

Demand-Avoidance Phenomena (“*Pathological*” / “*Extreme*” Demand Avoidance): What if it is a Neurodevelopmental Disorder?

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12th of December 2022.

PROFILING MYSELF.

Conflicts of interest.

- 1) Developing various DAP tools, e.g., Pathological Demand-Avoidance-Beliefs Scale (PDA-BS).
- 2) Income from delivering training sessions on DAP.
- 3) Reluctantly advocates for it to be diagnosed as a standalone construct.

PROFILING MYSELF.

My perspective.

- 1) Is autistic.
- 2) Meets Newson's DAP profile, is not emotionally attached to it.
- 3) Reflect upon "*how their values shape their understanding and construction of autistic people.*" (Botha 2021, p1).
- 4) Agenda is for at least inclusive good quality scientific-method based research & practice.
- 5) Favours a cross categorical approach & we should be aspiring to stop utilising Disorder based constructs in the future.
- 6) PhD is investigating DAP & part of CADS at LSBU.
- 7) My interpretation of DAP & its literature, others may disagree.

IN THE BEGINNING.

Introduction.

- 1) Apologies not talk advertised, EF & mental health issues.
- 2) Eaton & Weaver (2020) overview.
- 3) Thought experiment details.
- 4) Why do thought experiment.
- 5) DAP as a ND.
- 6) Estimated thought experiment results.
- 7) What we can infer from hypothesised results.
- 8) Seems concerns surrounding “*DAP Profile of ASD*” are valid.

PROFILING MYSELF.

My perspective.

1) CAS definition:

“The ‘criticality’ comes from investigating power dynamics that operate in Discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce ‘disability’.” (Waltz 2014, p1337).

LET'S TALK.

Eaton & Weaver (2020).

- 1) Carried analysis of 351 CYP assessed at Eaton's private clinic. Statistically significant differences in scores on Module 3 of ADOS-2, between autistic CYP without DAP & autistic CYP with DAP.
- 2) Module 3 includes variety of tasks like joint interactive play, telling a story from a book, conversation and reporting, and a series of questions examining a young person's understanding of their and others' emotions, as well as their perception of everyday social relationships. Differences appeared to occur due an inability or unwillingness to engage in the assessment, with creative attempts made to disrupt, avoid or delay completing the module. CYP with DAP more likely to score 3s (*“minimal or no response to the examiner's attempts to engage the participant”*) rather than 2s or 1s (PDA Society 2022).

LET'S TALK.

Eaton & Weaver (2020).

- 1) DAP was only diagnosed in those Eaton's private clinic believed are autistic.
- 2) Private clinic known for interest in DAP, which views it as a "*Profile of ASD*".
- 3) Data collection and diagnoses made by multidisciplinary team, a including clinical psychologist.
- 4) Post hoc data analysis by Eaton & Weaver. Unclear, but seems Eaton was involved in multidisciplinary team making diagnoses (Eaton & Weaver 2020).
- 5) Seems substantial risk of bias.

A WAR GAME?

Eaton & Weaver Diagnostic groups (Eaton 2018b).

Diagnostic group.	Number.	Percentage.
Autism without DAP	145	41
Autism with DAP	111	32
Neither Autism or DAP	95	27
Total	351	100

A ROLE PLAY?

Thought experiment.

- 1) Hypothetical replication of Eaton & Weaver (2020).
- 2) Same referral pattern of 351 autism assessments over a two-year period, using the same tools, & same reasonable adjustments to allow an ADOS assessment.
- 3) Differences are data collection by a team, with no knowledge of DAP. Diagnoses were made by a blinded-independent multi-disciplinary team. A person is diagnosed as being autistic due conforming to accepted understanding (i.e., the DSM-5 autism criteria), not due to expressing features of DAP. DAP is a Neurodevelopmental Disorder, independent of autism.
- 4) Purpose of changes is to reduce bias present.

A MATTER OF PERSPECTIVE.

Hypothesised study rigidly follows DSM-5 autism.

- 1) *“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.”* (Eaton 2018a, p176).
- 2) Not doing this!

A ROLE PLAY?

A person is not autistic due these traits.

- 1) Anxiety.
- 2) Demand-avoidance.
- 3) Fantasy and roleplay.
- 4) Harassment-bullying-stealing-lying-stalking etc.
- 5) Impulsiveness.
- 6) Obsessive behaviour.
- 7) Rapid mood changes.
- 8) Socially strategic-manipulative behaviours.

A ROLE PLAY?

Should DAP traits be associated with autism.

- 1) Last DRF talk describes how autistic persons are suffering greatly due to lack of support, stigma & prejudice (Woods 2021b).
- 2) Lack of debate if we want DAP traits to be associated with autism, either in part, or in entirety?
- 3) Do you want features like harassment, bullying, stealing, lying, stalking etc, to be associated with autism?

A ROLE PLAY?

Some demand to not associate aspects of DAP with autism.



1) Accept this is not research & is biased.

LET'S TALK.

A person is autistic due to DSM-5 autism criteria.

- 1) Claim autism expanded to include DAP (PDA Society 2022).
- 2) DAP features seen throughout autistic population (Woods 2019).
- 3) DAP is different from typical (accepted) autism understandings (i.e., DSM-5 autism) (O'Nions et al 2016b; PDA Society 2022).
- 4) All attempts to divide autism have failed (Woods et al 2019), if DAP is different to typical autism, DAP is not autism...

LET'S TALK.

A person is autistic due to DSM-5 autism criteria.

- 1) DAP should be diagnosed as part specifying an individual's characteristics (PDA Society 2022).
- 2) DSM-5 autism specifiers used denote co-occurring difficulties, e.g., LD or anxiety (APA 2013), i.e, non-autism features...
- 3) ADOS (1 & 2) not designed to assess for DAP.
- 4) O'Nions (2013) created ~ 30 ADOS-1 items to assess DAP, as typical ADOS items do not assess for DAP features.
- 5) If DAP features were representative of autism features, ADOS would assess for them...
- 6) Some claim autism has expanded too far (Woods 2020).

QUESTION TIME.

Quotes indicating DAP is not autism.

- 1) *“Although there are obvious differences from a classic ASD profile...”*
(O’Nions et al 2016b, p1).
- 2) *“Those who have an ASD diagnosis but it ‘doesn’t quite fit’ or who are on the cusp of, but do not meet, ASD diagnostic criteria...”* (PDA Society 2022, p6)
- 3) *“Whilst individuals with a PDA profile would be expected to meet the criteria for autism, the contributors’ accounts show that they often present with:*
 - *superficially better social interaction skills, often with good eye contact*
 - *fewer repetitive behaviours and less obvious routines (routines may be their own, rather than someone else’s, reflected in a strong need for control over their environment)*
 - *interests that may be intense but not so long standing, or more focused on people than things.”* (PDA Society 2022, p17).

LET'S TALK.

A person is autistic due to DSM-5 autism criteria.

- 1) Studies indicate ~ 33% drop off rate in DSM-5 autism versus DSM-4 autism subtypes (Attwood 2015; Bennett & Goodall 2016; Kulage et al 2014; Sturmey & Dalfern 2014). Particularly affects those with Asperger's Syndrome & PDD-NOS (Evers et al 2021).
- 2) Those diagnosed with Asperger's Syndrome & PDD-NOS, typically receive DAP diagnosis (Christie 2007; Christie et al 2012; Newson et al 2003; O'Nions et al 2015), most likely to not receive DSM-5 autism diagnoses.

LET'S TALK.

Why do the thought experiment?

- 1) No consensus over how to diagnose autism in UK (Eaton & Weaver 2020), or DAP in UK (PDA Society 2022).
- 2) Eaton & Weaver (2020) position on DAP is not representative of broader evidence, opinion, & practice.
- 3) DAP is essentially already viewed as a ND!
- 4) DAP originally a PDD, it is different & separate from autism, thus is not autism... (Newson et al 2003).
- 5) Allows us question to what if Newson's views are respected.
- 6) Clinical need from standalone DAP diagnoses (Woods 2021a).
- 7) Interrogate potential affects of bias in Eaton & Weaver (2020).
- 8) Interrogate how DAP interacts with ADOS-1 & ADOS-2.

DISORDER-ORGANISED.

DSM-5 Disorder Definition.

“A mental disorder is a syndrome characterized by clinically significant disturbance in an individual’s cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behavior (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above.” (APA 2013, p20).

DISORDER-ORGANISED.

What does a Neurodevelopmental Disorder look like?

- 1) A chapter in DSM-5, contains ADHD, autism, Intellectual Disability.
- 2) NDs often co-occur together.
- 3) Specifiers used to denote co-occurring conditions
- 4) Features often present before school age but can change with development of CYP.
- 5) Features often deficits that affect multiple functionings, but can appear in excess, like too many RRBIs in autism (APA 2013).
- 6) DAP in this thought experiment should be heterogeneous, and present from early infancy. DAP's features can present in social and other settings, and adversely affect a person.

DEFINITIONS DEFICITS.

“DAP Profile of ASD” PDD definitions.

1) **Pervasive** suggests that the effects can be seen in all a child’s development.

Developmental means that the disorder is present at birth, gradually becoming apparent during the course of development.

Disorder implies more than straightforward delay.” (Christie 2019).

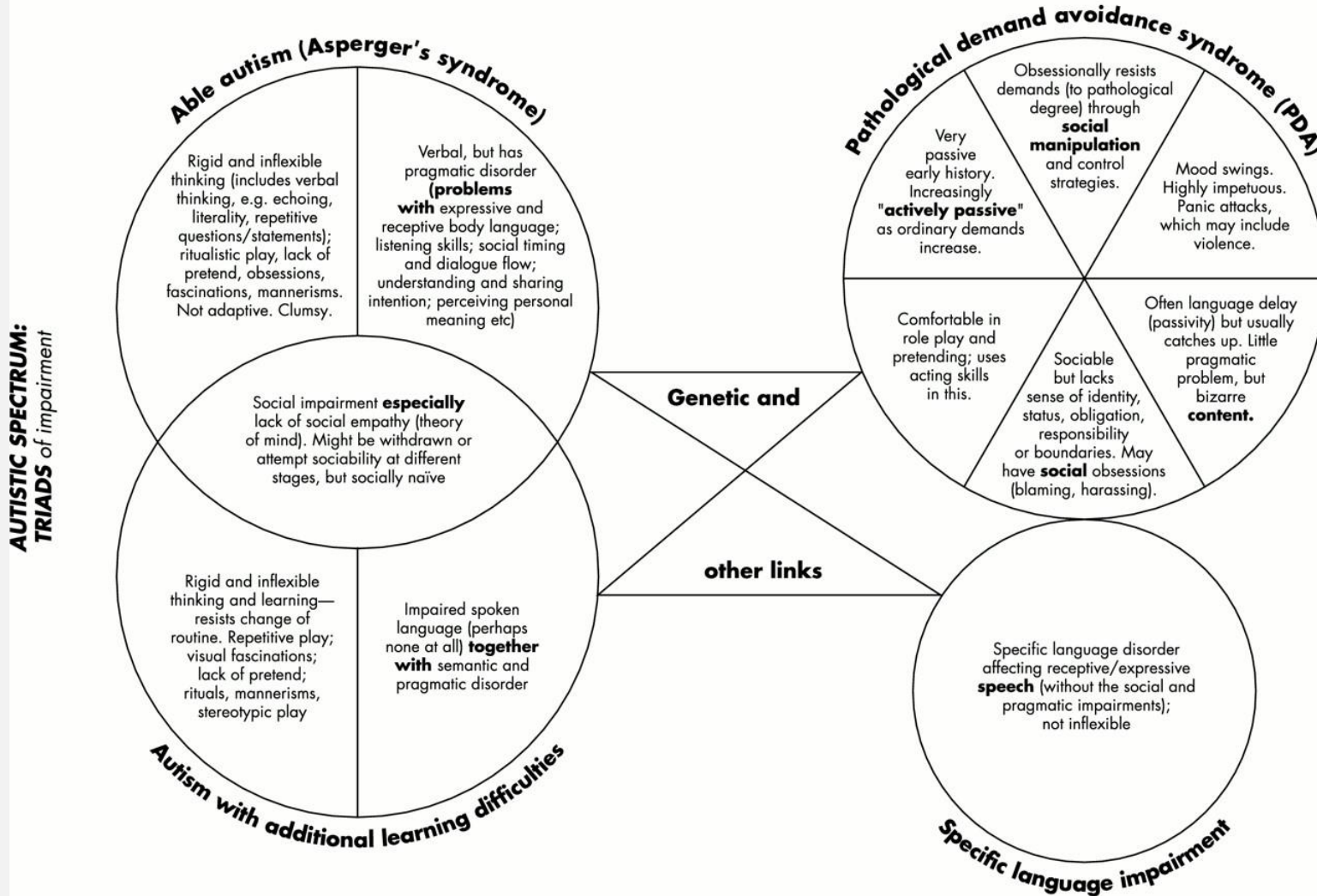
DEFINITIONS DEFICITS.

Eaton & Weaver DAP algorithm (2020, p37).

- 1) *“These were recorded as part of the child’s developmental history, as follows:*
 - *demand avoidance had been present since early infancy and presented across contexts and time*
 - *features of demand avoidance were noted in the child during the assessment process*
 - *avoidance was pervasive and often seemed illogical or perverse (eg the child may be unable to eat when hungry)*
 - *avoidance was not limited to a specific activity (or activities) or activities in a specific context (eg school)”*
- 2) Partly derived from their clinical opinion (Eaton & Weaver 2020).

SQUARE PEGS, ROUND HOLES?

THE "FAMILY" OF PERVASIVE DEVELOPMENTAL DISORDERS
 (sometimes "autistic spectrum" is loosely used to describe the **whole** family)



Pervasive Developmental Disorders (Newson et al 2003, p599).

SLIs did not have RRBIs.

DEFINITIONS DEFICITS.

“*DAP of ASD*” is more than a “*Profile*”.

- 1) Newson et al (2003) did not require PDDs to have RRBIs.
- 2) Christie (2019), Eaton & Weaver (2020) algorithm do not require DAP to have RRBIs, or social communication issues.
- 3) Claim DAP has different strategies to autism (PDA Society 2022).
- 4) “*DAP Profile of ASD*” definitions conform to ND understandings.
- 5) DAP already is a ND, not a “*Profile*”...

DEFINITIONS DEFICITS.

“DAP of ASD” is more than a “Profile”.

- 1) *“A cautionary counterview however (Green et al., 2018) is that the formulation of a PDA ‘diagnosis’ or ‘profile’ (terms often used interchangeably, as in the Stuart et al. paper) contains much more than a simple symptom description, but presupposes a specific personality or developmental identity in the child, linked to a set of management strategies, none of which has yet been established empirically. Starting from this point assumes a lot therefore and can create a circularity in clinical as well as research thinking that may well not serve children and families well.” (Green 2020, p74).*

FOREVER BLOWING BUBBLES.

Building DAP as a ND.

- 1) RCP describes DAP without social communication issues (Berney et al 2020).
- 2) ADHD threshold only needs to present in 2 settings (APA 2013).
- 3) Arbitrary to view DAP as pervasive.
- 4) Core 5 anxiety based RRBIs:
 - Comfortable in role play and pretending.
 - Continues to resist and avoid ordinary demands of life.
 - Lability of mood, impulsive, led by need to control.
 - Obsessive behaviour.
 - Strategies of avoidance are essentially socially manipulative (Woods 2022).

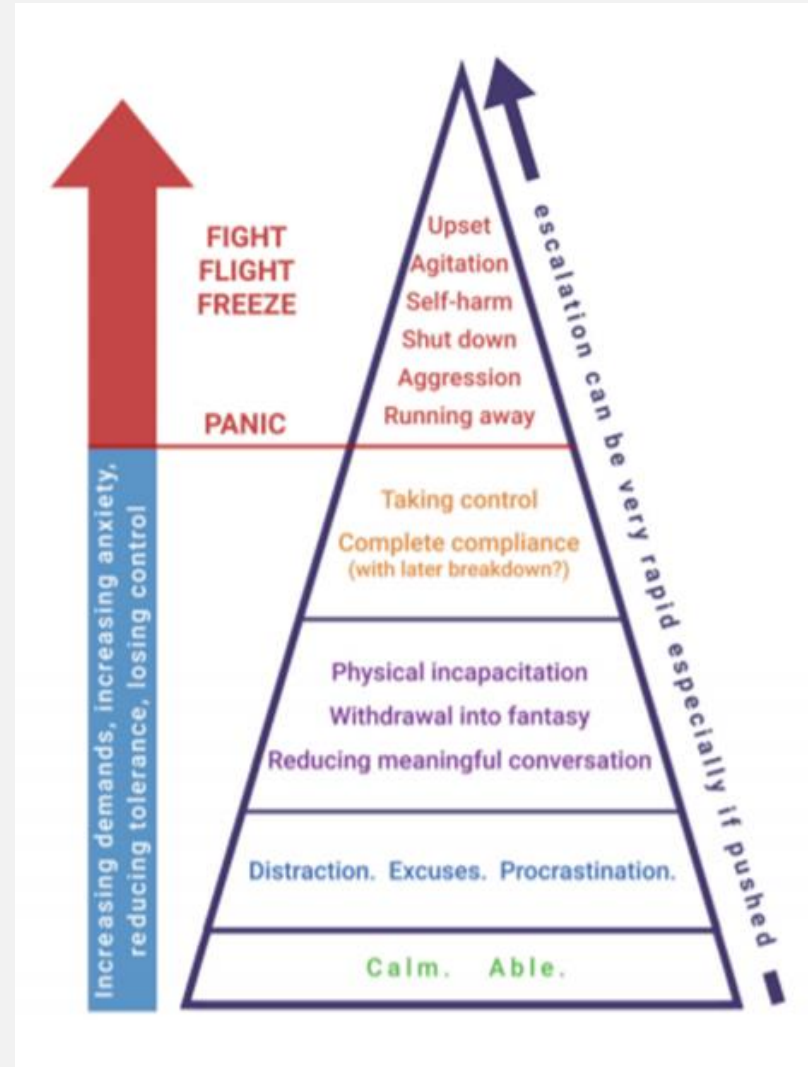
FOREVER BLOWING BUBBLES.

Merging core DAP traits with Eaton & Weaver (2020) algorithm.

- 1) • Avoidance features was pervasive, i.e., was not limited to a specific activity (or activities) or activities in a specific context (e.g., school), for instance features of demand-avoidance were noted in the child during the assessment process.
 - Comfortable in role play and pretending.
 - Demand-avoidance had been present since early infancy and presented across contexts and time.
 - Lability of mood, impulsive, led by need to control.
 - Obsessive behaviour.
 - Strategies of avoidance are essentially socially manipulative/strategic.

A STRESSFUL SITUATION.

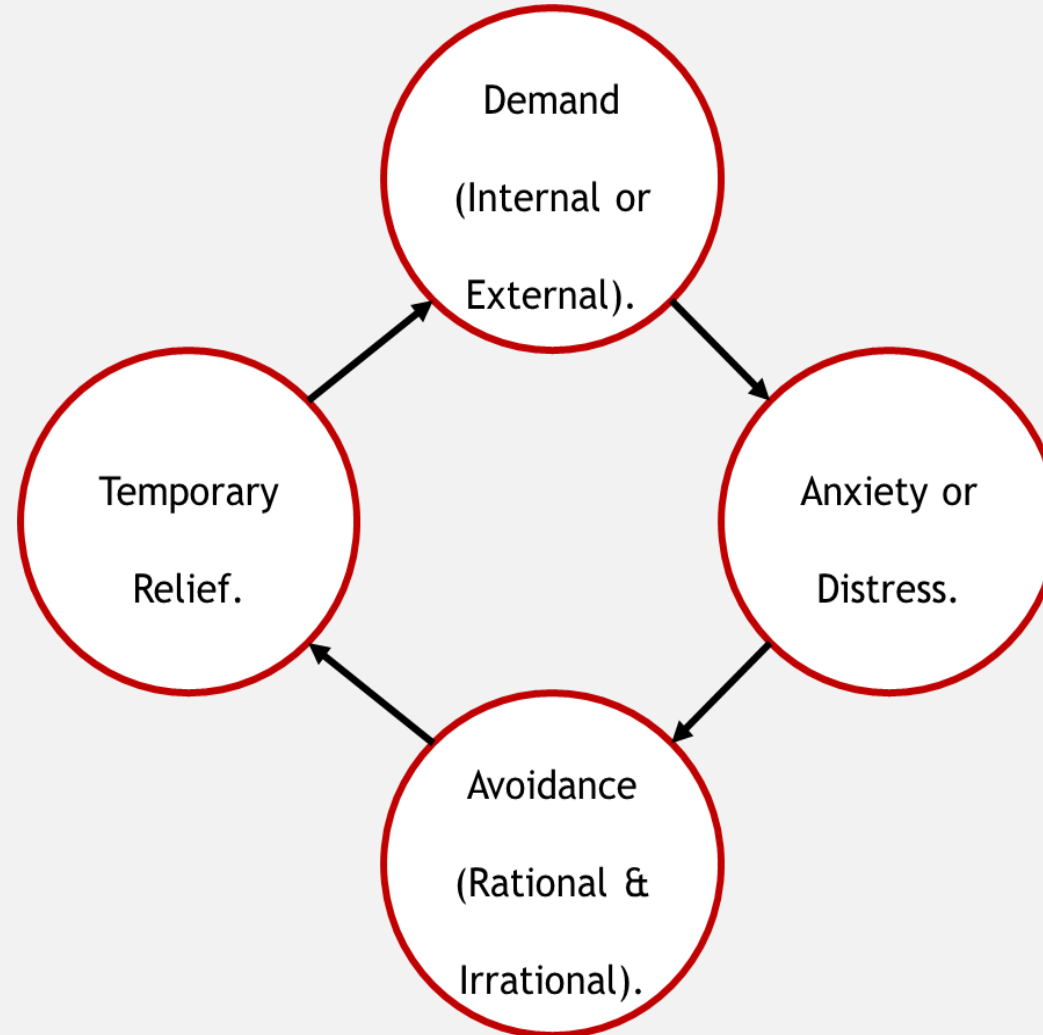
How are demands avoided. (PDA Society 2020, p7).



What if DAP is a Neurodevelopmental Disorder?

A STRESSFUL SITUATION.

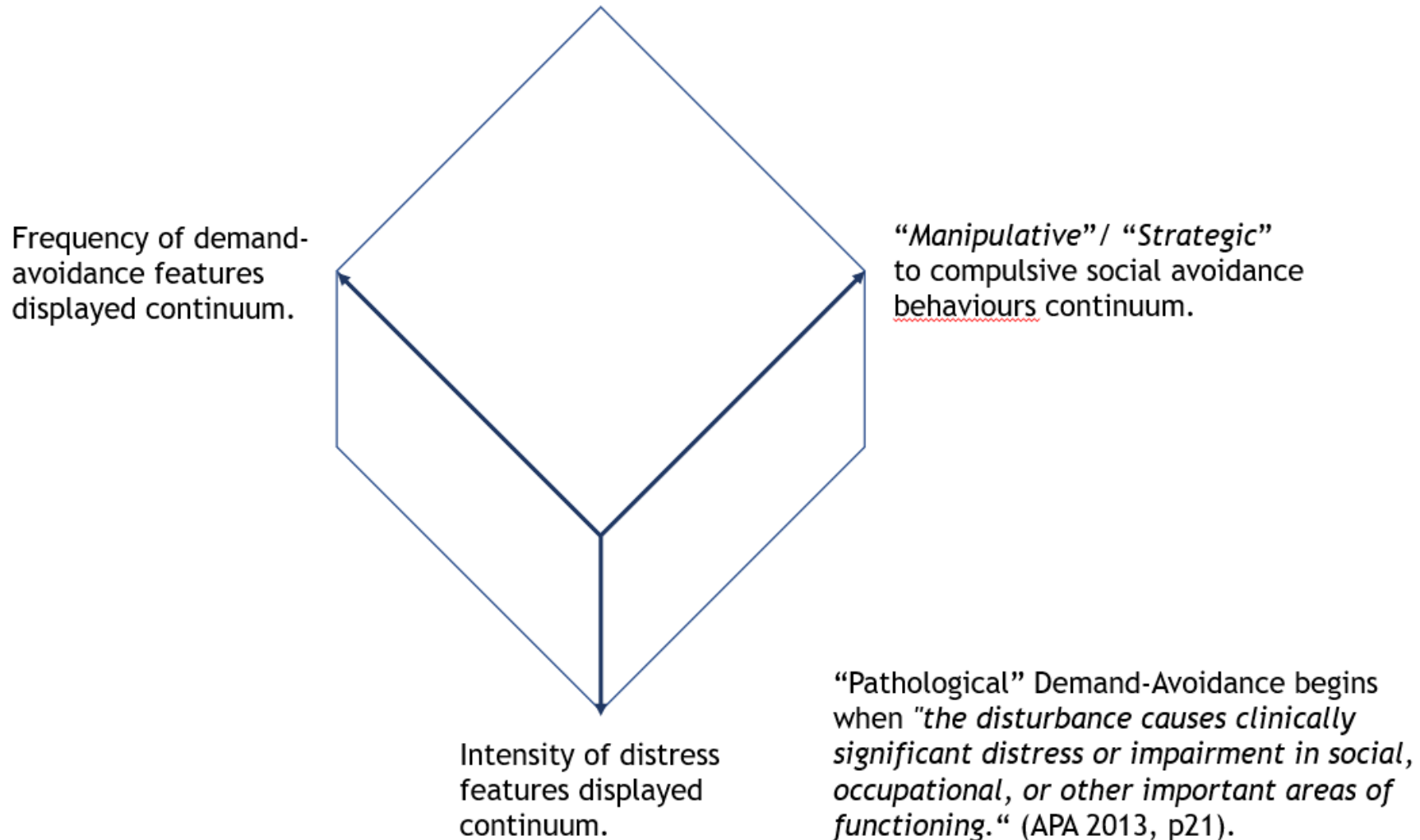
Demand Management Cycle (Woods 2022).



What if DAP is a Neurodevelopmental Disorder?

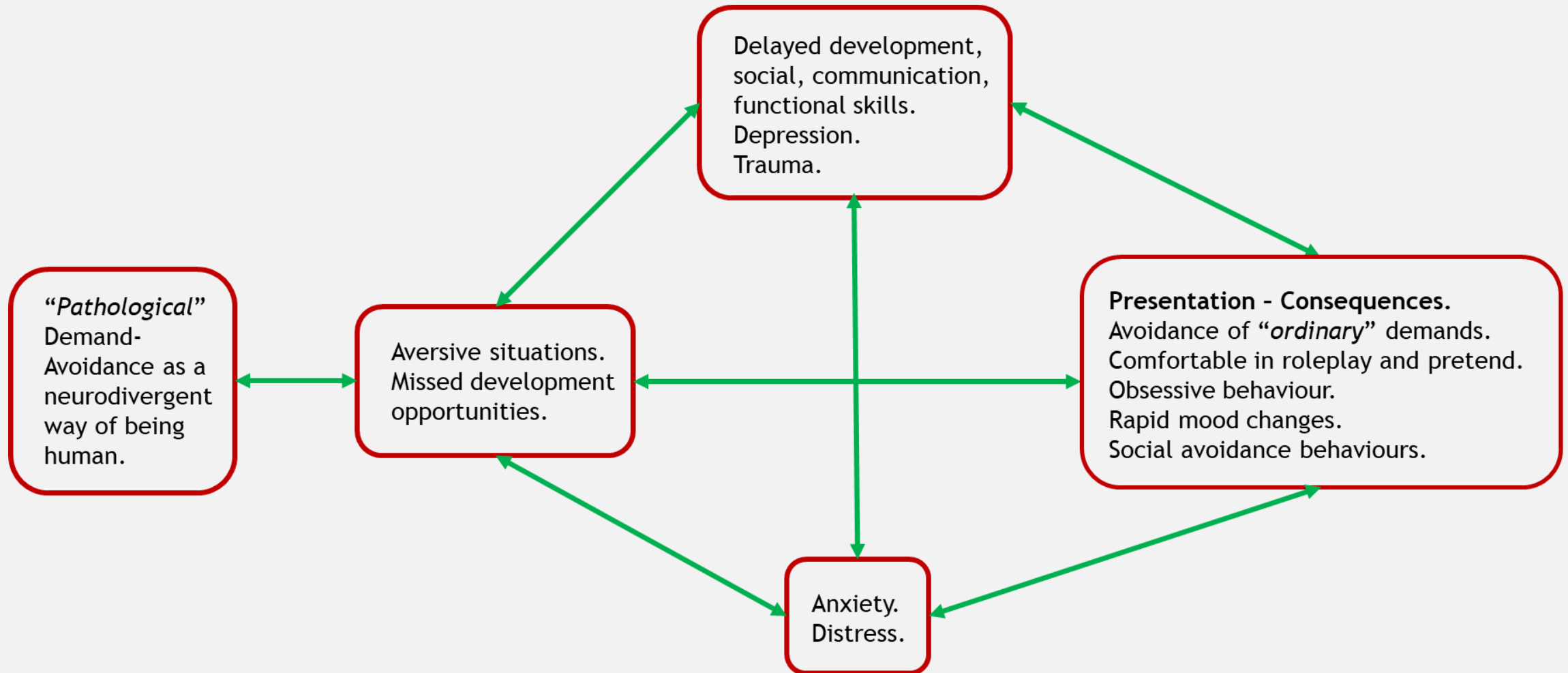
A STRESSFUL SITUATION.

THREE-DIMENSIONAL CONTINUUM OF “PATHOLOGICAL” DEMAND-AVOIDANCE.



A STRESSFUL SITUATION.

A transactional stress developmental model for DAP.



A WAR GAME?

Eaton & Weaver Diagnostic groups (Eaton 2018b).

Diagnostic group.	Number.	Percentage.
Autism without DAP	145	41
Autism with DAP	111	32
Neither Autism or DAP	95	27
Total	351	100

A WAR GAME?

A person is autistic due to DSM-5 autism criteria.

- 1) ADOS (1 & 2) not designed to assess for DAP.
- 2) O’Nions (2013) created ~ 30 ADOS-1 items to assess DAP, as typical ADOS items do not assess for DAP features.
- 3) If DAP features were representative of autism features, ADOS would assess for them...
- 4) Some claim autism has expanded too far (Woods 2020).

A WAR GAME?

Those with DAP often aversively experience ADOS assessments.

- 1) ADOS assessment contains many structured & semi-structured social interactions between an examiner & person suspected of being autistic.
- 2) ADOS assessment can take 30 - 60 minutes to complete.
- 3) Eaton & Weaver (2020) viewed DAP's demand-avoidance as highly likely to be driven by anxiety, including adapting the ADOS assessment to co-regulate anxiety levels of autistic persons suspected with DAP (p41).
- 4) ADOS assessment, places demands over an extended period of time, those with DAP often experienced it as intrusive & aversive.

A WAR GAME?

Those with DAP often aversively experience ADOS assessments.

- 1) ~ 20% of CYP assessed did not complete ADOS assessment O’Nions (2013).
- 2) *“Of those case participants for whom testing could not be completed, 6 displayed avoidance to the extent that testing could not take place. Of these, three had extreme reactions (tantrums/ outbursts of physical violence), which also occurred in three participants who did complete testing, Three participants could not be tested due to extreme avoidance plus learning difficulties. Testing was suspended for seven participants due to learning/ concentration difficulties. A further 2 participants were excluded prior to analyses due to learning difficulties, and 2 asked to leave the session early on in the protocol.”* (O’Nions 2013, p142).
- 3) *“accepting that when an individual is particularly avoidant, it may be difficult or even impossible to complete standardised assessment tools such as the ADOS”* (PDA Society 2022, P15).

A WAR GAME?

Those with DAP often aversively experience ADOS assessments.

- 1) Clinical assessment for autism, some CYP expressed would go into tents or under tables, conducting assessments to toys or teddies, or with CYP pretending to be superheroes or animals. Provide various “*inventive*” and “*elaborate*” excuses. Repetitively asking questions, or offering large amount of information relating to prescribed interests or previous experiences to an intense degree. Some CYP knocked objects of tables, threw objects, or removed themselves or assessment materials from the room. Rarely, CYP threatened clinicians with physical violence, usually after other attempts have failed. CYP had many methods like ways in which clinicians “*were allowed*” to deliver requests. (Eaton & Weaver 2020, pp35-36).

A WAR GAME?

What does this mean for thought experiment.

- 1) Hypothesised assessment team are making reasonable adjustments as when using ADOS.
- 2) Yet, they are not interested in DAP per se... Unlikely to be as motivated or experienced in working with those suspected of DAP, as Eaton & Weaver (2020).
- 3) Likely, a few percent less CYP with DAP will complete assessment process in thought experiment.

A WAR GAME?

Rigid DSM-5 autism criteria & diagnosing DAP as a ND.

- 1) DSM-5 autism criteria are rigidly adhered to in thought experiment.
- 2) Likely ~ 33% drop in autistic with DAP.
- 3) DAP features present throughout autistic population, including subclinical DAP as a ND thresholds.
- 4) Assuming Eaton & Weaver (2020) counting “*subclinical*” DAP as a ND features are autism features for diagnosing autism without DAP.
- 5) Likely significant drop in autistic persons without DAP, but less than ~ 33%.

A WAR GAME?

What reductions in autism with DAP & autism without DAP groups?

- 1) $\sim 33\% + \sim 4\% = \sim 37\%$ less autistics CYP with DAP.
- 2) $\sim 15\%$ less autistic CYP without DAP.
- 3) Obviously, an estimation, others might adopt different values.

A WAR GAME?

Estimated thought experiment diagnostic groups.

Diagnostic group	Number	Percentage sample
Autism without DAP	123	35
Autism with DAP	70	20
Non-autism (Other) without DAP	121	34
Non-autism (Other) with DAP.	37	11
Total	351	100

TRAVELING TO EARTH-616?

What can we infer?

- 1) DAP is seen in autistic CYP!
- 2) DAP can be diagnosed separately from autism...
- 3) Likely more than 37 non-autistic CYP with DAP due hypothesised clinicians not being “*on the lookout*’ for PDA features in their cases.” (O’Nions et al, 2016a, p418).
- 4) Thought experiment used largely same methodology as Eaton & Weaver, data collected should be largely similar to Eaton & Weaver (2020).
- 5) We can interrogate how DAP features are interacting with ADOS-2.

TRAVELING TO EARTH-616?

ADOS as a DAP tool.

- 1) *“accepting that when an individual is particularly avoidant, it may be difficult or even impossible to complete standardised assessment tools such as the ADOS, though the scoring algorithm does allow the examiner to score the interaction as a ‘3’ which reflects instances where the session was disrupted or where an individual refused to engage. The ADOS can still provide helpful information and be used to explore the overall nature of the interaction, even if it cannot be scored officially.”* (PDA Society 2022, p15).

TRAVELING TO EARTH-616?

ADOS as a DAP tool.

- 1) *“Module 3 includes a variety of tasks including joint interactive play, telling a story from a book, conversation and reporting, and a series of questions examining a young person’s understanding of their and others’ emotions, as well as their perception of everyday social relationships. The differences appeared to occur because of an inability or unwillingness to engage in the assessment, with creative attempts made to disrupt, avoid or delay completing the module. Children with a PDA profile were more likely to score 3s (“minimal or no response to the examiner’s attempts to engage the participant”) rather than 2s or 1s.” (PDA Society 2022, p19).*

TRAVELING TO EARTH-616?

ADOS as a DAP tool.

- 1) *“Each item within the ADOS-2 is assigned a score of ‘0’ (indicating no difficulties), ‘1’ (indicating mild difficulties), ‘2’ (indicating more significant difficulties) or ‘3’ (indicating marked or substantial difficulties).” (Eaton & Weaver 2020, p39).*
- 2) *“‘3’ (indicating marked or substantial difficulties)” is different to “3s (“minimal or no response to the examiner’s attempts to engage the participant”).”*
- 3) How is unwillingness to engage with assessment using *“creative attempts made to disrupt, avoid or delay completing the module.”* Indicative of autism?

TRAVELING TO EARTH-616?

ADOS as a DAP tool.

- 1) Much of DAP demand-avoidance seems compulsive. Argued to be developed & maintained via generic negative reinforcement cycle (Eaton & Weaver 2020; O’Nions & Eaton 2021).
- 2) Much of DAP features require intent to do actions, like its criminal acts: Harassment, stealing, lying, stalking etc (Woods 2022).
- 3) Likewise, if person is unwilling to engage with assessment, indicates by choice, i.e., with intent...

TRAVELING TO EARTH-616?

ADOS as a DAP tool.

- 1) ASD includes social communication issues (APA 2013).
- 2) How can DAP be autism, if person seems to not have social communication issues?
- 3) How can a person be autistic if they are deliberately expressing their self-agency by not engaging with ADOS assessment?

TRAVELING TO EARTH-616?

ADOS as a DAP tool.

- 1) Matters as Eaton & Weaver (2020) hypothesised DAP's supposed "*surface sociability*" should present in low ADOS-2 scores, i.e., scored "0", instead of being scored "3".
- 2) Eaton & Weaver (2020) often scored DAP's features with "3" due to quality of interactions. Acknowledge social interactions are subjective.
- 3) O'Nions (2013) attempted 96 ADOS assessments with bespoke ~ 30 items to assess for DAP.

TRAVELING TO EARTH-616?

ADOS as a DAP tool.

- 1) *“For example, a number of participants in the PDA group spoke for some of the session in a very babyish voice and style (e.g. using only single words), but at other times appeared age appropriate in their verbal communication. Therefore, unusual behavioural features may have reflected a style of interacting (which was inappropriate for the context), rather than a functional impairment in interactions per se.”* (O’Nions, 2013, 198).
- 2) Why did O’Nions (2013) find this, while Eaton & Weaver (2020) did not?

TRAVELING TO EARTH-616?

DAP ADOS Items examples.

1) *“Manipulative tactics.*

This item measures use of strategies or tactics that appear to be manipulative- NB this item relies on subjective interpretation about whether the participant is intending to be devious - rather than merely based on observations. You have to make a call. Note that this behaviour does not need to be successful - it can cover socially adept and unobtrusive manipulative behaviour

*0 « does not apply; 1 = uses tactics that could be interpreted as manipulative (i.e. with deliberate intent) - e.g. pretending not to know the answer, making threats, not speaking, telling blatant lies OR occasionally uses clearly manipulative tactics; 2 * uses tactics that are clearly manipulative (designed to be off-putting) persistently during the session.” (O’Nions, 2013, p238).*

TRAVELING TO EARTH-616?

DAP ADOS Items examples.

1) *“Impetuous/impulsive*

This item reflects the participant appearing impetuous or impulsive - characterised by sudden or rash actions, extreme responses, restlessness).

*0 * does not apply; 1 * impetuosity/ impulsiveness evident at times (e g. towards the end of the session); 2 « extreme impetuosity/impulsiveness throughout” (O’Nions, 2013, p239).*

TRAVELING TO EARTH-616?

DAP ADOS Items examples.

- 1) ***“Variable engagement with demands***
(PDA) This item reflects variability in response to demands: the participant cooperates with some things/ gives good answers/ checks they are doing them right; then refuses/ withdraws for others.
*0 * does not apply; 1 * applies to some extent; 2 * extremely characteristic of the interaction.”* (O’Nions, 2013, p239).

TRAVELING TO EARTH-616?

DAP ADOS Items examples.

1) *“Range of strategies to avoid*

This Kern reflects the participant using a variety of strategies in the service of avoiding and/or maintaining control during the session.

0 » does not apply; 1 » uses more than one strategy in the service of avoidance (e.g. changing the subject, making requests, interrupting, persuading, adopting a persona, refusing, bargaining, leaving the room); 2 uses more than three strategies.” (O’Nions, 2013, p238).

TRAVELING TO EARTH-616?

DAP ADOS Items examples.

- 1) ***“Quantity of avoidance behaviour (PDA) This item reflects the quantity of avoidance behaviour, whatever its nature (e.g. distraction, withdrawal, pretending not to know the answer etc.),
0* this was never true of the participant; 1 * this was somewhat true of the participant; 2 »this was always true of the participant”*** (O’Nions, 2013, p237).

TRAVELING TO EARTH-616?

DAP ADOS Items examples.

- 1) *“Can’t comply with certain things - demands seem to be too much for them (PDA) This item reflects that participant experiencing a clear negative emotional reaction when demands are placed on them. This should be evidenced by clear signs of anxiety, such as withdrawing, or a strong emotional reaction that overwhelms the participant and results in a display of anger or aggression, or loss of control (e g. growling). Do not code frustration or displays of annoyance or anger that seem devoid of a strong emotional component e g. physical aggression that appears designed to stop you from doing something. 0 * does not apply; 1 * certain questions/ demands cause participant to withdraw/ conceal themselves/ become upset/ palpably anxious/ lose control; 2 * much of the session causes participants to be unable to withdraw/ conceal themselves/ become upset/ palpably anxious/ lose control OR when this does happen in an isolated incident the effect on the participant is potent.”*
(O’Nions, 2013, p237).

TRAVELING TO EARTH-616?

DAP ADOS Items examples.

1) “*Uncooperative or not bothered*”

This item reflects a participant who appears to be aware of demands and able to respond, but does not. This could be by way of overt refusal, or passiveness. Do not code where participant seems disengaged/ distracted due to severe autistic features (e.g. RRBIs) (emphasis added by RW).

*0 * not at all; 1 * gives occasional signs; 2 * gives persistent signs” (O’Nions, 2013, p236).*

TRAVELING TO EARTH-616?

Problems with using ADOS as a DAP tool.

- 1) Seems O’Nions (2013) could “*quantitatively*” assess for DAP features, while Eaton & Weaver (2020) could not. Hence subjectively scoring ADOS-2 on quality of social interactions.
- 2) Only reason to score DAP features as “3” on ADOS-2 is if one assumes DAP is an ASD/ “*Profile of ASD*”.
- 3) Eaton & Weaver (2020) argue DAP is part of autism.
- 4) Eaton was a contributor to PDA Society (2022), which views DAP as a “*Profile of ASD*”.

TRAVELING TO EARTH-616?

Problems with using ADOS as a DAP tool.

- 1) *“The lack of research into symptom clustering means that the description of the concept of PDA still has little empirical support and is currently mainly based on clinical impressions of experts. The high recognition factor that Newson cites as evidence for strong coherence of PDA as an entity is subject to expectation and confirmation bias (8).”* (Mols & Danckaerts 2022, Discussion).
- 2) Are diagnoses & results described in Eaton & Weaver (2020) due to expectation &/ or confirmation bias?

UNCOMFORTABLE PRETENCE.

NICE Position on DAP.

- 1) Three NICE autism guidelines.
- 2) DAP only mentioned in CG128, diagnosing autism in CYP...
- 3) *“Pathological demand avoidance (PDA) has been described as a particular subgroup of autism with passive early onset, obsessive behaviours which are often person focussed with superficial social skills in whom the most striking feature is refusal to comply (excessive demand avoidance) even to events which the child enjoys. This oppositional behaviour can also be described as ODD. (emphasis added by RW)” (NICE 2021, pp.288-289).*

TRAVELING TO EARTH-616?

Problems with using ADOS as a DAP tool.

- 1) *“From the authors’ descriptions, the impression is that these children are likely to have had co-morbid developmental and psychiatric problems, varyingly including oppositional defiant and/or hyperkinetic disorder or social anxiety disorder of childhood.”* (Garralda 2003).
- 2) *“Is the demand avoidant or resistant behaviour that is central to the pathological demand avoidance construct a redescription of what is termed oppositional defiance disorder in people without autism spectrum disorder?...At the surface feature level, traits described as pathological demand avoidance are often highly overlapping with oppositional defiance disorder in an autism spectrum disorder context....”* (Green et al 2018a, p459).

TRAVELING TO EARTH-616?

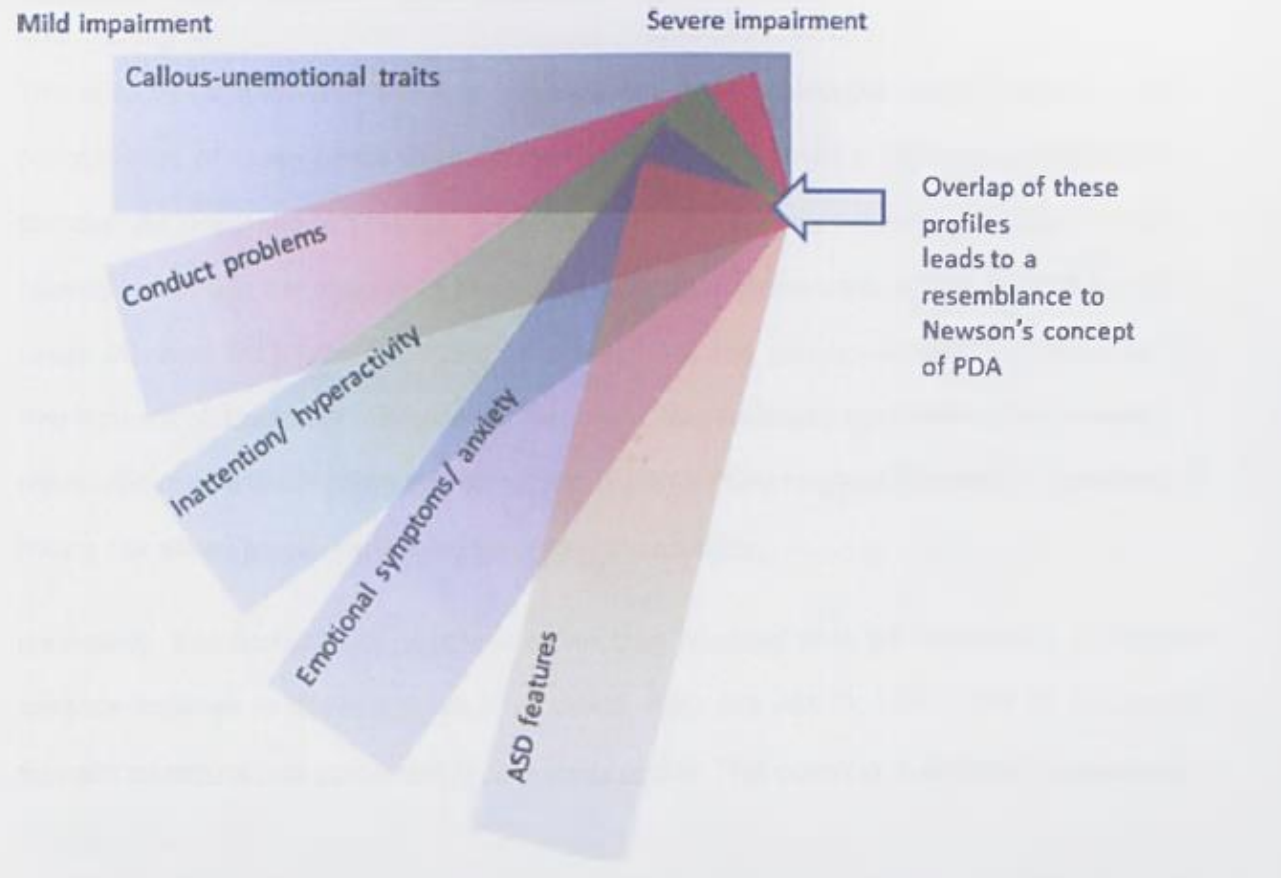
Problems with using ADOS as a DAP tool.

- 1) Eaton & Weaver (2020) claim followed DSM-5 autism criteria & NICE CG 128 guidelines.
- 2) Yet seem to be pathologising persons self-agency for unwilling to take part in assessments with DAP.
- 3) Are Eaton & Weaver redescribing features of what is termed ODD in people without autism?
- 4) Are Eaton & Weaver (2020) actually adhering to DSM-5 autism criteria?
- 5) Are Eaton & Weaver (2020) actually adhering to NICE CG 128 guidelines?

SPIKY PROFILE.

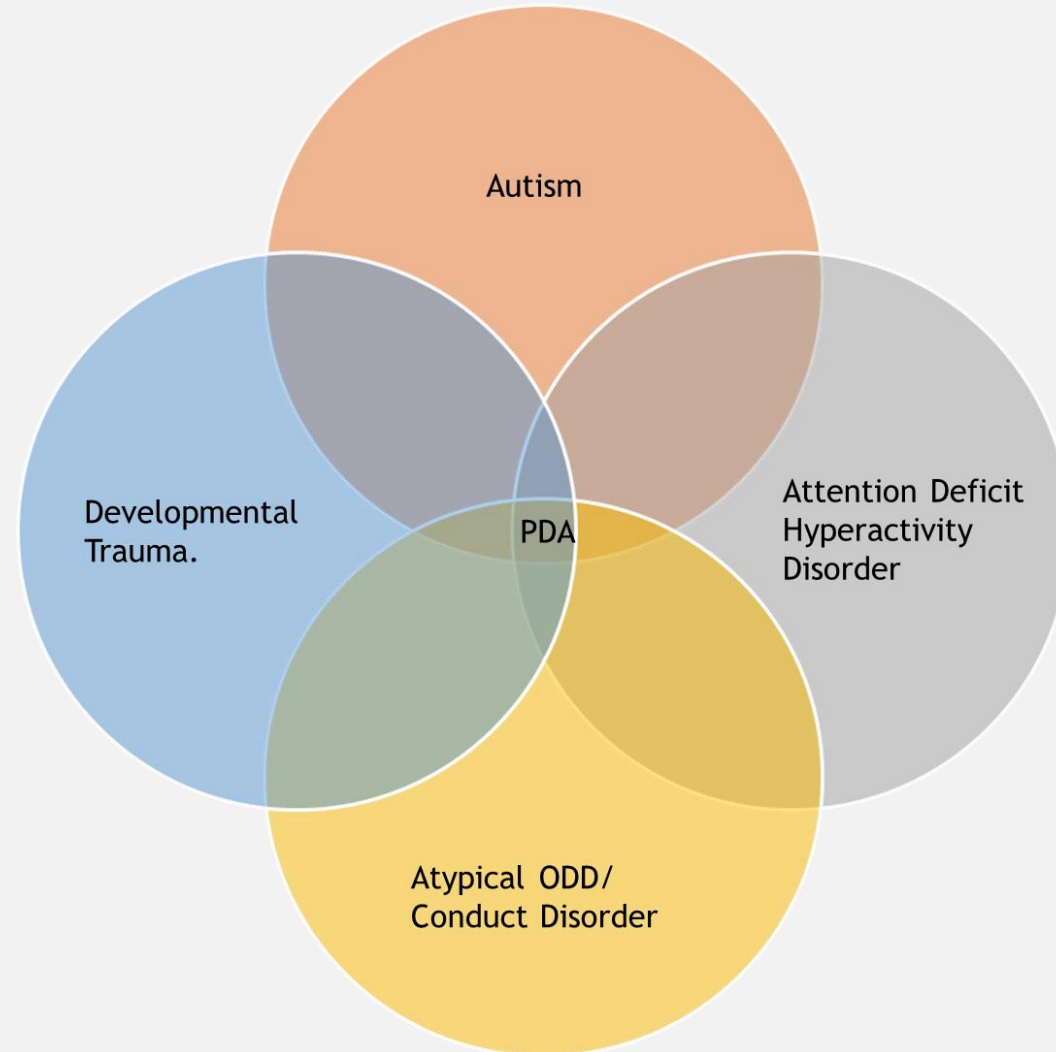
How accepted constructs may relate to DAP (O’Nions 2013, p93).

Figure 4-1: Schematic representation of dimensions of neuro-developmental and behavioural disorders in the general population that share features with PDA.



CIRCLE WARS, AGAIN.

Soppitt (2021, p299) DAP & its components diagram (my version).



What if DAP is a Neurodevelopmental Disorder?

AVOIDING VARIANCE.

Concluding comments.

- 1) Appears ADOS-2 is not suitable tools to assess for DAP.
- 2) Appears O’Nions (2013) ADOS DAP can “*quantitatively*” assess DAP features. Still has ethical issues with needlessly causing stress in those with DAP...
- 3) Seems “*DAP Profile of ASD*” redescibes aspects of ODD as autism features.
- 4) Basic logic of $A + B + C \neq A$, DAP cannot be autism, as it is more than autism features.
- 5) Seems outlooks which separate DAP from autism are valid.

AVOIDING VARIANCE.

Concluding comments.

- 1) CG 142 for assessing autism in CYP for describing DAP's demand-avoidance as ODD (NICE, 2021), appears suitable guidance for research and practice-based settings.
- 2) Lends credence to outlook DAP is an unnecessary arbitrary line in the sand (Milton 2017).
- 3) Seems concerns that DAP risks confusing caregivers and others (including clinicians) involved (Garralda, 2003; Green et al, 2018b), & DAP risks undermining validity of clinical based language (Green et al 2018b), are justified.

AVOIDING VARIANCE.

Concluding comments.

1) Do we want any of these difficulties to be autism features?

- Anxiety.
- Demand-avoidance.
- Fantasy and roleplay.
- Harassment-bullying-stealing-lying-stalking etc.
- Impulsiveness.
- Obsessive behaviour.
- Rapid mood changes.
- Socially strategic-manipulative behaviours.

2) Do we want a person to be autistic due to refusing take part in an autism assessment.

ANY QUESTIONS?

The End Game.

- 1) Contact Details: richardwoodsautism@gmail.com
- 2) Twitter handle:
@Richard_Autism
- 3) My researchgate:
https://www.researchgate.net/profile/Richard_Woods10
- 4) Any questions?

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ARE WE THERE YET?

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