In other news, I have realised I should probably add "Problematic Demand Avoidance" to list of names for PDA.

That I should call one clinic's PDA "Extreme Extreme Demand Avoidance" to accurately represent narrowness & seemingly absurdity of their position.

I have a list of 10 different PDA's name in print here: https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidance_and_the_DSM-5_a_rebuttal_to_Judy_Eaton

Screen shot of the list, as I forgot to include it before:

Demand avoidance is not necessarily defiance
Jonathan Green and colleagues have usefully outlined possible mechanisms that might represent vulnerability factors promoting habitual avoidance of routine demands in autism spectrum disorder and ot...
https://www.thelancet.com/journals/lanche/article/PIIS2352-4642(18)30171-8/fulltext

Now, for this Extreme Extreme Demand Avoidance. So, I am referring to the top threshold in the diagram in this blog.

In the blog I show how the top threshold appears to not be representative of PDA literature. From discussing it with the clinic, they seem have created that threshold from their clinical experience. This is reflected in a comment in their article.
To quote article:

"combined with the extensive clinical knowledge of the assessment team, led to the
development of an informal algorithm."... p37.

Be mindful, I have basically debunked the assertion it was constructed based with the
literature.

I am confident that there is one PDA when one focuses on the demand avoidance,
and that it is an anxiety based disorder. I go into reasons for this in a submitted essay.

So we have an extreme version PDA in the literature, and apparently not based on the
literature (which one could view as extreme and short sighted in itself).

So the response of the authors of this extreme version of PDA, seems to be view
anything below their threshold as "Rational Demand Avoidance" or Not PDA.
It matters when lower diagnostic thresholds are also called "Pathological Demand Avoidance" or "Extreme Demand Avoidance".

See Newson et al (2003):
https://adc.bmj.com/content/88/7/595

O’Nions et al (2014), with the EDA-Q validation paper.

Gillberg et al (2015) for Faroe Islands paper:

To be clear the clinic in question is developing a tool to screen for its version of PDA. No idea what happens to those with PDA at lower thresholds. Clinic views EDA-Q as being too easy to meet threshold on/ "false positives".
To be clear the EDA-Q title is "Extreme Demand Avoidance-Questionnaire".

The EDA-Q detects PDA at non-pervasive levels, i.e. some view it as not being "extreme enough" for PDA. From:

Now I need to create a Gaussian curve of PDA population, one end would Extreme Demand Avoidance & other Gillberg et al (2015).
I am still working out a suitable name for Gillberg et al (2015). I have:
Non - Extreme Demand Avoidance.
Barely clustering together PDA traits.
Sub clinical PDA.
Broader PDA Phenotype.

Back to the EDA-Q. The EDA-Q views PDA as an ASD, assumes PDA has coding issues (which is not assumption I would necessarily make). Views social demand avoidance to manipulative...

... Specialised autism experts consulted. Attempted to validate EDA-Q in autistic CYP. There seems to be non-autistic persons in the two PDA groups. O’Nions has not provided a robust reason to assume all CYP with PDA are autistic.
The point I am making here, is that if the tool that was designed by some autism expert researchers (at least Happe is) & over 10 other autism experts detects PDA in non-autistic persons - it should tell you that PDA is NOT autism.

I.e. it is highly questionable for any clinic, including a specialised autism and PDA clinic to discard the EDA-Q because it does not conform to their wishes.

There are other reasons to, such as sheer amount of our PDA knowledge that is related to the EDA-Q.

To me, that is nothing to do with science, but seems a self-validation exercise, especially when this seems to be going of the clinic's staff' opinions on autism and PDA.

I do not wish to make this point. Considering one of clinic's staff makes the quote of:

"Professionals and teams working with children need to become aware of the ways in which girls can mask their difficulties,...

... and need to move away from using the DSM as a 'bible'. Stating that someone does not fulfil criteria, when these criteria are based on upon a 'male' presentation of a disorder, is short sighted in the extreme."
It appears, one can make an equally valid statement about their position on PDA. That their position is short-sighted in the "extreme"; i.e. is an extreme position.

That is pretty much my rationale for "Extreme Extreme Demand Avoidance" name.

I am intending to make a Gaussian curve image later of PDA population.

I am going to clarify a bit more of the rationale for the names.

So Extreme Demand Avoidance is reflective of the clinic does not "Pathological" descriptor, viewing it as demeaning.

The point behind these suggested names is it possible for a person to meet its diagnostic threshold, without having core PDA traits present & therefore cannot reliably be sure Demand Management Cycle is present.
I am still working out a suitable name for Gillberg et al (2015). I have:
Non - Extreme Demand Avoidance.
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Broader PDA Phenotype.

I explain how core PDA traits might not be present at Gillberg et al (2015) threshold, here:

Core PDA traits are set out in this diagram comparing PDA traits vs DSM-5 autism criteria.

The point I am trying to make, is that one cannot be sure core traits are present, one cannot assume what is being diagnosed is actually PDA, sharing universal features of the proposed Disorder. It is one of the reasons why I prefer EDA-Q threshold.

Reason why EDA-Q is important to our PDA knowledge base.
I.e. it is highly questionable for any clinic, including a specialised autism and PDA clinic to discard the EDA-Q because it does not conform to their wishes.

There are other reasons to, such as sheer amount of our PDA knowledge that is related to the EDA-Q.

Also, the clinic's suggested name of "Extreme Anxiety" is important, as it also means name of "Extreme Extreme Demand Avoidance" is reflective of their position.

Pertinently, "Extreme Anxiety" supports my critique, behaviours being pathologised by high ADOS scores in their research are caused by anxiety & that its because ADOS
is interacting atypically with PDA behaviours as ADOS is not designed to assess PDA features

The point is ADOS mainly assesses for autistic social communication differences (Category A DSM-5 autism criteria). ADOS is atypically interacting with PDA’s anxiety based RRBIs and hence provided invalid social communication scores for it.

I will restate this, the case that PDA is an ASD, does genuinely appear to be on thin ice (so to speak).

Article showing how ADOS mainly assesses autistic social communication differences & how it is possible to meet DSM-5 autism threshold scoring only on Category A questions.

Theoretically possible for non-autistic person to meet DSM-5 autism threshold by expressing anxiety based demand avoidance RRBIs...

The core PDA traits are RRBIs in nature. See the blog post, where I argue PDA can be viewed as a form of OCD and Related Disorders.
"It is helpful to remember that children with a PDA profile are not deliberately difficult. If the socially strategic behaviour is seen for what it is—a scripted and limited strategy for ensuring predictability and control," P 415
This is image is from here, page 8

This image is from this booklet, p7.
pdasociety.org.uk/wp-content/upl...
This might seem like a tangent, but I am substantiating what I am saying to make it harder for others to dismiss.

I have a rough Gaussian Curve done, just need to map out the diagnostic thresholds and refine it.

![Gaussian Curve Image]

This is my best guess at this, others might produce something different to this.

![Gaussian Curve Image]

Extreme Extreme Demand Avoidance = Eaton and Weaver (2020).

I could not decide between what was a suitable name for Gillberg et al (2015), so I chose two names which should clinically mean the same thing: "Subclinical PDA Traits/ Broader PDA Phenotype". Others might disagree, would be open to other suggestions.

I have tried to keep the same style that I used in the previous version of the image, so people should be familiar with what I am meaning in the new Gaussian Curve image.
Same features include gradients, for light to dark, for light for lower frequency and intensity levels versus dark for higher frequency and intensity PDA behaviour levels.

I need to point out that not all the persons in this diagram would necessarily transfer over to a Gaussian curve of PDA population.

Reason for this is, that many/most persons at Gillberg et al (2015) or below are not displaying all core PDA traits & displaying Demand Management Cycle. I.e. these people should not count as having Pathological/Rational/ExtremeDemand Avoidance.
Although, saying this, I am tempted to rename "Extreme Extreme Demand Avoidance", to "Extreme Rational Demand Avoidance" to highlight, how I & @milton_damian would view it to be same construct throughout.

Main reason for sticking for "Extreme Extreme Demand Avoidance" is to respect clinics views over naming PDA.

I have also merged the DSM-5 OCD and EDA-Q thresholds as I consider them to be at comparable levels, but I admit this might not be the case. I figured it is better to reduce information being provided to not confuse people.

I changed the name of the diagram to "Gaussian curve of estimated PDA population and different diagnostic thresholds" to better represent what is actually be portrayed in it.

I think this is the version I will be using going forward, besides maybe minor tweaking.

I would welcome feedback on this diagram.

@Threadreaderapp Please could you unroll.
Thank you in advance.