

PE1732/F

The National Autistic Society Scotland renewed submission dated 28 January 2020

About autism

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while there are certain difficulties that everyone with autism shares, the condition affects them in different ways. Some autistic people are able to live relatively independent lives, while others will need a lifetime of specialist support. It affects more than one in 100 people in the UK¹.

About us

The National Autistic Society Scotland is a leading charity for autistic people in Scotland and their families. There are around 58,000 autistic people in Scotland, both children and adults, plus their more than 174,000 family members and carers. We provide local specialist help, information and care across Scotland to children, adults and families affected by autism. We offer a wide range of personalised quality support at home and in the community, both in groups and one-to-one. Our branches in Scotland offer families and autistic people help and mutual support, and our employment team support autistic people in work and their employers.

Introduction

Pathological demand avoidance (PDA) is a profile that describes those whose main characteristic is to avoid everyday demands and expectations to an extreme extent. This demand avoidance is often – but, according to some PDA adults, not always – accompanied by high levels of anxiety.

PDA was first identified by Professor Elisabeth Newson at the Child Development Research Unit of Nottingham University in the 1980s. However, it was not until 2003 that the first ever peer reviewed research paper on PDA was published. Professor Newson described PDA as sitting under the umbrella of Pervasive Developmental Disorder.

Currently the categories of Pervasive Developmental Disorders are being replaced by autism spectrum disorders. PDA is increasingly, but not universally, accepted as a profile that is seen in some autistic people. Although there is no prevalence study as yet, the demand avoidant profile is thought to be relatively uncommon.

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The existence of PDA as a ‘diagnostic term’ and how it fits within the autism spectrum is widely debated. With limited evidence-based research, there is no conclusive and

¹ Baird, G. et al. (2006) *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*. The Lancet, 368 (9531), pp. 210-215, and Brugha, T. et al (2009) *Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey, 2007*. Leeds: NHS Information Centre for Health and Social Care. Available to download at <http://www.hscic.gov.uk/catalogue/PUB01131>

agreed upon definition of PDA. International and American diagnostic manuals do not currently recognise PDA as a separate diagnosis or a subgroup within the autism spectrum. What is generally agreed upon is what is often referred to as a *PDA profile*. There has not been enough research conducted for PDA to be used as a diagnostic term, but some clinical diagnostic teams do describe it as a profile that they recognise within the autism spectrum. This recognition of need has been found to be helpful when signposting to other professionals for support.

In a survey of autistic people and family members in Scotland carried out by our charity, 50% of people who responded said they thought professional understanding of autism was poor or very poor. Anecdotally, we hear from parents that understanding among professionals of how someone with a PDA profile may present and the different strategies and type of support they might need is even lower. Greater awareness of the PDA profile is important so that clinicians can provide a more accurate profile of an individual's strengths and needs following a diagnostic assessment. This can lead to more appropriate support being put in place sooner.

Our ongoing work with autistic people across Scotland has continually highlighted to us that, generally, professionals across the country are still not receiving an adequate level of training in autism. A lack of knowledge and understanding of autism in all areas of service-provision is a crucial issue and one that is encountered by autistic people every day in Scotland. Our charity is consistently told of situations where, even when adequate service provision exists, the lack of autism-specific training among professionals and service-providers is still an incredibly difficult barrier to accessing satisfactory support. Therefore, should a toolkit or other such measures be put in place in order to support professionals assisting those with a PDA profile, it is of paramount importance that suitable and accessible training is provided in how to use such tools effectively.

Conclusion

The last five years have seen an increase in the number of research papers written about PDA. However, the research remains extremely limited. Within the research, there is some consensus that the term PDA may be a useful term to flag up a range of co-occurring difficulties for many people, with or without an autism diagnosis, and that any approach should be personalised to the needs of the individual. However, there is generally no consensus on whether PDA is a separate, clinically diagnosable condition; whether PDA is or is not a specific subtype of autism; and what the best approach is to support people with a PDA profile.

The National Autistic Society Scotland works hard every day in order to help make Scotland as autism-friendly a country as possible. To that end, we campaign for better services and support for all of Scotland's autistic people, from more efficient diagnosis services to suitable support for people in all stages of life post-diagnosis, and we will continue to work towards making these goals a reality. We are also clear that the standard of training in autism, and associated profiles such as PDA, among professionals and service-providers across Scotland is not at a satisfactory level and we will continue to state the case for widespread autism-specific training in order to rectify this.