

Opening Pandora's Box : First insights from the National Ex-PDA Research Project

Research Presentation
to
Bristol Autism Research Group
University of Bath
16th September 2015

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What is PDA ? (Pathological Demand Avoidance Syndrome)

- First identified by Prof Elizabeth Newson (Nottingham) in the 1980s as a distinct and separate presentation arising from an earlier ASD diagnosis
- Characterized by an anxiety-driven need to be in control
- Diagnostic features include :
 - Resists and avoids the ordinary demands of life
 - Lability of mood
 - Surface sociability and use of language to manipulate others
 - Neurological involvement (i.e. sensory processing difficulties)
 - Comfortable in role play and pretending (use of scripts)
 - Obsessive behaviour

First interests and the Pilot Study

- Research with parents of CYP with PDA in Staffordshire 2013
- Served as the Pilot Study for the present research
- Parents recruited by parents using a designated Fb page
- 7 parents participated in a focus group which was semi-structured.
- This led to the identification of several key issues relating to :
 - Diagnosis of PDA
 - Support for parents and youngsters
 - Training in PDA for staff who work with CYP with PDA
 - The dynamic presentation of CYP with PDA

The National Ex-PDA Study – Methodology 1

- Decision to roll out the research on a national basis
- Parents recruited at the NAS PDA conference in Cardiff, November 2014 and via parents through their Facebook groups
- Just over 40 parents (or sets of parents) signed up to receive information about the study

The National Ex-PDA Study – Methodology 2

- Design of a mixed-method questionnaire which covered the 4 areas identified in the Pilot
- Parents' consent sought in writing
- Parents' decision regarding level of anonymity or pseudonymity
- On receipt of signed consent form parents emailed questionnaire

The National Ex-PDA Study – Methodology 3

- By September 2015 20 completed questionnaires returned by parents
- Both quantitative and qualitative data secured from the completed questionnaires
- This preliminary data analysis is based on the 20 questionnaires – opportunities still remain for parents to contribute.

The National Ex-PDA Study – Findings

- Schooling :

- 20% of CYP are currently in a mainstream primary school setting
- 10% are in a mainstream secondary setting
- 20% are educated in a Local Authority Maintained Special School
- 20% are in an independent specialist school setting
- 30 % are not in school at all

The National Ex-PDA Study – Findings

- Of the 30% not in education
 - 10% are Home Educated
 - 60% are still having provision ‘sorted out’ by the LA
 - 10% have been permanently excluded by their most recent school
 - 20% are school refusing

The National Ex-PDA Study - Findings

- Diagnosis : who made the diagnosis of PDA in the CYP ?
- A) NHS Paediatrician/MD Team 33.3%
- B) Private Paediatrician/Psychologist 50%
- C) Elizabeth Newson Centre 8.3%
- D) Assessment by ENC pending 8.3%

The National Ex-PDA study - findings

- How was the assessment carried out?
 - In all cases involved observation and assessment of the CYP over a number of hours (typically between ½ and a full day)
 - And involved the reading and review of a substantial range of professional and medical reports, and viewing of parents' video clips
 - And a parental interview/ discussion

The National Ex-PDA study – findings

- How did parents rate the diagnostic process overall ?
- Parents quotes – Amanda
- Parents quotes- Jennie
- Parent quote- Michael's mum
- Parent quote – Mark

The National Ex-PDA Study Findings

- Parents' knowledge of PDA – where has it been developed from?

In 100% of cases parents identified multiple sources:

- 66% reported learning from living with their CYP day to day
- 75% have learned about PDA from information on the PDA Society Website, and the PDA resources website
- 25% have learned about it from Facebook and other social media
- 50% from attending workshops, conferences, seminars and presentations

The National Ex-PDA Study Findings

- Parents' knowledge (2)
 - 84% had developed their knowledge from reading one of the three books published on PDA
 - 25% listed other sources, such as accessing Jane Sherwin's blog, or from a very well informed early years team.
 - Parental quotes : Mark, Michael's mum;
 - Kerry's blog: <http://aspernavts.com/2015/01/02/continuing-parental-development-and-the-professionalisation-of-motherhood/>

The National Ex-PDA Study Findings

- Parents' experiences of Support for themselves and their CYP with PDA
- Nothing generally available through LA/Social Services
- One pupil had Autism Outreach Support teacher visit once a fortnight, and 2 hours per week of respite care in school holidays
- One parent (Jennie) was offered 2 hours respite, fought it and got 10 hours per week
- 2 parents started their own charities
- Almost 95% of parents used fb and social media to get support

The National Ex-PDA Study Findings

- Training in PDA
 - 50% of parents reported that staff in their CYP's school had received no training at all in PDA
 - 25% reported that school staff had received training from an established PDA trainer (e.g. Phil Christie, Ruth Fidler, HD)
 - 16.6% reported that they (parents) themselves had delivered training in schools, via talks to staff, sharing of information etc
 - 8.3% reported that staff from the local authority had delivered training (e.g. an early years advisory team).
 - Almost all parents expressed strong views that staff should be trained specifically in PDA *before* admitting a pupil with PDA

The National Ex-PDA Study - findings

- The changing nature of PDA manifestation and presentation
- Not covered as part of Elizabeth Newson's original diagnostic criteria, yet increasingly important to acknowledge
- Presentation can change moment to moment, day to day, week to week and year to year.
- This will be the subject of the next stage of data analysis

The National Ex-PDA Study – where from here?

- Two further strands of research for me to conduct :
- Understanding the mechanisms of the anxiety experienced by CYP with PDA from a learning analytics perspective
- Further extension of the National Ex-PDA to include a wider representation of parental/carers views and experiences.

Other current plans:

- Establish links with academic colleagues in Universities
- Establishing a National Centre for PDA research
- Establishing a website dedicated to PDA research at www.pdaresearch.org.uk

About Dr Hilary Dyer

- Dr Hilary Dyer is a Specialist Consultant Educational Psychologist based in Worcester
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- Hilary has a specialist practice in diagnosing PDA and a specialist research interest in PDA.

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