



Richard Woods @Richard_Autism

Oct 16, 2021 · 45 tweets · [Richard_Autism/status/1449350167984017410](#)



[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) The AET is potentially problematic as it has involvement from two charities who support ABA/ PBS. AET's legal responsibilities are run by NAS, whose agenda is NOT that of autistic persons.

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) Lets not forget NAS has been important in pushing & contributing towards "PDA Profile of ASD" being a "culture-bound concept" in the UK. It's stance on PDA contradicts reputable independent parties like [@NICEComms](#) & [@BPSOfficial](#)

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#)

Richard Woods @Richard_Autism

Replying to @Richard_Autism

Other sources of information
We examined an inquiry about pathological demand avoidance (PDA) that suggested PDA is not adequately addressed by the guidelines and that there is a failure to distinguish between PDA and oppositional defiant disorder (ODD) in this area, although we did not find a clear distinction between PDA and ODD in the guidelines. There was no new evidence identified about PDA and clinical opinion is very mixed about its status as a distinct developmental condition. The Reviewer assessed this inquiry as having no impact on recommendations.

Equalities
Topic experts and patient organisations indicated that transgender people and women may have a higher risk of autism. Additionally, the need to further engage hard to reach groups was highlighted, as well as concerns that uptake of the guidelines is low.

Surveillance proposal
We propose to update the sections of the NICE autism guideline covering surveillance conditions.
Surveillance conditions report October 2020 – Autism Theme (NICE guidelines CG142, CG143 and CG170)

Pathological demand aversion
Topic experts, patient groups, and other correspondence received since the NICE guideline was published has suggested that the guideline should consider pathological demand aversion as a specific profile for people with autism. The team is used to describe complex behavioural problems that mostly manifest as extreme avoidance of everyday requests and expected behaviours. Diagnostic criteria about whether pathological demand aversion should be recognised as a distinct diagnosis. Some topic experts considered that appropriate recognition of existing conditions and individualised management strategies are sufficient. Because we did not identify any new evidence in this area, pathological demand aversion is not being proposed as an area for action.

Surveillance proposal
We propose to update the sections of the NICE autism guideline covering surveillance conditions.
Surveillance conditions report October 2020 – Autism Theme (NICE guidelines CG142, CG143 and CG170)

Key messages
1. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.
2. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

Key messages (continued)
3. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.
4. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

Key messages (continued)
5. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

Key messages (continued)
6. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

Key messages (continued)
7. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

Key messages (continued)
8. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

Key messages (continued)
9. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

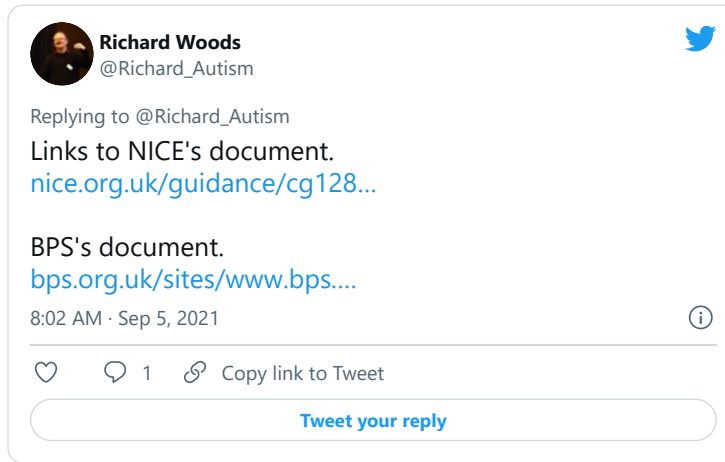
Key messages (continued)
10. Update the surveillance proposal to include the need for surveillance of people with PDA and oppositional defiant disorder (ODD) who are also autistic.

8:01 AM · Sep 5, 2021

Copy link to Tweet

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[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) You should note that organisations which do not have vested in viewing PDA as an ASD, are taking an unethical position, which is different to reputable bodies like [@NICEComms](#)

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Example of NAS's conflicts of interest on PDA




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 **Richard Woods**
@Richard_Autism

Replying to @Richard_Autism @laithdruim and 10 others
autismeducationtrust.org.uk/about/aet-board

Phil Christie

A consultant child psychologist, and former director of an autism specific school, working as part of autism associates.

 Phil Christie is a Consultant Child Psychologist and specialist adviser working on an independent basis, or with colleagues as part of Autism Associates. Phil was Director of Children's Services and Principal of Sutherland House School and the Elizabeth Newson Centre for more than 30 years. The Elizabeth Newson Centre provided diagnostic assessments of children from all over the UK and has a particular specialism in Pathological Demand Avoidance syndrome.

Phil is an Associate Editor of 'Good Autism Practice' and previously undertook the same role for 'Autism: International Journal of Research and Practice'. He was elected as Chair of the advisory council for the Autism Education Trust and is now Vice Chair of the programme board.

Phil has been involved in conferences, training sessions and presentations on a range of topics related to the autism spectrum across the UK and internationally. He has been extensively involved in leading training events around PDA for schools and other organisations providing for children with complex presentations on the autism spectrum.

Phil has published widely in the field of autism and has co-authored a number of books.


- First Steps in Intervention with your Child with Autism (with Elizabeth Newson, Wendy Prevezer and Susie Chandler). Jessica Kingsley Publishers, 2009.
- Understanding Pathological Demand Avoidance Syndrome in Children (with Margaret Duncan, Ruth Fidler and Zara Healy). Jessica Kingsley Publishers, 2011.

4:49 PM · Oct 15, 2021

♡ 1 ↻ Copy link to Tweet

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 **national autism standards**

Supported by
Department for Education

The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice

Phil Christie, UK

Taken from the Good Autism Practice Journal published by BILD, 2007, by kind permission

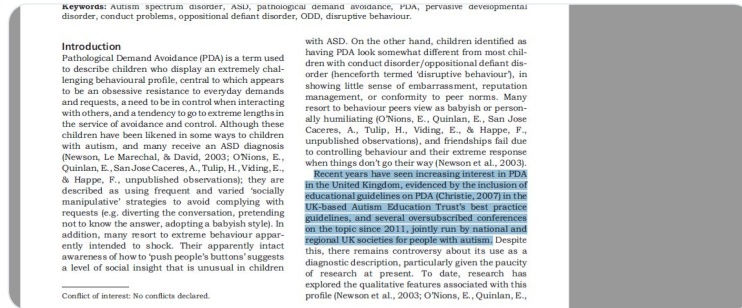
Address for correspondence:
Phil Christie
Director of Children's Services,
Elizabeth Newson Centre,
272, Longside Lane,
Ravenshead,
Nottinghamshire,
NG15 9AH

Acknowledgements: Special acknowledgement should go to Elizabeth Newson for her pioneering work in this area. Thanks are also due to staff at Sutherland House School and the parents who have contributed to this paper.

Editorial comment
Phil Christie is currently the Director of Children's Services within the Nottinghamshire Regional

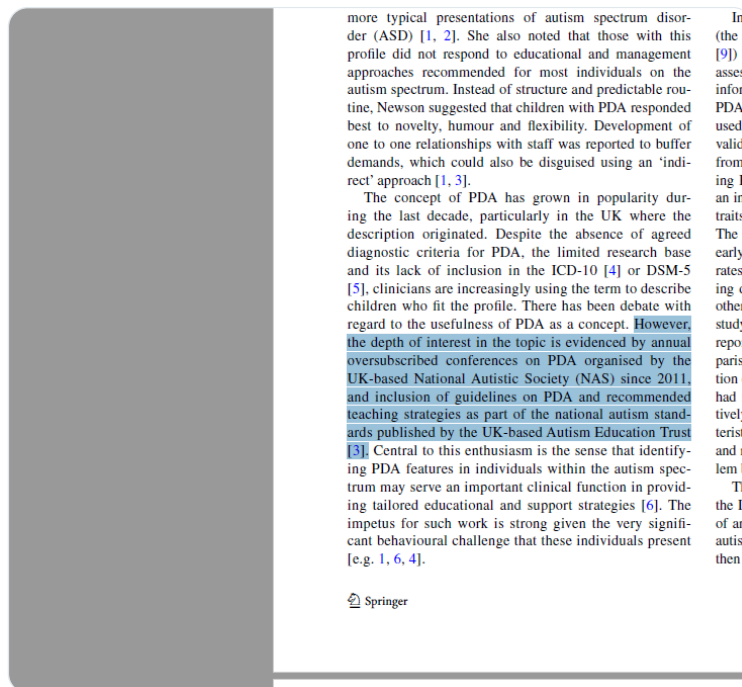
[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Link to AET's 2012 republished Christie's PDA article
<https://www.pdasociety.org.uk/wp-content/uploads/2019/07/AET-standards-for-PDA-Phils-GAP-1.pdf>

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#)
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[@BPSOfficial](#) Screenshot of mention AET's PDA guidelines in a 2013 article co-authored by Christie



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[@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#)
[@BPSOfficial](#) Link to said article, Christie is its second author.
<https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149>

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[@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#)
[@BPSOfficial](#) Screen shot of a second article co-authored article of Christie, again referring to AET's guidelines & note lack of stating his involvement in AET, or it being his article.



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[@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#)
[@BPSOfficial](#) Above image is from page 408 of this article, Christie is third author on this article.



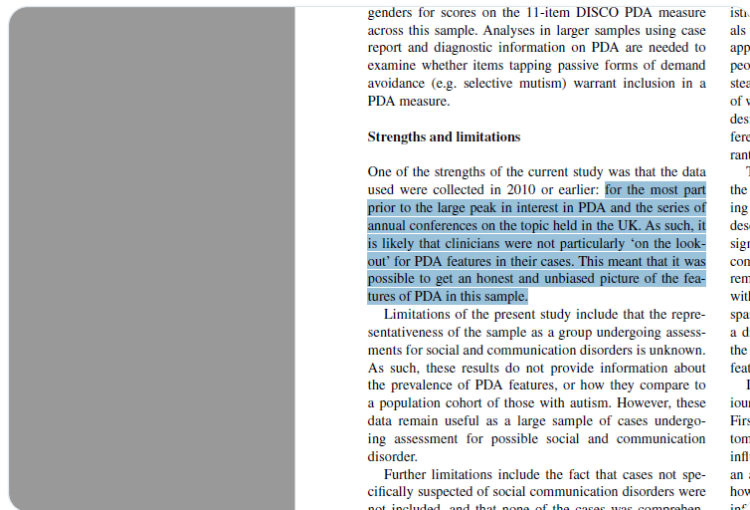
Identifying features of 'pathological demand...

European Child & Adolescent Psychiatry - The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit...

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

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) One should also note the reference in both articles to the overscribed PDA conferences held by NAS. Which Christie would often speak at, & help choose the agenda for (obviously these points are also not mentioned in the articles).

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Screenshot from page 418. In which said annual NAS conferences are causing there to be biased opinions on PDA, & leading perons being on the lookout for PDA. Note that the article assumed that its authors are unbiased.

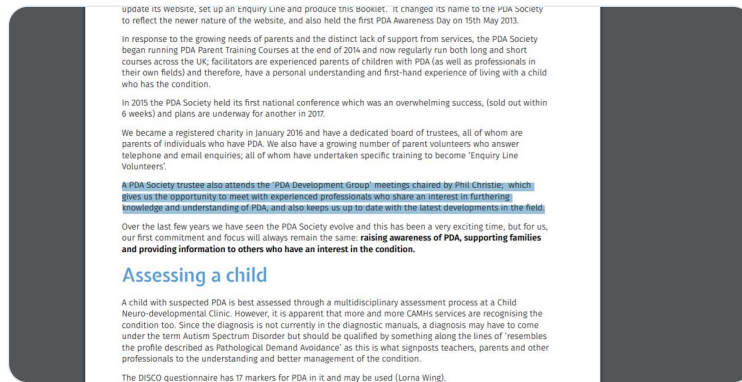


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[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Link to the committee's terms of reference which sets out that it set the agenda for NAS's online information sources, & their annual conferences.

<https://rationaldemandavoidancecom.files.wordpress.com/2020/08/pda-development-group-tor-july-2016.pdf>

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Screenshot from page 12 which shows Christie chaired that committee.



[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Link to said document confirming Christie's presence on said committee.

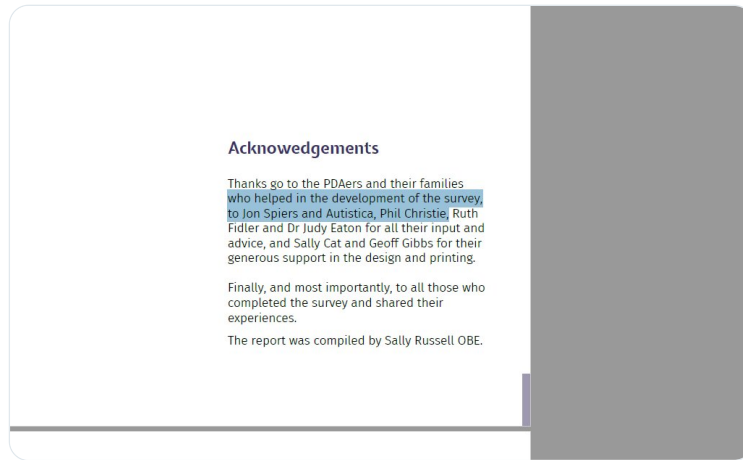
<http://www.pdaresource.com/files/pda-awareness-matters-booklet.pdf>

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) So we have Christie apparently heavily involved in the processes which contributed to surge in interest in PDA in the UK. This is also compounded by his statements trying to avoid debate on PDA.

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) "In this context, prolonged debate about whether PDA is a syndrome within the family of pervasive developmental disorders or a subgroup of what has become another umbrella term of ASD becomes rather distracting." (Christie 2007, p7).

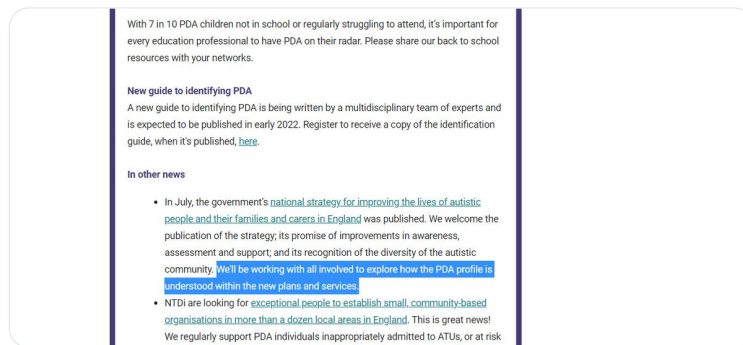
[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) "To build on developments, insights and increasing recognition of PDA but maintain the integrity of how the condition is understood and the nature of the support that is needed by individuals" (Christie 2016; 2018; 2019).

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Christie was also involved in creating the PDA Society's 2018 Being Misunderstood Report, which has been used to lobby government, & local bodies to accept "PDA Profile of ASD".



[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Link to said Being Misunderstood report.
<https://www.pdasociety.org.uk/wp-content/uploads/2019/08/BeingMisunderstood.pdf>

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Screenshot from PDA Society's most recent newsletter stating it is working with government as part England Autism strategy.



[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Bear in mind the charity is doing this while there little to no good quality evidence to warrant this, PDA's clinical nature & clinical need are highly contested. With PDA itself being a severely controversial.

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) So charity achieved, in part due to campaigning efforts which using the Being Misunderstood Report.

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Yes, the report is being used for campaigning efforts.

Being Misunderstood – regional & education reports

Our Being Misunderstood report published in May 2018 demonstrated the ways in which the PDA profile was being recognised by some clinicians but not by others. It highlighted the poor quality of services and lack of help being provided by those who seek help from CAMHS, and also demonstrated the significant numbers of young people who are either struggling to get into school or who are home-educated.

In a new series of reports:

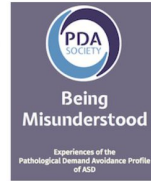
- the key data is broken down by region
- the educational experiences are specifically highlighted

Regional reports

It is hoped these will be of interest to autism advocates and charities as well as service providers. This should give new impetus to the drive to ensure that families are given good advice in the form of tailored support that is essential for all those with autism and specific understanding of the approaches that are helpful with PDA (helpfully summarised by our Panda Ambassador).

The reports also include many of the comments from survey participants, bringing to life the lived experience, with most feeling that they are fighting an uphill battle for their child to be understood and well-supported. Participants also told us of the greatest rewards of living with PDA, which are included in our section on positive PDA.

The reports can be accessed via these links:



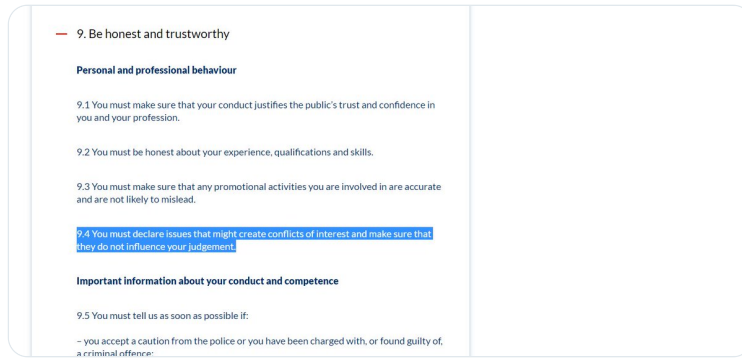
[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Link to page with where the screenshot is from.



[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) So yes, as I said it does appear that Christie being on the AET board is probably problematic, especially if AET have produced resources which state it is "Profile of ASD". Hence, why I state I need to check its resources.

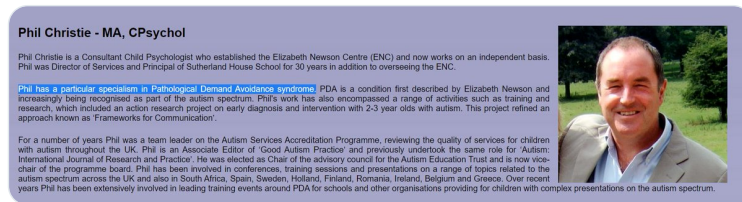
[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Must also be said, such conflicts of interest of Christie, are generally not stated, or considered much in PDA discourse. Despite declaring COIs is something Practising Psychologists regulator requires.

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) Screenshot of [@The_HCPC](#) standards which are there to protect the public.



@TwittingTheo @kimturner70 @LUC autism @autcareandshare @AutismKeynes @Autism @SENDinfoBucks @scarlet70020920 @JodieSmitten @NICEComms @BPSOfficial @The_HCPC Link to said standards.
<https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/>

@TwittingTheo @kimturner70 @LUC autism @autcareandshare @AutismKeynes @Autism @SENDinfoBucks @scarlet70020920 @JodieSmitten @NICEComms @BPSOfficial @The_HCPC Also for research purposes such COIs should be disclosed. Considering Christie started working independently, specialising in PDA.



@TwittingTheo @kimturner70 @LUC autism @autcareandshare @AutismKeynes @Autism @SENDinfoBucks @scarlet70020920 @JodieSmitten @NICEComms @BPSOfficial @The_HCPC Link to where previous screenshot is from:
autismassociates.co.uk

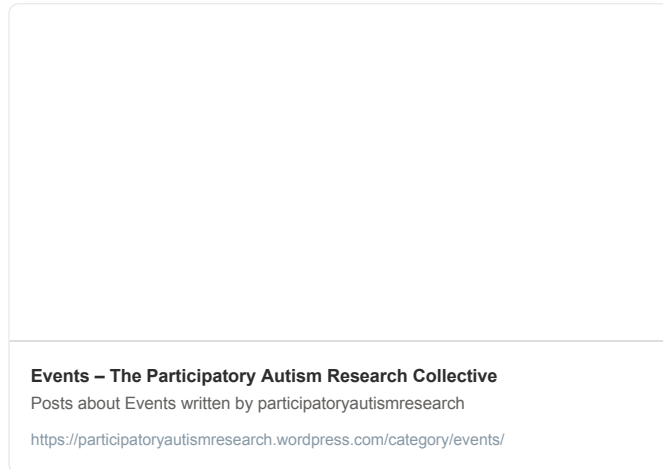
@TwittingTheo @kimturner70 @LUC autism @autcareandshare @AutismKeynes @Autism @SENDinfoBucks @scarlet70020920 @JodieSmitten @NICEComms @BPSOfficial @The_HCPC To add icing to the cake, much of the academic debate with PDA being viewed as an ASD can be traced back to him, as Newson consistently said PDA should not be viewed as an autism spectrum disorder.

@TwittingTheo @kimturner70 @LUC autism @autcareandshare @AutismKeynes @Autism @SENDinfoBucks @scarlet70020920 @JodieSmitten @NICEComms @BPSOfficial @The_HCPC I detail this out here:
https://www.researchgate.net/publication/351071989_Is_Pathological_Demand_Avoidance_a_meaningful_subgroup_of_autism

@TwittingTheo @kimturner70 @LUC autism @autcareandshare @AutismKeynes @Autism @SENDinfoBucks @scarlet70020920 @JodieSmitten @NICEComms @BPSOfficial @The_HCPC That is everything off the top of my head why I have concerns over Christie being a reputable information source on PDA, his involvement with AET's & about the accuracy of information on PDA in AET's various resources.

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[@BPSOfficial](#) [@The_HCPC](#) Yes, some of these points are likely to come up in my PARC talk on Tuesday.



[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) [@The_HCPC](#) To clarify this one. One should see that those vested in "PDA Profile of ASD", are taking an unethical position when compared to those who are not vested in "PDA Profile of ASD", like NICE & BPS etc.

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) [@The_HCPC](#) "Phil has been involved in conferences, training sessions and presentations on a range of topics related to the autism spectrum across the UK and internationally..."

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) [@The_HCPC](#) "... He has been extensively involved in leading training events around PDA for schools and other organisations providing for children with complex presentations on the autism spectrum."

From AET's website on its board members.

Phil Christie

A consultant child psychologist, and former director of an autism specific school, working as part of autism associates.



Phil Christie is a Consultant Child Psychologist and specialist adviser working on an independent basis, or with colleagues as part of Autism Associates. Phil was Director of Children's Services and Principal of Sutherland House School and the Elizabeth Newson Centre for more than 30 years. The Elizabeth Newson Centre provided diagnostic assessments of children from all over the UK and has a particular specialism in Pathological Demand Avoidance syndrome.

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Phil has published widely in the field of autism and has co-authored a number of books.

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- Understanding Pathological Demand Avoidance Syndrome in Children (with Margaret Duncan, Ruth Fidler and Zara Healy). Jessica Kingsley Publishers, 2011.
- Can I tell you about Pathological Demand Avoidance syndrome? A guide for friends, family and professionals (with Ruth Fidler). Jessica Kingsley Publishers 2015.
- Collaborative Approaches to Learning for pupils with PDA. Strategies for Education Professionals. (with Ruth Fidler) Jessica Kingsley Publishers. 2019

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) [@The_HCPC](#) So as an independent consultant, Christie seems to be having lots of work related to his views on a controversial topic, which medical nature & clinical need are both substantially contested.

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) [@The_HCPC](#) So it is reasonable to view that Christie potentially stands to gain from AET's public view on PDA, if it states PDA is a form of autism. Fair to say he has a COI for being involved with AET. Question is, will Christie recognise this himself?

[@TwittingTheo](#) [@kimturner70](#) [@LUC_autism](#) [@autcareandshare](#) [@AutismKeynes](#) [@Autism](#) [@SENDinfoBucks](#) [@scarlet70020920](#) [@JodieSmitten](#) [@NICEComms](#) [@BPSOfficial](#) [@The_HCPC](#) [@threadreaderapp](#) please can you unroll again?

Thank you in advance.