

Developing a multi-agency assessment pathway for children and young people thought to have a Pathological Demand Avoidance profile

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Editorial comment

Lisa Summerhill is the Lead Clinical Psychologist working in a specialist autism assessment service provided by the NHS. Kate Collett is the coordinator of the specialist post diagnostic autism team provided by the Local Authority. In this paper, they present the case for setting up an assessment pathway for children thought to fit the profile of Pathological Demand Avoidance (PDA). They were responding to increasing demands for PDA assessments and wanted to clarify the best course of action to support children who were often already diagnosed with autism but who were challenging schools and families. The authors are cautious about applying yet another label and strongly believe in assessment through intervention, that is, to observe a child's response to strategies and engage regularly with all concerned to discuss next steps. They would like to conduct further research on the effectiveness of the approaches used so that they can build on the expertise within Solihull on understanding and managing children who are often described as challenging and complex and who have been excluded from school.

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Introduction

As awareness and interest in PDA increase through conferences, publications and discussions within assessment teams on children who seem to be qualitatively different to others with autism, so the demand for assessments of this possible subtype grows. However, the latest clinical diagnostic criteria in DSM-5, the Diagnostic and Statistical Manual of Mental Disorders – 5th edition (American Psychiatric Association, 2013) do not reference PDA which makes it hard for clinicians to determine how best to assess this group. There is anecdotal evidence that perhaps children with PDA are not identified early and may then be viewed simply

as defiant and deliberately challenging and then excluded from schools as a result (Gore–Langton and Frederickson, 2015). This perpetuates the difficulties that these young people experience, with their learning, social relationships and mental health.

In Solihull, due to increasing demands for assessments of children thought to have PDA, it was decided that a distinct pathway needed to be developed to ensure that there was early recognition of PDA and appropriate early intervention.

Aim of the paper

The aim of this paper is to encourage discussion among service providers regarding PDA. It is hoped that the pathway we developed and model of 'assessment over time' will enable services to find ways of working together to better understand the complexities of some children's needs and to address these needs, without necessarily having to have confirmed a specific diagnosis.

Background

The concept of PDA was first introduced by Professor Elizabeth Newson, a Consultant Child Psychologist in the 1980s (Newson, 1989). In 2003, Newson and her colleagues published an article in which they proposed that PDA should be recognised as a separate entity within the diagnostic category of PDD (Pervasive Developmental Disorders). In 2008, information about PDA was provided by the National Autistic Society (NAS) on its website. When a proposed screening instrument for PDA was developed by Liz O'Nions in 2010, more literature quickly followed. Additionally, research has been completed with parents of children described as having PDA to determine the most important aspects of support for these children and their families (see Gore - Langton and Frederickson, 2015).

PDA and the diagnostic manuals

Although there has been a growing body of evidence for the existence of children with a PDA profile; who have some features in common with autism but who are also qualitatively different and do not respond to some of the usual approaches used with autistic children, the changes in the diagnostic criteria, such as those in the DSM-5 (American Psychiatric Association, 2013) have not recognised PDA as a clinical diagnosis. It is also anticipated that the 11th version of the International Classification for Diseases (World Health Organisation, 1990), due for publication in 2018, will not consider this sub-type as a clinical diagnosis. This has created uncertainty in services across the UK in deciding the most appropriate way to respond to an increasing demand for a PDA assessment; and knowing how to assess for something for which there is no standardised assessment or diagnostic criteria.

Additionally there have been changes in the literature suggesting that PDA may be more appropriately re-termed as 'Extreme Demand Avoidance' (Gillberg, 2014). Although a screening instrument has been designed for identifying EDA (O'Nions et al, 2014), there is yet no agreement in relation to the thresholds that need to be reached in the key areas of difference to confirm PDA/EDA as a diagnosis.

Services for children and young people with a diagnosis on the autism spectrum in Solihull

The Specialist Assessment Service (SAS) offers an assessment and diagnostic service for children and young people in Solihull up to the age of 18 who are thought to have autism. The service has been operational since 2002 and uses the International Classification of Diseases, ICD-10 (World Health Organisation, 1990) diagnostic criteria to reach diagnostic decisions. During the assessment, a profile of strengths and needs is drawn up and recommendations made to support the child and family.

Before a child can access the service, evidence is required from the referrer of a 'graduated response' where services and support should have already been put in place for a minimum of 6 months or 2 school terms. This 'graduated response' could be provided by Specialist Educational Services (internal or external to the school) or Specialist Health Services; Health Visiting, Paediatrics, Speech and Language Therapy, Occupational Therapy, Physiotherapy, Child and Adolescent Mental Health Service. The evidence needs to give details of the outcomes of the support given. The information gathered during the graduated response then forms an important part of the assessment process.

If the child receives a diagnosis on the autism spectrum, then s/he receives support from a team of autism education specialists, which is provided by Solihull Local Authority; the Specialist Inclusion Support Service Autism Team (SISS Autism Team). This team includes experienced practitioners with a specialism in autism and consists of specialist teachers and inclusion support practitioners. The aim of the service is to work alongside schools to provide advice, monitoring and levels of

support (dependent upon need). If a child attends either a specialist provision, or a school outside of Solihull, the family still receives initial post-diagnostic support. The team is an affiliated training hub for the Autism Education Trust (AET) and all support offered is linked to the AET framework (see www.autismeducationtrust.org.uk).

Audit of demand for PDA assessments

Since April 2016, an audit of demand has been recorded by the Specialist Assessment Service. Based on these data, the following conclusions can be drawn:

- There was an increasing demand for PDA assessments between April 2016 and December 2017
- The momentum for requests was building month upon month, as people became aware of the PDA Society (a national charity and support service) and Solihull's response to requests
- From May until December 2016, there were about two requests per month
- From January 2017, this had increased to three per month
- The highest demand had been from the Autism Intense Monitoring (AIM) provision from the SISS Autism Team. AIM targets children who are at significant risk of school exclusion
- A significant number of referrals were for children who had already been diagnosed with autism

It was believed there needed to be a multi-agency approach to requests for such assessments. Most requests came for children who had already received a diagnosis on the autism spectrum. There also appeared to have been a deterioration in the presentation of these children which was the result of a number of possible factors, as follows:

- The strategies recommended by colleagues in the SISS Autism Team were not being implemented
- The young person was developing a co-morbid mental health difficulty
- The young person had additional neuro-developmental difficulties, learning difficulties or attachment style difficulties that shared similar profiles to PDA

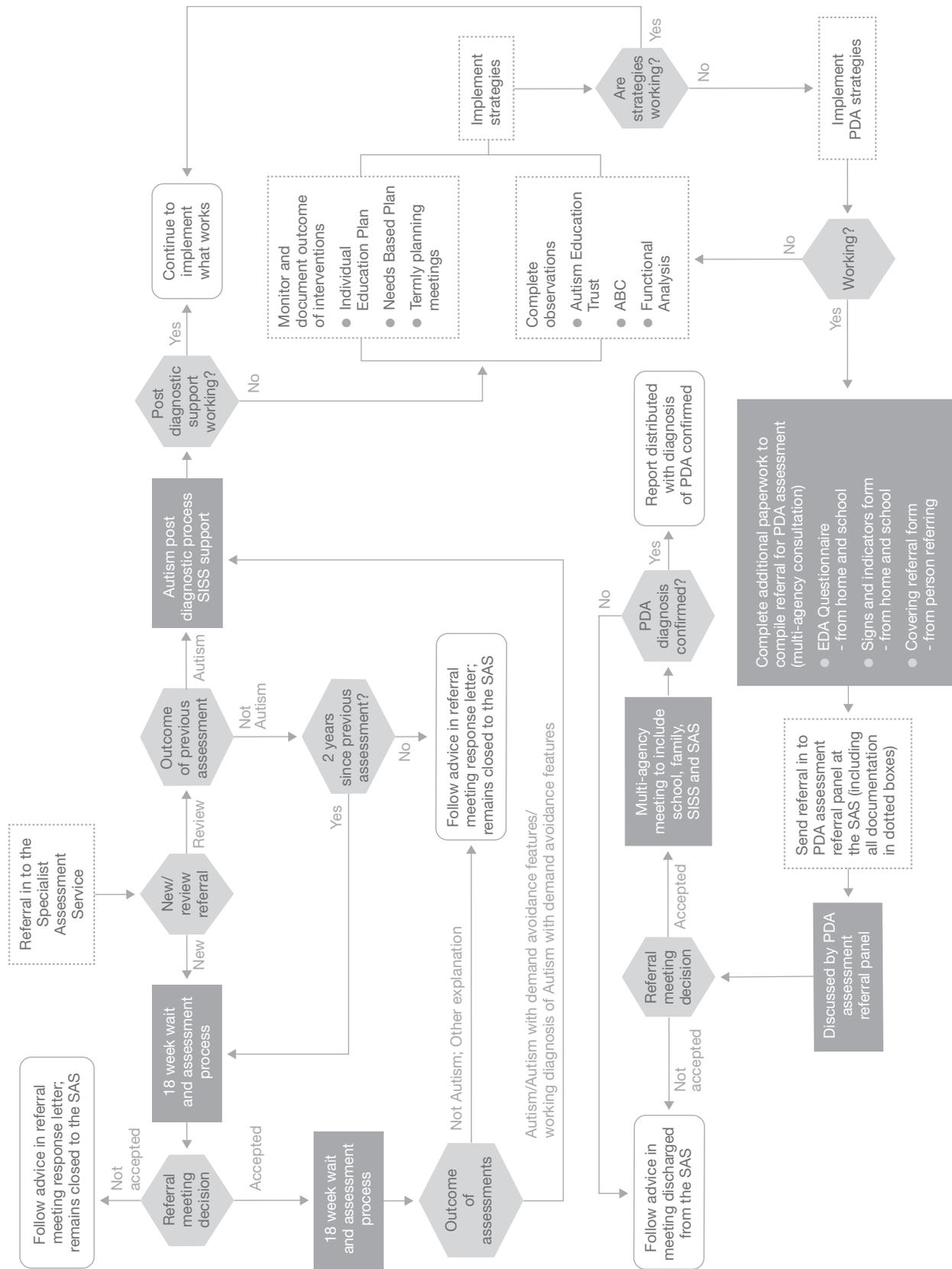
There was agreement across services that two key factors had to be considered when deciding how to respond to the increased demands for an assessment for PDA. The first was the cost to families and commissioners in sending these children for a PDA assessment at the Elizabeth Newson Centre in North Nottinghamshire, 70 miles away. Secondly, it was agreed that good practice suggests a child should be assessed over time and that the support and strategies used should be regularly reviewed and monitored and adjusted, without the need for further diagnostic labels.

Implications of the audit

It was clear from the audit that a number of steps were needed, as follows:

- Clinicians in the SAS, staff in schools and the SISS Autism Team needed to be skilled up in the assessment of PDA profiles and other atypical presentations
- If a child previously diagnosed with autism shows a significant deterioration in behaviour or academic performance, there needs to be a response from school and the SISS Autism Team to address the needs
- The young people that often met the profile of strengths and difficulties for PDA are the young people who have experienced several changes in their educational provision and are eventually permanently excluded or they withdraw from education for other reasons. It was agreed with the SISS Autism Team that there needed to be a timely response to reduce the potential of being without education
- For some families there has been a misunderstanding of the differential explanations given and further pathologising of the child

Figure 1: Flow chart of PDA pathway



The audit also raised questions as to:

- How to respond to children and families when they pursue a private assessment for PDA
- Whether Solihull should continue to refer children to the Elizabeth Newson Centre
- How Health and Education can work better together to ensure that through assessment over time, PDA does not become the 'catch all' explanation for children who deteriorate in their presentation, who do not meet diagnostic criteria for autism or who have complex social, emotional, behavioural and other factors contributing to their profile that could potentially be missed by rushing to add a further label of PDA
- How families are best supported to understand and manage children who present serious challenges to themselves and to services

Development and delivery of a PDA pathway in Solihull

Meetings were held between the SAS and the SISS Autism Team to regularly discuss the need for a possible PDA pathway. A preliminary pathway was mapped out (see *Figure 1*).

As can be seen from *Figure 1*, there were pre-existing procedures in place into which the PDA component could be integrated. The open referral process remained the same; with PDA referrals being considered from any referrer. If the child had not previously been assessed by the SAS, s/he would be considered in the same way as any other new referral. If accepted and the assessment indicated features suggestive of PDA, then they would receive a similar level of post assessment support from the SISS Autism Team as a child given an autism diagnosis (which may or may not include the implementation of PDA strategies). If the strategies were successful, no further actions would be required to either confirm or disprove PDA as a possible explanation. There were no perceived benefits to adding another label to a child if their needs were being met. However, if there were post SAS assessment concerns about the child having PDA and post assessment support was not successful, then the 'assessment over time' model would commence.

The 'assessment over time' model

The agreed assessment over time model reinforces the graduated response approach by information gathering and hypothesis testing through the use of:

- Meetings in school and information gathering (documented outcomes from agreed actions in school to meet need) through already established Special Educational Needs processes and procedures (as set out by the Department for Education and Department of Health, 2015)
- Behavioural observation/intervention
 - ABC analysis (Jones et al, 1979)
 - Functional analysis (Iwata et al, 1982)
- Implementation of PDA strategies as recommended by the SISS Autism Team, as part the assessment over time. These strategies were informed by the literature provided by:
 - The Autism Education Trust (www.autismeducationtrust.org.uk)
 - The PDA Society (www.pdasociety.org.uk)
 - Carlile (2011), Christie et al (2012a), Christie et al (2012), Sherwin (2015), Jones (2005), Harvey (2012)
- Completion of the EDA questionnaire (O'Nions et al, 2014)
- Draft signs and indicators form developed by the SAS for the SISS Autism Team to contribute information from their 'assessment over time'
- Covering summary referral form; which also seeks the views of the child at the point of referral

The aim of having all of these steps in place was to ensure that needs were fully understood and addressed. In addition, if the child did have a PDA profile, this would prevent the need to expose the child to additional assessments at the SAS, which from experience had proven extremely difficult for the children, their parents and professionals. Once all the information had been gathered, there was agreement that a new referral could be made to the SAS and the

referrals would be jointly screened by the Lead Clinical Psychologist and the lead from the SISS Autism Team to determine if the pathway should be progressed to the next stage – the consultation stage of assessment.

At this stage of the assessment, the Lead Clinical Psychologist from the SAS, the named teacher from the SISS Autism Team, a representative from the school and the parents/carers are invited to discuss all the information that has been provided to the SAS and to reach a shared multi-agency decision about the appropriateness of giving the label, PDA. In this meeting there is a shared understanding that the SAS will maintain a neutral position and will hold all views in mind when considering the appropriateness of the PDA description.

The process brings people together to develop a new shared understanding of the child's needs and to work together to provide appropriate support and services. One of the most important factors considered when deciding to give the label of PDA is the evidence around the implementation of PDA strategies. It is the opinion of clinicians in the SAS that PDA should be considered for children with a diagnosis of autism when the usual autism strategies are unsuccessful. In the absence of any agreed standardised diagnostic criteria for PDA, the principle of 'best interests' is applied, from Article 3 of the Convention on the Rights of the Child (United Nations General Assembly, 1989).

Pilot phase of delivery and the continued development of the pathway

With the parents' informed consent, it was agreed that the model would be trialled with one family who had requested a PDA assessment for their child who had already received a diagnosis of autism.

During the pilot phase the following developments occurred in the order listed below:

- Agreement about the assessments to be used to support the assessment over time model
- Agreement about paperwork to be completed by parents and education colleagues to support the referral request

- Trial of multi-professionals meeting to discuss all information gathered over time
- Assessing and comparing the level of concern at home and school. The family reported fewer concerns than school and this was causing tension between home and school
- Completion of additional assessments by a member of SAS to rule out any specific learning difficulties
- Creation of:
 - referral paperwork
 - response to referral letters received by the SAS
 - report template
- Delivery of PDA development days to key professionals involved in assessment and post assessment support in health and education
- Evaluation of PDA development days; key learning points, actions and next steps to consider in development
- Dissemination of the pathway to ensure that all stakeholders were aware of the reasons behind the levels of response to different types of demand for this type of assessment

Next phase in developing the PDA pathway

The Clinical Lead for the SAS presented the progress with this work to commissioners who were very supportive of the developments. It was agreed that a number of areas need to be addressed to further establish and embed the agreed pathway:

- To ensure that services and professionals are trained to respond to the needs of children with a PDA profile
- Continued Professional Development for PDA to be developed and disseminated
- Outcomes to be reviewed and adjustments made over time

- Parent training in relation to what to expect to see with a child with autism and/a PDA profile
- Creation of fact sheets/advice sheets on PDA
- Provide PDA consultation slots in education; an opportunity to discuss cases, resources and strategies
- Review of the pathway after one year to plan the next steps

Concluding comments

There have been increasing demands in Solihull for the assessment of PDA. There has been an attempt made by health and education to work together to best meet the complex needs of children for whom requests for PDA assessments are made. A pathway model of 'assessment over time' and multi agency consultation was developed. The model supports a 'graduated response' approach; working together to provide the support needed following assessment. Improvements in information sharing across health and education have enabled informed and more appropriate decisions to be made about these children.

By developing and adopting this pathway, there has been increased confidence in professionals' understanding and knowledge of PDA. So far the success of this model has been proven as it has prevented the need for multi-agency assessments and discussions on whether a child requires a PDA assessment and label to meet their needs. It has become apparent that since informing stakeholders of the open referral system for a PDA assessment, there are further branches of the pathway that need to be created for:

- children under 5 years of age
- children out of school

On a case by case basis, there have been a variety of responses to requests for these children and this needs to be reviewed and integrated into the pathway.

Families and professionals continue to require advice and support in relation to the best way to meet needs when children are thought to have a PDA profile. There is acknowledgment that these children often require a multi-agency approach to meet their needs. Work still needs to be done to overcome the organisational barriers to provide support to this population. For many of these children, their needs do not meet threshold criteria for acceptance into the services where the best expertise lies. There are many processes and procedures in place that prevent children from getting support early to prevent greater difficulties, such as exclusion from school and mental health difficulties, as well as family breakdown. It is understood that decisions need to be made at the commissioning level about how to best meet their needs. Money can be saved by developing expertise and services within Solihull rather than referring children to independent or specialist services elsewhere.

It would be beneficial to follow up the children who have been on the PDA assessment pathway to determine the costs and benefits. This follow up would require an evaluation of the views of the children and their parents, carers, teachers, education and health colleagues, as well as commissioners.

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