



Richard Woods @Richard_Autism

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[@noellevivante](#) Potentially disregarding a minority groups wishes is something I have been reflecting upon recently due to my own research & how some autistic persons strongly view they have extra rights because they identify with PDA.

[@noellevivante](#) First point, just because some persons think PDA is an ASD, & strongly identify with it, does not automatically grant them extra rights. One only has to look at perspective taken in recent systematic review, BPS & NICE to see that.

[@noellevivante](#) Some would argue that PDA gives them extra rights under "biological citizenship", & it is from birth. There is good case PDA does not have to be developmental in nature, & is probably caused by trauma/ aversive events.

[@noellevivante](#) There's no clear evidence to indicate what PDA is, automatically raises doubts over what it is they are exactly identifying with? This matters considering vulnerable persons seem prone to internalising & PDA's features are generic; it is easy to identify with.

[@noellevivante](#) There are also issues of, simply because some parties have arbitrarily chosen to view PDA as an ASD & mainly diagnose PDA in autistic persons, does not automatically grant those identifying with PDA with extra rights.

[@noellevivante](#) There are also huge ethical implications for those who have decided to arbitrarily view PDA as an ASD & diagnose it mainly in autism.

[@noellevivante](#) If independent persons & groups like NICE/ BPS are taking a neutral position, it is highly suggestive others should be taking that view to.

[@noellevivante](#) We know ethically, a balanced perspective should be presented on a topic, not making claims beyond the evidence base. Not conducting research to support prior assumptions.

[@noellevivante](#) None of these things seem applicable to PDA, & it has become a "culture-bound construct" as an ASD in the UK. To say key "PDA is an ASD" activists have acted ethically in pursuing their viewpoint seems, wishful thinking.

[@noellevivante](#) So it inherently seems ethically dubious to grant rights to persons, considering the apparent severe ethical issues around "PDA is an ASD". It is also terribly circular process.

[@noellevivante](#) Even if you ignore these other ethical issues, & the what seems a good case that PDA is not clinically needed. There are ethical issues only viewing PDA to be

specific to autistic persons.

[@noellevivante](#) Non-autistic persons with PDA are present in PDA research samples & many experts think PDA is seen outside of PDA. Systematic review, BPS, & NICE are taking a neutral position, treating all views equally. Thus, we cannot assume PDA is specific to autism.

[@noellevivante](#) If one considers arguments around clinical need, such as to protect persons from reinforcement-based approaches, they are also applicable to non-autistic persons with PDA.

[@noellevivante](#) SEND system is needs based, if one thinks PDA is needed for autistic persons, it is also needed for non-autistic persons with PDA. Treating non-autistic persons with PDA differently to autistic persons with them, discriminates against non-autistics with PDA.

[@noellevivante](#) If one invokes universal rights, such as under the Convention on the Rights of the Child, these are universal rights, & applicable to non-autistic persons CYP with PDA.

[@noellevivante](#) There are also issues, from a ideological perspective, I am a social model neurodiversity supporter, which is intrinsically about including persons; hence, I will naturally treat non-autistic persons with PDA the same autistic persons with PDA.

[@noellevivante](#) From an autistic persons preferences, most of us do not want autism to subdivided. Some are arguing we need better theories, instead of categories. Participatory research tends to go with majority's preference, e.g., identity first language.

[@noellevivante](#) From a participatory research perspective, I do not need to view PDA as a form of autism.

[@noellevivante](#) There are also issues with potentially the validity of what some "PDA is an ASD" autistic persons are saying, like it is from birth, or even saying it is a form of autism. Demand-avoidance is transactional process.

[@noellevivante](#) Anyone routing their demand-avoidance to deficits or problems in themselves, raises concerns over the validity over their views.

[@noellevivante](#) Likewise, similarly saying PDA has to be from early infancy. Passive early history features are generic & seem not to cluster with demand-avoidance features. We do not know if/ how much of their views are affected from confirmation bias.

[@noellevivante](#) The point about viewing PDA needing to be from early infancy, is also applicable to other stakeholders, it possibly applicable to one notable "PDA is an ASD" clinic. We know some of Newson's assumptions are wrong.

[@noellevivante](#) Bear in mind, some persons already think they know what PDA is, and believe in it. I get attacked for not believing in PDA.

Confirmation bias is an issue when dealing with PDA. It is reasonable to treat certain perspectives with caution.

[@noellevivante](#) This is a reasonable thing to do, as we tend to ignore anti-vaccers. Not that I am saying "PDA is an ASD" proponents are as bad anti-vaccers. I do accept the difficulties those with PDA, & their families face. I am never going to argue against that.

[@noellevivante](#) There is actually a good case for a person to reasonably not take "PDA is an ASD" supporters preferences seriously.

This is off the top of my head, there might be other points.

[@noellevivante](#) A couple of other reflective points to add.

[@noellevivante](#) [@LSBU](#) has sent an email about ethical decision making looks like, which includes:

Which option best protects the well-being of everyone involved?

Which option best respects the rights of all of those who will be affected?

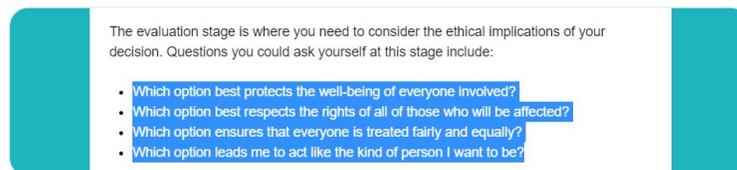
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[@noellevivante](#) [@LSBU](#) Which option ensures that everyone is treated fairly and equally?

Which option leads me to act like the kind of person I want to be?

[@noellevivante](#) [@LSBU](#) Screenshot of the relevant text.

How does viewing PDA as an ASD help non-autistic persons with PDA being protected from reinforcement-based approaches? I would argue it does not.



[@noellevivante](#) [@LSBU](#) How is viewing PDA as an ASD treats non-autistic persons equally & fairly? Obviously does not, if it intrinsically views them as non-entities.

Do I need to go on here?

[@noellevivante](#) [@LSBU](#) The last reflective point is that some would argue "PDA is an ASD" as it looks different in the autistic persons compared to non-autistic persons. Co-occurring conditions to autism, tend to present slightly differently inside vs outside of autism.

[@noellevivante](#) [@LSBU](#) Co-occurring conditions, can have slightly different causal mechanisms in autism vs non-autism. This seems to result from co-occurring conditions & autism simultaneously interacting with each other.

[@noellevivante](#) [@LSBU](#) The point is we should be expecting PDA to look different in autistic persons vs non-autistic persons. Yet there would only be ONE PDA Disorder, as it would fit our heterogeneous spectrum understandings of disorders.

[@noellevivante](#) [@LSBU](#) We do not have autism special behaviour profiles for co-occurring conditions, just one generic behaviour profile in each of the main diagnostic manuals.

As said above there would only be ONE PDA Disorder, possibly with subtypes.

[@noellevivante](#) [@LSBU](#) So claiming that PDA being different in autistic persons is insufficient to say it is an ASD, & thus grants other rights etc.

[@noellevivante](#) [@LSBU](#) On that note [@threadreaderapp](#), please could you unroll again?

Thank you advance.

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