020). Therefore, engaging in issues and debates, including those pertaining to PDA, can be seen to reflect EPs' professional responsibility for the advocacy of supporting CYP's welfare (BPS 2.1, 2.5, 2.10, Appendix P).

Contrary from the dominant narratives shared by the EPs which had been established in the current literature, as previously discussed in this chapter, it was interesting to see that some views did not map as congruently with existing interpretations of PDA; this aligns with EPs' obligation to engage with a diversity of knowledge for continued professional development (BPS, 2002; HCPC, 2023). For example, when 'Unpicking the Biological Factors', it seemed as though recognition of sensory differences was held in high regard by the EPs in supporting CYP with demand avoidant behaviours, with one EP (Kate) querying whether enough consideration is given to sensory regulation in understanding PDA. Aspects of sensory experiences were not described within Newson et al. (2003)'s proposed criteria for PDA. Similarly, the revised features published by the PDA Society (2022) additionally do not refer to sensory differences, and this area of need does not appear to have been given much focus in previous PDA research. However, with PDA being more commonly understood in the context of an autism diagnosis (Truman et al., 2021, PDA Society, n.d.-b), it could then be alluded to that these experiences are associated more significantly to CYP's autistic identity, as "hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment" has been defined within the DSM-V as a feature of autism (American Psychological Association, 2013, as cited in Grapel et al., 2015, p. 69). This has been

reflected in Green et al.'s (2018) article on PDA, as they consider the associated difficulties in the context of "social, sensory, and cognitive sensitivities in autism" (p.1).

Although existing research does not appear to have examined the relationship between PDA and sensory processing in detail, parents have previously identified sensory sensitivities as one of the triggers for demand avoidance behaviours (O'Nions et al., 2018). Furthermore, one parent quote from Gore Langton and Frederickson's (2018) study suggested that their CYP was assessed as having "severe sensory processing difficulties" (p.20). In a webinar published by Alison Hart, an occupational therapist (OT), she suggests that sensory processing needs can be the "missing link" to understanding why some environments and situations can be challenging for some individuals (PDA Society, 2017, para. 1). This fits with the previously mentioned framework for IOU in autism (Boulter et al., 2014), with sensory sensitivities noted as a contributing factor (see Figure 2 in chapter one). It could then be suggested from this finding that examination of the sensory profile for CYP who present with demand avoidant behaviours may be an important area of formulation and support in EP practice, as well as an area for future research around PDA to explore in greater depth.

Previous research has suggested that CYP behaviours which challenge may be linked to both more authoritarian and more accommodating parenting styles (see O'Nions et al., 2020). However, the idea that parenting has an influence on demand avoidant presentations has been previously contested, as families have shared experiences of feeling judged or blamed (Truman et al., 2021). This can also be seen to be a controversial perspective, given that PDA is heavily understood to be neurodevelopmental in origin. Nonetheless, a couple of the EPs spoke to parenting styles within the context of PDA and insinuated that they might wonder whether parenting approaches may have an impact on a CYP's presentation. More specifically, one EP (Kate) hypothesised the influence of parenting in the early years through her anecdotal experiences, which can be seen to align with ideologies of attachment theory



(Bowlby, 1969), stipulating the importance of the emotional bond between CYP and key adults on their development. However, since these perspectives are likely to create tensions among the communities who advocate for a universal understanding of PDA, it could be postulated that publications on PDA have not pursued this school of thought due to anticipation of backlash. As with previous ideas on attachment considered within the ‘Unpicking the Socioenvironmental Factors’ subtheme, this view is described whilst noting that the concept of neurodivergence was not contested, indicating that this perspective may not fully reject more widely accepted notions of PDA, but rather considers whether external influences may contribute to these behavioural presentations.

#### ***5.2.4 School provisions have a key role***

Throughout the interviews, it was clear that the EPs were recognising challenges that behaviour associated with PDA presents to schools. Notably, within theme 2: ‘Challenges are Prevalent’, experiences of CYP being excluded from school were mentioned, as well as CYP not accessing mainstream education and settings pursuing alternative or specialist provisions, as they struggle to meet the needs of CYP with demand avoidant behaviours. These accounts are consistent with the parental perspectives and experiences cited within Gore Langton and Frederickson’s (2016) research, where CYP identified with PDA were found to display significant levels of behaviour that challenges in school, and experienced high incidences of placement breakdown or exclusion. Similarly, in the research of Doyle and Kenny (2023), 17% of parents reported their CYP was not attending mainstream education, and most parents felt that support provided in schools (and healthcare settings) was ineffective. This therefore supports the premise that CYP presenting with PDA characteristics are likely to have negative experiences of schooling, and that existing education provisions may not be conducive to supporting these CYP.

Within the current research, it was further noted that difficulties in supporting CYP with PDA presentations were seen more dominantly by EPs within early years and secondary settings, which may be when their involvement has been sought. Some of the EPs reflected on why these challenges or outcomes are prominent across schools and considered whether the academic demands of the curriculum have an impact, alongside behaviour policies and systems being unsupportive of these CYP. For secondary schools, it could be suggested that academic stress in working towards and achieving General Certificate of Secondary Education (GCSE) qualifications as well as managing the increasing social expectations associated with adolescence could lead to heightened experiences of anxiety when navigating school life. Likewise, in nurseries, it may be that the introduction of formal routine and adult-directed learning may overwhelm some CYP (BPS 7.3, Appendix P). This could be argued to correspond with parental views from Truman et al.'s (2021) research, in which CYP's experiences of anxiety and mental health difficulties were thought to be attributed to negative experiences of school. Aligning with these views and hypotheses, the EPs' perspectives suggest that factors relating to the high levels of expectation in a CYP's school experiences could be contributing to the presentation of demand avoidant behaviours. Based on the analysis, a diagram explaining this link is proposed in Figure 8.

### Figure 8

*A hypothetical trajectory for demand avoidance in schools, based on some of the comments shared by the EP participants*



Whilst the role of schools seemed crucial in understanding and supporting CYP's needs, this was not without acknowledgement of demand avoidance existing in other

contexts. One EP (Lucy) discussed that for a CYP who was not currently in school, their parent was continuing to struggle to educate them at home. Another EP (Kate) noted a CYP identified with PDA displayed avoidance behaviours when being in the same room as their father. It could be argued that this avoidance could be attributed to other influences, however, it remained that introducing non-demanding approaches helped to repair this relationship. Nonetheless, focusing on supportive provisions within schools is an important part of the EP role (BPS 1.5, Appendix P), and establishing that difficulties are faced in educational settings appears to be central in advocating the relevance of the PDA narrative in EP practice.

### ***5.2.5 Incongruencies in labelling should be considered sensitively***

Just as some LAs and NHS Trusts are known to have stated their position on labelling PDA as part of the autism spectrum (see PDA Society, n.d-b), the EPs shared a recognition that these positions varied across the country, with two of the EPs (Kate and Charlie) pertinently naming this as the ‘postcode lottery’. This disparity was discussed within theme 3: ‘Different Labels, Different Places’. Some EPs worked within LAs which had established service positions on PDA, which included recognising PDA in the context of a robust autism diagnosis and conveying a preference for the terminology ‘demand avoidant profile’ or ‘extreme’ demand avoidance (EDA). The growth of EDA as alternative terminology has been noted within the literature (Gillberg, 2014) and advocated for more readily within research (for example O’Nions et al., 2014a, 2015, 2021; Reilly et al., 2014; Truman et al., 2021), which was broadly referred to in the development of the service position shared by one EP (Charlie). However, some other EPs were uncertain on their local service position on PDA. This lack of clarity may reflect where PDA is less well known or not recognised in some areas of the UK and may inform EPs’ cautious approach to using this term with families who might then struggle to access formal identification of PDA. It may also be that the concept of PDA generates psychological ambiguity (Curley et al., 1986) where there is a lack of

consensus surrounding this term, which EPs may then be reluctant to explore due to the investment of potentially engaging in this debate and the tensions it may provoke.

A common premise which arose across the EP interviews was one of PDA being regularly identified or named by private practitioners, and this was often discussed in the instances of families not being able to access this label through their local NHS Trust. Given that Moore (2020) had previously noted an increase in private practitioners offering a diagnosis of autism with a PDA profile, these accounts are unsurprising. In fact, the researcher's experiences of identifying PDA were within the context of a private assessment clinic, and so they were readily aware of the niche landscape for families across the country seeking to understand their CYP's needs through accessing the PDA label. Whilst the EPs did not appear to dispute the identification of PDA through private assessments, the socioeconomic inequalities of this practice were acknowledged (BPS 3.3, Appendix P). This is an important consideration as financial barriers to accessing the PDA label is likely to create a bias between the CYP who are identified in this way, and those whose needs may be understood differently, similarly to the socioeconomic influence of dyslexia labelling (Knight, 2019). One of the EPs (Kate) also described the political tensions of PDA being named privately within her LA, which did not recognise this label. Altogether, this means that the EPs were perhaps apprehensive about introducing the term PDA, if families are then unable to access this label more officially, or if this could cause contention within and across services. Furthermore, this may also link to a hesitancy to medicalise CYP's behaviour, similarly to other diagnoses such as ADHD (Hill & Turner, 2016).

Cautious thinking around working with the term PDA may also additionally sit with the notion that the EPs felt it was not their role to label PDA, despite common associations that this may be within their professional remit (Lauchlan et al., 2017). However, this distanced view on labelling is already well supported within psychological literature (Baxter

& Frederickson, 2005; Cameron, 2006), and sits with ongoing conversations that a label or diagnosis should not be required for CYP to access further support (BPS, 2022). Relating back to the theme 1 ‘Look at the Bigger Picture’, it might also be that EPs are reluctant to ‘pathologize’ a CYP through labelling of PDA, as they advocated for exploring the wider social and environmental influences on their presentation as well as the more ‘within-child’ neurodevelopmental differences. In EP practice, this outlook can be seen to be wedded to Vygotsky’s sociocultural theory of child development (1978) which stipulates that human learning occurs through social interactions, and relates to the concept of neuroplasticity, with research recognising the brain’s capacity to adapt and change its neural networks in CYP (Weyandt et al., 2020) (BPS 1.1, Appendix P). However, the debate as to whether PDA behaviours can be learned (as described by Lucy in her interview) or exist innately remains.

### **5.3 RQ1b: How do EPs communicate and give advice when PDA is raised?**

#### ***5.3.1 Promoting multisystemic collaboration***

In consideration to RQ1b, which was concerned with how EPs communicate and give advice around PDA, it was evident that the EPs advocated for working collaboratively with the CYP, their school and wider professionals who are also involved, as reflected in theme 4: ‘We Need to Work Together’. This perspective marries with the findings of Doyle and Kenny (2023), who additionally highlighted that there was a disconnect between education and health systems and suggested that multidisciplinary approaches to support were crucial. Likewise, this echoes recommendations by Gore Langton and Frederickson (2018), who additionally proposed that professionals should be “liaising with other services which can meet families’ health and care needs” (p. 23) (BPS 7.6, Appendix P). Although working in conjunction with families was also named during some of the EPs’ interviews (BPS 1.7, Appendix P), this was less strongly conveyed than the multidisciplinary approaches. Where Gore Langton and Frederickson (2018) additionally suggest professional support should

include allowing families to “build relationships and receive continuity of care” (p. 23), it may be that continuity of care is seen less within EP involvement, especially those who are LA employed, as their role means they are more likely to work closely with schools than with parents. This might also reflect the solitary nature of EP involvement for individual CYP through assessment, where ongoing relationships with the families are then often limited.

Demonstrating a more systemic approach identified within this research, specific collaborative roles for the EPs included providing training to schools (BPS 8.2, Appendix P), and offering supervisory support to staff who are supporting CYP with this presentation (BPS 1.5, Appendix P). However, there was additional discussion about the voice of the EP within multidisciplinary teams that prepare service positions on PDA (BPS 7.8, Appendix P). Previous research by Gore Langton and Frederickson (2018) had indicated that EPs were readily involved with CYP with PDA presentations, but this appeared to mostly be within the context of assessment. As the data was gathered from parental perspectives, it is likely that the scope of EP contributions in supporting CYP within schools or wider systems was not fully reflected, and the findings of this research shed additional light on the distinctive support that EPs can provide.

### ***5.3.2 Caution around using the term PDA***

When considering theme 3 ‘Different Labels, Different Places’, it was striking that EPs demonstrated some apprehension around the labelling of PDA. Despite prior research suggesting that EPs have sometimes been the professional to introduce the idea of PDA (Gore Langton & Frederickson, 2018), this was not fully reflected in the current research. Although overall, the EPs seemed to accommodate the premise of a PDA presentation, it was clear that they did not feel that it was their role to provide this label. Furthermore, the EPs conveyed discretion about how they use the term PDA, with some stating that they would not describe PDA at all. Nonetheless, examples of EPs who would use the term PDA included writing it in

their reports when a CYP has already been ‘formally’ labelled in this way and raising it with schools or families to support their understanding of a CYP. These approaches somewhat observe Eaton’s (2020) argument that PDA is currently the most used descriptor within the literature (as cited in Woods, 2020b), as opposed to other terms such as EDA or rational demand avoidance (RDA), and therefore using this term offers a clear avenue for others to explore and learn about this presentation further.

Interestingly, although the EPs shared a variety of preferred terminology in place of PDA, it was not explicit whether these were terms that they were applying themselves in practice. Both ‘demand avoidant profile’ and ‘EDA’ were described by EPs as terms which were more substantially positioned and accepted within their LAs, but they did not seem to refer to introducing these terms in conversations with families or schools. It is possible that this relates to the same apprehensions which EPs have around using the PDA term, as where alternative terminology still constitutes a label, they may not wish to provide that label. This sits with the idea that EPs may be reluctant to apply labels more generally (Baxter & Frederickson, 2005; Cameron, 2006), as previously discussed. Furthermore, where PDA ideologies are not consistently recognised or accepted across the country, it may be that EPs are less confident to introduce and therefore have ownership of these concepts, irrespective of how they are named. This links with the ideas discussed earlier in this chapter, where ‘incongruencies in labelling should be considered sensitively’, with acknowledgement that PDA-related labels may not be easily accessible. Overall, there was a sense that EPs may reserve from using labelling terms directly and are more likely to focus conversations on the presenting needs, and how to support these, over naming them.

### ***5.3.3 Relationships Make a Difference***

Under the umbrella of theme 4: ‘We Need to Work Together’, it seemed pertinent to emphasise the value the EPs placed on building trusting relationships with CYP to support them effectively. This was an unsurprising contribution within the interviews, as it is known that CYP relationships with teachers play a significant role in positive educational experiences and improving developmental outcomes such as wellbeing and academic achievement (Allen et al., 2021). The premise of building trusting relationships is also well established across advice for supporting CYP with PDA features. Within guidance published for supporting CYP with PDA presentations at school, Syson and Gore Langton (n.d.) note that “it is important to develop a strong relationship with a child who has high anxiety” (p. 8). Furthermore, subsequent guidance produced from the output of Doyle and Kenny’s (2023) study emphasises that within primary school settings, adults should “allow time to build a relationship with the pupil” and that it is important for pupils with PDA presentations to “form trusting relationships with adults” (from PDA Society, n.d.-d, p. 1).

When analysing the data, a more specific concept of working in a partnership with CYP was identified within one of the EP interviews (Lucy). Through further examination of the relational concepts which were discussed across the interviews, the idea of a ‘partnership’ resonated as a useful way of describing what the EPs suggested that CYP were seeking from the adults who support them. As such, this term was explicitly utilised within the subtheme ‘Child-Adult Partnerships’. Within a partnership, the idea that CYP with PDA characteristics find it difficult to understand social hierarchy in adult-child relationships (Syson & Gore Langton, n.d.) is addressed, as many of the EPs suggested that adults should strive to work alongside CYP as an equal partner. Alongside ideas around learning together, and sharing the ‘demand load’, this relational approach emphasises a key implication for ongoing practice (BPS 1.5, Appendix P).



### 5.3.4 Adopting the PANDA

A key question within the semi-structured interview schedule centred around the advice and recommendations that the EPs provide when PDA is raised. Alongside the pertinence of working in partnership with the CYP, there was a clear narrative around working non-judgementally, flexibly, and in a personalised way, as described within theme 5: ‘Adapt to Accommodate’. Indeed, across many of the EP interviews, there were multiple references to approaches of support which have been named within the PDA Society’s “helpful approaches for a PDA profile of autism” (2021), which have been represented through the mnemonic of ‘PANDA’. Some of the EPs referred to the PDA Society’s recommendations explicitly, and others’ suggestions for support can be seen to align with the ideas described within the PANDA approaches. An adaptation of this infographic with supportive suggestions is displayed below in Table 7.

**Table 7**

*The ‘PANDA’ approaches*

P	<b>Pick Battles</b> – Minimise rules, enable some choice and control, explain reasons, accept that some things can’t be done
A	<b>Anxiety Management</b> – Use low arousal approach, reduce uncertainty, recognise underlying anxiety and/or sensory challenges, think ahead, treat distressed behaviours as panic attacks: support throughout and move on
N	<b>Negotiation and Collaboration</b> – Keep clam, proactively collaborate, and negotiate to solve challenges, fairness and trust are central
D	<b>Disguise and Manage Demands</b> – Phrase any requests indirectly, constantly monitor tolerance for demands and match demands accordingly, doing things together helps

---

A **Adaptation** – Try humour, distraction, novelty, and role play, be flexible, have a plan B, allow plenty of time, try to balance the amount of “give and take”

---

*Note.* Adapted from PDA Society’s helpful approaches infographic (2021).

Some of the more specific aspects of the PANDA approach which were inferred during the EP interviews included using novelty (see also Newson et al., 2003), giving breaks from expectations, allowing time to process information, providing controlled choices, and adjusting the language used with CYP (see Appendix N for corresponding codes).

Interestingly, although sensory processing needs were raised by the EPs in terms of understanding CYP’s behaviours, considerations around environmental adaptations were not discussed in detail. As previously mentioned, sensory processing differences are regularly established for autistic individuals, and several of the EPs alluded to the notion of ‘typical’ autism strategies already being implemented within schools. It could be suggested that if these provisions include accommodations for supporting sensory regulation, then it may be less pertinent for EPs to introduce these strategies as part of their recommendations.

Furthermore, this area could also be less prominent for EPs to focus their involvement on if an OT has previously addressed sensory processing needs within their professional remit (for example Gore Langton & Frederickson, 2018; PDA Society, 2017). However, as signposting to the PDA Society recommendations or the PANDA approach was described more generally by some EPs, this may also insinuate that the strategies under the PANDA umbrella which were not named unambiguously are still being advocated for within EP involvement.

It is important to note that when viewing the resource for the PANDA approach, it is broadly unclear how these recommendations have been generated. However, other resources describe contributions from a special school-based working group (Christie, 2007), a case study (Carlile, 2011) and interviews with teachers and parents (Syson & Gore Langton, n.d.) which have provided insights about supportive strategies, and these appear to align with ideas

within the PANDA approach. As previously discussed, O’Nions et al.’s (2020) findings of supportive parenting strategies in the realms of accommodation, reinforcement approaches and reducing uncertainty can also be seen to relate to the PANDA approach. Within the interviews, some of the EPs referred to experiences of seeing success from these strategies, which promote their credibility and could further contribute to the evidence-base (BPS 1.2, Appendix P). However, EP involvement is often likely limited in nature due to the increase in statutory demand for EHC needs assessments (Atfield et al., 2023) and as such, EPs may not be involved in the assess, plan, do, review cycle (SEND Code of Practice, 2015) of supporting CYP (BPS 2.2, 7.2, Appendix P). Therefore, it may be that other outcomes from these recommendations are not known, and it could be difficult to ascertain how ‘helpful’ they are for schools in practice. Nonetheless, as EPs are readily guided by current literature and research in their work, which is currently limited around the PDA concept, there may be crucial opportunities for extending an understanding of strategies which may or may not be supportive.

#### **5.4 The Story of the Data**

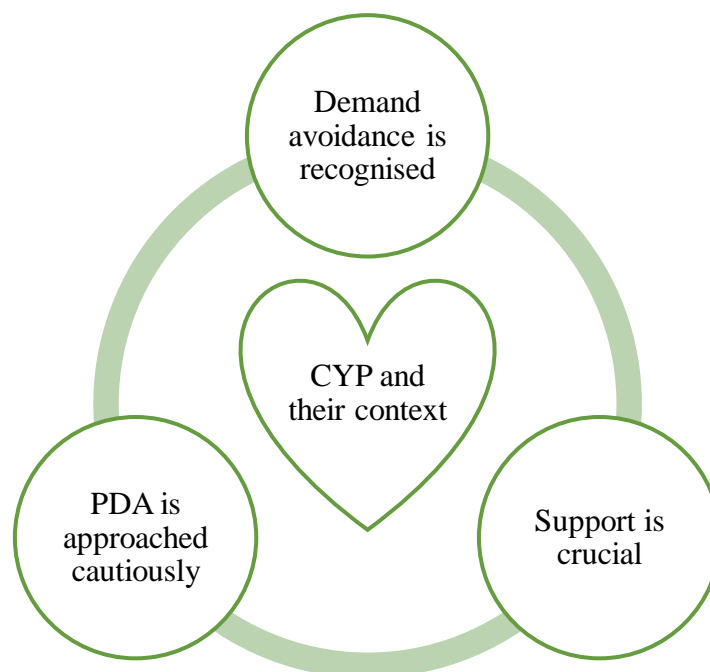
The aim of this research was to explore EPs’ perspectives on PDA, with a focus on their views on working with this term and how they communicate and give advice when PDA is raised. In line with Braun and Clarke’s (2021) guidelines for implementing RTA, the themes should be linked and collated to tell an overall story of the data. From the researcher’s interpretations of the data, it is proposed that this research story profoundly describes EP advocacy for supporting the experiences of those who present with PDA features. The EPs perceive that the PDA presentation of behaviours is prevalent, regardless of the controversy on how these are conceptualised, and in-depth consideration is required for understanding and navigating the challenges this presents to the individual, their family, their school and for the professionals involved. The EP voice demonstrates caution in approaching the PDA

concept, but with each individual CYP's best interests and their context at the heart of EP involvement. A visual representation of this story is displayed in Figure 9.

In correspondence with the overall story of the data, the findings of this research offer unique contributions to the EP profession by providing suggested models of factors for EPs to consider when exploring PDA presentations (Figure 6) and a flow diagram capturing the hypothetical trajectory of demand avoidant behaviours in schools (Figure 8).

### Figure 9

*The overall story of the data*



### 5.5 Reflexivity

As a reflexive approach was taken towards the analysis in this research, it is therefore important to address the possible influence that the researcher may have had, specifically in generating the themes and subsequent conclusions. Whilst the researcher acknowledges that they hold their own biases and experiences which have the potential to influence their interpretations of the data, practising reflexivity throughout this research encouraged the researcher to stay true to the data, and the views and experiences described by the participants. Throughout the remainder of the reflexivity and strengths and limitations

sections of this chapter, the researcher will refer to themselves in the first person as to reflect their personal engagement and interaction with the research process.

My motivation to pursue research around the topic of PDA originates from previous experiences of working in neurodevelopmental assessment services, prior to training as an EP. I had first encountered the term PDA when working in a SEN school, however, I had greater exposure to this concept when the services I worked in recognised PDA as a profile of the autism spectrum, and as such, I developed my understanding of PDA in line with this. Within these roles, I spoke with numerous families and heard about their experiences of their CYP who presented with PDA features and became increasingly interested in the unique characteristics these CYP appeared to portray. It was not until I began sharing my experiences of PDA with other EPs during my training that I realised there were a variety of perspectives and positions on this concept. Looking back, I recognise that I had adopted a singular narrative of PDA based on the context of my previous roles, and through my curiosity, have sought to expand my understanding of these alternative perspectives (BPS 2.9, Appendix P). Acknowledging the contention around PDA, I have taken the position of accepting that there are variable conceptualisations and views on PDA and have sought to reflect this position through the social constructionist lens of this research.

Through assumptions I had formed from anecdotal conversations with other EP colleagues, I was anticipating that the overarching EP perspectives of PDA would be unfavourable, with regards to both the concept and the label. This was in part because I hold the view that EPs are more likely to adopt a 'needs-led' approach, than seek to provide a label for a CYP. However, during the recruitment period, I recognised that several interested EPs practised privately; this may correspond with the evolution of the EP role from working in LAs, to working in traded services (Lee & Woods, 2017) to many EPs now choosing to work privately, as this offers opportunities to do more varied work (Atfield et al., 2023) (BPS 2.2,

Appendix P). I wondered whether EPs practising privately may be more likely to give value to PDA, as these practitioners may be potentially more bound by supporting families who are paying for their involvement, which may lead to complicity or reduced cautiousness in embracing the PDA label. I was also unsure whether some of these EPs might identify or apply the label PDA themselves, since previous research (Gore Langton & Frederickson, 2018) had indicated that EPs were often the professional to introduce the PDA concept to families. I also deliberated this in the context of the similar controversy for labelling of dyslexia (Knight, 2019). Nonetheless, it seemed that all the EPs were amenable to the ideology of a PDA presentation, although few of them appeared to express that they would identify this directly with families.

Although I had prepared a semi-structured schedule for conducting my interviews, I experienced feelings of uncertainty about the flexibility I could, or should, deliver within the dialogue. This was likely due to my limited experience as a researcher, and my cautious disposition in seeking to facilitate the interviews as neutrally as possible. As recommended by Braun and Clarke (2021) as part of the RTA process, I regularly wrote in a reflexive journal (see Appendix O) which enabled me to both capture and question my thoughts and feelings following the interviews with the participants, in turn crafting a story of my research journey. For example, I noticed when I became drawn into what a participant was saying, I found it more difficult to keep on my 'researcher hat', which may in turn have influenced my approach to the interview and subsequent data analysis. In addition, where I had reflexively appraised my role within an interview, I speculated whether this had a compensatory effect in subsequent interviews. To further manage these queries and the emotions which arose through the data gathering process, I engaged in regular discussion with my research supervisor which supported me to reflect on my impressions of the interviews, the data gathered and the richness of the picture it was creating (BPS 10.2, 10.5, Appendix P).

### *5.5.1 A Reflection on Social Graces*

Alongside being a term which was coined in the UK, most previous literature regarding PDA has originated from western countries, and this research is consistent with that pattern. It was not pertinent to the research questions to directly explore the role of protected characteristics in the context of EP perspectives on PDA, but reflection on the scope of which these were raised is arguably useful in evaluating this research, given the lack of commentary on aspects of identity in earlier studies. Crucially, the socioeconomic privilege of accessing private professionals who would provide a PDA label is pertinent to consider from the findings of this research, as it could therefore be suggested that this label is reserved only for those who can afford to pursue it (BPS 3.3, Appendix P). Two detailed accounts of casework pertaining to both a male and female CYP were shared during the EP interviews, which reflects observations of PDA presenting equally across genders (Newson et al., 2003). Regarding Burnham's social graces (2018), it can be noted that other characteristics pertaining to age, geography, and education were also considered within EPs' perspectives on PDA. The majority of these areas could be seen to correspond with the diversity, and potential inequalities, in identification and support systems which are recognised within EP practice, and it is helpful to consider that these differences could fuel further controversy in the PDA debate (BPS 3.2, 3.7, Appendix P).

Together with the aspects of identity which were noted within the EP interviews, it is also important to recognise the absence of organic discussions around other characteristics such as race, ethnicity, and cultural values. Where the intersection of Burnham's social graces and PDA has not been previously examined, this likely reflects wider implications for how or whether PDA is understood across a range of communities (BPS 3.2, 3.7, Appendix P). However, a clear viewpoint shared by the EPs was to consider the CYP within their context and to 'Look at the Bigger Picture', and although these factors were not named explicitly, this

could indirectly allude to aspects of identity being held in mind during assessment, formulation, and intervention.

In commenting on influences of culture and identity within this research, I candidly observed that the EP participant sample predominantly appeared to be from a white ethnic background (one EP was not seen on camera, and therefore a comment on ethnicity cannot be made). It has been thoroughly documented that there is a lack of diverse racial representation in psychology (BPS, 2019), which may account for the prominence of white-presenting EPs who took part in this research. Given this bias, and the limited discourse around the social graces, it should be contemplated whether the assumptions and beliefs of white individuals which are centred in what is considered normal, a construct known as “whiteness” (Gillborn, 2015, p. 278), could interplay with the EPs’ conceptualisations and perspectives of PDA. Furthermore, most of the EP participants presented as female. This similarly reflects the gender imbalance in the profession as 80% of EPs are women, which creates ramifications for those who would prefer to work with a male EP (Johnson et al., 2020). Interestingly, a significant number of previous studies relating to PDA have also been led by female-presenting researchers, such as Newson, O’Nions and Gore Langton. Stereotypically, it could be argued that women may be more likely to pursue career opportunities which pertain to working with CYP and this may account for the skew of females contributing to literature on PDA in CYP. However, it is unclear whether EP gender may also influence their perspectives on PDA (BPS 3.7, Appendix P).

I was then inclined to reflect upon my own identity as a White British female, with a higher level of education pertaining to pursuing doctoral research. I considered my own experiences of PDA in professional practice, and informally acknowledged where I have often shared characteristics such as race and culture with these CYP. I believe this has been crucial to the process of reflexivity in the analysis of my data, as I recognise that my interest



in the PDA concept could in part be skewed by an unconscious affinity with the families who have pursued this label. These reflections also further inform my advocacy towards a transcultural approach in future PDA research (BPS 3.2, 10.2, Appendix P).

### **5.6 Strengths and Limitations**

Within their description of RTA, Braun and Clarke (2021, p. 270) caution against "positivism creep", where principles from quantitative positivist-empiricist research are integrated into qualitative research. Through theoretical awareness of the social constructionist positions which underpin this research, it is understood that an individual's realities are subjective and created through social interactions. As such, it is important to acknowledge that this research does not aim for objectivity, instead representing interpretations of the data obtained from a particular group of individual EPs in relation to their perspectives on PDA, at a specific point in time. However, to ensure quality during each stage of the research processes (Yardley, 2000), a transparent audit trail of the data analysis and my reflexive accounts are appended to this write-up.

The participants were recruited for this research using a self-selecting method, through the established EP networking platform, EPNET (JISC Mail, n.d.). This meant that the participants would volunteer to take part if they felt they met the inclusion criteria for the research. Whilst this strategy led to successful and timely recruitment, it should be considered that this approach may have prompted interest from EPs with strong views regarding PDA, or with prominent personal or professional experiences of the PDA concept. This could in turn have created a bias towards EPs who wish to advocate favourably for PDA recognition, or those who disagree with the label or premise. As such, the perspectives shared by the EPs in this research may be less representative of those who have less exposure to or understanding of PDA. However, in a growing literature base where PDA is currently not widely recognised, the accounts of EPs who are more familiar with the term are highly valuable in

contributing to raised awareness among the profession. It should also be considered that this research received good interest from other prospective EP participants, and if further participants had been included to create a larger recruitment sample, this may have broadened the findings.

Regarding the participant sample, it should also be noted that this research was solely focused on gathering EPs' perspectives, and therefore only sought input from EPs. However, seeking the perspectives of other professionals, such as teachers or clinical practitioners, may have enriched the information gathered on how PDA is understood and supported for CYP. Furthermore, there is currently a lack of literature on the lived experience of CYP who are identified with PDA, and this equally would have offered an essential perspective to the PDA conversation. Therefore, these should be considered as areas for future research.

During the data collection process, I observed that most of my interviews were reasonably short in duration (ranging from 12 to 50 minutes), and I queried whether the interview schedule was prompting sufficient detail from the participants' responses. On the other hand, two of the interviews were significantly lengthier in duration. I noticed that the EPs who shared greater amounts of information during their interviews had spoken in depth about individual CYP they had continued involvement with. It could therefore be hypothesised that these EPs had a greater wealth of experience of the PDA topic to reflect upon in comparison to the other participants, who may have had more limited involvements. Notably, one of the participants disclosed that their own CYP had been provided with a PDA label. Furthermore, two of the participants divulged that they identified with having ADHD. Aligning with personal interests and experiences of the PDA topic, I wondered whether EPs who identify as neurodivergent were more likely to participate in this research and may have varied communication styles in their approaches to responding. For example, between the two participants who identified with having ADHD, one of these interviews was the shortest

in duration (12 minutes), with the participant also sharing that they speak concisely, and the other was one of the longest interviews (44 minutes). As indicated in my reflexive diary (see Appendix O), the shortest interview was also my first interview, and I therefore reflected on whether initially taking a more cautious approach as a novice researcher could have influenced the outcomes of this interview. Nevertheless, as the interviews progressed, I also wondered whether the length of the interviews may be representative of the amount of knowledge EPs had on the PDA topic, hence influencing scope for reflection on this. Overall, I noticed that there had been a reasonable mixture of EPs' insights and experiences with PDA, which was felt to be a good reflection of the EP community at large, and I wondered whether this was influenced by the various contexts of the EP role for each participant.

Generalisability from the sample size as a traditional limitation of qualitative research is not deemed to be applicable in RTA due to its methodological orientations (Braun and Clarke, 2021). However, the transferability of the qualitative data was maintained following processes of quality assurance outlined in chapter three (Lincoln & Guba, 1986; Yardley, 2000). Regardless, other limitations or challenges were faced within this research. Due to the time-consuming nature of qualitative analysis, and the restrictions of completing this thesis, it is possible that the aggregation of individual accounts and the complexity of ideas within the data were difficult to fully capture within the analysis. As well as qualitative analysis being subjective in nature, it is also acknowledged that RTA involves "craft skills" (Braun & Clarke, 2021, p. 261) which may not be perceived as rigorous as it is difficult to guide pragmatically and can limit its interpretative power. However, by discussing the themes generated in relation to theoretical frameworks and previous literature, it is hoped that these findings offer a valuable contribution to the PDA research base and to the practice of EPs. It may also open further discussions and debate in the profession around the PDA label, which could result in further research and consideration, including examination of the EP role.

## **5.7 Summary of Discussion**

This research indicates that the concept of PDA is a complex, controversial issue arising for EPs, both regarding the challenges faced by CYP, families and schools experiencing demand avoidant behaviours, and in how the term PDA is applied in their practice. There is recognition of the increasing prevalence of the PDA narrative, although EPs may query the usefulness of the label, particularly in relation to the language used to describe these characteristics. Although it is not necessarily their role to provide the PDA label themselves, EPs are aware of the discrepancy across services as to where or who is applying this label. When supporting schools and families with PDA-related concerns, it is deemed appropriate to adopt a holistic approach and explore a range of contributing and maintaining factors during assessment of need, and it may also be helpful to collaborate with other professionals involved and recommend approaches which alleviate the experience of demands. Crucially, adults working with CYP with PDA presentations should focus on developing a trusting partnership, as a key facilitator towards positive outcomes. These EP perspectives align suitably with the initial rationale of this research, by conveying a more dynamic and systemic lens towards understanding and navigating the PDA concept.

## **5.8 Implications**

### ***5.8.1 Recommendations for EP Practice***

This research provides insights from EPs around how PDA could be thought about and how CYP who present with demand avoidant behaviours should be supported both at home and at school. As such, EPs who encounter the term PDA within their practice may wish to consider the following principles, linked to the themes from this research (see Table 8). Furthermore, the inductive thinking models generated throughout this discussion can also be considered in conjunction with these recommendations (see Figures 6, 8 and 9).

**Table 8***Principles for EP Practice in consideration of PDA*


---

- Be curious when PDA is raised by families and schools, and seek to understand why they feel this term applies for a CYP (Look at the Bigger Picture; We Need to Work Together)

---

- Explore the possible range of factors which could underpin demand avoidant presentations (Look at the Bigger Picture)

---

- Recognise the challenges in supporting CYP with demand avoidant presentations and seek to promote inclusion in mainstream settings where possible (Adapt to Accommodate; Challenges are Prevalent)

---

- Seek to find out their LA's position on PDA, and if there is not one, advocate for working with multidisciplinary professionals to determine a position from the existing research base (Different Labels, Different Places; Multidisciplinary Support)

---

- Be aware of the disparities in accessing a PDA label so that this can be communicated clearly to families and schools, and promote a 'needs-led' approach (What's in a Name?; Adapt to Accommodate)

---

- Where a PDA label has been provided by another professional, seek to understand the context and motivations which led to the identification of PDA. Ascertain how the PDA narrative has been taken up by asking the CYP and those who support them what sense they have made of this label (Different Labels, Different Places; We Need to Work Together; Child-Adult Partnerships)

---

- Invite schools to try different strategies separate to those which are traditionally successful for autistic CYP. Encourage working in partnership with the CYP, using

---

---

personalised, non-judgemental, and flexible approaches (Child-Adult Partnerships; Adapt to Accommodate)

---

- Offer training and supervision to schools in implementing approaches and strategies suitable to CYP with demand avoidant presentations (Multidisciplinary Support)
- 

### ***5.8.2 Suggestions for Future Research***

The present research focused on exploring EPs' perspectives on PDA, including their views on working with the term PDA, and how they communicate and give advice when PDA is raised. Based on the findings of this research and with consideration to the existing literature base, the following areas could be considered for future research:

- *Examining EP awareness and understanding of the term PDA across the UK (using a mixed methods approach).* This would provide broader information from across the EP profession as to whether PDA is commonly recognised, as this will have implications for schools and families that seek EP involvement regarding CYP presenting with PDA features.
- *Exploring teachers' perspectives on PDA and experiences of supporting CYP identified with PDA.* This would generate greater insight into current classroom practice and the potential impact of CYP's demand avoidant behaviours on school staff, which has been alluded to in the present research. Previous research has suggested that 'tensions' in supporting autistic pupils inform the types of support that teachers then put in place (Emam & Farrell, 2009), reflecting value in exploring how teacher perspectives of PDA-related needs may influence provisions and outcomes.
- *Exploring CYP's experiences of being identified/self-identifying with PDA.* This would offer a crucial viewpoint on the value of the PDA label to the CYP it is being

applied to, following existing discussions from adults identifying with PDA (Cat, 2019; Wilding, 2020) in understanding and navigating their needs.

- *Exploring EPs' views and experiences of supporting neurodevelopmental assessment.* The EPs in the current research did not see that it was their role to provide the PDA label, although one participant (Lucy) indicated that EPs could have a valuable role in supporting neurodevelopmental assessments. Previous research has noted that EPs have often been involved in the diagnosis of autism (Sadreddini et al., 2019) which is readily related to PDA. Therefore, it would be beneficial to further explore the EP contribution these types of assessments more broadly.
- *Exploring EPs' experiences of working in a multidisciplinary team.* The current research highlighted that working alongside other professionals is valued for supporting CYP with PDA presentations, and therefore consideration should be given to the successes and potential barriers to facilitating this.
- *Exploring the cognitive and/or learning profiles of CYP identified with PDA.* Previous research has not regularly examined PDA from a cognitive perspective, and this lack of empirical consideration was reflected in the EP interviews for this research. As such, it will be valuable to explore areas of cognition as part of the PDA picture. In particular, the relationship between PDA and executive functions should be further investigated (Goodson, 2018).
- *Exploring the sensory profiles of CYP identified with PDA.* The EPs in this research indicated that it is important to consider CYP's sensory processing needs within their assessment, however, sensory processing differences are currently not well-established within literature on PDA. Although sensory sensitivities have sometimes been noted in the context of PDA (Gore Langton & Frederickson, 2018; O'Nions et al., 2018; PDA Society, 2017), further exploration may provide a broader

understanding of the PDA presentation and how differing sensory profiles can be accommodated within support strategies.

- *Examining the demographics of CYP identified with PDA, including race and culture.*

Previous research has not readily documented aspects of identity when recruiting participants identified with PDA. It will be important to apply a cultural lens in exploring the distribution of PDA labelling, to examine whether there are patterns or discrepancies among the individuals and communities who are given the PDA label.

- *Exploring the conceptualisation and identification of PDA in Non-Western cultures.*

Previous research appears to have solely originated from Western cultures (see chapter two), and therefore little is currently known as to how or whether PDA is regarded multiculturally. This direction of research will be pertinent for professionals in considering culturally sensitive assessment and recommendations (BPS 3.2, Appendix P).

## **5.9 Dissemination Strategy**

It was reflected by several of the EP participants that they hope for greater and a more unified understanding of PDA in the future, with one participant (Taylor) explicitly stating that this means that EPs can make better recommendations to home and school. It is therefore hoped that the dissemination of this research will increase awareness of and support surrounding the PDA concept within EP practice. For the EPs who either participated or expressed an interest in participating in this research, a summary of the data analysis will be shared. A presentation about this research will be given to colleagues within my EPS, and it is also hoped that I can offer to present this research within other LAs or at conferences relevant to EP practice. Lastly, it is hoped that this research will be submitted for publication within relevant peer-reviewed journals, such as the British Journal of Educational



Psychology, Educational Psychology in Practice, or the International Journal of Inclusive Education, which will then be readily accessible for EPs to read (BPS 9.5, 9.9, Appendix P).

### **5.10 Conclusion**

This research sought to answer two sub-questions within EPs' perspectives on PDA: 'what are EPs' views on working with the term PDA?', and 'how do EPs communicate and give advice when PDA is raised?'. The key findings of this research highlighted that the EPs valued a holistic, multidisciplinary approach to working with CYP identified with PDA features, with recognition of the challenges that demand avoidant presentations create across contexts. The disparity and controversy of the PDA label was recognised, and the EPs exercised some caution over the use of this terminology. Regarding advice, the EPs advocated for working adaptively and in partnership with the CYP. Overall, the implications of these findings suggest that EPs should deliver comprehensive assessment and vigilant discussion with families and schools when PDA is considered, with careful thought given to whether introducing this term or the concept of a label will be beneficial for the CYP. These findings also indicate that EPs should offer systemic involvement, such as training and supervision, and work alongside those who work directly with CYP with PDA characteristics to provide a better understanding of their needs and promote effective facilitation of support.

**Word count: 38,443**

## References

- Allen, K. A., Slaten, C. D., Arslan, G., Roffey, S., Craig, H., & Vella-Brodrick, D. A. (2021). School belonging: The importance of student and teacher relationships. In *The Palgrave handbook of positive education* (pp. 525-550). Cham: Springer International Publishing.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders 5th ed. (DSM-5)*, Washington, DC: American Psychiatric Association Publishing.
- Arishi, A., Boyle, C., & Lauchlan, F. (2017, December). Inclusive education and the politics of difference: Considering the effectiveness of labelling in special education. British Psychological Society.
- Astle, D. E., Holmes, J., Kievit, R., & Gathercole, S. E. (2022). Annual Research Review: The transdiagnostic revolution in neurodevelopmental disorders. *Journal of Child Psychology and Psychiatry*, *63*(4), 397-417.
- Atfield, G., Baldauf, B., & Owen, D. (2023). Educational psychology services: workforce insights and school perspectives on impact.
- Baxter, J., & Frederickson, N. (2005). Every child matters: Can educational psychology contribute to radical reform?. *Educational psychology in Practice*, *21*(2), 87-102.
- Bélanger, P. (2011). *Theories in adult learning and education* (p. 106). Verlag Barbara Budrich.
- Benning, T. B. (2015). Limitations of the biopsychosocial model in psychiatry. *Advances in Medical Education and practice*, 347-352.
- Boulter, C., Freeston, M., South, M., & Rodgers, J. (2014). Intolerance of uncertainty as a framework for understanding anxiety in children and adolescents with autism spectrum disorders. *Journal of autism and developmental disorders*, *44*, 1391-1402.

- Bowlby, J. (1969). *Attachment and loss. Volume 1: Attachment (2nd ed.)*. Hogarth Press and The Institute of Psychoanalysis.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, 11(4), 589-597.
- Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis?. *Qualitative research in psychology*, 18(3), 328-352.
- Braun, V. & Clarke, V. (2021). *Thematic analysis: A practical guide*. Sage.
- Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, 9(1), 3.
- Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E. (2017). Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school. *Autism & Developmental Language Impairments*, 2.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard university press.
- Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development*. Sage.
- Bronfenbrenner, U., & Morris, P. A. (2007). The bioecological model of human development. *Handbook of child psychology*, 1.
- Burnham, J. (2018). Developments in Social GRRRAAACCEEESSS: visible– invisible and voiced–unvoiced 1. In *Culture and reflexivity in systemic psychotherapy* (pp. 139-160). Routledge.
- Burr, V. (2015). *Social Constructionism (3rd ed.)*. Routledge.
- <https://doi.org/10.4324/9781315715421>

- Cabaroglu, N., Basaran, S., & Roberts, J. (2010). A comparison between the occurrence of pauses, repetitions and recasts under conditions of face-to-face and computer-mediated communication: A preliminary study. *Turkish Online Journal of Educational Technology*, 9(2), 14-23.
- Cameron, R. J. (2006). Educational psychology: The distinctive contribution. *Educational Psychology in Practice*, 22(4), 289-304.
- Carlile, J. (2011). Helping your child with PDA to play: Eight strategies for supporting a child with Pathological Demand Avoidance Syndrome at home. *Good Autism Practice (GAP)*, 12(2), 51-55.
- Cat, S. (2023a, March 23). Sally Cat PDA. A blog about adult PDA with illustrative memes. Pathological demand avoidance is classed as an autism spectrum condition. <http://www.sallycatpda.co.uk/>
- Cat, S. (2023b, February 10). The Polyvagal Theory and PDA. <http://www.sallycatpda.co.uk/2023/02/the-polyvagal-theory-and-pda.html>
- Cat, S. (2019, December 2). "Pathological demand avoidance" or needing to be free?". <http://www.sallycatpda.co.uk/2019/12/pathological-demand-avoidance-or.html>
- Charmaz, K., & Henwood, K. (2017). Grounded theory methods for qualitative psychology. *The SAGE handbook of qualitative research in psychology*.
- Cherry, K. (2021, March). The Role of the Biological Perspective in Psychology. <https://www.verywellmind.com/what-is-the-biological-perspective-2794878>
- Christie, P. (2007). The distinctive clinical and educational needs of children with pathological demand avoidance syndrome: guidelines for good practice. *Good Autism Practice (GAP)*, 8(1), 3-11.
- Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners. *Successful qualitative research*, 1-400.

- Costescu, C., Adrian, R., & Carmen, D. (2023). Executive functions and emotion regulation in children with autism spectrum disorders. *European Journal of Special Needs Education*, 1-10.
- Curley, S. P., Yates, J. F., & Abrams, R. A. (1986). Psychological sources of ambiguity avoidance. *Organizational behavior and human decision processes*, 38(2), 230-256.
- Dawson, P., & Guare, R. (2018). *Executive skills in children and adolescents: A practical guide to assessment and intervention*. Guilford Publications.
- Davidson, C., Moran, H., & Minnis, H. (2022). Autism and attachment disorders—how do we tell the difference?. *BJPsych Advances*, 28(6), 371-380.
- Deakin, H., & Wakefield, K. (2014). Skype interviewing: Reflections of two PhD researchers. *Qualitative research*, 14(5), 603-616.
- Department for Education. (2014). *Children and Families Act*. London: DfE.
- Department for Education. (2015, December). Area guidelines for SEND and alternative provision.  
<https://assets.publishing.service.gov.uk/media/5f23ec4e8fa8f57ac968fb11/BB104.pdf>
- Department for Education and Department of Health. (2015, January). *Special educational needs and disability code of practice: 0 to 25 years*.  
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>
- Diamond, A. (2005). Attention-deficit disorder (attention-deficit/hyperactivity disorder without hyperactivity): A neurobiologically and behaviorally distinct disorder from attention-deficit/hyperactivity disorder (with hyperactivity). *Development and psychopathology*, 17(3), 807-825.
- Division of Educational and Child Psychology. (2002). *Professional Practice Guidelines*. Leicester: British Psychological Society.

- Doyle, A., & Kenny, N. (2023). Mapping experiences of pathological demand avoidance in Ireland. *Journal of Research in Special Educational Needs*, 23(1), 52-61.
- Duncan, M., Healy, Z., Fidler, R., & Christie, P. (2011). *Understanding pathological demand avoidance syndrome in children: A guide for parents, teachers and other professionals*. Jessica Kingsley Publishers.
- Eaton, J. (2017). *A guide to mental health issues in girls and young women on the autism spectrum: Diagnosis, intervention and family support*. Jessica Kingsley Publishers.
- Eaton, J., Duncan, K., & Hesketh, E. (2018). Modification of the Coventry Grid Interview (Flackhill et al, 2017) to include the Pathological Demand Avoidant profile. *Good Autism Practice (GAP)*, 19(2), 12-24.
- Egan, V., Linenberg, O., & O’Nions, E. (2019). The measurement of adult pathological demand avoidance traits. *Journal of Autism and Developmental Disorders*, 49, 481-494.
- Emam, M. M., & Farrell, P. (2009). Tensions experienced by teachers and their views of support for pupils with autism spectrum disorders in mainstream schools. *European journal of special needs education*, 24(4), 407-422.
- Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, 196(4286), 129-136.
- Engel, G. L. (1981). The clinical application of the biopsychosocial model. *The Journal of medicine and philosophy*, 6(2), 101-124.
- Enns-Kananen, J. (2019). Knowledge is power is knowledge: Can we break the cycle of epistemic and epistemological injustice? *Tiedepolitikka*, 44(4), 33-40.
- Fairchild, G., van Goozen, S. H., Stollery, S. J., Aitken, M. R., Savage, J., Moore, S. C., & Goodyer, I. M. (2009). Decision making and executive function in male adolescents

- with early-onset or adolescence-onset conduct disorder and control subjects. *Biological psychiatry*, 66(2), 162-168.
- Frances, A., & Batstra, L. (2013). Why so many epidemics of childhood mental disorder?. *Journal of Developmental & Behavioral Pediatrics*, 34(4), 291-292.
- Frederickson, N. & Cline, T. (2002). *Special educational needs, inclusion and diversity: A textbook*. Buckingham and Philadelphia, PA: Open University Press.
- Freeman, L., & Miller, A. (2001). Norm-referenced, criterion-referenced, and dynamic assessment: What exactly is the point? *Educational Psychology in Practice*, 17(1), 3-16.
- Friedlmeier, W., Corapci, F., & Cole, P. M. (2011). Emotion socialization in cross-cultural perspective. *Social and personality psychology compass*, 5(7), 410-427.
- Fylan, F. (2005). Semi-structured interviewing. *A handbook of research methods for clinical and health psychology*, 5(2), 65-78.
- Gibbs, S. J., & Elliott, J. G. (2020). The dyslexia debate: Life without the label. *Oxford Review of Education*, 46(4), 487-500.
- Gillberg, C. (2014). Commentary: PDA—public display of affection or pathological demand avoidance?—reflections on O’Nions et al.(2014). *Journal of Child Psychology and Psychiatry*, 55(7), 769-770.
- Gillberg, C., Gillberg, I. C., Thompson, L., Biskupsto, R., & Billstedt, E. (2015). Extreme (“pathological”) demand avoidance in autism: a general population study in the Faroe Islands. *European Child & Adolescent Psychiatry*, 24(8), 979-984.
- Gillborn, D. (2015). Intersectionality, critical race theory, and the primacy of racism: Race, class, gender, and disability in education. *Qualitative inquiry*, 21(3), 277-287.

- Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in psychology*, 8, 438.
- Gilmore, R., Beezhold, J., Selwyn, V., Howard, R., Bartolome, I., & Henderson, N. (2022). Is TikTok increasing the number of self-diagnoses of ADHD in young people?. *European Psychiatry*, 65(S1), S571-S571.
- Gioia, G. A., Kenworthy, L., & Isquith, P. K. (2010). Executive function in the real world: BRIEF lessons from Mark Ylvisaker. *The Journal of head trauma rehabilitation*, 25(6), 433-439.
- Goodson, A. (2018). *Emotion Regulation and Executive Function in Children and Adolescents with Autism Spectrum Disorder and Pathological Demand Avoidance Traits* (Doctoral dissertation, UCL (University College London)).
- Gore Langton, E., & Frederickson, N. (2016). Mapping the educational experiences of children with pathological demand avoidance. *Journal of Research in Special Educational Needs*, 16(4), 254-263.
- Gore Langton, E., & Frederickson, N. (2018). Parents' experiences of professionals' involvement for children with extreme demand avoidance. *International Journal of Developmental Disabilities*, 64(1), 16-24.
- Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health information & libraries journal*, 26(2), 91-108.
- Grapel, J. N., Cicchetti, D. V., & Volkmar, F. R. (2015). Sensory features as diagnostic criteria for autism: Sensory features in autism. *The Yale journal of biology and medicine*, 88(1), 69.



- Green, J. (2020). Commentary: Anxiety and behaviour in and beyond ASD; does the idea of ‘PDA’ really help?—a commentary on Stuart et al.(2020). *Child and Adolescent Mental Health*, 25(2), 74-76.
- Green, J., Absoud, M., Grahame, V., Malik, O., Simonoff, E., Le Couteur, A., & Baird, G. (2018). Pathological demand avoidance: symptoms but not a syndrome. *The Lancet Child & Adolescent Health*, 2(6), 455-464.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Hannes, K., Lockwood, C., & Pearson, A. (2010). A comparative analysis of three online appraisal instruments’ ability to assess validity in qualitative research. *Qualitative health research*, 20(12), 1736-1743.
- Harrell, M. C., & Bradley, M. A. (2009). *Data collection methods. Semi-structured interviews and focus groups*.
- Harper, D., & Thompson, A. R. (Eds.). (2011). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. John Wiley & Sons.
- Harvey, A. G., Watkins, E., & Mansell, W. (2004). *Cognitive behavioural processes across psychological disorders: A transdiagnostic approach to research and treatment*. Oxford University Press, USA.
- Hayes, N., O’Toole, L., & Halpenny, A. M. (2022). *Introducing Bronfenbrenner: A guide for practitioners and students in early years education*. Taylor & Francis.
- Health & Care Professions Council. (2016). *Standards of conduct, performance and ethics*. <https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/>
- Health and Care Professions Council. (2023). *The standards of proficiency for practitioner psychologists*. London: Health and Care Professions Council.

- Hill, V. C., & Turner, H. (2016). Educational psychologists' perspectives on the medicalisation of childhood behaviour: A focus on Attention Deficit Hyperactive Disorder (ADHD). *Educational & Child Psychology, 33*(2), 12-29.
- JISC Mail. (no date). *Email discussion lists for the UK Education and Research communities. Psychology*. <https://www.jiscmail.ac.uk/maillinglists/category/L4.html>
- Johnson, J., Madill, A., Koutsopoulou, G. Z., Brown, C., & Harris, R. (2020, July 24). Tackling gender imbalance in psychology. *The British Psychological Society*. <https://www.bps.org.uk/psychologist/tackling-gender-imbalance-psychology>
- Kelly, D., & Gray, C. (2000). *Educational Psychology Services (England)*. The research report.
- Kildahl, A. N., Helverschou, S. B., Rysstad, A. L., Wigaard, E., Hellerud, J. M., Ludvigsen, L. B., & Howlin, P. (2021). Pathological demand avoidance in children and adolescents: a systematic review. *Autism, 25*(8), 2162-2176.
- Knight, C. (2019). *The dyslexia system: Using the Millennium Cohort Study and a survey of teachers to investigate the perceptions, predictors and repercussions of the dyslexia label* (Doctoral dissertation, Cardiff University).
- Lauchlan, F., & Boyle, C. (2007). Is the use of labels in special education helpful?. *Support for learning, 22*(1), 36-42.
- Lauchlan, F., Boyle, C., Gibbs, S., & Resing, W. (2017, December). Labelling and diagnosis. British Psychological Society.
- Lee, K., & Woods, K. (2017). Exploration of the developing role of the educational psychologist within the context of “traded” psychological services. *Educational Psychology in Practice, 33*(2), 111-125.
- Lewis, L. F. (2016). Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of psychiatric nursing, 30*(5), 575-580.

- Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New directions for program evaluation*, 1986(30), 73-84.
- Lui, M., & Tannock, R. (2007). Working memory and inattentive behaviour in a community sample of children. *Behavioral and Brain Functions*, 3(1), 1-11.
- Lockwood, C., Porrit, K., Munn, Z., Rittenmeyer, L., Salmond, S., Bjerrum, M., Loveday, H., Carrier, J., & Stannard, D. (2020). Chapter 2: Systematic reviews of qualitative evidence. In E. Aromataris & Z. Munn (Eds.), *JBI Manual for Evidence Synthesis* (pp. 22–70). JBI. <https://synthesismanual.jbi.global>
- Longhurst, R. (2003). Semi-structured interviews and focus groups. *Key methods in geography*, 3(2), 143-156.
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), 466-474.
- Mahdi, S. (2020). Preparing to be an ethically minded educational psychologist: Examining conceptualisations of social justice and a reflexive exploration of values. *Educational Psychology Research and Practice*, 6(1), 1-7.
- Malik, O., & Baird, G. (2018). Commentary: PDA-what's in a name? Dimensions of difficulty in children reported to have an ASD and features of extreme/pathological demand avoidance: a commentary on O'Nions et al.(2017). *Child and Adolescent Mental Health*, 23(4), 387-388.
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative health research*, 26(13), 1753-1760.
- Marques, D., & Cladellas, R. (2018). Implications of executive functions in academic learning. *Journal of Psychological and Educational Research*, 26(2), 114-131.

- May, T., Pilkington, P. D., Younan, R., & Williams, K. (2021). Overlap of autism spectrum disorder and borderline personality disorder: A systematic review and meta-analysis. *Autism Research, 14*(12), 2688-2710.
- Mayes, S. D., Calhoun, S. L., Mayes, R. D., & Molitoris, S. (2012). Autism and ADHD: Overlapping and discriminating symptoms. *Research in Autism Spectrum Disorders, 6*(1), 277-285.
- McKenzie, R., & Dallos, R. (2017). Autism and attachment difficulties: Overlap of symptoms, implications and innovative solutions. *Clinical child psychology and psychiatry, 22*(4), 632-648.
- Milton, D. (2013). 'Natures answer to over-conformity': deconstructing Pathological Demand Avoidance.
- Milton, D. (2018). Pathological Demand Avoidance (PDA) and alternative explanations: a critical overview.
- Minnis, H., Messow, C. M., McConnachie, A., Bradshaw, P., Briggs, A., Wilson, P., & Gillberg, C. (2020). Autism and attachment disorder symptoms in the general population: Prevalence, overlap, and burden. *Developmental Child Welfare, 2*(1), 37-51.
- Mittmann, G., Schrank, B., & Steiner-Hofbauer, V. (2023). TV Series in Mainstream Media Depicting Autism and Self-Diagnosis of Autism in a General Population of Young Adults. *Journal of Autism and Developmental Disorders, 1-5*.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLOS Medicine, 6*(7), Article e1000097.
- Monk, R., Whitehouse, A. J., & Waddington, H. (2022). The use of language in autism research. *Trends in Neurosciences, 45*(11), 791-793.

- Moola, S., Munn, Z., Tufanaru, C., Aromataris, E., Sears, K., Sfetcu, R., Currie, M., Lisy, K., Qureshi, R., Mattis, P., & Mu, P. (2020). Chapter 7: Systematic reviews of etiology and risk. In E. Aromataris & Z. Munn (Eds.), *JBI Manual for Evidence Synthesis* (pp. 217–269). JBI. <https://synthesismanual.jbi.global>
- Moore, A. (2020). Pathological demand avoidance: What and who are being pathologised and in whose interests?. *Global Studies of Childhood*, 10(1), 39-52.
- Moran, H. (2010). Clinical observations of the differences between children on the autism spectrum and those with attachment problems: The Coventry Grid. *Good Autism Practice (GAP)*, 11(2), 46-59.
- National Autistic Society. (n.d.-a). Demand avoidance. Retrieved May 4, 2024, from: <https://www.autism.org.uk/advice-and-guidance/topics/behaviour/demand-avoidance>
- National Autistic Society. (n.d.-b). Pre-diagnosis support – a guide for adults who think they might be autistic. Retrieved December 22, 2023, from: <https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pre-diagnosis/adults>
- National Institute for Health and Care Excellence. (2011, September). Autism spectrum disorder in under 19s: recognition, referral and diagnosis. <https://www.nice.org.uk/guidance/cg128/resources/autism-spectrum-disorder-in-under-19s-recognition-referral-and-diagnosis-pdf-35109456621253>
- Newby, J. M., McKinnon, A., Kuyken, W., Gilbody, S., & Dalgleish, T. (2015). Systematic review and meta-analysis of transdiagnostic psychological treatments for anxiety and depressive disorders in adulthood. *Clinical psychology review*, 40, 91-110.
- Newson, E. L. M. K., Le Marechal, K., & David, C. (2003). Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Archives of Disease in Childhood*, 88(7), 595-600.

- Norman, K. (2017). Reinforce, reframe or remove? What should psychologists do with diagnostic labels? *Assessment and Development Matters*, 9(4), 7-10.
- Ogundele, M. O. (2018). Behavioural and emotional disorders in childhood: A brief overview for paediatricians. *World journal of clinical pediatrics*, 7(1), 9.
- O’Nions, E., Ceulemans, E., Happé, F., Benson, P., Evers, K., & Noens, I. (2020). Parenting strategies used by parents of children with ASD: Differential links with child problem behaviour. *Journal of Autism and Developmental Disorders*, 50, 386-401.
- O’Nions, E., Christie, P., Gould, J., Viding, E., & Happé, F. (2014a). Development of the ‘Extreme Demand Avoidance Questionnaire’(EDA-Q): preliminary observations on a trait measure for Pathological Demand Avoidance. *Journal of Child Psychology and Psychiatry*, 55(7), 758-768.
- O’Nions, E., Gould, J., Christie, P., Gillberg, C., Viding, E., & Happé, F. (2016). Identifying features of ‘pathological demand avoidance’ using the Diagnostic Interview for Social and Communication Disorders (DISCO). *European child & adolescent psychiatry*, 25, 407-419.
- O’Nions, E., Happé, F., Viding, E., & Noens, I. (2021). Extreme demand avoidance in children with autism spectrum disorder: Refinement of a caregiver-report measure. *Advances in Neurodevelopmental Disorders*, 5(3), 269-281.
- O’Nions, E., Viding, E., Floyd, C., Quinlan, E., Pidgeon, C., Gould, J., & Happé, F. (2018). Dimensions of difficulty in children reported to have an autism spectrum diagnosis and features of extreme/‘pathological’ demand avoidance. *Child and Adolescent Mental Health*, 23(3), 220-227.
- O’Nions, E., Viding, E., Greven, C. U., Ronald, A., & Happé, F. (2014b). Pathological demand avoidance: exploring the behavioural profile. *Autism*, 18(5), 538-544.

Overton, G. L., Marsa-Sambola, F., Martin, R., & Cavenagh, P. (2023). Understanding the self-identification of autism in adults: A scoping review. *Review Journal of Autism and Developmental Disorders*, 1-21.

Oxford English Dictionary. (2023). "Pathological".

<https://www.oed.com/search/dictionary/?scope=Entries&q=pathological>

Paat, Y. F. (2013). Working with immigrant children and their families: An application of Bronfenbrenner's ecological systems theory. *Journal of Human Behavior in the Social Environment*, 23(8), 954-966.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *International journal of surgery*, 88, 105906.

PDA Society. (n.d.-a). About the PDA Society. Retrieved May 4, 2024, from

<https://www.pdasociety.org.uk/about-us-landing/about-us/>

PDA Society. (n.d.-b). Local position statements and information on PDA. Retrieved May 4,

2024, from <https://www.pdasociety.org.uk/resources/local-position-statements-on-pda/>

PDA Society. (n.d.-c). Sources of further understanding. Retrieved January 11, 2024, from

<https://www.pdasociety.org.uk/resources/sources-of-further-understanding/>

PDA Society. (n.d.-d). Supporting Children with PDA in Primary School Settings.

<https://www.pdasociety.org.uk/wp-content/uploads/2020/02/1-PDA-Supporting-Children-with-PDA-in-Primary-School-Settings.pdf>

PDA Society. (n.d.-e). What is demand avoidance? Retrieved May 4, 2024, from

<https://www.pdasociety.org.uk/what-is-pda-menu/what-is-demand-avoidance/>

PDA Society. (2017). PDA and Sensory Processing.

<https://www.pdasociety.org.uk/resources/pda-and-sensory-processing/>

PDA Society. (2021). Helpful approaches infographic: PANDA approaches.

<https://www.pdasociety.org.uk/resources/helpful-approaches-infographic/>

PDA Society. (2022, January). Identifying and Assessing a PDA profile – Practice Guidance.

<https://www.pdasociety.org.uk/wp-content/uploads/2023/02/Identifying-Assessing-a-PDA-profile-Practice-Guidance-v1.1.pdf>

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381-396.

Porges, S. (2011). The polyvagal theory: Neurophysiological foundations of emotions of emotions, attachment, communication and self-regulation. *Norton Series on Interpersonal Neurobiology*. Norton & Co. Inc.

Raval, V. V., & Walker, B. L. (2019). Unpacking ‘culture’: Caregiver socialization of emotion and child functioning in diverse families. *Developmental Review*, 51, 146-174.

Reilly, C., Atkinson, P., Menlove, L., Gillberg, C., O’Nions, E., Happé, F., & Neville, B. G. (2014). Pathological demand avoidance in a population-based cohort of children with epilepsy: four case studies. *Research in developmental disabilities*, 35(12), 3236-3244.

Saarijärvi, M., & Bratt, E. L. (2021). When face-to-face interviews are not possible: tips and tricks for video, telephone, online chat, and email interviews in qualitative research.

Sadreddini, S., Bond, C., & Oldfield, J. (2019). How do Educational Psychologists in the UK and Ireland assess the needs of autistic children and young people?. *Good Autism Practice*, 20(1).

Sarrett, J. C. (2016). Biocertification and neurodiversity: The role and implications of self-diagnosis in autistic communities. *Neuroethics*, 9, 23-36.



- Schommer-Aikins, M., & Hutter, R. (2002). Epistemological beliefs and thinking about everyday controversial issues. *The journal of Psychology, 136*(1), 5-20.
- Scottish Executive. (2002). *Review of the Provision of Educational Psychology in Scotland (The Currie Report)*. Edinburgh: Scottish Government Publication.
- Seifert, K., & Sutton, R. (2019). *Educational Psychology Second Edition*.
- Shields, G. S., Moons, W. G., Tewell, C. A., & Yonelinas, A. P. (2016). The effect of negative affect on cognition: Anxiety, not anger, impairs executive function. *Emotion, 16*(6), 792.
- Sinson, J. (2013). Understanding pathological demand avoidance syndrome in children.
- Smith, J. A., & Fieldsend, M. (2021). *Interpretative phenomenological analysis*. American Psychological Association.
- Stuart, L., Grahame, V., Honey, E., & Freeston, M. (2020). Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents. *Child and Adolescent Mental Health, 25*(2), 59-67.
- Syson, Z., & Gore Langton, E. (n.d.). Simple strategies for supporting children with Pathological Demand Avoidance at school. <https://www.pdasociety.org.uk/wp-content/uploads/2020/01/Positive-PDA-booklet.pdf>
- Taurines, R., Schwenck, C., Westerwald, E., Sachse, M., Siniatchkin, M., & Freitag, C. (2012). ADHD and autism: differential diagnosis or overlapping traits? A selective review. *ADHD Attention Deficit and Hyperactivity Disorders, 4*, 115-139.
- The British Psychological Society. (2019, December 2). BAME representation and psychology. <https://www.bps.org.uk/psychologist/bame-representation-and-psychology>
- The British Psychological Society. (2021, December). *Code of ethics and conduct*.

- The British Psychological Society. (2021, April). *Code of Human Research Ethics*.  
<https://cms.bps.org.uk/sites/default/files/2022-06/BPS%20Code%20of%20Human%20Research%20Ethics%20%281%29.pdf>
- The British Psychological Society. (2022, March 7). Disorders and labelling in school.  
<https://www.bps.org.uk/psychologist/disorders-and-labelling-school>
- The National Archives. *Data Protection Act 2018*.  
<https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>
- Thunberg, S., & Arnell, L. (2022). Pioneering the use of technologies in qualitative research—  
 A research review of the use of digital interviews. *International Journal of Social Research Methodology*, 25(6), 757-768.
- Toland, J., & Carrigan, D. (2011). Educational psychology and resilience: New concept, new opportunities. *School Psychology International*, 32(1), 95-106.
- Truman, C., Crane, L., Howlin, P., & Pellicano, E. (2021). The educational experiences of autistic children with and without extreme demand avoidance behaviours. *International Journal of Inclusive Education*, 1-21.
- Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.
- Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: a model whose time has come. *Clinical rehabilitation*, 31(8), 995-1004.
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical psychology review*, 29(3), 216-229.
- Wilding, T. (2020, April 4). Changing the name PDA. <http://tomlinwilding.com/changing-the-name-pda/>

- Willig, C., & Rogers, W. S. (2017). *The SAGE handbook of qualitative research in psychology*. SAGE Publications, Ltd.
- Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). The diagnostic interview for social and communication disorders: Background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry*, 43(3), 307–325.
- Woods, R. (2019). Demand avoidance phenomena: circularity, integrity and validity—a commentary on the 2018 National Autistic Society PDA Conference. *Good Autism Practice*, 20(2), 28-40.
- Woods, R. (2020a). Commentary: Demand Avoidance Phenomena, a manifold issue? Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents—a commentary on Stuart et al.(2020). *Child and Adolescent Mental Health*, 25(2), 68-70.
- Woods, R. (2020b). Pathological Demand Avoidance and the DSM-5: a rebuttal to Judy Eaton’s response. *Good Autism Practice*, 21(1), 74-76.
- Woods, R. (2020c, August). PDA—a new type of disorder?. The British Psychological Society.
- World Health Organisation. (2018). *ICD-11 International Classification of Diseases for Mortality and Morbidity Statistics Eleventh Revision*. Geneva: World Health Organisation.
- Weyandt, L. L., Clarkin, C. M., Holding, E. Z., May, S. E., Marraccini, M. E., Gudmundsdottir, B. G., ... & Thompson, L. (2020). Neuroplasticity in children and adolescents in response to treatment intervention: A systematic review of the literature. *Clinical and Translational Neuroscience*, 4(2), 21.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health*, 15(2), 215-228.

- Young, S., & Newland, J. (2002). Attention deficit hyperactivity disorder and mild learning disabilities: a case study. *British Journal of Learning Disabilities*, 30(2), 73-77.
- Zeng, X., Zhang, Y., Kwong, J. S., Zhang, C., Li, S., Sun, F., Niu, Y., & Du, L. (2015). The methodological quality assessment tools for preclinical and clinical studies, systematic review and meta-analysis, and clinical practice guideline: A systematic review. *Journal of Evidence-Based Medicine*, 8(1), 2-10.

## Appendices

### Appendix A: Summary of Studies included in Literature Review

Author/Year	Research Focus	Location	Participant Description	Research Approach	Key Findings
Doyle & Kenny (2023)	Experiences of PDA	Ireland	264 parents, 9 life partners, 6 individuals experiencing PDA, 54 practitioners	Surveys, individual interviews and focus groups	<ul style="list-style-type: none"> <li>Using a flexible, informed and individualised approach to assessment and provision is crucial.</li> <li>Streamlined, integrated and multidisciplinary approaches are deemed necessary.</li> <li>There is a disconnect between education and health systems</li> </ul>
Gillberg et al. (2015)	Examining the prevalence of PDA in a population	Faroe Islands	50 parents of 15–24-year-olds who met the criteria for autism	Parent interviews using DISCO	<ul style="list-style-type: none"> <li>Almost 1 in 5 CYP had indications of PDA alongside autism in their childhood.</li> <li>Only 1 CYP met the “full criteria” between the ages of 15-24.</li> </ul>
Gore Langton & Frederickson (2016)	Educational experiences of CYP with PDA	UK	42 parents whose children were screened and considered to have PDA	Parental reports	<ul style="list-style-type: none"> <li>CYP displayed high levels of behaviour that challenges in school, SEND support and involvement from professionals</li> <li>CYP experienced high rates of placement breakdown or exclusion</li> </ul>

					<ul style="list-style-type: none"> <li>• EPs were sometimes one of the professionals involved in identifying PDA in CYP</li> <li>• 88% of parents had an EP involved with their CYP</li> </ul>
Gore Langton & Frederickson (2018)	Exploring parents' experiences of professional involvement for PDA	UK	42 parents whose children were screened and considered to have PDA	Questionnaires	<ul style="list-style-type: none"> <li>• CYP had a high level of professional involvement, and the majority of these experiences were deemed to be helpful</li> <li>• Helpful input was deemed as the skills and qualities of the professionals, enabling access to resources and services and providing assessment and strategies.</li> <li>• 57% of EP involvements were deemed to be helpful. EPs were the second most frequently beneficial professional.</li> </ul>
Newson et al. (2003)	Examining differential diagnoses of autism and PDA	UK	50 CYP with a 'clear cut' PDA diagnosis, 20 with a 'classic' autism diagnosis and 20 identified with Asperger's syndrome.	Comparing clinical cases	<ul style="list-style-type: none"> <li>• Proposal of PDA as distinct pervasive developmental disorder</li> </ul>
O'Nions et al. (2014a)	Development of the EDA-Q	UK	Parents of 102 typically developing CYP, 36 autistic CYP without disruptive behaviour, 48 autistic CYP with disruptive behaviour, 67 CYP with suspected PDA, 50 CYP identified with PDA and 23	Comparing parent surveys	<ul style="list-style-type: none"> <li>• Scores on the EDA-Q for CYP identified with PDA were significantly higher compared to other comparison groups.</li> <li>• Females scored higher on the EDA-Q than males</li> </ul>

CYP with behavioural concerns not related to autism or PDA					
O’Nions et al. (2014b)	Comparing PDA profiles with autism and conduct disorders	UK	25 CYP labelled as having PDA, 39 with an autism diagnosis and 28 with conduct or emotional difficulties.	Comparing parent reports	<ul style="list-style-type: none"> <li>• PDA CYP displayed comparable autistic traits and anti-social behaviours related to conduct disorders.</li> <li>• PDA CYP displayed higher levels of emotional difficulties.</li> </ul>
O’Nions et al. (2016)	Examining the DISCO for items characteristic of PDA	UK	153 individuals assessed for autism using the DISCO	Anonymous scores and details from DISCO data	<ul style="list-style-type: none"> <li>• 11 of the originally derived PDA items had low endorsement rates in a generalised autistic population.</li> <li>• 27 individuals were identified as having high levels of PDA features.</li> </ul>
O’Nions et al. (2018)	Exploring the profile of PDA	Belgium/UK	29 parents following EDA-Q screening	Semi-structured interviews, coded against the DISCO	<ul style="list-style-type: none"> <li>• Themes included seeking control over situations and other’s activities.</li> <li>• Avoidant behaviours were deemed to be ‘strategic’.</li> <li>• Extreme behaviours were thought to be triggered by negative emotional response to demands, phobias, novelty, and uncertainty.</li> </ul>
O’Nions et al. (2020)	Examining parenting strategies used in autistic CYP, including PDA	Belgium/UK	222 parents of autistic CYP	Parent Strategies Questionnaire	<ul style="list-style-type: none"> <li>• Three parenting subscales were revealed: accommodation, reinforcement approaches and reducing uncertainty.</li> </ul>

					<ul style="list-style-type: none"> <li>• Accommodation and reducing uncertainty were linked to behaviour that challenges (including PDA)</li> <li>• CYP characteristics of ‘socially inflexible’, ‘non-compliance’ and ‘intolerance of uncertainty’ were predictors of variance in parenting.</li> <li>• CYP factors bared no relationship to reinforcement approaches.</li> </ul>
O’Nions et al. (2021)	Refinement of the EDA-Q	UK	Parents of 334 CYP with autism	Parent reports	<ul style="list-style-type: none"> <li>• 8 of the items from the EDA-Q were discriminating indices of PDA features.</li> </ul>
Reilly et al. (2014)	Examining co-occurrence between PDA and epilepsy	UK	4 CYP with significant PDA traits	Case studies	<ul style="list-style-type: none"> <li>• All four CYP met the criteria for ADHD.</li> <li>• Three met the criteria for autism and developmental co-ordination disorder.</li> <li>• Two met the criteria for ODD.</li> </ul>
Stuart et al. (2020)	Exploring intolerance of uncertainty and anxiety in PDA	UK	69 participants with a PDA diagnosis, 151 parents of those identified with PDA features	Online survey, followed by telephone interviews (n=11)	<ul style="list-style-type: none"> <li>• Demand avoidant behaviour can be partly conceptualised as an attempt to increase certainty and predictability to alleviate increasing anxiety.</li> <li>• Strategies to manage intolerance of uncertainty included control behaviour, withdrawal into fantasy and meltdown.</li> </ul>



---

Truman et al. (2021)	Comparing educational experiences of CYP with and without PDA	UK	211 parents whose CYP had been labelled with PDA, displayed PDA behaviours or neither	Online questionnaires	<ul style="list-style-type: none"><li>• School exclusion rates did not significantly differ between groups</li><li>• CYP with PDA presentations showed higher levels of behaviours that challenge</li><li>• CYP with PDA presentations had incredibly negative school experiences, ascribed to lack of understanding of PDA and targeted support</li></ul>
----------------------	---	----	---	-----------------------	--

---

## Appendix B: Critical Appraisal of Literature Review Papers

### JBI Critical Appraisal Checklist for Analytical Cross-Sectional Studies

Study	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of the condition?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the outcomes measured in a valid and reliable way?	Was appropriate statistical analysis used?
Newson et al. (2003)	No	No	N/A	No	No	No	N/A	No
O’Nions et al. (2014a)	Yes	Yes	N/A	No	No	No	N/A	Yes
O’Nions et al. (2014b)	Yes	Yes	N/A	No	No	No	N/A	Yes
Gillberg et al. (2015)	Yes	Yes	N/A	Yes (DISCO)	No	No	N/A	Yes
O’Nions et al. (2016)	Yes	Unclear	N/A	Yes (DISCO)	No	No	N/A	Yes
Gore Langton & Frederickson (2016)	Yes	Unclear	N/A	Yes (EDA-Q)	No	No	N/A	Yes

O’Nions et al. (2020)	Yes	Yes	N/A	Yes (EDA-Q)	No	No	N/A	Yes
Stuart et al. (2020)	Yes	Yes	N/A	Yes (EDA-Q)	No	No	N/A	Yes
Doyle & Kenny (2023)	Yes	Yes	N/A	No	No	No	N/A	Yes
Truman et al. (2021)	Yes	Yes	N/A	Yes (EDA-Q)	No	No	N/A	Yes
O’Nions et al. (2021)	Yes	Yes	N/A	Yes (EDA-Q and SDQ)	No	No	N/A	Yes

## JBI Critical Appraisal Checklist for Case Reports

Study	Were patient's demographic characteristics clearly described?	Was the patient's history clearly described and presented as a timeline?	Was the current clinical condition of the patient on presentation clearly described?	Were diagnostic tests or assessment methods and the results clearly described?	Was the intervention(s) or treatment procedure(s) clearly described?	Was the post-intervention clinical condition clearly described?	Were adverse events (harms) or unanticipated events identified and described?	Does the case report provide takeaway lessons?
Reilly et al. (2014)	Yes	Yes	Yes	N/A	Yes	Yes	N/A	Yes

JBI Critical Appraisal Checklist for Qualitative Research

Study	Is there congruity between the stated philosophical perspective and the research methodology?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice-versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Gore Langton & Frederickson (2018)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes

---

O'Nions et al. (2018)	No	No	No	Yes	Yes	No	No	Yes	Yes	Yes
-----------------------------	----	----	----	-----	-----	----	----	-----	-----	-----

---

## Appendix C: Extreme Demand Avoidance 8-item measure

Cited from O’Nions et al. (2021)

### Extreme Demand Avoidance 8-item measure (EDA-8)

*A brief caregiver-report measure of EDA traits for caregivers of children aged 5 – 17 years.*

Please answer the questions thinking about your child’s behaviour during the last six months. Please read each item carefully and fill in the answer that best applies.

*Please tick one option per question only:*

		Not true	Somewhat true	Mostly true	Very true
1	Obsessively resists and avoids ordinary demands and requests.				
2	Is driven by the need to be in charge.				
3	Tells other children how they should behave, but does not feel these rules apply to him/herself.				
4	Has difficulty complying with demands unless they are carefully presented.				
5	Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police).				
6	Mood changes very rapidly (e.g. switches from affectionate to angry in an instant).				
7	Uses outrageous or shocking behaviour to get out of doing something.				
8	Has bouts of extreme emotional responses to small events (e.g. crying/giggling, becoming furious).				

#### **Scoring:**

- Please note that the EDA-8 was designed to measure EDA traits for research purposes, and is not a diagnostic instrument.
- All items are scored as follows: **Not true = 0; Somewhat true = 1, Mostly true = 2, Very true = 3.**
- Our research shows that the EDA-8 scale can measure the severity of EDA characteristics well at modest levels, but at high levels, more in-depth measurement is needed.
- Scores over 19 could indicate the need for more in-depth measurement of EDA, but do not necessarily suggest a PDA-profile.
- This questionnaire asks about a person’s presentation not the causation of this presentation. There are a range of reasons for why a person may present with extreme demand avoidance besides PDA. More in-depth assessment is needed to establish whether a PDA profile underpins demand avoidance behaviours. This would consider early development and any situational factors affecting current behaviour. More information about identifying and assessing for a PDA profile can be found at <https://www.pdasociety.org.uk/what-is-pda-menu/identifying-assessing-pda/>

#### **Key reference:**

O’Nions, Happé, Viding & Noens (2021) Extreme Demand Avoidance in Children with Autism Spectrum Disorder: Refinement of a Caregiver-Report Measure. *Advances in Neurodevelopmental Disorders*, 5, 269–281 <https://link.springer.com/article/10.1007/s41252-021-00203-z>

© O’Nions, Christie, Gould, Viding, & Happé

**Tavistock and Portman Trust Research Ethics Committee (TREC)**  
**APPLICATION FOR ETHICAL REVIEW OF STUDENT RESEARCH PROJECTS**

This application should be submitted alongside copies of any supporting documentation which will be handed to participants, including a participant information sheet, consent form, self-completion survey or questionnaire.

Where a form is submitted and sections are incomplete, the form will not be considered by TREC and will be returned to the applicant for completion.

For further guidance please contact Paru Jeram ([academicquality@tavi-port.nhs.uk](mailto:academicquality@tavi-port.nhs.uk))

**FOR ALL APPLICANTS**

**If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters. You need only complete sections of the TREC form which are NOT covered in your existing approval**

Is your project considered as 'research' according to the HRA tool? ( <a href="http://www.hra-decisiontools.org.uk/research/index.html">http://www.hra-decisiontools.org.uk/research/index.html</a> )	Yes/No
Will your project involve participants who are under 18 or who are classed as vulnerable? (see section 7)	Yes/No
Will your project include data collection outside of the UK?	Yes/No

**SECTION A: PROJECT DETAILS**

<b>Project title</b>	An exploration of Educational Psychologists' perspectives on Pathological Demand Avoidance (PDA) and their approaches to this term in practice		
<b>Proposed project start date</b>	March 2023	<b>Anticipated project end date</b>	May 2024
<b>Principle Investigator (normally your Research Supervisor):</b> Jude Mortell			
<b>Please note: TREC approval will only be given for the length of the project as stated above up to a maximum of 6 years. Projects exceeding these timeframes will need additional ethical approval</b>			
<b>Has NHS or other approval been sought for this research including through submission via Research Application System (IRAS) or to the Health Research Authority (HRA)?</b>	<b>YES (NRES approval)</b>	<input type="checkbox"/>	
	<b>YES (HRA approval)</b>	<input type="checkbox"/>	
	<b>Other</b>	<input type="checkbox"/>	
	<b>NO</b>	<input checked="" type="checkbox"/>	
<b>If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters.</b>			

**SECTION B: APPLICANT DETAILS**

<b>Name of Researcher</b>	Fay Johnson
---------------------------	-------------



<b>Programme of Study and Target Award</b>	Professional Doctorate in Child, Community and Educational Psychology (M4)
<b>Email address</b>	<a href="mailto:fjohnson@tavi-port.nhs.uk">fjohnson@tavi-port.nhs.uk</a>
<b>Contact telephone number</b>	


**SECTION C: CONFLICTS OF INTEREST**

<p><b>Will any of the researchers or their institutions receive any other benefits or incentives for taking part in this research over and above their normal salary package or the costs of undertaking the research?</b></p> <p>YES <input type="checkbox"/> NO <input checked="" type="checkbox"/></p> <p>If YES, please detail below:</p>
<p>Is there any further possibility for conflict of interest? YES <input type="checkbox"/> NO <input checked="" type="checkbox"/></p>
<p><b>Are you proposing to conduct this work in a location where you work or have a placement?</b></p> <p>YES <input type="checkbox"/> NO <input checked="" type="checkbox"/></p> <p>If YES, please detail below outline how you will avoid issues arising around colleagues being involved in this project:</p>


<p><b>Is your project being commissioned by and/or carried out on behalf of a body external to the Trust? (for example; commissioned by a local authority, school, care home, other NHS Trust or other organisation).</b></p> <p><small>*Please note that 'external' is defined as an organisation which is external to the Tavistock and Portman NHS Foundation Trust (Trust)</small></p> <p>If YES, please add details here:</p>	<p>YES <input type="checkbox"/> NO <input checked="" type="checkbox"/></p>
<p><b>Will you be required to get further ethical approval after receiving TREC approval?</b></p> <p>If YES, please supply details of the ethical approval bodies below AND include any letters of approval from the ethical approval bodies (letters received after receiving TREC approval should be submitted to complete your record):</p>	<p>YES <input type="checkbox"/> NO <input checked="" type="checkbox"/></p>
<p>If your project is being undertaken with one or more clinical services or organisations external to the Trust, please provide details of these:</p>	
<p>If you still need to agree these arrangements or if you can only approach organisations after you have ethical approval, please identify the types of organisations (eg. schools or clinical services) you wish to approach:</p>	

<p><b>Do you have approval from the organisations detailed above? (this includes R&amp;D approval where relevant)</b></p> <p>Please attach approval letters to this application. Any approval letters received after TREC approval has been granted MUST be submitted to be appended to your record</p>	<p>YES <input type="checkbox"/> NO <input type="checkbox"/> NA <input checked="" type="checkbox"/></p>
---	--

**SECTION D: SIGNATURES AND DECLARATIONS**

<p><b>APPLICANT DECLARATION</b></p> <p>I confirm that:</p> <ul style="list-style-type: none"> <li>• The information contained in this application is, to the best of my knowledge, correct and up to date.</li> <li>• I have attempted to identify all risks related to the research.</li> <li>• I acknowledge my obligations and commitment to upholding ethical principles and to keep my supervisor updated with the progress of my research</li> <li>• I am aware that for cases of proven misconduct, it may result in formal disciplinary proceedings and/or the cancellation of the proposed research.</li> <li>• I understand that if my project design, methodology or method of data collection changes I must seek an amendment to my ethical approvals as failure to do so, may result in a report of academic and/or research misconduct.</li> </ul>	
<b>Applicant (print name)</b>	FAY JOHNSON
<b>Signed</b>	
<b>Date</b>	20.01.23

**FOR RESEARCH DEGREE STUDENT APPLICANTS ONLY**

<b>Name of Supervisor/Principal Investigator</b>	Jude Mortell
<p><b>Supervisor –</b></p> <ul style="list-style-type: none"> <li>• Does the student have the necessary skills to carry out the research? <b>YES</b> <input checked="" type="checkbox"/> <b>NO</b> <input type="checkbox"/></li> <li>▪ Is the participant information sheet, consent form and any other documentation appropriate? <b>YES</b> <input checked="" type="checkbox"/> <b>NO</b> <input type="checkbox"/></li> <li>▪ Are the procedures for recruitment of participants and obtaining informed consent suitable and sufficient? <b>YES</b> <input checked="" type="checkbox"/> <b>NO</b> <input type="checkbox"/></li> <li>▪ Where required, does the researcher have current Disclosure and Barring Service (DBS) clearance? <b>YES</b> <input checked="" type="checkbox"/> <b>NO</b> <input type="checkbox"/></li> </ul>	
<b>Signed</b>	
<b>Date</b>	31.01.23

<p><b>COURSE LEAD/RESEARCH LEAD</b></p> <p>Does the proposed research as detailed herein have your support to proceed? YES <input checked="" type="checkbox"/> NO <input type="checkbox"/></p>	
<b>Signed</b>	

	A Styles
Date	01.02.2023

## **SECTION E: DETAILS OF THE PROPOSED RESEARCH**

**1. Provide a brief description of the proposed research, including the requirements of participants. This must be in lay terms and free from technical or discipline specific terminology or jargon. If such terms are required, please ensure they are adequately explained (Do not exceed 500 words)**

Pathological Demand Avoidance (PDA) is a term first coined in the UK by Professor Elizabeth Newson in the 1980s (Newson et al., 2003). Following their work in a specialistic clinic for complex communication and developmental difficulties (Christie, 2007), Newson and colleagues proposed PDA as a “separate entity within pervasive developmental disorders (PDDs)” (p595, 2003). However, PDA is not included as diagnostic category within the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013) or the International Classification of Diseases (ICD-11) (World Health Organisation, 2018).

In the current context, PDA is becoming more widely recognised as behavioural profile under the umbrella of autism spectrum conditions (Truman et al., 2021). Nonetheless, there is continuing debate as to whether PDA is disparate from other conditions, or whether its features are seen across a range of other existing diagnoses (Gillberg, 2014). Whilst many academics seek to uncover and advocate for ‘what PDA is’, it is important to acknowledge that regardless of this, PDA is a term that already exists and is being used within both health and education systems, and this term is prone to carrying different meanings for different individuals and organisations.

Previous studies have suggested that some Educational Psychologists (EPs) are using the term PDA in their practice, including identifying PDA (Gore Langton & Frederickson, 2016, 2018), however it is unclear as to how they are conceptualising this term. Research has also indicated that EPs are one of the professionals most likely to be involved for children identified with PDA (Gore Langton & Frederickson, 2016, 2018), and although assessment purposes are occasionally referenced, little is known about how EPs tailor their involvement more generally.

This research will explore:

- How EPs understand the term ‘PDA’
- Where EPs’ understanding of PDA has come from
- EPs views on the use of the term ‘PDA’
- When the term ‘PDA’ has been used in EP practice.
- What advice and recommendations EPs make when PDA is raised

Both local authority and independent EPs will be recruited for the research through an online advertisement, and they will be invited to take part in a virtual semi-structured interview. They will be asked to share where they are employed as part of data collection. This interview will take place via Microsoft Teams from a private room and will last for up to 1 hour. The qualitative data from the interviews will then be analysed using reflexive thematic analysis.

**2. Provide a statement on the aims and significance of the proposed research, including potential impact to knowledge and understanding in the field (where appropriate, indicate the associated hypothesis which will be tested). This should be a clear justification of the proposed research, why it should proceed and a statement on any anticipated benefits to the community. (Do not exceed 700 words)**

In the last decade, research suggests that there has been a noteworthy increase in families in the United Kingdom (UK) requesting identification and labelling of pathological demand avoidance (PDA) for their children (Green et al., 2018; Stuart et al., 2020). This is likely because some parents and clinicians feel that it can be difficult to access appropriate educational support without the PDA label (Sherwin, 2015). Gore Langton and Frederickson (2018) reported that some parents felt that ‘the identification of PDA was the route to the professional being able to suggest appropriate management strategies’ for daily living (p. 22).

However, since the term PDA was first conceived approximately 40 years ago (Newson et al., 2003), there has been ongoing debate as to whether this should be considered as a standalone diagnosis, or whether it better describes features of other conditions (Gillberg, 2014). Considering the controversy generated regarding PDA, literature has recognised that professional's responses to and willingness to use this term may vary (Gore Langton & Frederickson, 2018; O'Nions et al., 2014b). It is therefore possible for tensions to arise where different positions on PDA are taken; notably, parents have reported feeling judgement or blame in relation to their child's (demand avoidant) behaviours (Truman et al., 2021). Previous research into Educational Psychologist (EP) involvement for children and young people (CYP) identified with PDA is currently limited, and there is seemingly minimal documentation of how this term is understood and addressed by EPs.

Therefore, the proposed research is constituted of two aims:

- To explore EPs' perspectives on PDA, given the debate around its status, and how they understand this term.
- To explore how EPs then approach the term PDA in their practice, including what advice and support they offer within their involvement.

This study is highly relevant to the EP profession, as it will distinctly offer the EP voice within an increasingly growing body of research on PDA. As literature has demonstrated that EPs appear to be readily involved with CYP identified with PDA, this study will further explore whether EPs are using this term within their practice themselves. Additionally, this research will provide insight into how PDA is understood by EPs, and how this compares with the diversity of definitions or positions surrounding PDA. Whilst 'PDA strategies' have been proposed within the literature (Gore Langton, 2018; Woods, 2019), this study will further explore the specific approaches that EPs are taking when working with families and schools in supporting CYP's needs, which could in turn be applied in wider EP practice. This research will be disseminated by submission for publication, offer for presentation at Trainee EP conferences, and sharing its findings with LAs.

**3. Provide an outline of the methodology for the proposed research, including proposed method of data collection, tasks assigned to participants of the research and the proposed method and duration of data analysis. If the proposed research makes use of pre-established and generally accepted techniques, please make this clear. (Do not exceed 500 words)**

This research is underpinned by a relativist ontology and a social constructionist epistemology.

This research will employ a qualitative design, and the data will be collected using semi-structured interviews. Using semi-structured interviews allows for specific information on EPs' perspectives and approaches to PDA to be gathered, whilst additionally allowing participants to share their experiences and thoughts around PDA more broadly (Fylan, 2005). This is especially appropriate given the exploratory design of the research, as it provides depth in its contribution to a presently limited literature base. Semi-structured interviews are considered a valuable method as they will allow participants to share their opinions and practices more freely and in greater detail, without the influence of others or uneasiness of potential conflict or judgement. By developing a semi-structured interview protocol which considers appropriate probes to address the research questions, the impact of researcher bias is also reduced (Harrell & Bradley, 2009). The interviews will be recorded and transcribed for the purpose of analysis.

The data from the semi-structured interviews will be analysed using reflexive thematic analysis (RTA), an approach conceptualised by Braun and Clarke (2019) from their original 2006 model for thematic analysis. Engaging with the data within RTA is a six-phase process, which allows for common themes to be searched for and generated, whilst also recognising individual perspectives and experiences; this aligns with the researcher's rationale for use of semi-structured interviews. Within RTA, it is also recognised that the researcher holds their own biases and subjectivity. Once data is coded, practicing reflexivity will encourage the researcher to identify whether their own judgements or beliefs may have affected the analysis.

Data analysis is expected to take place over 2-3 months.

## **SECTION F: PARTICIPANT DETAILS**

**4. Provide an explanation detailing how you will identify, approach and recruit the participants for the proposed research, including clarification on sample size and location. Please provide justification for the exclusion/inclusion criteria for this study (i.e. who will be allowed to / not allowed to participate) and explain briefly, in lay terms, why these criteria are in place. (Do not exceed 500 words)**

The participants for this research will be recruited purposively through a sample of between 6 to 8 registered, practitioner Educational Psychologists (EPs). This number of participants is deemed appropriate for this research as it allows for the rich, individual data to be valued, whilst also accounting for feasibility of transcribing and analysing the data within a certain timeframe. The EPs will be required to have encountered the term PDA during their qualified practice. To represent a broader scope of perspectives and approaches, both local authority employed and independent EPs will be invited and selected to participate. The researcher will also seek to recruit EPs who are employed across different services, to additionally account for whether service positions or policies may inform perspectives and approaches to PDA. Recruitment for this research will take place using an advertisement on the online forums EPNNet and Twitter.

After a prospective participant has responded to the online advertisement, the researcher will thank them for their interest and send them the information and consent form. The participants will be advised to read through the information and send back the consent form if they are still interested in taking part. They will also be informed that they are welcome to contact the researcher if they have any further questions, and they are not required to respond if they are no longer interested.

The information sheet will specify that the researcher has the capacity to interview up to 8 people, with a view to recruit a balance of local authority employed and independent EPs. The first 8 EPs who consent to the research will make up the participant sample.

As soon as the recruitment sample is achieved, the online advertisements will be removed from EPNNet and Twitter. Any further EPs who express interest will be thanked for their interest and informed that the recruitment sample has been achieved. They will also be advised that they will be sent a summary of the findings at a later date.

**5. Please state the location(s) of the proposed research including the location of any interviews. Please provide a Risk Assessment if required. Consideration should be given to lone working, visiting private residences, conducting research outside working hours or any other non-standard arrangements.**

**If any data collection is to be done online, please identify the platforms to be used.**

Data collection will take place online using the platform Microsoft Teams. The researcher will conduct the interviews from a private room and confidentiality of the interviews will be further protected by the researcher using headphones.

The participants will be advised to organise a private room for themselves whilst taking part in the interview to protect their own information.

**6. Will the participants be from any of the following groups? (Tick as appropriate)**

- Students or Staff of the Trust or Partner delivering your programme.
- Adults (over the age of 18 years with mental capacity to give consent to participate in the research).
- Children or legal minors (anyone under the age of 16 years)<sup>1</sup>
- Adults who are unconscious, severely ill or have a terminal illness.
- Adults who may lose mental capacity to consent during the course of the research.
- Adults in emergency situations.
  - Adults<sup>2</sup> with mental illness - particularly those detained under the Mental Health Act (1983 & 2007).
  - Participants who may lack capacity to consent to participate in the research under the research requirements of the Mental Capacity Act (2005).
  - Prisoners, where ethical approval may be required from the National Offender Management Service (NOMS).

- Young Offenders, where ethical approval may be required from the National Offender Management Service (NOMS).
- Healthy volunteers (in high risk intervention studies).
  - Participants who may be considered to have a pre-existing and potentially dependent<sup>3</sup> relationship with the investigator (e.g. those in care homes, students, colleagues, service-users, patients).
- Other vulnerable groups (see Question 6).
- Adults who are in custody, custodial care, or for whom a court has assumed responsibility.
- Participants who are members of the Armed Forces.

<sup>1</sup>If the proposed research involves children or adults who meet the Police Act (1997) definition of vulnerability<sup>3</sup>, any researchers who will have contact with participants must have current Disclosure and Barring Service (DBS) clearance.

<sup>2</sup> ‘Adults with a learning or physical disability, a physical or mental illness, or a reduction in physical or mental capacity, and living in a care home or home for people with learning difficulties or receiving care in their own home, or receiving hospital or social care services.’ (Police Act, 1997)

<sup>3</sup> Proposed research involving participants with whom the investigator or researcher(s) shares a dependent or unequal relationships (e.g. teacher/student, clinical therapist/service-user) may compromise the ability to give informed consent which is free from any form of pressure (real or implied) arising from this relationship. TREC recommends that, wherever practicable, investigators choose participants with whom they have no dependent relationship. Following due scrutiny, if the investigator is confident that the research involving participants in dependent relationships is vital and defensible, TREC will require additional information setting out the case and detailing how risks inherent in the dependent relationship will be managed. TREC will also need to be reassured that refusal to participate will not result in any discrimination or penalty.

**7. Will the study involve participants who are vulnerable? YES  NO**

For the purposes of research, ‘vulnerable’ participants may be adults whose ability to protect their own interests are impaired or reduced in comparison to that of the broader population. Vulnerability may arise from:

- the participant’s personal characteristics (e.g. mental or physical impairment)
- their social environment, context and/or disadvantage (e.g. socio-economic mobility, educational attainment, resources, substance dependence, displacement or homelessness).
- where prospective participants are at high risk of consenting under duress, or as a result of manipulation or coercion, they must also be considered as vulnerable
- children are automatically presumed to be vulnerable.

**7.1. If YES, what special arrangements are in place to protect vulnerable participants’ interests?**

If YES, a Disclosure and Barring Service (DBS) check **within the last three years** is required.

Please provide details of the “clear disclosure”:

Date of disclosure:
Type of disclosure:
Organisation that requested disclosure:
DBS certificate number:

(NOTE: information concerning activities which require DBS checks can be found via <https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance>). Please **do not** include a copy of your DBS certificate with your application

**8. Do you propose to make any form of payment or incentive available to participants of the research?**  
YES  NO

If **YES**, please provide details taking into account that any payment or incentive should be representative of reasonable remuneration for participation and may not be of a value that could be coercive or exerting undue influence on potential participants' decision to take part in the research. Wherever possible, remuneration in a monetary form should be avoided and substituted with vouchers, coupons or equivalent. Any payment made to research participants may have benefit or HMRC implications and participants should be alerted to this in the participant information sheet as they may wish to choose to decline payment.

**9. What special arrangements are in place for eliciting informed consent from participants who may not adequately understand verbal explanations or written information provided in English; where participants have special communication needs; where participants have limited literacy; or where children are involved in the research? (Do not exceed 200 words)**

N/A

## **SECTION F: RISK ASSESSMENT AND RISK MANAGEMENT**

**10. Does the proposed research involve any of the following? (Tick as appropriate)**

- use of a questionnaire, self-completion survey or data-collection instrument (attach copy)
- use of emails or the internet as a means of data collection
- use of written or computerised tests
- interviews (attach interview questions)
- diaries (attach diary record form)
- participant observation
- participant observation (in a non-public place) without their knowledge / covert research
- audio-recording interviewees or events
- video-recording interviewees or events
- access to personal and/or sensitive data (i.e. student, patient, client or service-user data) without the participant's informed consent for use of these data for research purposes
- administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process
- performance of any acts which might diminish the self-esteem of participants or cause them to experience discomfiture, regret or any other adverse emotional or psychological reaction
- Themes around extremism or radicalisation
- investigation of participants involved in illegal or illicit activities (e.g. use of illegal drugs)
- procedures that involve the deception of participants
- administration of any substance or agent
- use of non-treatment of placebo control conditions
- participation in a clinical trial
- research undertaken at an off-campus location (risk assessment attached)
- research overseas (please ensure Section G is complete)

**11. Does the proposed research involve any specific or anticipated risks (e.g. physical, psychological, social, legal or economic) to participants that are greater than those encountered in everyday life?**

YES  NO

If **YES**, please describe below including details of precautionary measures.

**12. Where the procedures involve potential hazards and/or discomfort or distress for participants, please state what previous experience the investigator or researcher(s) have had in conducting this type of research.**

Whilst it is not anticipated that participants will experience discomfort or distress, the researcher has knowledge, skills and experience as a Trainee Educational Psychologist. This role means that the researcher has often consulted with vulnerable people and understands how to navigate and manage conversations sensitively.

**13. Provide an explanation of any potential benefits to participants. Please ensure this is framed within the overall contribution of the proposed research to knowledge or practice. (Do not exceed 400 words)**

**NOTE:** Where the proposed research involves students, they should be assured that accepting the offer to participate or choosing to decline will have no impact on their assessments or learning experience. Similarly, it should be made clear to participants who are patients, service-users and/or receiving any form of treatment or medication that they are not invited to participate in the belief that participation in the research will result in some relief or improvement in their condition.

The participants recruited for this research will potentially benefit through satisfaction of contributing to the EP profession, having their views heard and understood, and having an opportunity to reflect.

**14. Provide an outline of any measures you have in place in the event of adverse or unexpected outcomes and the potential impact this may have on participants involved in the proposed research. (Do not exceed 300 words)**

In the event of a participant showing signs of distress during the interview, the researcher will consult with the participant to consider whether pausing or stopping the interview may be in their best interests.

Time will be allocated following the interviews to debrief with participants over any anxieties or distress raised through the interview process.

The researcher will ensure that participants still have access to the information and consent forms, and that the participants are aware they can contact the researcher via email where they may have concerns at a later date.

**15. Provide an outline of your debriefing, support and feedback protocol for participants involved in the proposed research. This should include, for example, where participants may feel the need to discuss thoughts or feelings brought about following their participation in the research. This may involve referral to an external support or counseling service, where participation in the research has caused specific issues for participants.**

Time will be allocated following the interviews to discuss any thoughts or feelings raised through the interview process. A debrief and feedback form will also be provided, to include researcher gratitude for their interest and/or participation in the research, contact details for the researcher and information about where participants will be able to find the full thesis when available.



<p><b>16. Please provide the names and nature of any external support or counselling organisations that will be suggested to participants if participation in the research has potential to raise specific issues for participants.</b></p>
N/A
<p><b>17. Where medical aftercare may be necessary, this should include details of the treatment available to participants. Debriefing may involve the disclosure of further information on the aims of the research, the participant's performance and/or the results of the research. (Do not exceed 500 words)</b></p>
<p>Distress or adverse outcomes are unlikely to be anticipated from the research, and therefore specific aftercare is difficult to identify. A debrief form will be provided to participants including the contact details of the researcher, and any needs that arise from the interview can be discussed with the researcher as necessary.</p>

**FOR RESEARCH UNDERTAKEN OUTSIDE THE UK**

<p><b>18. Does the proposed research involve travel outside of the UK?</b> <span style="float: right;"><input type="checkbox"/> YES <input checked="" type="checkbox"/> NO</span></p> <p><b>If YES, please confirm:</b></p> <p><input type="checkbox"/> I have consulted the Foreign and Commonwealth Office website for guidance/travel advice? <a href="http://www.fco.gov.uk/en/travel-and-living-abroad/">http://www.fco.gov.uk/en/travel-and-living-abroad/</a></p> <p><input type="checkbox"/> I have completed a RISK Assessment covering all aspects of the project including consideration of the location of the data collection and risks to participants.</p> <p>All overseas project data collection will need approval from the Deputy Director of Education and Training or their nominee. Normally this will be done based on the information provided in this form. All projects approved through the TREC process will be indemnified by the Trust against claims made by third parties.</p> <p>If you have any queries regarding research outside the UK, please contact <a href="mailto:academicquality@tavi-port.nhs.uk">academicquality@tavi-port.nhs.uk</a>:</p>
<p>Students are required to arrange their own travel and medical insurance to cover project work outside of the UK. Please indicate what insurance cover you have or will have in place.</p>
<p><b>19. Please evidence how compliance with all local research ethics and research governance requirements have been assessed for the country(ies) in which the research is taking place. Please also clarify how the requirements will be met:</b></p>
N/A

**SECTION G: PARTICIPANT CONSENT AND WITHDRAWAL**

**20. Have you attached a copy of your participant information sheet (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**

YES  NO

If **NO**, please indicate what alternative arrangements are in place below:

**21. Have you attached a copy of your participant consent form (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**

YES  NO

If **NO**, please indicate what alternative arrangements are in place below:

**22. The following is a participant information sheet checklist covering the various points that should be included in this document.**

- Clear identification of the Trust as the sponsor for the research, the project title, the Researcher and Principal Investigator (your Research Supervisor) and other researchers along with relevant contact details.
- Details of what involvement in the proposed research will require (e.g., participation in interviews, completion of questionnaire, audio/video-recording of events), estimated time commitment and any risks involved.
- A statement confirming that the research has received formal approval from TREC or other ethics body.
- If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity.
- A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support.
- Assurance that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied.
- Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.
- A statement that the data generated in the course of the research will be retained in accordance with the [Trusts 's Data Protection and handling Policies](https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/): <https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/>
- Advice that if participants have any concerns about the conduct of the investigator, researcher(s) or any other aspect of this research project, they should contact Simon Carrington, Head of Academic Governance and Quality Assurance ([academicquality@tavi-port.nhs.uk](mailto:academicquality@tavi-port.nhs.uk))
- Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

**23. The following is a consent form checklist covering the various points that should be included in this document.**

- Trust letterhead or logo.
- Title of the project (with research degree projects this need not necessarily be the title of the thesis) and names of investigators.
- Confirmation that the research project is part of a degree
- Confirmation that involvement in the project is voluntary and that participants are free to withdraw at any time, or to withdraw any unprocessed data previously supplied.
- Confirmation of particular requirements of participants, including for example whether interviews are to be audio-/video-recorded, whether anonymised quotes will be used in publications advice of legal limitations to data confidentiality.
- If the sample size is small, confirmation that this may have implications for anonymity any other relevant information.
- The proposed method of publication or dissemination of the research findings.

- Details of any external contractors or partner institutions involved in the research.
- Details of any funding bodies or research councils supporting the research.
- Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

**SECTION H: CONFIDENTIALITY AND ANONYMITY**

**24. Below is a checklist covering key points relating to the confidentiality and anonymity of participants. Please indicate where relevant to the proposed research.**

- Participants will be completely anonymised and their identity will not be known by the investigator or researcher(s) (i.e. the participants are part of an anonymous randomised sample and return responses with no form of personal identification)?
- The responses are anonymised or are an anonymised sample (i.e. a permanent process of coding has been carried out whereby direct and indirect identifiers have been removed from data and replaced by a code, with no record retained of how the code relates to the identifiers).
- The samples and data are de-identified (i.e. direct and indirect identifiers have been removed and replaced by a code. The investigator or researchers are able to link the code to the original identifiers and isolate the participant to whom the sample or data relates).
- Participants have the option of being identified in a publication that will arise from the research.
- Participants will be pseudo-anonymised in a publication that will arise from the research. (i.e. the researcher will endeavour to remove or alter details that would identify the participant.)
- The proposed research will make use of personal sensitive data.
- Participants consent to be identified in the study and subsequent dissemination of research findings and/or publication.

**25. Participants must be made aware that the confidentiality of the information they provide is subject to legal limitations in data confidentiality (i.e. the data may be subject to a subpoena, a freedom of information request or mandated reporting by some professions). This only applies to named or de-identified data. If your participants are named or de-identified, please confirm that you will specifically state these limitations.**

YES  NO

If NO, please indicate why this is the case below:

**NOTE: WHERE THE PROPOSED RESEARCH INVOLVES A SMALL SAMPLE OR FOCUS GROUP, PARTICIPANTS SHOULD BE ADVISED THAT THERE WILL BE DISTINCT LIMITATIONS IN THE LEVEL OF ANONYMITY THEY CAN BE AFFORDED.**

**SECTION I: DATA ACCESS, SECURITY AND MANAGEMENT**

**26. Will the Researcher/Principal Investigator be responsible for the security of all data collected in connection with the proposed research? YES  NO**

If **NO**, please indicate what alternative arrangements are in place below:

**27. In line with the 5<sup>th</sup> principle of the Data Protection Act (1998), which states that personal data shall not be kept for longer than is necessary for that purpose or those purposes for which it was collected; please state how long data will be retained for.**

1-2 years  3-5 years  6-10 years  10> years

**NOTE:** In line with Research Councils UK (RCUK) guidance, doctoral project data should normally be stored for 10 years and Masters level data for up to 2 years

**28. Below is a checklist which relates to the management, storage and secure destruction of data for the purposes of the proposed research. Please indicate where relevant to your proposed arrangements.**

- Research data, codes and all identifying information to be kept in separate locked filing cabinets.
- Research data will only be stored in the University of Essex OneDrive system and no other cloud storage location.
- Access to computer files to be available to research team by password only.
- Access to computer files to be available to individuals outside the research team by password only (See 23.1).
- Research data will be encrypted and transferred electronically within the UK.
- Research data will be encrypted and transferred electronically outside of the UK.

**NOTE:** Transfer of research data via third party commercial file sharing services, such as Google Docs and YouSendIt are not necessarily secure or permanent. These systems may also be located overseas and not covered by UK law. If the system is located outside the European Economic Area (EEA) or territories deemed to have sufficient standards of data protection, transfer may also breach the Data Protection Act (1998).

Essex students also have access the 'Box' service for file transfer: <https://www.essex.ac.uk/student/it-services/box>

- Use of personal addresses, postcodes, faxes, e-mails or telephone numbers.
  - Collection and storage of personal sensitive data (e.g. racial or ethnic origin, political or religious beliefs or physical or mental health or condition).
- Use of personal data in the form of audio or video recordings.
- Primary data gathered on encrypted mobile devices (i.e. laptops).

**NOTE:** This should be transferred to secure University of Essex OneDrive at the first opportunity.

- All electronic data will undergo secure disposal.

**NOTE:** For hard drives and magnetic storage devices (HDD or SSD), deleting files does not permanently erase the data on most systems, but only deletes the reference to the file. Files can be restored when deleted in this way. Research files must be overwritten to ensure they are completely irretrievable. Software is available for the secure erasing of files from hard drives which meet recognised standards to securely scramble sensitive data. Examples of this software are BC Wipe, Wipe File, DeleteOnClick and Eraser for Windows platforms. Mac users can use the standard 'secure empty trash' option; an alternative is Permanent eraser software.

- All hardcopy data will undergo secure disposal.

**NOTE:** For shredding research data stored in hardcopy (i.e. paper), adopting DIN 3 ensures files are cut into 2mm strips or confetti like cross-cut particles of 4x40mm. The UK government requires a minimum standard of DIN 4 for its material, which ensures cross cut particles of at least 2x15mm.

**29. Please provide details of individuals outside the research team who will be given password protected access to encrypted data for the proposed research.**

**30. Please provide details on the regions and territories where research data will be electronically transferred that are external to the UK:**

## **SECTION J: PUBLICATION AND DISSEMINATION OF RESEARCH FINDINGS**

**30. How will the results of the research be reported and disseminated? (*Select all that apply*)**

- Peer reviewed journal
- Non-peer reviewed journal
- Peer reviewed books
- Publication in media, social media or website (including Podcasts and online videos)
- Conference presentation
- Internal report
- Promotional report and materials
- Reports compiled for or on behalf of external organisations
- Dissertation/Thesis
- Other publication

- Written feedback to research participants
- Presentation to participants or relevant community groups
- Other (Please specify below)

**SECTION K: OTHER ETHICAL ISSUES**

**31. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of Tavistock Research Ethics Committee (TREC)?**

N/A

**SECTION L: CHECKLIST FOR ATTACHED DOCUMENTS**

**32. Please check that the following documents are attached to your application.**

- Letters of approval from any external ethical approval bodies (where relevant)
- Recruitment advertisement
- Participant information sheets (including easy-read where relevant)
- Consent forms (including easy-read where relevant)
- Assent form for children (where relevant)
- Letters of approval from locations for data collection
- Questionnaire
- Interview Schedule or topic guide
- Risk Assessment (where applicable)
- Overseas travel approval (where applicable)

**34. Where it is not possible to attach the above materials, please provide an explanation below.**

## Have you encountered the term Pathological Demand Avoidance (PDA) in your EP practice?

My name is Fay Johnson and I'm a Trainee Educational Psychologist.

For my doctoral thesis, I am looking to speak with **qualified Educational Psychologists in the UK** about their views on PDA and their experiences of the term PDA in their practice.

### What does it involve?

You will be invited to take part in virtual interview via Microsoft Teams for a duration of up to 1 hour.

### How can I take part?

For more information or to express your interest, please contact me at:

[fjohnson@tavi-port.nhs.uk](mailto:fjohnson@tavi-port.nhs.uk)

## **Appendix B**

### **Title: An exploration of Educational Psychologists' perspectives on Pathological Demand Avoidance (PDA) and their approaches to this term in practice.**

#### **Who is doing the research?**

My name is Fay Johnson. I am a Trainee Educational Psychologist (TEP) in my second year of studying for the professional Doctorate in Child, Community and Educational Psychology. I am carrying out this research as part of my course.

#### **What is the aim of the research?**

This research aims to explore Educational Psychologists' (EPs) perspectives on pathological demand avoidance (PDA) and how they understand this term. It will also explore how EPs then approach the term PDA in their practice, including what advice and support they offer within their involvement. It is hoped that participating will enable participant's voices to be heard on this matter, alongside providing an opportunity to reflect on their role and contribute to knowledge that could be used to improve outcomes in supporting families and schools were the term 'PDA' is raised.

#### **Who has given permission for this research?**

The Tavistock and Portman NHS Foundation Trust has given ethical approval to carry out this research.

#### **Who can take part in this research?**

EPs who have encountered the term PDA during their qualified practice.

#### **What does participation involve?**

If you agree to take part, the interview will be conducted on Microsoft Teams. I will then ask you questions about your views and experiences of the term 'PDA'. There will be opportunity to discuss any thoughts or feelings raised with the researcher following the interview. All interviews will be recorded and transcribed. Recordings will be deleted after transcription. A summary information sheet will be provided to participants with the main findings once data analysis is complete, alongside an opportunity to discuss the findings with me.

#### **What will happen to the findings from the research?**

The findings will be presented within my thesis, which will be read by examiners and subsequently be publicly available to read, upon request, via Ethos (an electronic database, run by the British Library, that provides online access to UK doctoral theses). I may also publish the research at a later date in a peer reviewed journal. You will have the option to read a summary of my findings, or the full thesis, once completed. The findings will also be fed back in service development days and may be used to inform professional development activities.

#### **Do I have to participate?**

Participation in this research is entirely voluntary. If you do decide to participate but then change your mind, you can withdraw at any time up until the data has been analysed, at which point your participation will have already influenced the findings of the study.

#### **Will my taking part in this study be kept confidential?**

Yes. All records related to your participation in this research study will be handled and stored securely on an encrypted drive using password protection. Your identity on these records will be indicated by a pseudonym rather than by your name. The data will be kept for a minimum of 6 years. Data collected during the study will be stored and used in compliance with the UK Data Protection Act (1998) and the University's Data Protection Policy.

#### **Are there times when my data cannot be kept confidential?**

Confidentiality is subject to legal limitations or if a disclosure is made that suggests that imminent harm to self-and/or others may occur. The small sample size (6-8 EPs) may also mean that you recognise some examples and experiences you have shared in interviews. However, to protect your identity, pseudonyms will be used, and any identifiable details changed.



**Further information and contact details**

If you have any questions or concerns about any aspect of the research, please contact me:

Email: [FJohnson@tavi-port.nhs.uk](mailto:FJohnson@tavi-port.nhs.uk)

**If you have any concerns about the research, then you can contact the Trust Quality Assurance Officer**

Paru Jeram, [pjeram@tavi-port.nhs.uk](mailto:pjeram@tavi-port.nhs.uk)

**Appendix C**



**Research Title: An exploration of Educational Psychologists’ perspectives on Pathological Demand Avoidance (PDA) and their approaches to this term in practice.**

**Please initial the statements below if you agree with them:**

**Initial here:**

1. I have read and understood the information sheet and have had the chance to ask questions.	
2. I understand that my participation in this research is entirely voluntary, and I am free at any time to withdraw consent up until data analysis, at which point my participation will have influenced the results, without giving a reason.	
3. I agree for my interviews to be recorded.	
4. I understand that my data will be anonymised so that I cannot be linked to the data.	
5. I understand that there are limitations to confidentiality relating to legal duties and threat of harm to self or others.	
6. I understand that my interviews will be used for this research and cannot be accessed for any other purposes.	
7. I understand that the findings from this research will be published in a thesis and potentially in a presentation or peer reviewed journal as well as being fed back in service development days.	
8. I am willing to participate in this research and feel I meet the criteria of having encountered the term PDA during my qualified practice.	

Your name: .....

Signed.....

Date...../...../.....

Researcher name: Fay Johnson

Signed.....

Date...../...../.....

**Thank you for your help**

## Appendix D

**The following questions are reflective of the themes which will inform the interview schedule:**

- What is your understanding of the term 'PDA'?
- Where has your understanding of PDA come from?
- What are your views on use of the term 'PDA'?
- When has the term 'PDA' been used in your practice?
- What advice and recommendations do you make when PDA is raised?
- Is there anything else you would like to share?

## Appendix E: Recruitment Advert Posted on EPNET

~~~~~  
To reply privately to author: use Reply button

To reply publicly on EPNET: use Reply To All button  
~~~~~

Have you encountered the term Pathological Demand Avoidance (PDA) in your EP practice?

My name is Fay Johnson and I'm a Trainee Educational Psychologist at The Tavistock and Portman NHS Foundation Trust. For my doctoral thesis, I am looking to speak with qualified Educational Psychologists in the UK about their views on PDA and their experiences of the term PDA in their practice.

You will be invited to take part in a virtual interview via Microsoft Teams for a duration of up to 1 hour.

For more information or to express interest, please contact me at: [fjohnson@tavi-port.nhs.uk](mailto:fjohnson@tavi-port.nhs.uk)

Thank you!

-----  
Go to the EPNET home page at [www.jiscmail.ac.uk/epnet](http://www.jiscmail.ac.uk/epnet)  
to join or leave, change your mail settings, and see archived messages  
-----

[Top of Message](#) | [Previous Page](#) | [Permalink](#)

## Appendix F: Interview Schedule

### Interview Schedule

Thank you for meeting with me today. We are here for a research interview to explore your views and experiences of the term 'PDA'. And to reassure you, there are no right or wrong answers, and all views and experiences are welcome. Just to let you know that I am wearing headphones / the door is shut to protect confidentiality.

It is anticipated that the interview will last between 30 minutes to an hour in duration – Would you be happy to continue if it goes beyond that?

I know you received a copy of the information sheet, but before we get started, I would like to run through some of the key information about this research with you.

- Ethical approval to carry out this research has been obtained.
- The interview will be recorded and transcribed. The recording will be deleted after transcription.
- Participation in this research is entirely voluntary, and you can stop the interview at any time.
- There will also be opportunity to discuss any thoughts or feelings raised following the interview.
- Confidentiality in the interview is subject to legal limitations or if a disclosure is made that suggests that imminent harm to self-and/or others may occur.
- You will be provided with a summary information sheet with the main findings once data analysis is complete, alongside an opportunity to discuss the findings with me.
- The findings will be also presented within my thesis and will be publicly available to read. I may publish the research at a later date, and the findings will also be fed back in service development days and may be used to inform professional development activities.

Do you have any questions before we begin?

**I'm going to start the recording now.**

1. Can you describe the context you work in at the moment?

- a. How long have you been involved in that context for?
- b. Would you be happy to share if you work in the North, Midlands or South of the UK?

- What is your understanding of the term 'PDA'?
- Where has your understanding of PDA come from?
  - a. Could you comment on your LA's position on PDA?
- What are your views on the use of the term 'PDA'?
- When has the term 'PDA' been used in your practice?
- What advice and recommendations would you make if PDA is raised?
- Is there anything else you would like to share?

**Prompt question:** *Can you tell me a bit more?*

**I'm going to stop the recording now** - Thank you for taking the time to talk with me today.

Is there anything from the interview you would like to ask or discuss further?

Just to let you know:

- I am interviewing a small number of EPs and will be looking at themes in my data.
- If you do decide to change your mind, you can withdraw at any time up until the data has been analysed, at which point your participation will have already influenced the findings of the study.
- All records related to your participation in this research study will be handled and stored securely. Your identity on these records will be indicated by a pseudonym rather than by your name.
- The small sample size may also mean that you recognise some examples and experiences you have shared in interviews. However, to protect your identity, any identifiable details will be changed.

## Appendix G: Initial Familiarising and Coding by Hand

fundamentals around everyone's need to be safe. Some things we would never put expectations around, because it's not worth the fight with him. So if he wants to... He has got quite concern around cleanliness and hygiene, so if he wants to spray down his table and his laptop kind of 20 times a day, that's OK, we'll let him do that. If he wants staff to leave the room, that's OK, we'll let him do that. We're never going to impose that we stay in the room and then there's things that are in the middle. So we created a table of like bottom line expectations, things we never put demands over, and then things in the middle that are mood dependent and arousal level based and then that links in with the second point about kind of anxiety management. So then it's about reading the young person's arousal level to see what he can manage in that moment. So if he's really heightened, any kind of demands, phrased in any way are going to be too much for him so the adult completely steps back and doesn't put demands in place. If he is really calm, if he's engaging with staff, if he's having a laugh with them and using humour, if he is engaged and he's learning, then staff know that they can put more demands in, it will never be kind of demands that are kind of unrealistic, but it might be a little bit of challenge around the work that he's doing, so it might be "how about linked to that we try this?" but again it would still be put forward to him in terms of he's got a choice around it. It would never be OK, we're doing this now. And that is very much about reading his arousal level and staff do that so brilliantly by tuning into his nonverbal communication, his verbal communication. So there are times when he will just start to be, he will start to challenge staff members and will start to be unkind to them or he will start to swear or he'll start to kind of bang on the computer, or he'll stand up and seem to be agitated. Staff will read those signals and they will say to him "I'm just going to leave and give you some space and I'll come back when you when you're ready for me to come back in". We are as a school, we're an emotion coaching school, so we're not a punitive school who use kind of rules and rewards and consequences. That's just not what we're about. We're about relational approaches and reading the arousal level of young people, so that's quite kind of easy for our staff to manage generally, the core staff team, I mean there would be, there would be some staff members across school who would find it really difficult to support this young person. So that's why SLT have had to think really carefully about who it is that supports him, so these are staff members who are super, super patient, super, super nurturing, super fun and non-judgmental and are very good at kind of regulating their own arousal level and their own rejection around being told they need to leave the room at any point. So that core team has been carefully selected and over time that core team has had to change as well, based on breakdowns in that relationship, when things have gone badly and and then staff have found that hard and if staff at any point think that they're going to find it difficult and they're not able to give the young person what they need, then there's that kind of flexibility around, OK, let's, let's take you away because there's an acknowledgement that if staff don't feel that they're in a good place to support this young person, he will pick up on that. He's very perceptive to staff members arousal levels as well and he really needs to feel this sense of non-judgement from them, otherwise that makes things difficult. So I think that's probably most of the things that I want to say about the anxiety management. In terms of the negotiation and collaboration bit, it's about always working with his interests first. And then staff can negotiate based on what he's showing an interest in and can say, "OK, so you've started talking about this, I've got something you might be interested in. What do you think about this?" And so it's always kind of based on his interests and he's always got choice about things. And that was part of kind of what went wrong recently was that the young person had said that they wanted to go into a classroom. So there is no expectation from staff for him to go into the classroom, but it was transition day and people were going into their new classrooms and he was curious and he'd said "I want to go into my new classroom". And so we'd allowed that to happen yesterday, and he'd had a couple of lessons that had gone really, really well. And at that point then there was a kind of a discourse from staff

## Appendix H: Coding Extract from NVivo

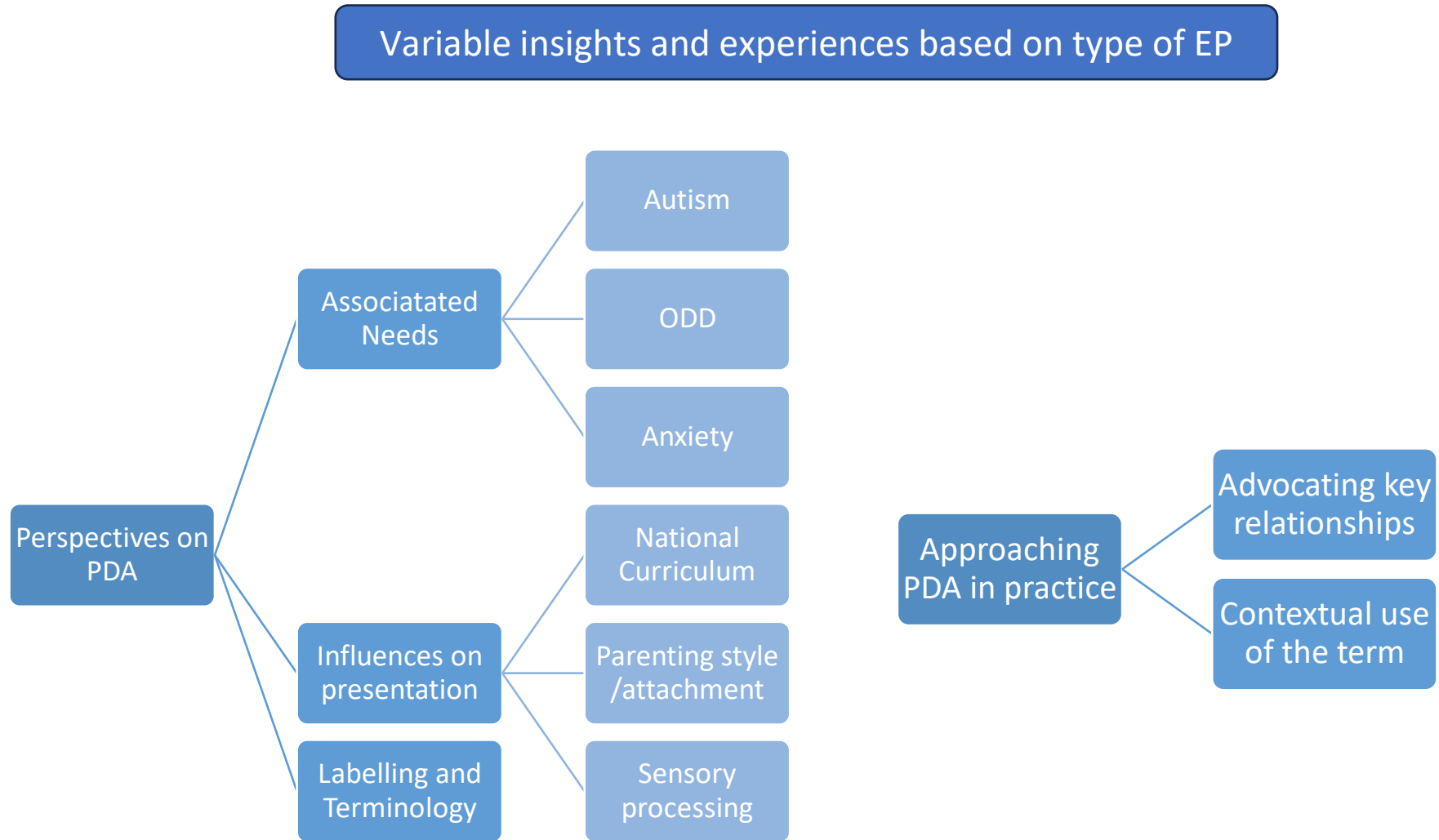
The screenshot displays the NVivo software interface. The top menu bar includes Home, Edit, Import, Create, Explore, Share, and Modules. The left sidebar contains navigation options: IMPORT (Data, Files, File Classifications, Externals), ORGANIZE (Coding, Codes, Cases, Notes, Sets), and EXPLORE (Queries, Visualizations). The main workspace shows a transcription document titled 'Transcription - Research Interview 8'. The text is highlighted in yellow, and the right sidebar displays a list of code stripes. The code stripes are:

- There is Confusion Around What PDA is
- PDA Encountered in Specialist Settings
- Support Should be Needs-Led
  - Negative View of PDA label
- EFs Often Don't Laise with People with the Power to Change a System
- Perception and Impact of Demand Avoidance on Others
- Unpicking Language and Behaviour
- PDA Behaviours Create Challenges in Mainstream Settings
- Behaviourist Policies in Secondary Schools Have a Negative Impact
- Positive Value of Labelling
- Persuing Specialist Provisions through Lab

The transcription text is as follows:

I've sort of tussled with this a little bit, because I think in a way, if it is diagnosed and it is used in a way that helps to understand experience and helps to understand needs, I think like any diagnostic label, it can have its uses, um, you know, if it's used to understand experience, develop empathy, develop the right support. Get the get a real understanding of the needs and then put the right support in place. It can be very, very useful and it could also open up uh narratives around, you know, the young person understanding themselves, the family being able to understand, you know, I I, the young people that I've met that did present as quite demand avoid with that quite demand avoidant profile, the the family were finding it very difficult to manage at home as well. So I think you know it could, it could be very helpful to get that understanding and that empathy and and to see it as you know, this is an actual thing that's happening for this young person. Um, so I think on one hand, it could be very useful, I think how I've heard it used is not always useful. It can be used very negatively. It can be used like I've already said, to kind of say, well, well, you know, they're just naughty. Some it often feels to me like the label is used synonymously with "they're naughty, or they've got PDA, they're demand avoidant", and therefore that means that they're naughty. Um, and so I think it can be, it can be unhelpful as well. Um, and I think I've also encountered it being used quite a lot as a as an excuse to not do anything, like ohh the the "they're demand avoidant, what can we do?" You know, in in mainstream we can't possibly meet their needs because they've got this PDA or they've got this demand, and I do hear PDA used a lot even though there's no, there's no diagnosis of that. And I do challenge that and I say, oh, you know, is, have they got a diagnosis of PDA and then they sort of backpedal a bit and they say, well, you know, the they're just demand avoidant, but it sometimes it seems to be used as a way of saying "their needs are too great for us to manage in mainstream". Um, I have actually been working with a young person recently that that has been labelled as demand avoidant. That the, you know, the the school have said he's got PDA. He hasn't, um, as far as the diagnostic criteria is concerned and they've excluded him because they've said that he can't, uh, they can't meet his needs in mainstream, you know, he, he he won't comply with anything that they ask him to do and it almost becomes an excuse to not do anything because they've sort of very much there's this narrative built up that this child won't comply. We, what can we possibly do? He needs to go to a specialist provision. Therefore, the only thing the only possible answer is for us to exclude them, um, and I have seen that quite a few times, I think because of maybe the complexity of the needs of children and young people who present in this way, and it can be very complex and you know, speaking from experience I've worked with children and young people who present as demand avoidant. It's difficult. It's draining. You know, it's not, it seems quite different from autism in that there's there doesn't seem to be, you know, that rigidity of routine and the predictability doesn't always sort of transcribe to young people that are demand avoidant. And yet, you feel like you're having to mix up your support. And, you know, what works one day doesn't work the next day. And and it can be quite emotionally draining. It can be really tiring and and I think you know, understandably, it's difficult in schools. So schools, when faced with that, they find that complexity very different, they find, difficult, sorry, they find the support, they don't know kind of how to offer the support or you know the the the getting that consistency is really difficult and so maybe it's easier to just say they've got PDA, they're demand avoidant. Therefore, we can't meet their needs. Therefore, they need to go to somebody and they sort of, they kind of, the school that I've just been working with has dressed it up very much as, um, "but we're just trying to, you know, think about what's best for him and what's best for him is he needs to go to a specialist provision where they can meet these needs and they understand him better". I completely disagree. I think you know with, with the right support he would be absolutely fine in mainstream, but it feels like, the label is being used to come to certain narratives and conclusions and therefore meet the needs of the school, really, and not the child.

**Appendix I: Visual mapping during Stage 1 of RTA**







**Appendix K: Initial Code Group Names in Stage 3 of RTA**

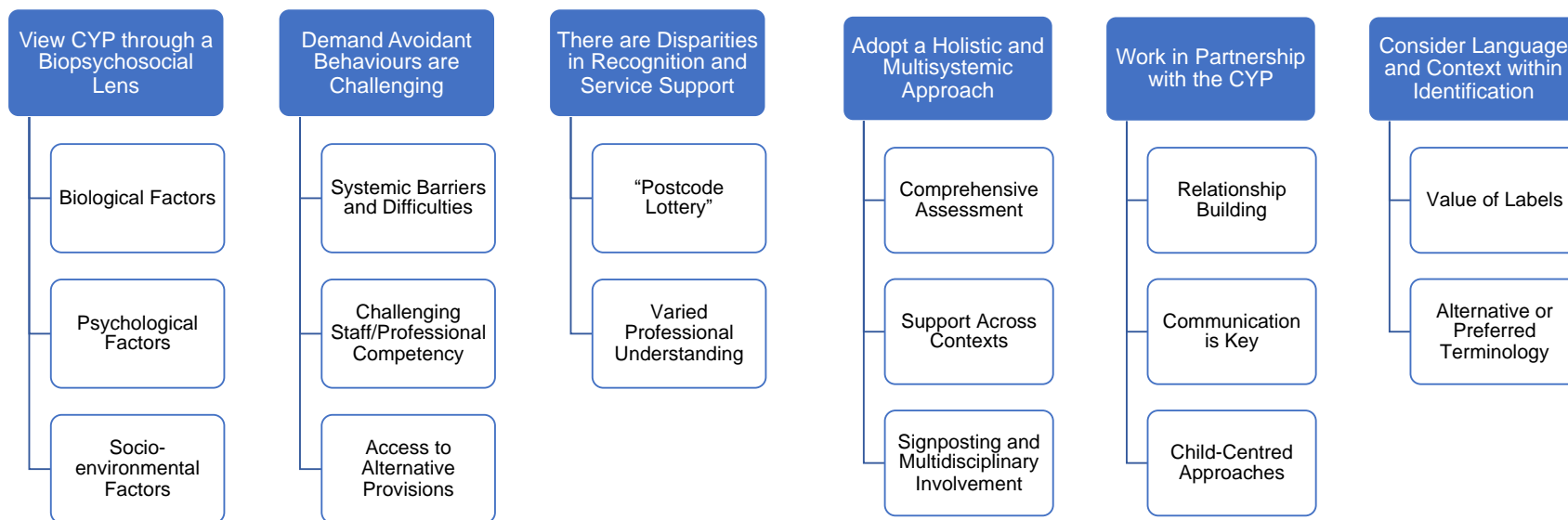
Systemic and Multidisciplinary Positions	Barriers and Challenges	Conceptualisations of PDA	EP Role	Approaches to Support	Developing Understanding
Recognition and Labelling	Factors to Consider	Alternative Provisions	Current Context	Relationships	

## Appendix L: Visual Mapping during Stage 3 of RTA

**What are EP's perspectives on PDA?**

**How do EPs approach the term PDA in their practice?**

EP Insights and Experiences Vary Based on The Context of Their Role



## Appendix M: Codes Mapped Against Themes in Microsoft Excel

Home    Insert    Draw    Page Layout    Formulas    Data    Review    View			
Paste		Arial    10    A <sup>+</sup> A <sup>-</sup>	General
B    I    U    A		Conditional Formatting	
E1			
	A	B	C
1	Name	Files	Reference
2	Theme		
2	'Demand Avoidant Profile' as Alternative Terminology	2	7 What's in a Name?
3	A Child-Centred Approach is Needed	4	12 Child-Adult Partnerships
4	Academics Known for PDA Involvement	1	2 Different Labels, Different Places
5	Accepting The Lifestyle or Learning Preferences that Meet PDA Needs	1	1 Adapt to Accommodate
6	Acknowledging What a CYP Can Manage	1	1 Child-Adult Partnerships
7	Adaptions Should Be Made Around a CYP	2	2 Adapt to Accommodate
8	Adjusting the System to Meet CYP's Needs	1	1 Adapt to Accommodate
9	Adult Capacity to Read CYP's Behaviours and Repond Appropriately	1	1 Child-Adult Partnerships
10	Adult Regulation Levels have an Impact	1	2 Unpicking the Socio-environmental Factors
11	Advocating Support Across Contexts	1	1 We Need To Work Together
12	All Possible Factors for Demand Avoidance Should Be Considered	2	6 Look at the Bigger Picture
13	Avoidance of Learning Tasks	2	2 Unpicking the Psychological Factors
14	Avoidance of Particular Individuals	1	1 Unpicking the Socio-environmental Factors
15	Behaviourist Policies in Secondary Schools Have a Negative Impact	1	1 Challenges are Prevalent
16	Challenges in Labelling Faced by Clinical Professionals	1	1 Different Labels, Different Places
17	Characteristics of a PDA CYP	1	1 Look at the Bigger Picture
18	Clinical Psychologists will Label and Advocate for PDA	3	5 Different Labels, Different Places
19	Conceptualised as 'Bad Behaviour'	1	1 Challenges are Prevalent
20	Concerns on Impact of Parental Preferences	1	1 Unpicking the Socio-environmental Factors
21	Considerations around Expectations on CYP	2	10 Adapt to Accommodate
22	Contextual Factors Should Be Considered	4	10 Look at the Bigger Picture
23	COVID Led to Gaps in CYP Development	1	1 Unpicking the Socio-environmental Factors
24	CYP are Attending Residential Schools	1	1 Challenges are Prevalent
25	CYP are Attuned to the Adults Supporting Them	1	2 Child-Adult Partnerships
26	CYP Are More Comfortable with Non-School Professionals	1	1 We Need To Work Together
27	CYP Experiencing a Stress or Threat Response	5	13 Unpicking the Biological Factors
28	CYP Find Demands Difficult to Manage	4	4 Look at the Bigger Picture
29	CYP Have a Desire for Control	2	2 Unpicking the Psychological Factors
30	CYP Have Negative Experiences of School	1	2 Challenges are Prevalent
31	CYP in Psychiatric Settings	1	1 Challenges are Prevalent
32	CYP May Respond to Novelty	1	2 Adapt to Accommodate
33	CYP Need Breaks from Expectations	1	2 Adapt to Accommodate
34	CYP Need Time to Process the Information Given	2	2 Adapt to Accommodate

## Appendix N: Codes Grouped by Theme

Theme/Subtheme	Codes
Look at the Bigger Picture	All Possible Factors for Demand Avoidance Should Be Considered Characteristics of a PDA CYP Contextual Factors Should Be Considered
Unpicking the Context	CYP Find Demands Difficult to Manage CYP Present with Social Differences Demand Avoidance Presents through Unmet Needs Developing Understanding of PDA Over Time Development of Assessment Practice is Needed Disliking Demands is a Normal Attribute EP Role in Monitoring Vulnerable Learners EP Role is About Unpicking Behaviours and Identifying Support Ideal for the EP Role is to Know and Understand a CYP Over Time Influence of Bodily Demands for PDA Interactive Factors Should Be Considered Limitations for Comprehensive Assessment Means of Identifying PDA Need for Comprehensive Assessment PDA Associated with Other Diagnoses PDA Behaviours Exist in Adults as well as CYP PDA Experience is CYP Dependent PDA is Associated with Difficulties PDA is Different to ODD Recognising Behaviour as Communication Recognition of Need over Diagnosis Understanding the Feeling Behind the Behaviours Understanding the Triggers for PDA Behaviours Unpicking Language and Behaviour
Unpicking the Biological Factors	CYP Experiencing a Stress or Threat Response Demand Avoidance Alongside Autism Diagnostic Criteria Demands Trigger a Stress Response EP Role is About Building Understanding of Neurodiversity Parents Associated with Being Autistic PDA Associated with Neurobiological Factors PDA Associated with Sensory Processing Experiences PDA is a profile of Autism PDA is Associated with Autism PDA is Different to Autism Understanding of PDA Through Understanding of Autism

Unpicking the Psychological Factors	<p>Avoidance of Learning Tasks</p> <p>CYP Striving for Autonomy</p> <p>CYP Striving for Control</p> <p>PDA Behaviours are Learnt</p> <p>PDA Behaviours May Precipitate Through Cognitive Factors</p> <p>PDA Behaviours Precipitate Through Level of Emotional Arousal</p> <p>PDA is Associated with Anxiety</p> <p>PDA is Associated with Emotional Regulation Difficulties</p> <p>PDA May Relate to Emotionally Based School Non-Attendance</p> <p>Presentations of Sensitivity</p>
Unpicking the Socioenvironmental Factors	<p>Adult Regulation Levels have an Impact</p> <p>Avoidance of Particular Individuals</p> <p>Concerns on Impact of Parental Preferences</p> <p>COVID Led to Gaps in CYP Development</p> <p>Demanding Curriculums Have an Impact</p> <p>Environmental Factors Should Be Considered</p> <p>Family Dynamics May Play a Role</p> <p>Impact of Parenting Style</p> <p>Parental Wellbeing May Play A Role</p> <p>PDA Behaviours Related to Trauma</p> <p>PDA is Associated with Attachment</p> <p>Socioeconomic Influence on Areas of Need</p>
Challenges are Prevalent	<p>Behaviourist Policies in Secondary Schools Have a Negative Impact</p> <p>Conceptualised as 'Bad Behaviour'</p> <p>CYP are Attending Residential Schools</p> <p>CYP Have Negative Experiences of School</p> <p>CYP in Psychiatric Settings</p> <p>CYP Not Accessing Mainstream Education</p> <p>CYP with PDA Behaviours Require Access to Alternative School Systems</p> <p>EPs Often Don't Liaise with People with the Power to Change a System</p> <p>Existing Provisions Aren't Supportive</p> <p>Families May Choose Different Education Styles</p> <p>PDA Behaviours are Challenging</p> <p>PDA Behaviours are Challenging Professional Competency</p> <p>PDA Behaviours are Difficult for School Staff to Support</p> <p>PDA Behaviours Create Challenges in Mainstream Settings</p> <p>PDA Behaviours Create Difficulties in Secondary Schools</p> <p>PDA Behaviours Result in Exclusion</p> <p>PDA Encountered in Specialist Settings</p> <p>Perception and Impact of Demand Avoidance on Others</p> <p>Pursuing Specialist Provisions through Labelling</p> <p>Schools Are Not Supportive for Sensitive CYP</p> <p>Schools Won't Support PDA Behaviours</p> <p>Systemic Issues with Managing Demand Avoidance</p> <p>There Are Difficulties Facilitating TA Support</p>

---

Different Labels, Different Places	Academics Known for PDA Involvement Challenges in Labelling Faced by Clinical Professionals Clinical Psychologists will Label and Advocate for PDA
Recognition of PDA	EP Perspective Not Included in Service Position Paper EPs Are Not Identifying PDA EPs Have Developed Their Own Understanding of PDA EPs Introducing the Concept of Demand Avoidance EPs Use The Term PDA Exposure to PDA Through Teaching Experience Exposure to the Term PDA Through Working in Schools Health Services Recognise PDA High Prevalence of Demand Avoidant Presentations Impact of Extensive Waits for Assessments Increasing Prevalence of the Term PDA Through Online Information Introduced to PDA Post-Qualifying Labels Exist as Social Constructs Learning About PDA Through Assessments Local Authorities Do Recognise PDA Other Professionals More Likely To Use The Term PDA Parents are Seeking Diagnosis or Label Parents are Using the Term PDA PDA Named by Medical Professionals Queries Around 'What is PDA' Relevance of Diagnostic Manuals in Identification of Need Reviewing Diagnoses of PDA Role of Private Services in Identifying and Supporting PDA Seeking Wider Understanding of PDA Service Position Includes What is Known and Implications for Practice Service Position is Research Informed Service Position is Unclear or Unknown Service Position of EDA over PDA Service Recognition is a Postcode Lottery Service Support or Recommendations are Unclear Services Do Not Use the Term PDA Socioeconomic Influence on PDA Identification Some Services Provide Support for PDA Behaviours There are Variable Positions from Health Services There Have Been Contentions around PDA Diagnoses There is a Lack of Labelling or Diagnosis There is a Limited Understanding of Demand Avoidance There is Confusion Around What PDA Is There is Disparity on EPs Approach to PDA There is Inconsistent Recognition and Labelling Type of EP Role Impacting Experiences of Providing Support Unclear Criteria for Identification

---

What's in a Name?	<p>'Demand Avoidant Profile' as Alternative Terminology</p> <p>Difficulty with the Word 'Demand'</p> <p>EP Wariness of Labelling</p> <p>EPs Are Not Using The Term PDA</p> <p>Negative View of PDA label</p> <p>Negative View on the Word 'Pathological'</p> <p>PDA Can Be Inappropriately Labelled</p> <p>PDA is Not Recognised</p> <p>PDA Known As 'Pathological Demand Avoidance'</p> <p>PDA Known is 'Persistent Drive for Autonomy'</p> <p>PDA Provides Understanding of Need</p> <p>Personal Experience of PDA</p> <p>Positive Value of Labelling</p> <p>Preference for the Term EDA Over PDA</p> <p>Professional Interest and Personal Research</p> <p>Professional Understanding of PDA</p> <p>Queries Around PDA Terminology</p> <p>Recognition Despite Lack of Diagnostic Clarity</p> <p>Recognition of PDA as a Diagnosis</p> <p>Recognition of PDA as an Entity</p> <p>The PDA Concept is Valid</p> <p>The Term PDA is Used Cautiously</p> <p>There are Variable Opinions on Preferred Terminology</p> <p>Understanding of PDA Through Experience</p>
We Need to Work Together	<p>Advocating Support Across Contexts</p> <p>CYP Are More Comfortable with Non-School Professionals</p> <p>CYP Require Multidisciplinary Support</p>
Multidisciplinary Support	<p>CYP Supported by Other Teams Asides from EPs</p> <p>Early Intervention Is Needed</p> <p>Early Support To Alleviate The Need for an EHCP</p> <p>EP Indirect Relationships with CYP</p> <p>EP Role in Supporting Teaching or Learning Support Assistants</p> <p>EP Role Involves Providing Training</p> <p>EP Role is About Supporting Staff</p> <p>EPs Involved in Multidisciplinary Position Paper</p> <p>EPs May Not Offer Advice around PDA</p> <p>Professional Understanding of PDA Supports Relationships with Families</p> <p>Social Care Considerations Are Needed</p> <p>Support for Schools Through Supervision</p> <p>Value of Speech and Language Involvement</p> <p>Working Alongside the Family</p> <p>Working Sensitively with Families and Professionals around Preferred Language</p>



---

Child-Adult  
Partnerships

A Child-Centred Approach is Needed  
Acknowledging What a CYP Can Manage  
Adult Capacity to Read CYP's Behaviours and Respond Appropriately  
CYP are Attuned to the Adults Supporting Them  
It is Important to Repair Relationships with School Staff  
Learning Alongside the CYP  
Punitive Approaches Should Be Avoided  
Relationship Building is Important  
Responding to What the CYP Wants or Needs  
Taking a Non-Judgemental Approach  
Working in Partnership with the CYP  
Working on CYP's Own Terms

---

Adapt to  
Accommodate

Accepting The Lifestyle or Learning Preferences that Meet PDA Needs  
Adaptions Should Be Made Around a CYP  
Adjusting the System to Meet CYP's Needs  
Considerations around Expectations on CYP  
CYP May Respond to Novelty  
CYP Need Breaks from Expectations  
CYP Need Time to Process the Information Given  
CYP Should be Provided with Controlled Choices  
Demands Can Be Perceived  
Demands on the CYP Should Be Reduced  
Freedom of Choice Builds Confidence  
How an Adult Communicates is an Important Strategy  
Implementation of the PANDA Approach  
Importance of Understanding Communication Style  
Importance of Using Flexible Approaches  
PDA Behaviours Present Due to Misunderstandings  
Producing a Resource of Recommendations  
Progress Through Supportive Strategies  
Providing an Adapted Curriculum  
Recommendations from the PDA Society  
Support Includes 'Picking Battles'  
Support Needs to be Creative and Adaptive  
Support Should be Needs-Led  
Typical Autism Strategies are Unhelpful  
Visual Supports May Be Useful

---

## Appendix O: Reflexive Diary Extracts

### *Positioning myself in the research...*

“I always knew that I would undergo my thesis research on PDA, but choosing to take a more curious position about this has made me feel a little uneasy. How can I explore the alternative narratives about PDA when I had professionally taken up a more distinct position before? Does this disservice the families who I have worked with and supported in obtaining this label? I think I need to remind myself that the intention of this research is not to discredit the experiences of those who identify with PDA and how they understand PDA. It is also the voices of others that will be conveyed, not my own, and it is the open curiosity that will help to expand the knowledge base on this topic.”

### *Preparing for the interviews...*

“I can’t believe I have managed to obtain my recruitment sample so quickly. It makes me think how prominent PDA might actually be as a topic in the EP world. Now I’m feeling nervous about starting the interviews – I’m wondering what it really means for an interview to be semi-structured. How much do I diverge from my interview schedule? And how do I ensure I am not introducing researcher bias? I hope the pilot interview will help...”

### *During the interviews...*

1. “My first interview complete, but it was quite short. Did I get enough detail? Was I perhaps being overly rigid in my questioning? I am also aware that I asked an additional question outside of the interview schedule because I was interested, but I think this was still a prompt for the participant to share more.”
2. “Lots of dialogue during this interview, so I am no longer concerned about whether the questions are provoking enough detail. I found it difficult to keep on my researcher hat once all the questions had been asked.”
3. “Really interesting that PDA was discussed as a ‘diagnosis’, but this has likely struck me where my in depth reading into the topic has guided me away from this idea.”
4. “I felt quite concerned about being in a different environment facilitating this interview and having a pre-existing relationship with this participant. I felt annoyed with myself that I asked if they were happy to end the recording before they had finished sharing what they had wanted to, and hence it took me up to an hour afterwards to write about it!”
5. “I was really fascinated by the insights shared today. I noticed myself prompting for information more, and wondered if I was overcompensating for the previous interview. Overall, I am happier with the length”
6. “Another longer interview. I wonder whether it’s easier to discuss PDA experiences when the participant is situated in a continuous context”
7. “Much like the last interview, I am thinking about the impact of role context again on the insights shared, as they seem to be doing less direct work”
8. “It struck me that this interview also referred to PDA as a ‘diagnosis’, and I continue to find this interesting.”

### ***Undergoing the analysis...***

“I feel like the common concepts are quite clear to me. I am really seeing all the different factors that the participants are considering in the context of PDA (e.g. sensory, anxiety, attachment). I’ve seen that other theses have uncovered something like 1000 codes from their transcripts, and I’m not sure that I am going to be able to generate that many, which makes me feel worried that my analysis won’t be good enough...”

“I’ve found it helpful to speak to Nikki about my coding and notice my own tendency to want to draw connections. It is interesting to reflect that I find it difficult to spend time focusing on details, as I find it easier to see the bigger picture. I guess that is the advantageous nature of this analysis being reflexive – It becomes what I give to it!”

### ***Writing up...***

“I am definitely finding that having a structured work plan with small, achievable goals is keeping me from feeling overwhelmed. Nonetheless, I am still finding it difficult to channel my thinking into writing. Because I am such a concise writer, it’s worrying to me that I’ve heard others are exceeding their word counts. Should I be finding it easier to have a flow of written dialogue?”

## Appendix P: Linked BPS competencies and HCPC Proficiencies

BPS Code	BPS competencies	HCPC Proficiency Codes
<b>1) Promoting Development and Education</b>		
BPS 1.1 PDE	Understand individual differences in developmental progression by demonstrating knowledge of theories of psychology relevant to: <ul style="list-style-type: none"> <li>• cognitive development and learning (e.g. maths and literacy)</li> <li>• language and communication</li> <li>• social, emotional and mental health and wellbeing, and behaviour</li> <li>• physical and sensory development</li> </ul>	12, 7.3, 12.1, 12.29, 12.30, 12.36, 12.39, 13.57
BPS 1.4 PDE	Demonstrate knowledge and understanding of biological, cultural, and social influences on learning, cognitive, social-emotional functioning, mental health and developmental processes, and application of evidence-informed curriculum and instructional strategies.	2.14 5.8, 12.1, 12.29, 12.30, 12.32, 12.35, 12.38, 12.39, 12.40
BPS 1.5 PDE	Demonstrate skills to work collaboratively with children, young people and the adults who care, work and plan for them to develop and implement practices and strategies to create and maintain effective and supportive learning environments.	5.5, 12.3
BPS 1.7 PDE	Demonstrate knowledge and understanding of parenting and family functioning and evidence working in partnership with parents and carers.	12.3, 12.34, 12.35
<b>2) Personal and Professional Values, Ethics and Skills</b>		
BPS 2.1 PPES	Demonstrate professional and ethical practice which adheres to the British Psychological Society's Code of Ethics and Conduct and the HCPC Standards of Conduct, Ethics and Performance.	2.1, 2.4, 2.7, 2.12, 2.13, 5.2, 6, 6.1, 6.2, 7.8, 7.12, 9.1, 9.2, 13.7, 13.29, 13.59
BPS 2.2 PPES	Apply knowledge of, and demonstrate the ability to operate effectively within, the legal, national and local frameworks for educational psychology practice	2.1, 2.4, 2.10, 5.2, 6.2

BPS 2.4 PPES	Demonstrate awareness of role boundaries and limits to legitimate professional expertise.	1.1,2.1, 2.9, 2.10, 2.12, 2.13, 4.4, 4.5,12.6, 12.28
BPS 2.5 PPES	Challenge views and actions judged potentially harmful to the child or young person.	2.2, 2.7, 2.9, 5.5, 5.6, 13.34, 13.59
BPS 2.8 PPES	Demonstrate an appreciation of the importance of the wellbeing of those with whom they work.	2.3, 13.24, 13.59
BPS 2.9 PPES	Demonstrate the ability to identify and communicate personal values and reflect honestly on the implications for their professional practice.	5.3, 10.1, 10.3
BPS 2.10 PPES	Ensure that they seek, secure and make effective use of supervision, consultation and other resources to improve and extend knowledge, understanding and skills.	3.5, 4.8, 10.4

### **3) Diversity and Cultural Differences**

BPS 3.2 DCD	Demonstrate understanding and application of equality and diversity principles and actively promote inclusion and equity in their professional practice.	5.1, 5.5, 12.32
BPS 3.3 DCD	Demonstrate understanding of the impact of inequality and poverty and their implications for wellbeing, access to resources and services.	5.1, 5.5, 12.32
BPS 3.6 DCD	Be aware of attitudes to impairment, disability, and neurodiversity and where relevant, redress influences which risk diminishing opportunities for all vulnerable children and young people including those with SEND and their families.	5.1, 5.3, 5.4, 5.8, 12.32
BPS 3.7 DCD	Demonstrate knowledge and understanding of race, religion or belief, gender, sexuality and their intersection as relevant to professional practice. This will include showing an understanding of the impact of stigmatising beliefs.	5.1, 5.8, 7.3, 12.32, 12.35

### **5) Psychological Assessment and Formulation**

BPS 5.3 PAF	Use and interpret psychological and educational assessments cautiously and ethically taking into account contextual and systemic factors.	13.3, 13.7, 13.21, 13.53
----------------	---	--------------------------

### **7) Service Delivery and Organisational Change**

BPS 7.2 SDOC	Demonstrate knowledge and understanding of key legislation, central to supporting commissioning authorities and services used by children and young people to meet their statutory responsibilities and to fulfil the educational psychologists' statutory role including the production of high-quality psychological advice.	2.10, 5.2, 5.4, 11.1, 11.8, 12.4, 12.6, 12.28
BPS 7.3 SDOC	Identify and understand policies, structures and accountability systems in a range of educational and other settings (e.g. early years, school, further education, youth justice) to ensure effective service delivery for all children.	2.10, 2.14, 12.4, 12.29, 12.32
BPS 7.6 SDOC	Work effectively with, and learn from, a range of professionals from health and social care backgrounds (e.g. speech and language therapists, occupational therapists, Child and Adolescent Mental Health Service (CAMHS) staff, social workers) and have an understanding of their knowledge base so that collaborative working is enhanced by identification of distinctive and complementary areas of practice.	2.14, 4.4, 7.14, 12.4
BPS 7.8 SDOC	Contribute a distinct psychological perspective within multi-professional teams and organisations.	4.4, 7.14, 10.2, 12.3, 13.62

### **8) Training and Development**

BPS 8.2 TD	Develop 'bespoke' training with clear, defensible, psychological foundations to address the training needs of service users and commissioners.	2.2, 11.8, 12.34, 13.12
---------------	--	-------------------------

### **9) Research**

BPS 9.4 RE	Develop a critical understanding of research design, including the rationale for the choice of alternative techniques, the formulation of 'researchable' questions and appropriate alternative approaches to research.	12.2, 13.27
BPS 9.5 RE	Plan and conduct rigorous research i.e. identify research questions, demonstrate an understanding of ethical issues, choose and implement appropriate methods and analysis, report outcomes and identify	2.7, 6.2, 7.16, 11.3, 11.6, 13.6, 13.11, 13.15, 13.27, 13.29, 13.54

---

appropriate pathways for dissemination, including publication and contribution to the professional knowledge base.

---

BPS 9.9 RE	Disseminate research to a range of audiences, through presentation and writing research reports and contribute to the professional knowledge base.	13.9, 13.55
---------------	--	-------------

---

**10) Transferrable skills**

---

BPS 10.2 TS	Demonstrate self-awareness and work as a reflective practitioner.	3.1, 3.2, 4.1, 4.8, 7.15. 10.1, 10.3
----------------	---	--------------------------------------

---

BPS 10.5 TS	Engage in and learn from interactive reflexive supervision processes.	3.5, 4.8, 10.1, 10.3, 10.4
----------------	---	----------------------------

---

BPS 10.11 TS	Make appropriate decisions about the use of interactive digital technology.	6.5, 7.7, 9.3, 13.1
-----------------	---	---------------------

---