

WHAT MAKES A GOOD DIAGNOSTIC ASSESSMENT FOR A CHILD WITH A PDA PROFILE? - A BASIC GUIDE

INTRODUCTION

This paper is aimed at those who may be wondering if their child's profile of development and behaviour fits with the descriptions of Pathological Demand Avoidance (PDA). It briefly sets out some of the key issues around what a diagnosis is for, what steps are considered important in arriving at a diagnosis and current views about where PDA fits within this. The information on diagnosis found on the National Autistic Society website is also very helpful: <http://www.autism.org.uk/about/diagnosis>

PDA is now widely understood to be part of the autism spectrum. Children who present with this particular diagnostic profile are driven to avoid everyday demands and expectations to an extreme extent. This is rooted in an anxiety-based need to be in control.

What is a diagnosis and why is this helpful?

A diagnostic opinion is a way of identifying and gaining a better understanding of a child's development and needs. As well as giving a description of the child's profile it should include an assessment and analysis of individual characteristics, strengths and needs, as well as setting out some of the priorities in terms of supporting the individual and their family.

A diagnosis may be given by clinicians, or team of professionals, who are working in a variety of different situations. For example, this might be in a child development centre or through a Child and Adolescent Mental Health team (CAMHS). In the process of diagnosis clinicians may refer to one of the diagnostic manuals: ICD-10 (published by the World Health Organisation) or DSM 5 (produced by the American Psychiatric Society). Different local areas may have policies that include guidelines about working within one of these systems, but this is not always the case.

The diagnostic manuals continue to evolve and develop over time and this reflects changes brought about by both research and clinical practice. A number of different terms are used in the diagnosis of individuals who are seen as being within the autism spectrum. Both recent and forthcoming changes means that autism spectrum disorder (ASD) is likely to become the most widely used term but additional ones will often be used to describe particular profiles presented by individual children.

Where does the PDA profile fit within this?

As the notion of the autism spectrum has developed over recent years, PDA has become increasingly understood as being part of this spectrum. Research has accumulated evidence that the features of PDA are dimensional (which means they vary in intensity) within the autism spectrum and affect individuals to a varying extent. The demand avoidant profile is distinctive and identifiable in children when a number of these features exist at a particular frequency and intensity.

While PDA is relatively uncommon it is important to recognise and understand the distinct profile because it has implications for the way children are best supported and managed.

It is important to remember that we are still at a very early stage in our understanding of PDA. There is continuing debate and research over the exact nature of the profile and how it is described alongside other diagnostic terms. When profiles, or conditions, are defined by a number of behavioural features there will be obviously be connections and overlaps between them. Similar behaviours can be seen within other conditions and for other reasons. For a clinician teasing out the underlying causes can be very difficult. This underlines the importance of detailed assessments including the taking of a developmental history, direct observation and information from all those concerned.

Where and how is the PDA profile most likely to be identified and assessed?

Sometimes the initial question of whether a child's development and behaviour might best be explained by the PDA profile is first raised by an individual professional, who may have had some experience of other children with this pattern of development and behaviour. More often, though, it is first raised by parents who are struggling to understand their child and have come across information about PDA. At this point, different families will vary in the amount and type of contact that they have had with professionals. This might reflect the age of the child, the severity of any behavioural issues, variations in local practice and the families own preference. The child may already have had a diagnosis of some sort, or they might not have had one at all.

If an assessment is to be carried out which might consider the possibility of the PDA profile this is most likely to occur within the local pathway for children with suspected ASD, which is by way of a referral usually triggered by a professional who is involved with the child.

What are the elements of a good diagnostic process?

There are national guidelines for the assessment of autism published by NICE <https://www.nice.org.uk/Guidance/QS51>. Amongst other things these guidelines recommend an appointment within three months of referral and an assessment by a multidisciplinary team.

In practice there are great variations in the way this happens in different parts of the country according to local practice, clinical differences and availability of resources. In many cases this assessment is carried out by a child development clinic, but Child and Adolescent Mental Health Services (CAMHS) are increasingly involved in autism assessments. In other situations diagnosis is made by individual clinicians but this would not be seen as best practice.

Exploring the PDA profile in an assessment is especially complex. Aspects of the profile may be variable at different times and in different places. There is also the potential for some behaviours and their causes to be confused with different conditions. Sometimes clinicians can focus on one aspect of a child's presentation and miss the underlying difficulties that contribute to this. This makes a detailed and comprehensive process critical. The key elements to this would be:

- more than one professional involved in the assessment
- direct observation of the child
- a detailed history from the parents or carers
- information gained from more than one setting
- extensive clinical experience within the assessment team

During many assessments of autism spectrum disorders diagnostic tools are used to collect information in order to help to decide whether someone has a profile that is on the spectrum. The ADOS (Autism Diagnostic Observation Schedule) and the ADI-R (Autism Diagnostic Interview-Revised) are examples, both of which are based on the diagnostic manuals. The DISCO (Diagnostic Interview for Social and Communication Disorders) uses a more dimensional approach and gives an understanding of an individual's profile and needs, as well as a diagnostic formulation. An advantage of these diagnostic tools is that they can help to provide some consistency in the assessment process followed in a particular region, or within a service. They are not, though, intended to be screening instruments or stand-alone tools. They are there to gather information, or structure the observations, that professionals make as part of their assessment. They have to be used with some flexibility and are still reliant on an individual clinician's experience, judgement and interpretation. This is especially the case when picking up less typical presentations of autism (such as PDA), where some of the difficulties in social understanding and social communication can be more subtle and are less apparent at first.

As a parent how can I access an appropriate diagnostic assessment and best support the process?

The answer to much of this will be based on local information relating to the area you live in. This might be provided through your GP or your child's school in the first place. The National Autistic Society may also be able to help through its Autism Helpline or directory of services, as will the PDA Society helpline. It is often helpful for families to have the support of an individual professional who knows the child well, even though they may not be part of the diagnostic service.

In advance of the assessment it is useful to know as much about what to expect on the day as possible. This might include practical information about where to park, how long the appointment will last or who will be working with your child. It's also helpful to have an idea of the sorts of questions you might be asked or if there are other reports you need to bring. Some organisations are better at providing this as a matter of course than others. In some situations you may need to get in contact yourself to ask for this sort of detail.

Inevitably the assessment process can be stressful both for parents and children, so it is best to be as well prepared as possible. Gathering and organising your thoughts and observations about your child and writing these down, or keeping a diary before the assessment can be helpful. Some people find it helpful to take photo albums which can help them to remember things when they are asked questions about their child's early development and history. Previous reports and feedback from how the child is in other settings is also very important.

When PDA is being considered as a potential diagnosis the Extreme Demand Avoidance Questionnaire (EDA-Q) can be useful to help organise your thoughts and to use as a basis for discussion with the assessment team:

<http://www.pdasociety.org.uk/resources/extreme-demand-avoidance-questionnaire>

It is important, though, to remember that the EDA-Q was developed for research purposes and is not a diagnostic tool. Outside of research it can be used as a guide to identify PDA traits and point to the need for further evaluation.

A diagnostic opinion may be given at the end of the assessment, either in discussion with the team or in the written report that follows. There should be an opportunity to discuss the report and its findings with a member of the team. A good diagnostic assessment should

not only give a diagnosis but also explain how this was arrived at and the way in which this description fits with the individual child's profile. It should also point out other issues about the child's strengths and needs and how they may best be supported.

In terms of the PDA profile there may be different terms used such as PDA, Autism Spectrum Disorder characterised by extreme demand avoidance, or ASD with a PDA profile. These terms may reflect the individual characteristics of the child, or the practitioner's preference for particular terminology. Any of these terms can be sufficient as long as they sit alongside a detailed description of the child's individual profile and provide a signpost to the most appropriate support and management strategies.

For more information about PDA please see the National Autistic Society website www.autism.org.uk/pda and The PDA Society website www.pdasociety.org.uk

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www.pdasociety.org.uk/professionals/pda-development-group