

## **PE1732/C**

National Autistic Society Scotland submission of 23 October 2019

### **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 UK<sup>1</sup>.

### **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 increasingly, but not universally, accepted as a behaviour profile that is seen in some individuals on the autism spectrum. People with a demand avoidant profile share difficulties with others on the autism spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours, activities or interests. However, those who present with this particular diagnostic profile are driven to avoid everyday demands and expectations to an extreme extent. This demand avoidant behaviour is rooted in an anxiety-based need to be in control.

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. The concept of a PDA behaviour profile is still evolving and developing.

The National Autistic Society Scotland is clear that PDA is part of the autism spectrum (more information on PDA can be found on [our website](#)).

### **Petition PE1732**

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<sup>1</sup> 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>

National Autistic Society Scotland welcomes an opportunity to raise awareness of PDA within the Scottish Parliament. 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 behaviour profile may present and the different strategies and type of support they might need is even lower. Greater awareness of PDA 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.

As a behaviour profile on the autism spectrum, PDA brings with it its own unique challenges and issues, both for the individual and for their family and carers. Therefore, putting measures in place to assist professionals in diagnosing and designing therapeutic support for children, young people and adults who have PDA is a crucial step, particularly given the lack of awareness and understanding of the behaviour profile in general. Appropriate education, therapies and interventions to reduce or minimise the effects of the condition for the individuals and their families and carers is also a vital part of any steps towards providing PDA support.

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 PDA, it is of paramount importance that suitable and accessible training is provided in how to use such tools effectively.

## **Conclusion**

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 support 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 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.

Our objective is a Scotland that works for its autistic people, including all behaviour profiles and associated conditions. However, while we continue to work hard to achieve that objective, we do welcome moves to improve services and support for specifically identified behaviour profiles such as pathological demand avoidance. Therefore, National Autistic Society Scotland can confirm that it fully supports the actions proposed in this petition.