



**Richard Woods** @Richard\_Autism

2 Jun 20 · 28 tweets · [Richard\\_Autism/status/1267774851772809216](https://twitter.com/Richard_Autism/status/1267774851772809216)



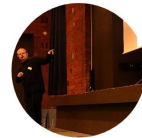
So I am googling PDA Development Group. All that seems to come out of it is: that they think PDA is part of the autism spectrum, mainly from their own (poor quality) research.

### Thread reader



THREAD BY RICHARD WOODS (@RICHARD\_AUTISM)

Thread on weaknesses of Help4Psychology PDA database: [ingentaconnect.com/contentone/bil...](https://ingentaconnect.com/contentone/bil...) From public information sources, that indicate it has severe limitations. The database is constructed by only diagnosing PDA in those the clinic believes are...



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<https://threadreaderapp.com/thread/1251878076465774592.html>

The PDA Society activities include collaborating with medical professionals as part of the PDA Development Group. [@Allison66746425](https://twitter.com/Allison66746425) that explains why Judy Eaton was claiming who has expertise over PDA. i.e. clinicians etc.

<https://councilfordisabledchildren.org.uk/members/meet-our-members/pda-society>

#### Our current activities include:

- Supporting discussions around people's experiences of living with PDA
- Providing support to those living and working with PDA
- Campaigning for greater recognition of the PDA profile
- Providing training to different audiences
- Sharing good practice and supportive ideas
- Developing new materials and tools which can aid understanding
- Collaborating with medical professionals as part of the PDA Development Group

So PDA Development Group is described as shadowy collection of clinicians and professionals with representation of NAS and PDA Society. So it is not even public who is on it.

**PDA**

# Development

## Pathological Demand Avoidance: summary sheet

A one-page explanation of the PDA profile, produced by the PDA Development Group and published in June 2016. It describes the main features and the key approaches to supporting a PDA person. The P...

<https://www.pdasociety.org.uk/resources/pathological-demand-avoidance-summary-sh...>

## Pathological Demand Avoidance: summary sheet

### Description:

A one-page explanation of the PDA profile, produced by the **PDA Development Group** and published in June 2016. It describes the main features and the key approaches to supporting a PDA person.

**The PDA Development Group comprises a group of clinical and professional experts, and includes representation from the NAS and PDA Society.** The document is an authoritative and helpful summary for those who are new to the topic.

Luckily I saved documents from PDA Society's previous website telling us what PDA Development Group does.

<https://www.pdasociety.org.uk/resources/pathological-demand-avoidance-syndrome-reference-booklet-for-health-education-and-social-care-practitioners/>

### Background

The group was established around the time of the first NAS/AEM (then NoRSACA) conference held in January 2011, which has subsequently become an annual event.

Meetings were originally of a very informal nature, taking place twice a year. They initially focussed on preparing the programme for the conferences, updating on issues within the relevant service and sharing good practice, information and resources. As time has gone on, the group has also used meetings to be updated on current research, been involved in revising the information on PDA on the NAS website and made some suggestions about possible future developments in training.

**The group originally comprised those involved with the Elizabeth Newson Centre/Sutherland House School, the Lorna Wing Centre/NAS and Robert Ogden School. This has gradually widened to include representation from the PDA Society, those involved in research and practitioners interested in PDA who are working in different settings eg NHS, Universities and independent organisations.**

At the meeting in December 2016 it was put forward that with the expansion of the group it was timely to consider more formalised arrangements in relation to a terms of reference and membership.

To provide a forum to update and discuss developments in research, practice, and training.

To exchange plans about further development of training and conference materials

To share information on upcoming publications and other resources

**To undertake specific pieces of work as requested and follow agreed actions from each meeting**

**To take a proactive role in advising on necessary developments in the above areas**

### Membership of group

The membership shall comprise representation from the NAS and PDA Society and individual practitioners with an interest in PDA from a range of

In 2015 the PDA Society held its first national conference which was an overwhelming success, (sold out within 6 weeks) and plans are underway for another in 2017.

We became a registered charity in January 2016 and have a dedicated board of trustees, all of whom are parents of individuals who have PDA. We also have a growing number of parent volunteers who answer telephone and email enquiries, all of whom have undertaken specific training to become 'Enquiry Line Volunteers'.

**PDA Society trustee also attends the 'PDA Development Group' meetings chaired by Phil Christie, which gives us the opportunity to meet with experienced professionals who share an interest in furthering knowledge and understanding of PDA, and also keeps us up to date with the latest developments in the field.**

Over the last few years we have seen the PDA Society evolve and this has been a very exciting time, but for us, our first commitment and focus will always remain the same: **raising awareness of PDA, supporting families and providing information to others who have an interest in the condition.**

**Assessing a child**

### Frequency and location of meetings

Every six months. Venues to be agreed at each meeting.

### Standing Agenda

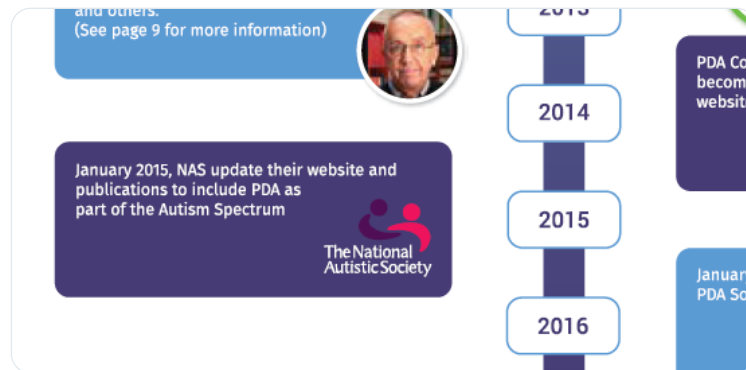
1. Research Updates
2. Other publications
3. Conferences and Training
4. Update from PDA Society
5. Diagnostic Issues
6. Other relevant updates from services
7. AOB and next meeting date

### Chairing of Group/Meetings

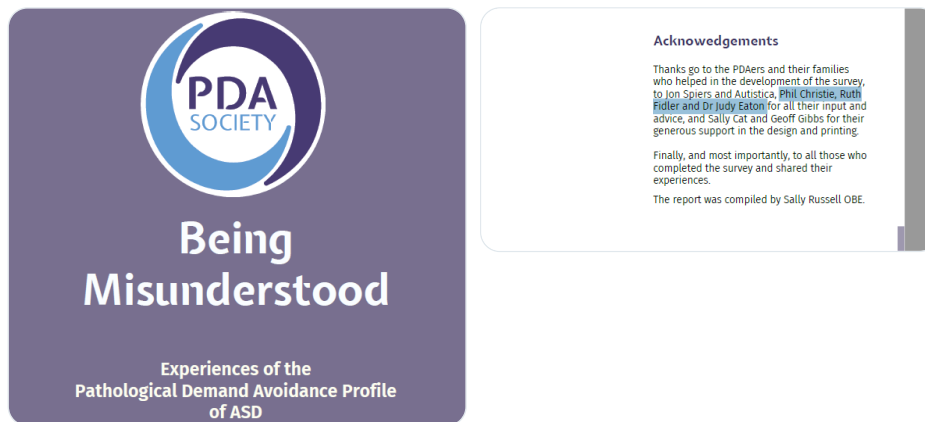
The group will elect the chair on a bi-annual basis.

What the PDA Development Group essentially seems to be about is furthering the view that PDA is an autism subtype. Bearing in mind NAS recognised PDA as an ASD in 2015, in the same year research from Lorna Wing Centre is published:

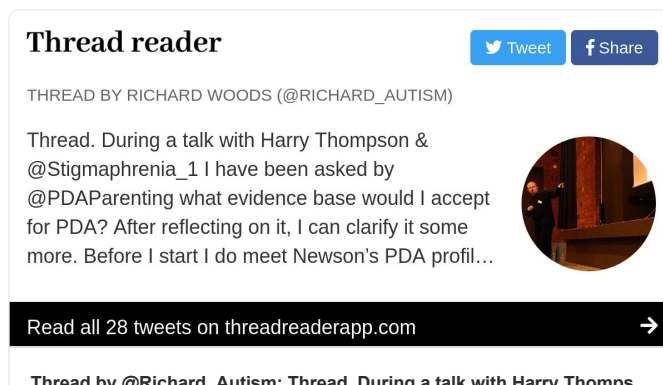




Or the PDA Society has lobbied for PDA to be recognised as an ASD based of the research from members of the PDA Development Group. 1,445 people responded in 2 weeks to this piece of campaigning. At least 2 members of PDA Development Group advised on it.




Considering that PDA is acknowledge as controversial. These activities can be considered a conflict of interests. They have set their own (low quality) research agenda they think is needed to for PDA to be clinically accepted.



Thread by @Richard\_Autism: Thread. During a talk with Harry Thompson & @Stigmaphrenia\_1 I have been asked by @PDAParenting what evidence accept for PDA? After reflecting on it, I can clarify it s...

<https://threadreaderapp.com/thread/1267430454052913156.html>

Especially as it then includes professionals who benefit from the activities being conducted by other members of the PDA Development Group, such as other research of campaigning efforts to get PDA recognised.

**Richard Woods**  
@Richard\_Autism

Replying to @Richard\_Autism


So PDA Development Group is described as shadowy collection of clinicians and professionals with representation of NAS and PDA Society. So it is not even public who is on it.  
[pdasociety.org.uk/resources/path...](https://pdasociety.org.uk/resources/path...)

**Pathological Demand Avoidance: summary sheet**

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The PDA Development Group comprises a group of clinical and professional experts, and includes representation from the NAS and PDA Society. The document is an authoritative and helpful summary for those who are new to the topic.



11:12 AM · Jun 2, 2020

  See Richard Woods's other Tweets

To say I (and others will probably have) substantial ethical issues around the nature and conduct of the PDA Development Group, is putting it mildly.


Considering their collective effort to make PDA recognised as an autism subtype, one can predict they will staunchly resist any attempts for good quality scientific method research that potentially undermines their agenda.

**Thread reader**

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THREAD BY RICHARD WOODS (@RICHARD\_AUTISM)

So I am googling PDA Development Group. All that seems to come out of it is: that they think PDA is part of the autism spectrum, mainly from their own (poor quality) research.  
[threadreaderapp.com/thread/1251878...](https://threadreaderapp.com/thread/1251878...) The PDA...



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<https://threadreaderapp.com/thread/1267774851772809216.html?refreshed=yes>

To clarify, these are my notes on the research agenda for PDA by the PDA Development Group (Christie et al, 2011, 182-186).

Research is needed to examine continuity between PDA and other conditions at genetic, neural and cognitive levels. Next step is look at “cognitive continuity”.

Talks about Theory of Mind research in autism and how autistic persons are meant to have great difficulty deceiving others (in other literature it is acknowledged that the manipulative aspect of PDA makes it problematic fitting it into autism).

<https://www.emerald.com/insight/content/doi/10.1108/JIDOB-07-2016-0013/full/html>

with autism or Asperger's syndrome, although they were often seen as atypical in some way. Over time, Newson noticed that while these children were atypical of the clinical picture of autism or Asperger's syndrome, they were typical of each other in some very important ways. The main feature that was characteristic of all the children was "an obsessional avoidance of the ordinary demands of everyday life" (Newson, 1990; Newson *et al.*, 2003). Newson found that this was combined with sufficient social understanding to enable the child to be "socially manipulative" in their avoidance. It was this level of social understanding, along with a capacity for imaginative play, which most strongly countered as a diagnosis of autism. The clinical description of PDA was refined (Newson and David, 1999) and validation studies demonstrated the robustness of the clinical descriptions from childhood into adulthood (Newson, 1996; Newson and Le Maréchal, 1998) and PDA was recognised as a separate entity within pervasive developmental disorders.

There will be research into if those with PDA have difficulties with their Theory of Mind.

If Theory of Mind is not implicated in PDA, other avenues to be explored include: emotion processing, empathy, emotional detachment and sense of their own agenda.

Other hypotheses may come from why typically developing children so readily comply, to better understand why CYP with PDA refuse to.

Tentative hypothesis is that Typically Developing CYP have a need to please others (perhaps lacking in PDA), a fear of being rejected by them, a herd instinct, a need to maintain their social standing and reputation.

This aspect supports concerns about how PDA is related to non-compliance:

[kar.kent.ac.uk/62694/](http://kar.kent.ac.uk/62694/)

To develop tools to identify PDA is important for research and diagnosis purposes. Questionnaires are useful to clinicians to make diagnostic or referral decisions in a systematic manner.

Apparently, there is a new parent report questionnaire (i.e. EDA-Q). Refers to original PDA items from DISCO. Says there are 17 questions, this is more than the 15 items commonly referred to in articles.

No idea if the 17 DISCO items are typo or 2 were removed for whatever reason. Other 15 are mentioned:



12.8.2019, 14:00:00  
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### Identifying features of 'pathological demand avoidance' us

The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obsessive resistance to everyday demands and...

<https://link.springer.com/article/10.1007/s00787-015-0740-2>

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### Extreme ("pathological") demand avoidance in autism: a gen

Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexistent in spite of the frequent reference to...

<https://link.springer.com/article/10.1007/s00787-014-0647-3>

Far Child Adolesc Psychiatry (2015) 24:979–984

of the almost complete lack of scientific study  
tion, there has been considerable dispute and  
(whether or not PDA should be regarded as a  
autism spectrum disorders (ASDs). The resist-  
of PDA (which could be construed as resist-  
ance/insistence on sameness), the obsessive  
some of the social impairment problems, the  
play and the "neurological involvement" are  
cal/common in ASD. However, the apparently  
manipulative behaviour is not characteristic of  
i, in fact, by some, considered to be an exclu-  
sion for a diagnosis of ASD. Wing et al. [18]  
at PDA might be a "double hit", that PDA is an  
problem in ASD but not due to ASD. Related to  
her study, it was shown in a small group of boys  
ho also had psychopathic tendencies [12].  
s been no previous study of the prevalence of  
general population. We recently conducted a  
ation study of ASD in the Faroe Islands [6].  
y we covered all the symptoms of PDA in an  
ith a parent of individuals suspected of suf-  
ASD. We therefore decided that these data  
ide a good opportunity to get a handle on the  
of PDA (or, at least, PDA symptoms) in the  
ulation of individuals with a diagnosis of

DISCO item and corresponding PDA symptom area	Variable name
Unusually quiet and passive in infancy (1)	UQUIET
Clumsy in gross movements (6)	CCLUMBY
Communicates through doll, puppet, toy animal etc. (5)	CCDOLL
Lacks awareness of age group, social hierarchy etc. (3)	CIDET
Rapid inexplicable changes from loving to argument (4)	CENAPP
Uses peers as "mechanical aids": bossy and dominating (3) and (4)	CPEERAD
Repetitive role play—lives the part, not usual pretence (5) and (7)	CTROL
Hands seem limp and weak for unvelcome tasks (8)	CNOHAND
Repetitive questioning (7)	QUESREP
Obsessed with a person, real or fiction (7)	PERS
Blames others for own misdeeds (3)	BLAME
Harmes another person—may like or dislike them (3) and (7)	HARAS
Socially manipulative behaviour to avoid demands (2)	MANBEH
Socially shocking behaviour with deliberate intent (2) and (3)	SROCK
Lies, cheats, steals, fantasises, causing distress to others (3) and (7)	LYING

Figures in brackets—(1) through (8)—refer to the eight defining characteristics of Newson's PDA

...ABILITY OF MOOD, appar-  
sive need for control, and  
) volatile behaviour towards  
irth characteristic was a ten-  
le in role play and pretend-  
rth characteristic was a ten-  
in the manner of a teacher).  
guage delay, which was con-  
y, obsessive behaviour often  
e or their characteristics, a  
urological involvement (e.g.  
ess, seizures or absences in a

...communication disorders (DISCO) [12]. This semi-structured  
interview is widely used as an assessment tool for autism  
spectrum conditions and covers a wide range of behaviours  
associated with the phenotype. The original DISCO assess-  
ment included some items relevant to PDA and the instru-  
ment was later extended to include specific items captur-  
ing Newson's description of PDA [12]. Although Wing and  
Gould's draft 15-item PDA list comprising these items was  
never formally validated, it has been used, for example, to  
study the prevalence of PDA within a general population  
study of autism in the Faroe Islands [11]. Notably, Wing  
and Gould's draft list covers some very distinctive charac-  
teristics of PDA (e.g. socially shocking behaviour), as well  
as less PDA-specific indicators (e.g. attention, passive

Say EDA-Q once validated will be useful screening tool for researchers and clinicians.

There needs to be an Observational Schedule for clinical interviews/ play assessments. Mentions how ADOS is used in autism assessments.

Planned to develop some questions to measure PDA-related behaviours that occur in clinical/ play based assessments. Items could reflect if the child wants (says wants, not need) to be in control of the session.

Additional tasks to measure Theory of Mind, pro-sociality, desire to manage their reputation and empathy that can be included into an assessment.

Agenda is critical to support clinical understandings that have been developed (Christie et al, 2011, p186), i.e. PDA is an ASD. This research agenda was provided by

Happe and O'Nions at the 2011 National Autistic Society/ Autism East Midlands PDA Conference.



To me it seems this research agenda presumes PDA is an autism subtype and this would seem to be reflected in the research coming out from the PDA Development Group.

The cover of the journal 'Psychiatry' is shown. It features a blue background with a white and yellow abstract shape. The title 'Psychiatry' is in large white letters. Below the title, it says 'Official journal of the European Society for Child and Adolescent Psychiatry'. A list of articles is visible on the left side.

**Identifying features of 'pathological demand avoidance' us**

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<https://link.springer.com/article/10.1007/s00787-015-0740-2>

&

The cover of the journal 'Child and Adolescent Mental Health' is shown. It features a green background with white text. The title 'Child and Adolescent Mental Health' is in large green letters. Below the title, it says 'Official journal of the European Society for Child and Adolescent Psychiatry'. A list of articles is visible on the left side.

**Dimensions of difficulty in children reported to have an autism spectru...**

Read the full Commentary on this article at doi: 10.1111/camh.12273 Read the full Response to the Commentary on this article at doi: 10.1111/camh.12287

<https://acamh.onlinelibrary.wiley.com/doi/10.1111/camh.12242>

## Thread reader



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