

Demand-Avoidance Phenomena (“*Pathological*” / “*Extreme*” Demand Avoidance): As a Social Construct.

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07th of April 2022.

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) PhD is investigating DAP & part of CADS at LSBU.
- 6) My interpretation of DAP & its literature, others may disagree.

PROFILING MYSELF.

A note on terminology:

- 1) Assuming you have read mandatory reading.
- 2) OK using medical model terminology, such as Disorders & deficits. If one is clear with medical model's limitations...
- 3) Favours a transdiagnostic approach & we should be aspiring to stop utilising Disorder based constructs in the future.

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.

IN THE BEGINNING.

Introduction.

- 1) Current situation of DAP.
- 2) DAP's 4 main school's of thought.
- 3) Arbitrary nature DAP.
- 4) Transactional-stress DAP model.
- 5) Autism & DAP stereotypes.
- 6) Autistic persons internalizing DAP stereotypes.
- 7) DAP strategies.
- 8) Bias of researchers.

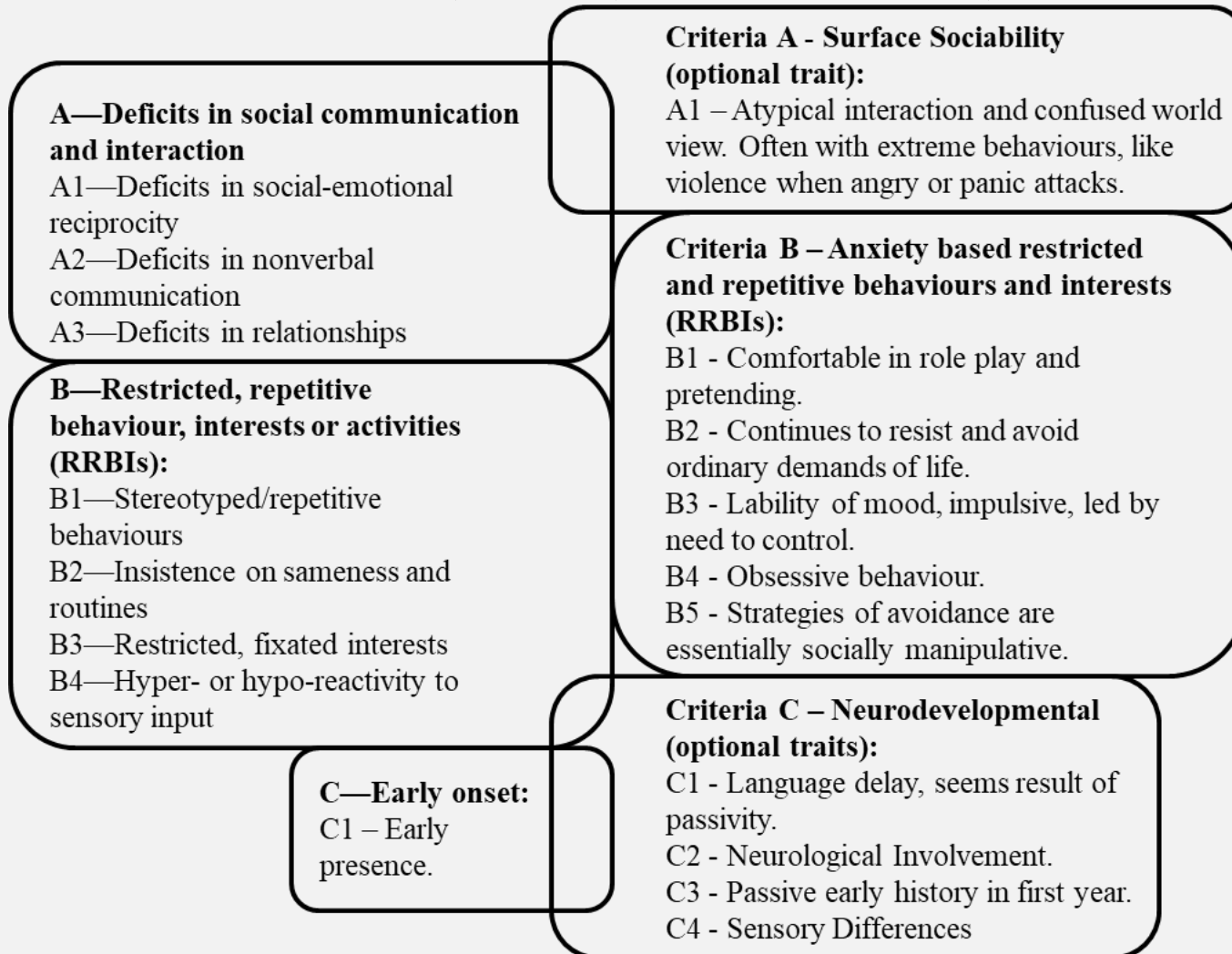
THE BIG BANG.

Davidson & Orsini CAS Definition (2013, p12):

- 1) *“Careful attention to the ways in which power relations shape the field of autism*
- 2) *Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy, and popular culture*
- 3) *Commitment to develop new analytical frameworks using inclusive and nonreductive methodological and theoretical approaches to study the nature and culture of autism. The interdisciplinary research required (particularly in the social sciences and humanities) demands sensitivity to the kaleidoscopic complexity of this highly individualised, relational (dis)order.”*

TIME TO PROFILE YOU.

Autism (left) + DAP Traits (right), my view (Woods 2021, p11).



AVOIDING DEMANDS OF ORDINARY RESEARCH.

DAP in the UK.

- 1) Research DAP via their autism understandings (O’Nions et al 2016b).
- 2) Caregivers are highly motivated to take part in research (O’Nions et al 2016b).
- 3) *“interest in the concept of PDA largely centres on the UK, it is at present a culture-bound concept”* (O’Nions et al 2020, p398).
- 4) UK DAP interest has risen sharply over last 10 years & it way outstrips its research base (O’Nions & Eaton 2021).
- 5) Due to campaigning efforts persons can be on the look-out for DAP & is a potential source of bias (Woods 2020a).

AVOIDING DEMANDS OF ORDINARY RESEARCH.

Should there be a bubble on “*DAP Profile of ASD*”? - NO!

- 1) “*DAP Profile of ASD*” proponents likely argue it should be a globally accepted construct.
- 2) DAP is controversial (Falk 2020; Fidler & Christie 2019; Green et al 2018b; O’Nions et al 2014a; O’Nions et al 2014b).
Independent reputable parties recently concluded no good quality evidence to suggest what DAP is, or what features are associated with it. Divergent opinion was treated equally (Berney et al 2020; Howlin et al 2021; Kildahl et al 2021; NICE 2021).

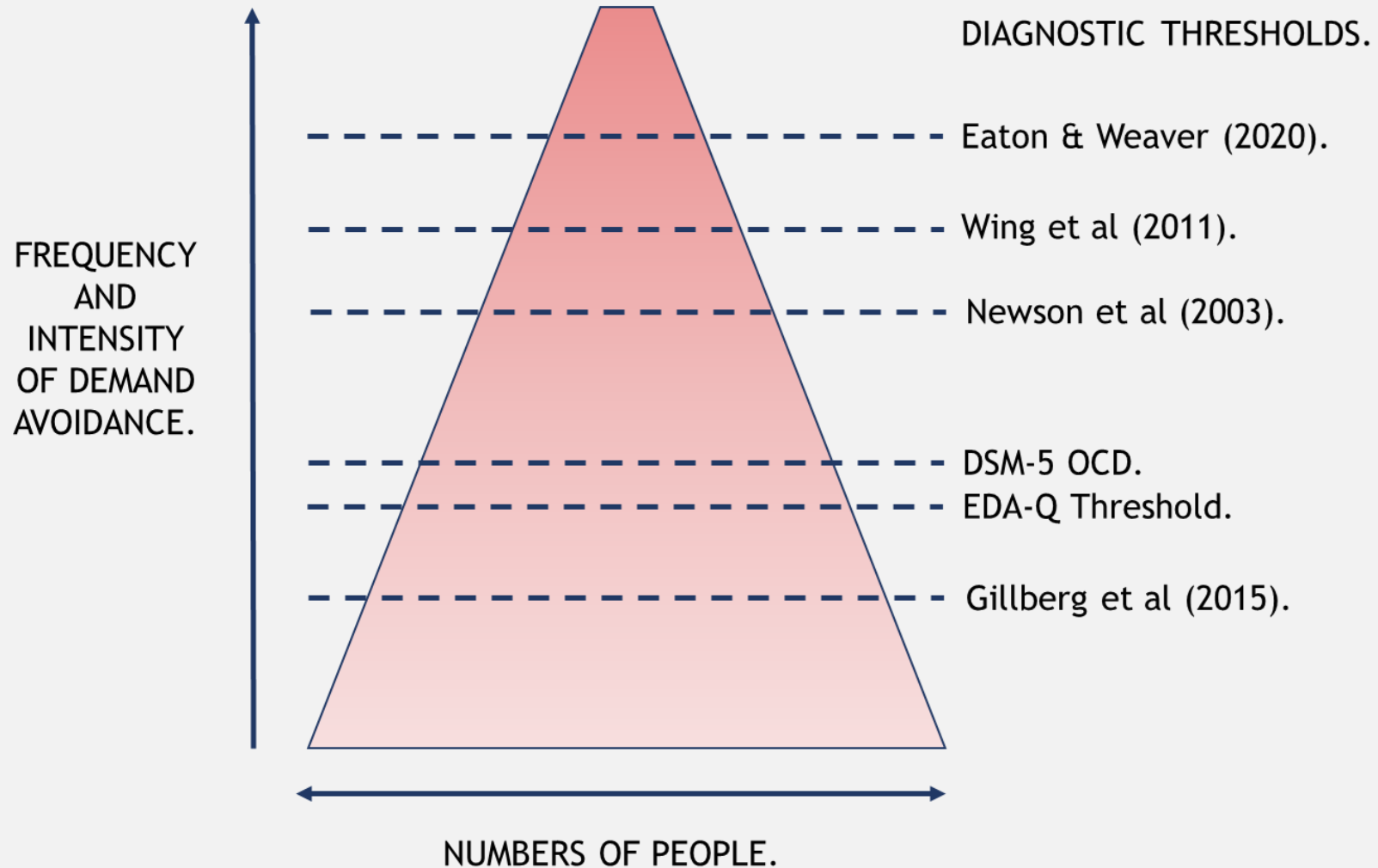
AVOIDING DEMANDS OF ORDINARY RESEARCH.

Robust challenges & substantial divergent opinion both exist.

- 1) Robustly challenged for almost 2 decades (Garralda 2003; Green et al 2018a; Green et al 2018b; Green 2020; Malik & Baird 2018; McElroy 2016; Milton 2017; Moore 2020; Wing 2002; Wing & Gould 2002; Woods 2017a; Woods 2019a; Woods 2020a).
- 2) Three other prominent schools of thought:
 - Common mental disorder.
 - Rebranded autism.
 - Symptoms from interaction between autism & co occurring conditions (Woods 2021c).

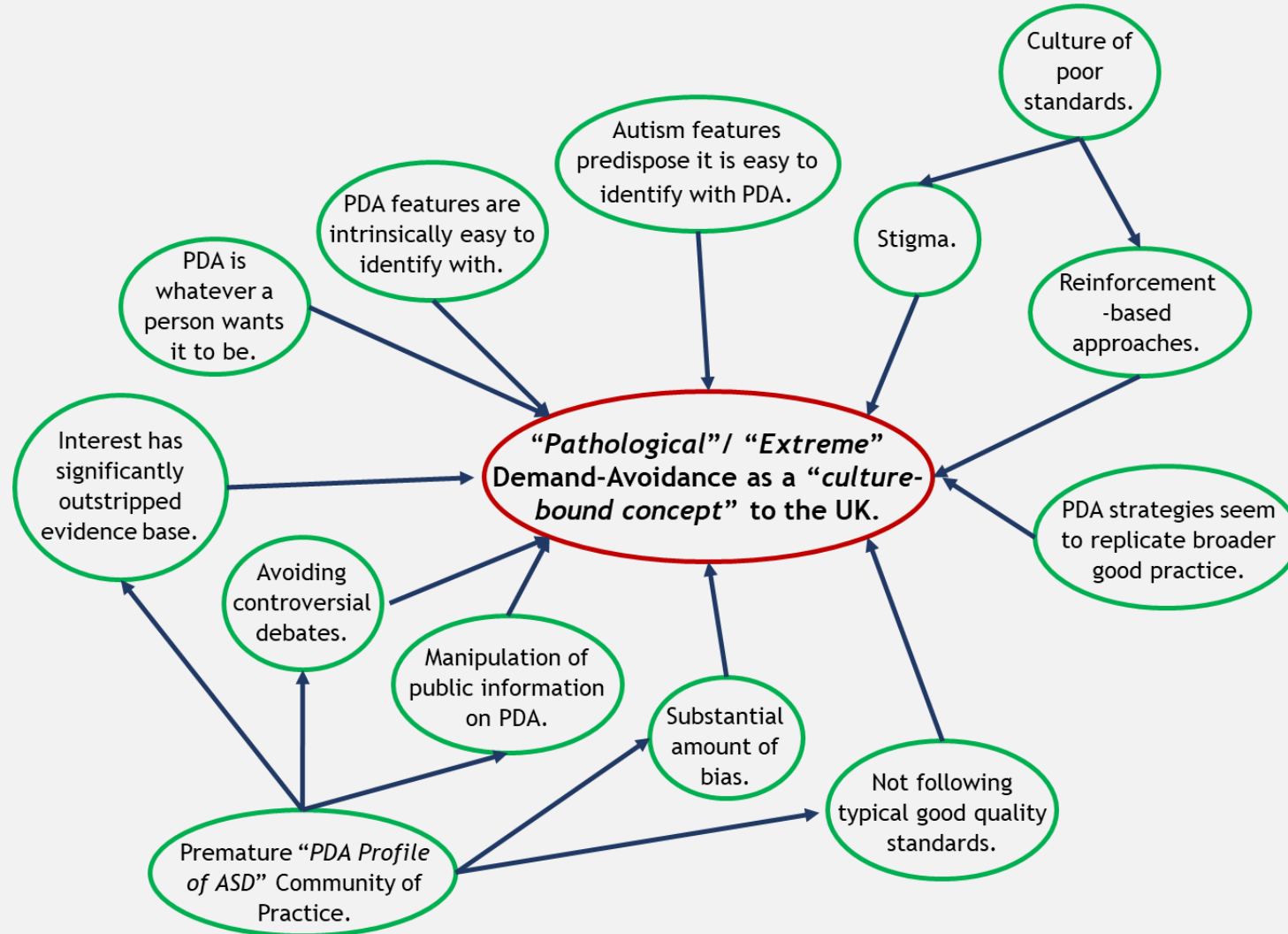
TIME TO PROFILE YOU.

Different DAP diagnostic thresholds (Woods 2021a).



INSERT TEXT.

Why is “DAP Profile of ASD” a “culture-bound concept” in UK?



AN OLD ROLEPLAY.

Newson's DAP research history.

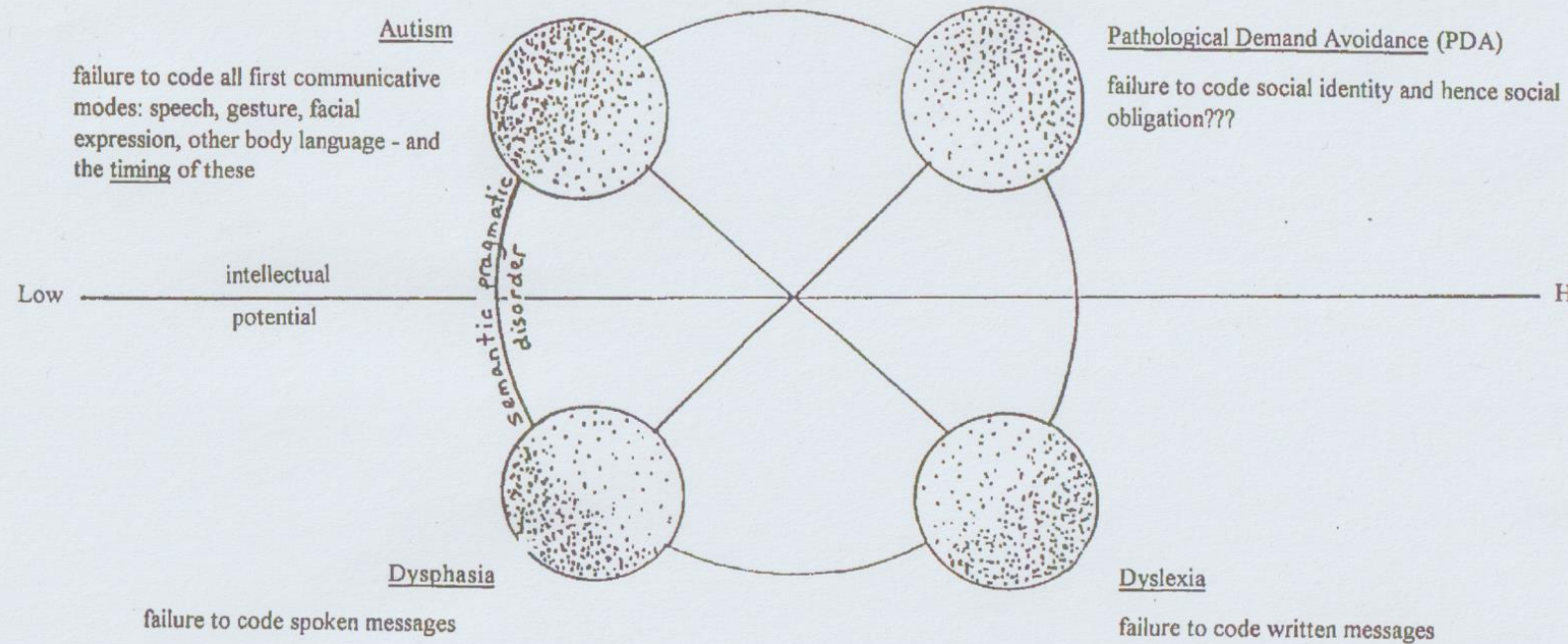
Year.	Event.	Reference.
1975.	Starts gaining cases for DAP.	Newson et al (2003).
1980.	Seminal Lecture on 12 cases & chooses it's name.	Gillberg (2014).
1983.	Publishes first article on discussing DAP using 9 cases.	Newson (1983)
1986.	Creates " <i>Pervasive Developmental Coding Disorders</i> " diagnostic grouping & creates a diagram.	Newson (1996).
1988.	Used 36 cases to create first DAP behaviour profile.	Newson (1996).
1995.	Refines behaviour profile by adding " <i>Language Delay</i> " trait.	Newson et al (2003).
1996.	Has 120 cases & was still using " <i>Pervasive Developmental Coding Disorders</i> " diagnostic grouping.	Newson (1996).
1999.	Places DAP into " <i>Pervasive Developmental Disorders</i> " diagnostic grouping & creates new diagram.	Newson (1999).
2000.	Has 150 cases & stops adding new cases to research cohort.	Newson et al (2003).
2003.	Research is published after peer review. Revises " <i>Pervasive Developmental Disorders</i> " diagram. Revises behaviour profile for ease of " <i>diagnostic argument</i> ".	Newson et al (2003).

SQUARE PEGS, ROUND HOLES?

Table 1

Schema for the

PERVASIVE DEVELOPMENTAL CODING DISORDERS



Note: interconnections imply the possibility of overlap of two or more disorders in particular children, as well as the possibility of a focus somewhere between two disorders. Speckles indicate possibility of greater or lesser severity.

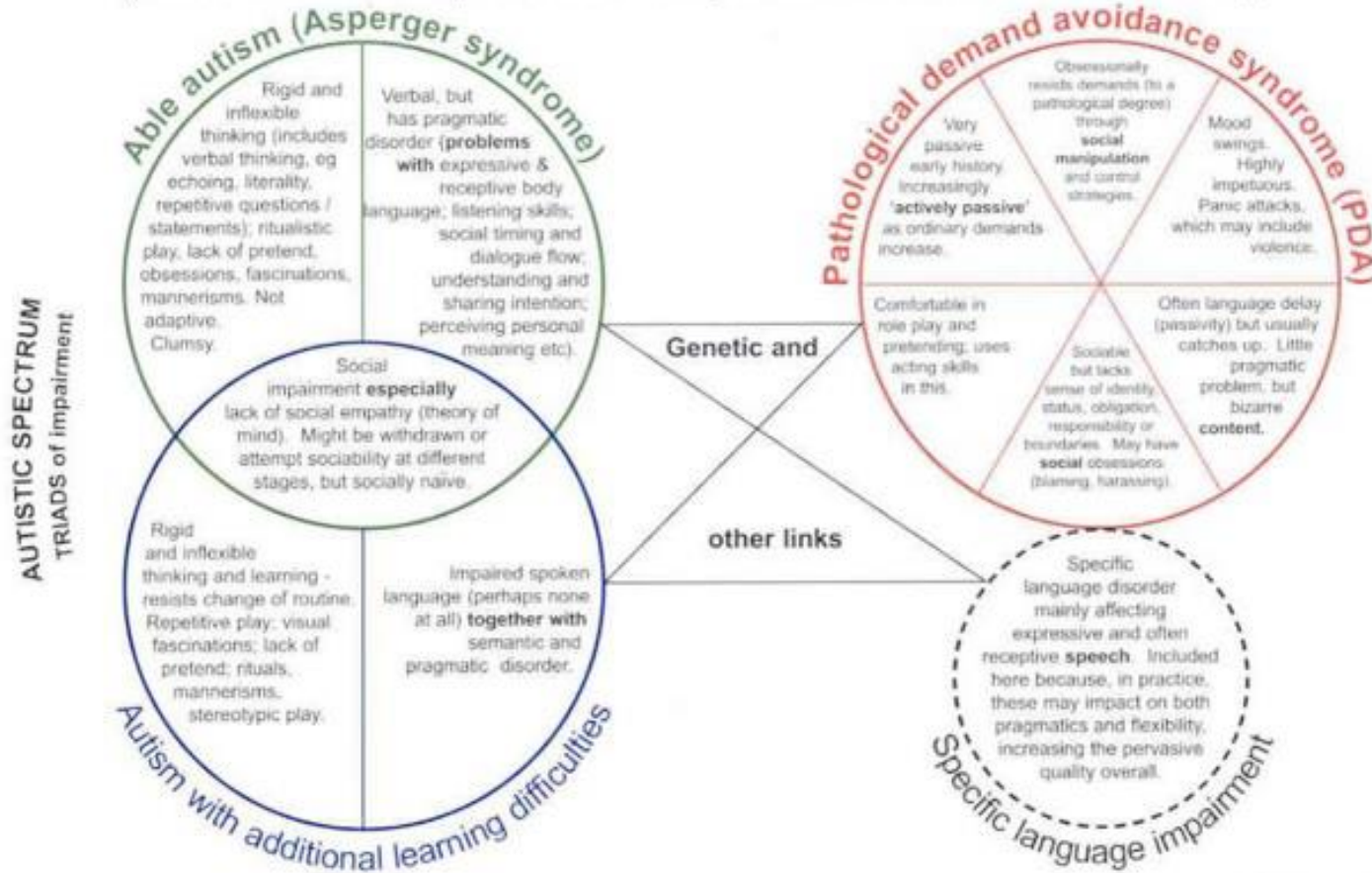
Elizabeth Newson
Nottingham University
March 1986

Pervasive Developmental Coding Disorders (Newson 1989; 1996).

SQUARE PEGS, ROUND HOLES?

THE 'FAMILY' OF PERVASIVE DEVELOPMENTAL DISORDERS

(sometimes 'autistic spectrum' is loosely used to describe the whole family)



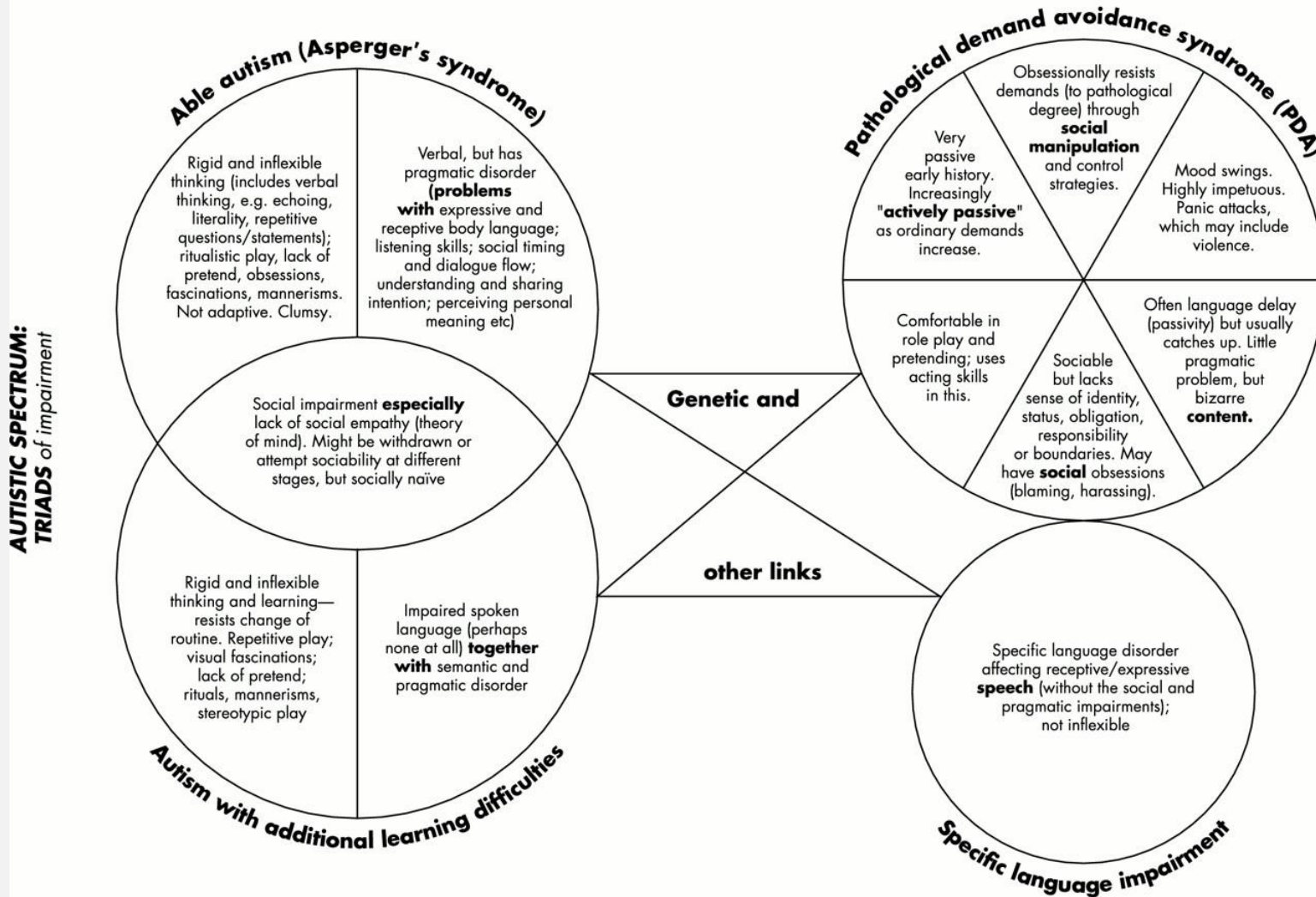
Pervasive Developmental Disorders (Newson 1999).

(The diagram shows clusters of symptoms making up specific disorders/syndromes)

Elizabeth Newson 1999

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).

It is problematic fitting Newson's diagnostic constructs into accepted practice.

DEFINITIONS DEFICITS.

PDD Family Diagram Definitions.

- 1) Newson et al used DSM-4 PDD definitions.
- 2) “**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).
- 3) AND **Coding** issues- not processing/ understanding certain aspects of communication (Newson et al 2003).

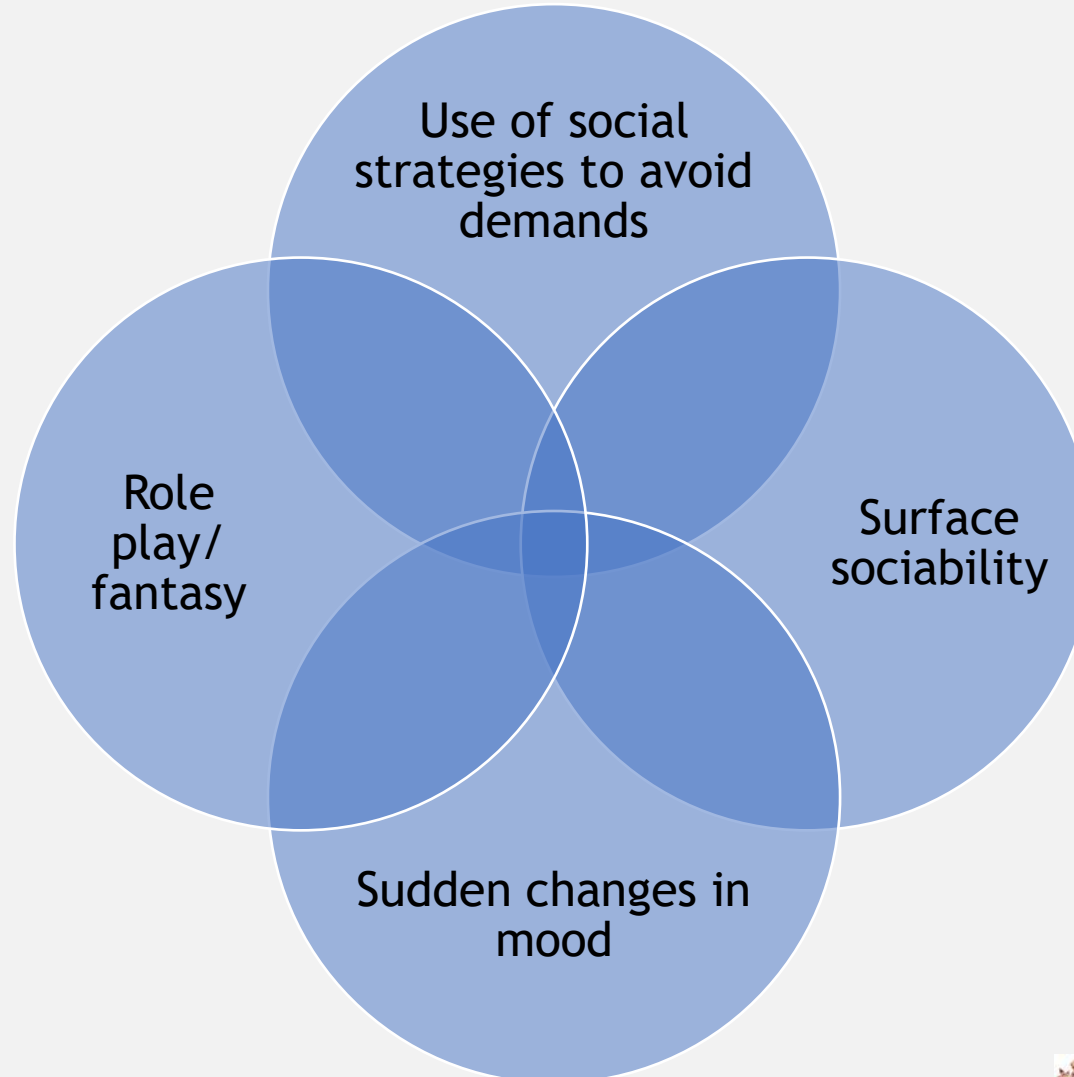
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“DAP Profile of ASD” history.

Year.	Event.	Reference.
2007.	First proposed in print DAP is a profile of ASD.	Christie (2007).
2008.	NAS publishes DAP information on its website.	PDA Society (2016).
2011.	First NAS annual DAP conferences.	PDA Society (2016).
2011.	PDA Development Group is created.	PDA Development Group (2016)
2011.	“DAP Profile of ASD” research agenda proposed.	Christie et al (2012).
2011.	DAP maybe a female form of ASD.	Gould & Ashton-Smith (2011).
2012.	AET support’s DAP & republishes Christie’s article.	PDA Society (2016).
2015.	NAS recognises DAP as a Profile of ASD.	PDA Society (2016).
2016.	Researching DAP from their understanding of ASD.	O’Nions et al (2016b).
2018.	PDA Society Being Misunderstood report used for campaigning for “DAP Profile of ASD”.	Russell (2018).
2021	DAP research overview published viewing it as “Profile of ASD”.	O’Nions & Eaton (2021).
2021.	PDA Society working government. DAP itself is not mentioned in England Autism Strategy.	PDA Society (2021).

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A unique clustering (BPS 2022)?



DAP: As a Social Construct 07th of April 2022.

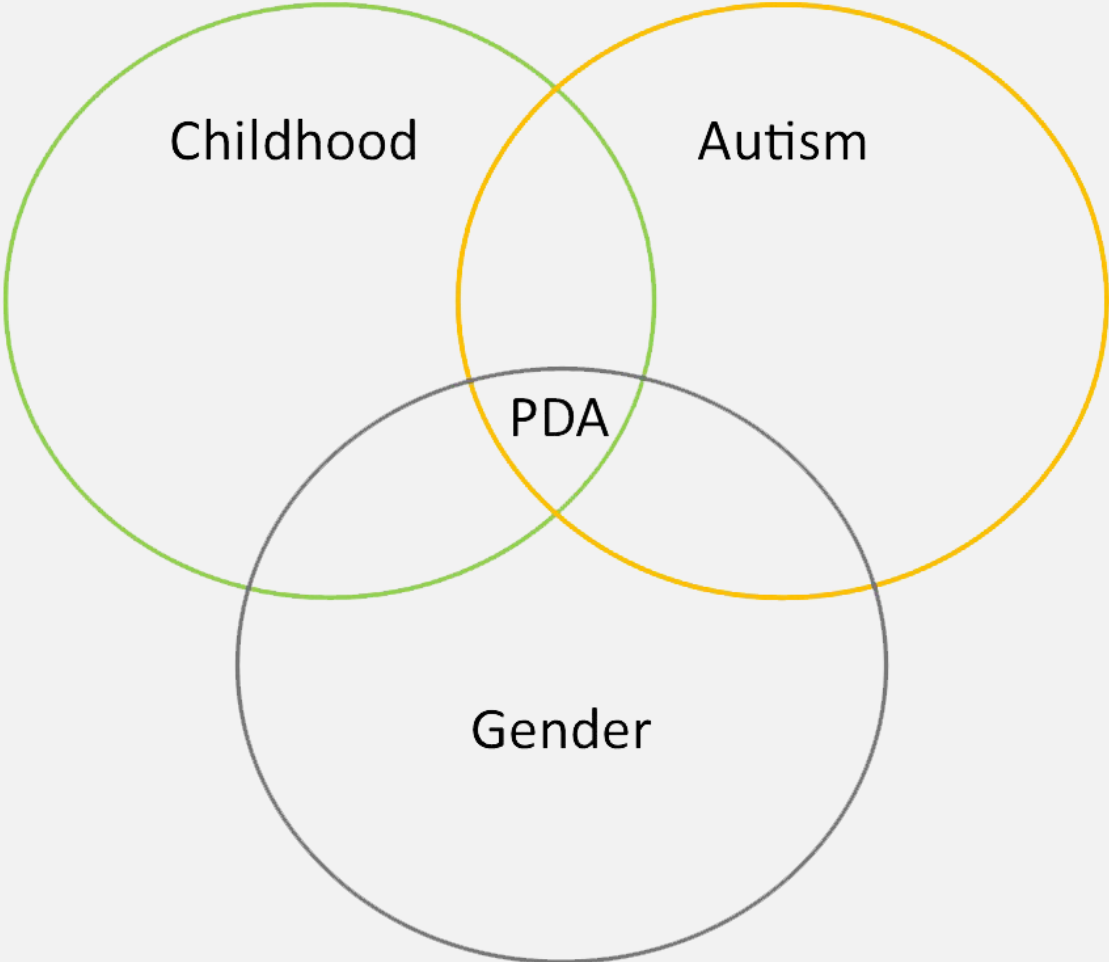
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“Rebranded Autism” history.

Year.	Event.	Reference.
2002.	Remains to be seen if DAP is a real syndrome & its features are seen throughout autistic population.	Wing (2002).
2002.	Not a syndrome & features are seen in autistic persons.	Wing & Gould (2002).
2011.	Gould stats at NAS DAP conference, its features are present throughout entire autistic population.	Christie et al (2012).
2013.	Pathologising of autistics asserting their self-agency.	Milton (2017).
2017.	DAP is commodification of autistic self-advocacy & poses a threat as can view self-agency as manipulative.	Woods (2017).
2018.	Autistic DAP may be due to EF, autistic inertia, & Monotropism.	Milton (2018).
2019.	DAP features represents actions persons asserting self-agency, distress features, & criminal conduct.	Woods (2019b).
2019.	Intersection of childhood, gender & autism diagram.	Moore (2019).
2020.	DAP represents pathologising of those transgressing cultural norms, often while asserting self-agency.	Moore (2020).

CIRCLE WARS.

Rebranded autism (Moore 2019).



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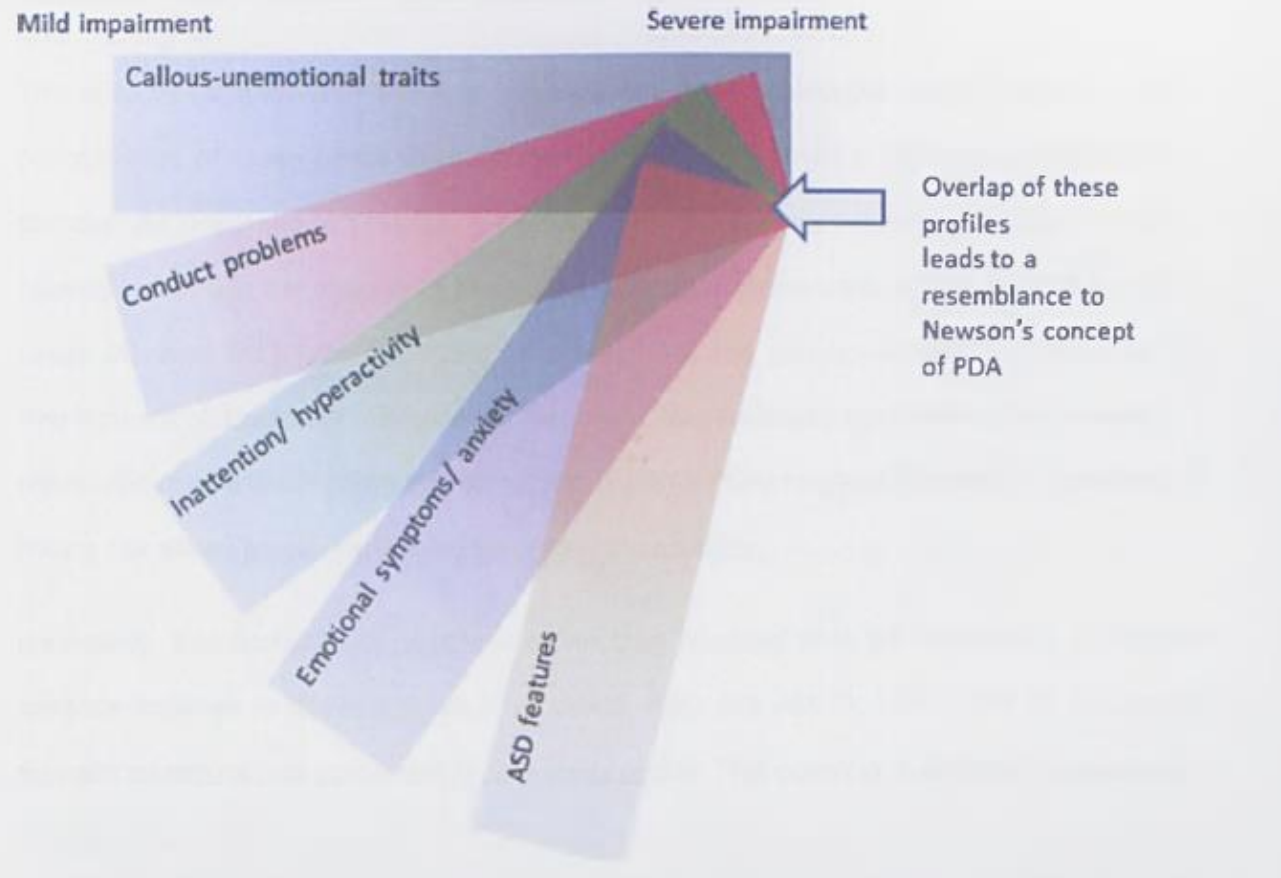
“Pseudo-Syndrome” history.

Year.	Event.	Reference.
2003.	Newson’s cohort likely had co-occurring ADHD, ODD, social anxiety disorder & precursors for schizotypal disorder.	Garralda (2003).
2011.	“ <i>Double hit</i> ” of psychopathic behaviour not caused by autism.	Wing et al (2011).
2011.	Maybe triple hit of anxiety, conduct problems & autism.	Christie et al (2012).
2013.	Combined profile of ASD & CP/HCU. Schematic diagram containing: Autism; anxiety/ emotional symptoms; inattention/ hyperactivity; conduct problems; callous-emotional problems.	O’Nions (2013).
2015.	Maybe ‘ <i>triple hit</i> ’ of autism, conduct problems & anxiety.	Langton & Frederickson (2016).
2018.	Best explained through interaction of autism & its common co-occurring conditions. Is seen in non-autistic persons.	Green et al (2018a).
2018.	features are seen in autism, CD, ODD, anxiety/ mood Disorders. DAP features are seen in non-autistic CYP.	Malik & Baird (2018).
2019.	DAP & its possible medical ontologies table.	Woods (2019a).
2021.	DAP’s relationship with other conditions diagram.	Soppitt (2021).
2021.	Equally respected divergent opinions on DAP.	NICE (2021).

SPIKY PROFILE.

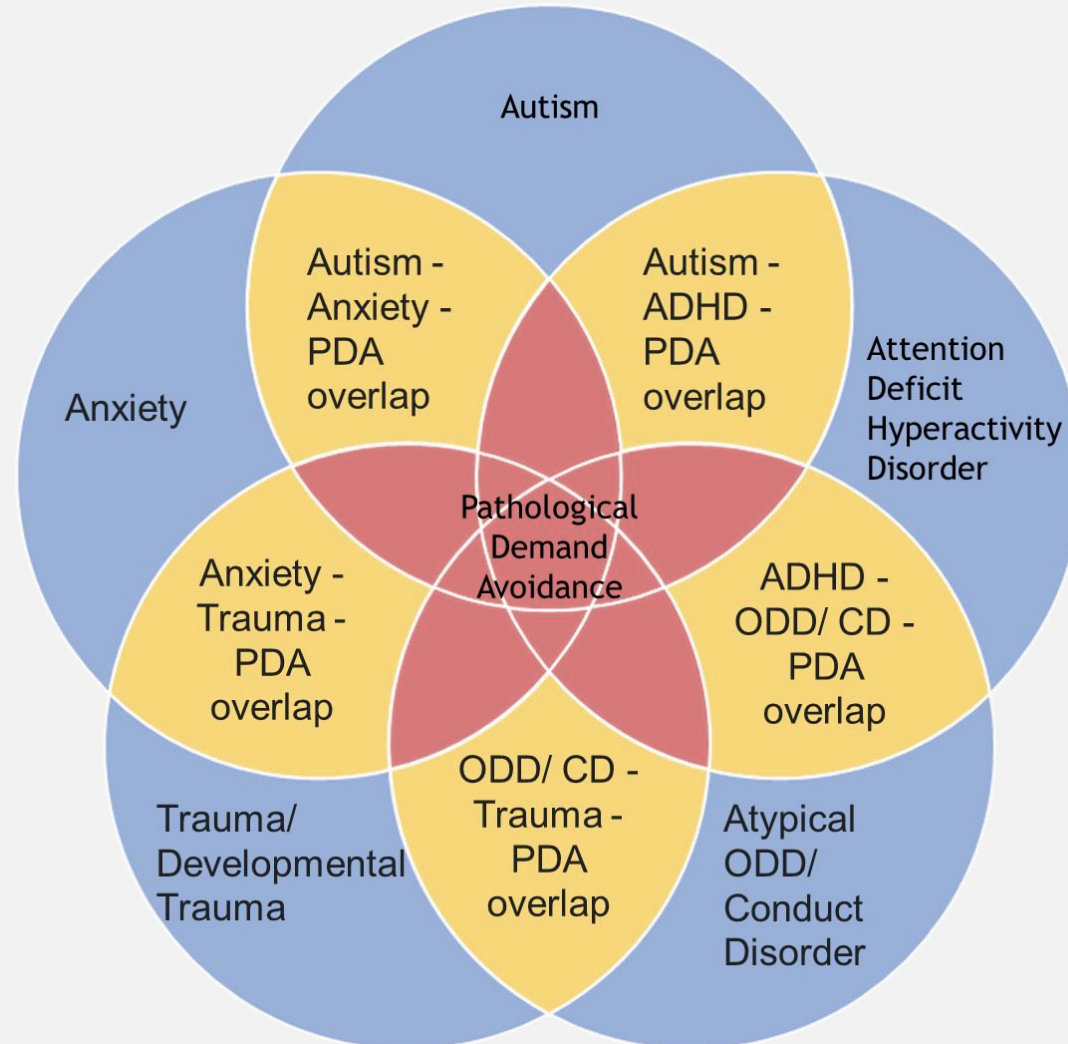
How accepted constructs may relate to DAP (O’Nions 2013, p93).

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



SPIKY PROFILE.

DAP & its constituent components (Woods 2021c, p12).



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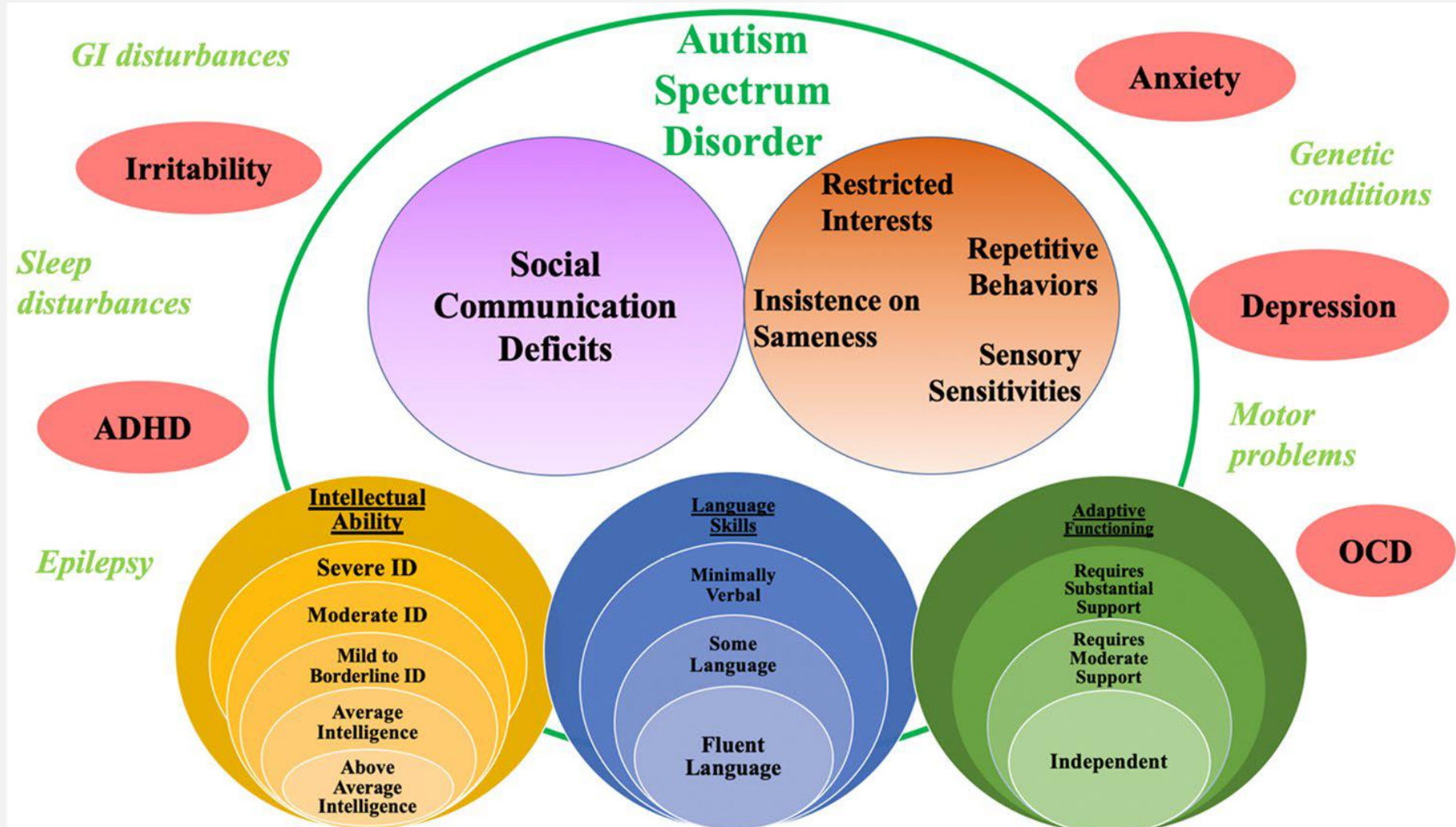
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“Common Mental Disorder” history.

Year.	Event.	Reference.
2007.	Maybe Attachment Disorder or a Personality Disorder.	Christie (2007).
2013.	Behaviour & cognitive investigated DAP as a Disorder.	O’Nions (2013).
2013.	Proposed DAP maybe a new type of Disorder & common. Suggests DAP is seen in various conditions.	Gillberg (2014).
2013.	DAP features overlap Attachment Disorder & maybe dangerous to dismiss this due to lack of evidence.	Milton (2017).
2014.	Predicted prevalence of 3%-5% of certain populations.	Gillberg et al (2015).
2015.	Overlap between DAP & Attachment Disorder.	McElroy (2016).
2015.	DAP maybe seen in ADHD & Conduct Disorder.	Flackhill et al (2017).
2018.	Indicates DAP is seen in non-autistic persons.	Egan et al (2019).
2020.	DAP may have multiple developmental pathways.	Woods (2020a).
2020.	Compares DAP with Personality Disorders & considers if DAP is a distinct condition.	Potts (2020).
2021.	Rights of non-autistic CYP with PDA.	Woods (2021b).
2021.	Is DAP a Disorder at a lower diagnostic threshold?	Woods (2021c).

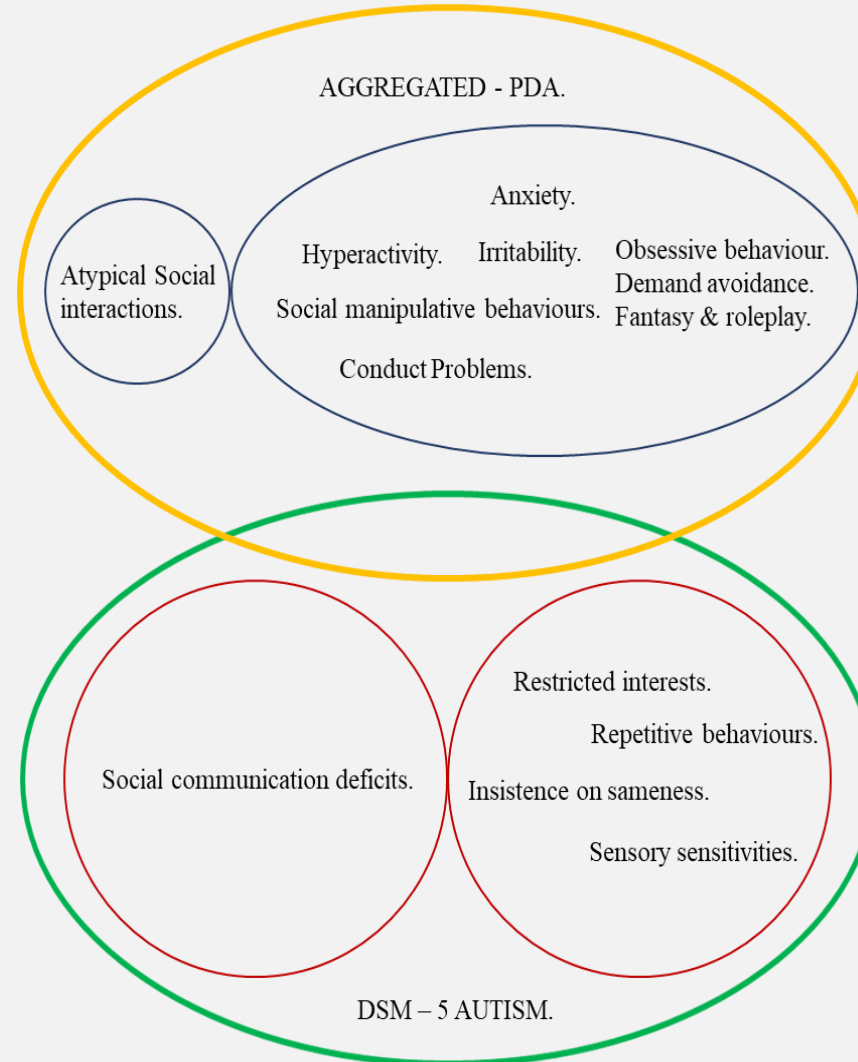
SPITTING IMAGES OR SPLITTING IMAGES?

Rosen et al (2021) DSM-5 Autism Image.



SPITTING IMAGES OR SPLITTING IMAGES?

DSM-5 Autism vs Aggregated DAP Diagram.



DAP: As a Social Construct 07th of April 2022.

DEAD ENOUGH FOR LIFE, OR LIFE ENOUGH FOR DEATH?

Resurrecting a dead category?

- 1) Asperger ignored Sukhareva, & Kanner ignored Asperger.
- 2) Childhood Schizophrenia is a dead dx used in 1920s - 1980s.
- 3) Much lack of consensus over what features were in CS.
- 4) Widely known & diagnosed in CYP, including autistic CYP.
- 5) Kanner folded autism into CS (Silberman 2015).
- 6) Newson's clinic specialised in demographics CS often dx in.
- 7) Newson collected cases from 1975, when CS was common dx.
- 8) Newson's DAP fundamentally same since 1975...
- 9) What if DAP is based on CS?
- 10) Would explain Newson's methodology & axiology.

DEAD ENOUGH FOR LIFE, OR LIFE ENOUGH FOR DEATH?

Childhood Schizophrenia vs Newson's DAP Descriptions.

Childhood Schizophrenia (Silberman 2015, p341).	Newson et al (2003) DAP Criteria & Descriptions.
Gross and sustained impairment of emotional relationships with people.	Lability of mood, impulsive,... Switches from cuddling to thumping for no obvious reason; or both at once.
Apparent unawareness of his own personal identity to a degree inappropriate to his age.	Surface sociability, but apparent lack of sense of social identity, pride, or shame. motivation to avoid demands is so sustained, and because the child knows no boundaries to avoidance. <i>Linked to illogical anxiety as in CS trait 6?</i>
Pathological preoccupation with particular objects or certain characteristics of them, without regard to their accepted functions.	Obsessive behaviour: Much or most of the behaviour described is carried out in an obsessive way
Sustained resistance to change in the environment and a striving to maintain or restore sameness.	Continues to resist and avoid ordinary demands of life. (WITH) strategies of avoidance are essentially socially manipulative.
Abnormal perceptual experience (in the absence of discernible organic abnormality).	Comfortable in role play and pretending.
Acute, excessive, and seemingly illogical anxiety as a frequent phenomenon.	led by need to control outbursts, screaming, hitting, kicking; best construed as panic attack. Repetitive questions used for distraction, but may signal panic. 60% have extreme outbursts or panic attacks goes "over the top" in protest or in fear reaction.
Speech either lost, or never acquired, or showing failure to develop beyond a level appropriate to an earlier age.	Language delay, seems result of passivity.
Distortion in motility patterns.	Neurological involvement: Soft neurological signs are seen in the form of clumsiness and physical awkwardness.
A background of serious retardation in which islets of normal, near-normal, or exceptional intellectual function or skill may appear.	<i>Unsure, still reflecting upon this one.</i>

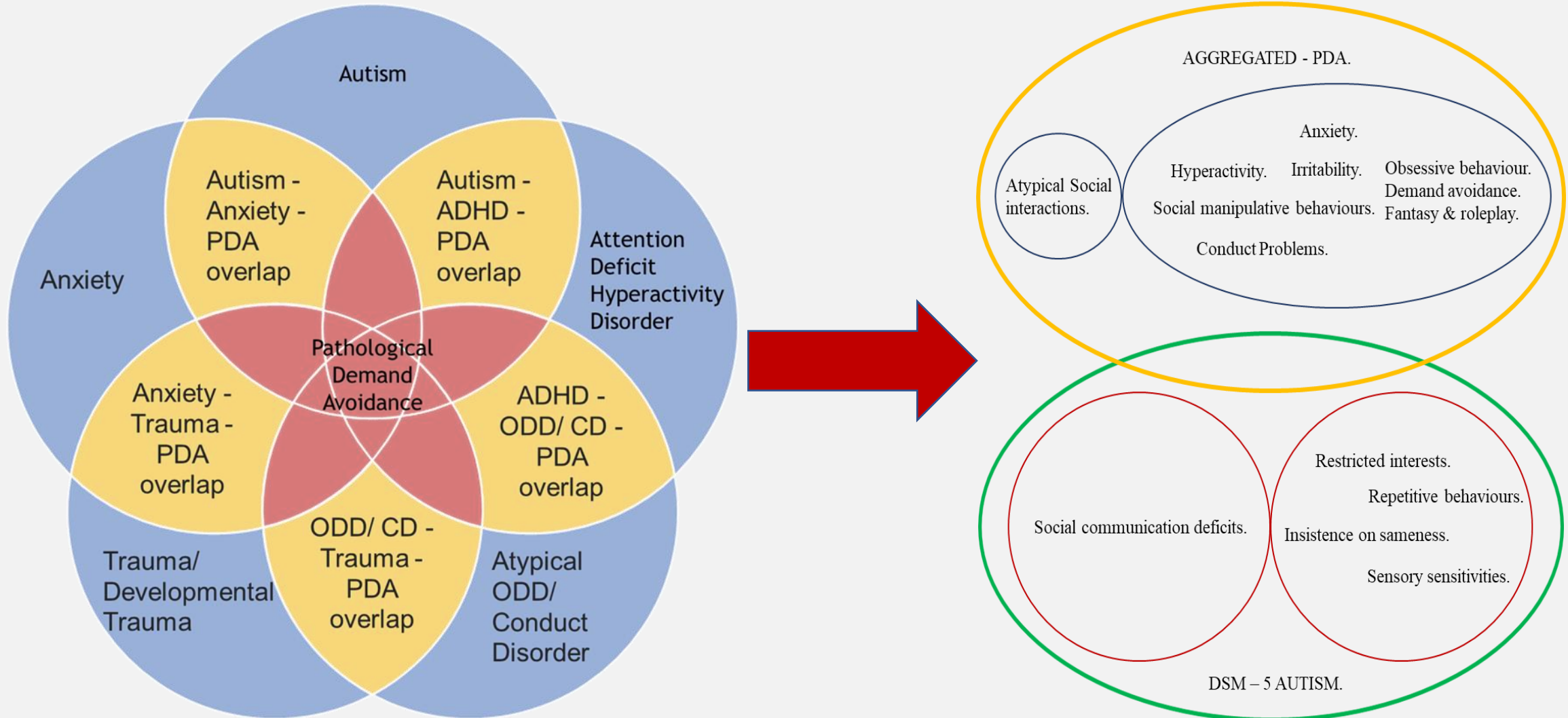
SPITTING IMAGES OR SPLITTING IMAGES?

Combining different DAP.

- 1) Co-occurring categories can unpredictably interact with each other.
- 2) Making some features more intense, while other characteristics less intense.
- 3) Sometimes creating novel features, that can be more intense than features associated with original categories; creating novel categories (Petrolini & Vincente 2022).
- 4) DAP maybe result of such unpredictable interactions between competing co-occurring conditions & be a new type of Disorder.

SPITTING IMAGES OR SPLITTING IMAGES?

Co-occurring difficulties interacting might create DAP?



UNCOMFORTABLE PRETENCE.

Why do these different schools of thought matter?

- 1) If one critically engages with DAP, it should be clear, DAP is a not a “*Profile of ASD*”...
- 2) Other 3 schools of thought seem to be valid.
- 3) Autistic persons wishes not to divide autism (Fletcher-Watson & Happé 2019; Kapp & Ne’eman 2019).
- 4) Non-autistic persons with DAP have equal rights to diagnoses, research & support.
- 5) How would you feel about autistic persons creating a Disorder that pathologises your non-compliance in creating an autism friendly world and lack of empathy towards us?

DISORDER-ORGANISED.

DSM-5 Disorder definition:

- 1) *“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).

A NOVEL ROLEPLAY.

What does a modern Disorder look like?

- 1) Are heterogenous in nature, with porous boundaries.
- 2) Most have features overlapping with other Disorders & are spectrum in nature.
- 3) May have conflicting evidence for which diagnostic groupings best fit; e.g., ADHD & disruptive, impulse-control, & conduct disorders, instead of neurodevelopmental disorders.
- 4) No longer sensible to strive for homogeneous subtypes within Disorders (APA 2013).
- 5) *"the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning."* (APA 2013, p21).

AVOIDING VARIANCE.

When does DAP become “*Pathological Demand Avoidance*”?

- 1) DAP presents as a continuum in human population.
- 2) Fluid & transient over lifespan & diverse situations.
- 3) "*the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.*" (APA 2013, p21).
- 4) “*...start to display avoidant behaviour and challenging behaviour in response to a particular stressor...*” (Eaton 2018b, p20).
- 5) Around EDA-Q threshold and/ or “*problematic demand avoidance*” (O’Nions et al 2018).

UNCOMFORTABLE PRETENCE.

Are these schools of thought arbitrary?

- 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 speaker)” (NICE 2021, pp.288-289).*
- 4) Demand-avoidance is by choice...

UNCOMFORTABLE PRETENCE.

RCP DAP definition:

- 1) Confusion due to demand avoidance is a common feature.
- 2) *“PDA has been used mainly to describe children who present with a behaviour profile characterised by the very abnormal:
 - avoidance of compliance with everyday demands (using a variety of social strategies, ranging from excuses and distraction),
 - anxiety when demands cannot be avoided,
 - attempts to control situations,
 - impulsivity as well as sudden and extreme changes of mood.”*

(Berney et al 2020, p30).
- 3) Lacks social communication issues...

A LEVEL PLAYING FIELD.

DAP diagnostic thresholds vs number of settings expressed in.

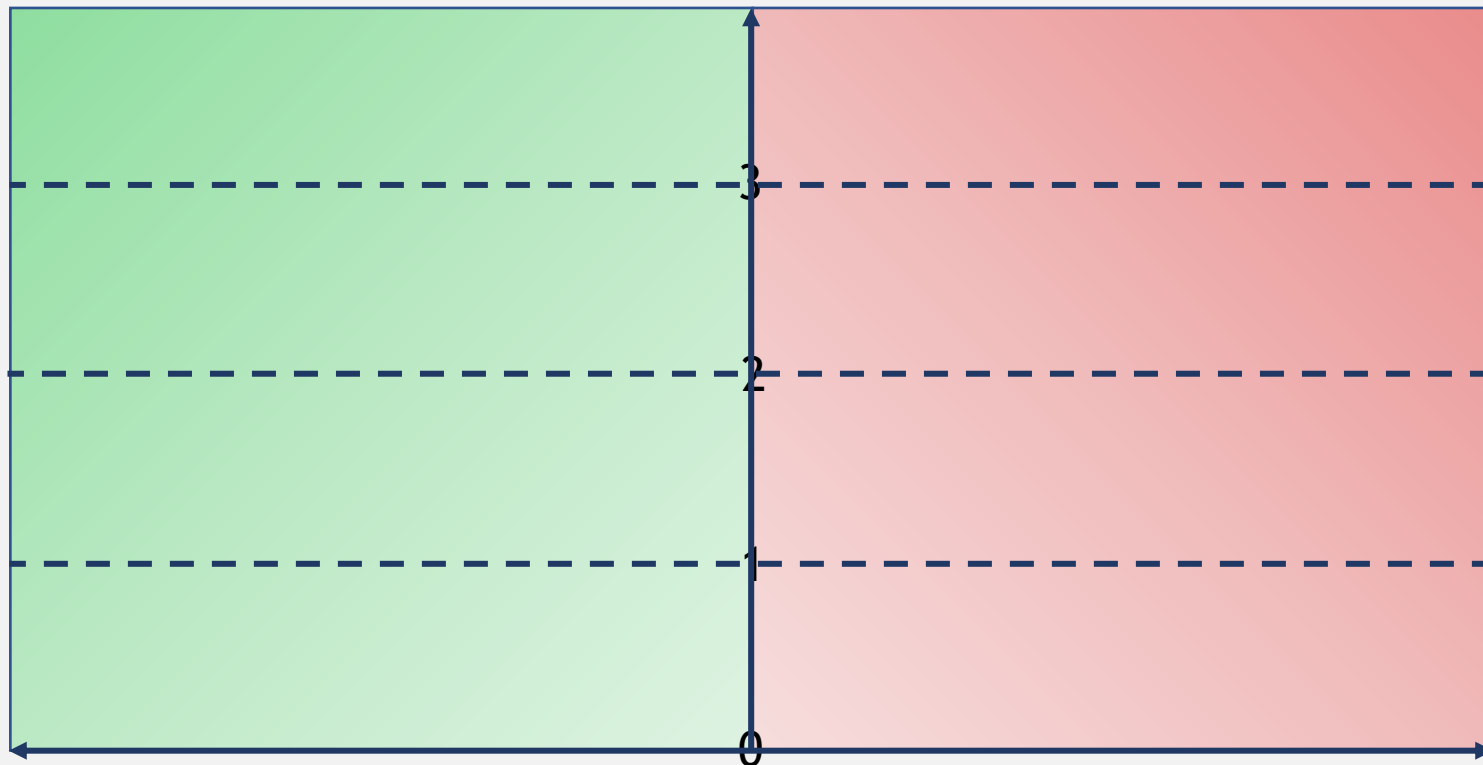
ODD Specifiers.	ADHD.	Autism.	Help4Psychology DAP.	OCD.	ODD.	Transactional Stress DAP.
Mild: features confined to only one setting (APA 2013).	Not Applicable.	Not Applicable.	<p><i>“Rational Demand Avoidance”</i> : CYP express features in one setting, due to stressor, e.g., school (Eaton 2018b).</p> <p>Not universally accepted.</p>	Features time-consuming take more than 1 hour per day), or cause significant distress, or impairment key settings (APA 2013).	Behaviours cause distress to the surrounding persons, or impacts key settings (APA 2013).	Significant distress or impairment in social, occupational, or other important settings (APA 2013).
Moderate: features present in at least two settings (APA 2013).	Several features present in two or more settings. Features impact key functionings (APA 2013).	Not Applicable.	Not Applicable.	Not Applicable.	Not Applicable.	High stress/ distress → features expressed in more settings.
Severe: features are present in three or more settings (APA 2013).	Not Applicable.	Cause significant impairment in social, occupational, or other important settings (APA 2013).	<p><i>“Extreme Demand Avoidance”</i>: Features expressed in all settings, including from early infancy & during assessment (Eaton & Weaver 2020).</p>	Not Applicable.	Not Applicable.	



A LEVEL PLAYING FIELD.

“PATHOLOGICAL” DEMAND-AVOIDANCE (PDA) INTERNALISING - EXTERNALISING CONTINUUM VERSUS NUMBER OF SETTINGS DEMAND-AVOIDANCE PRESENTS IN 2D MODEL.

FREQUENCY AND INTENSITY OF DEMAND-AVOIDANCE ACROSS A
NUMBER OF IMPORTANT AREAS OF FUNCTIONING (SETTINGS).



Severe PDA = DSM-5 Autism/
Help4Psychology PDA.

Moderate PDA = DSM-5 ADHD.

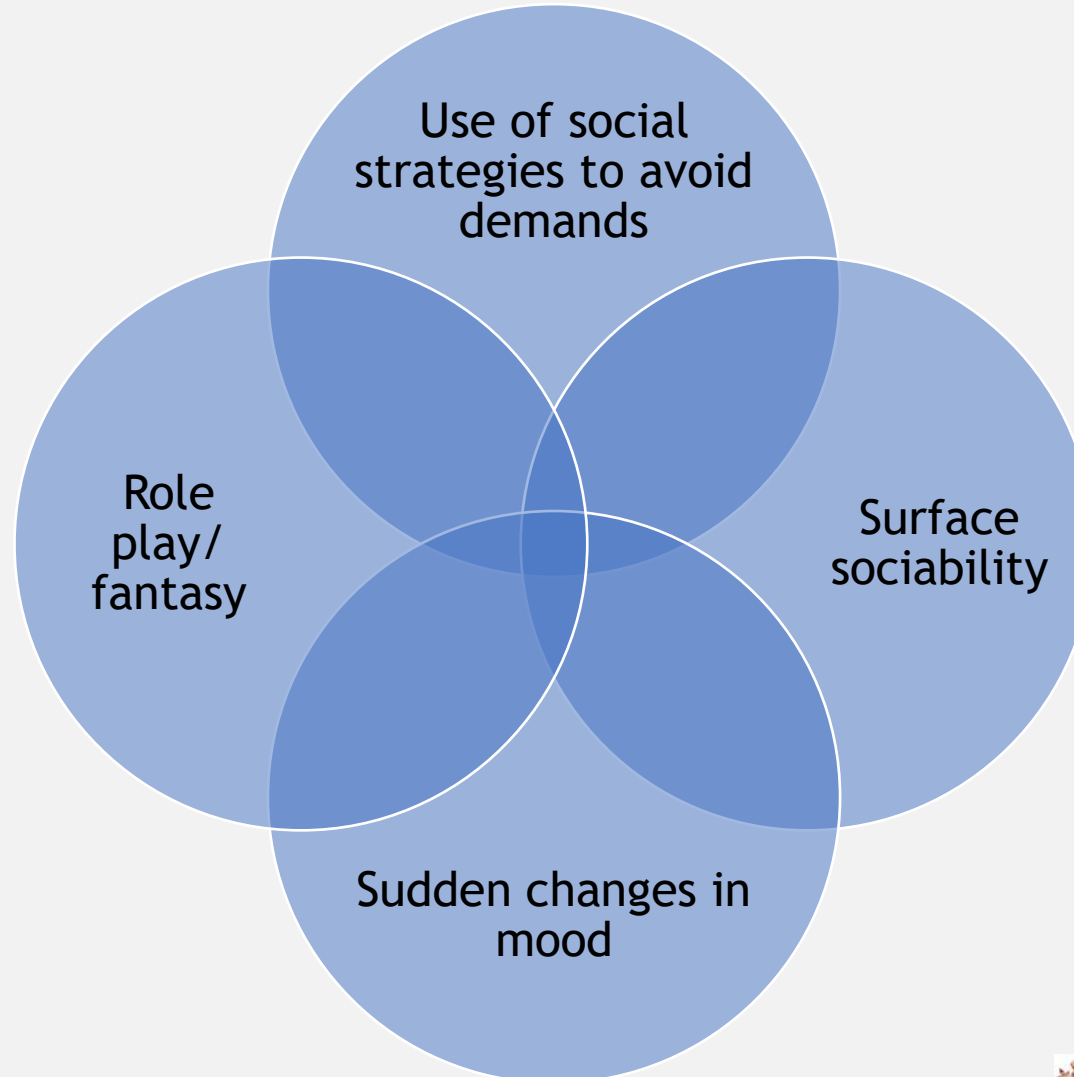
Mild PDA = EDA-Q/
DSM-5 OCD/ DSM-5 ODD.

INTERNALISING
FEATURES.

EXTERNALISING
FEATURES.

CIRCLE WARS.

What has choices have been made to create this clustering?



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A FEATURE FILM?

Associated with trauma or highly distressed individuals:

- 1) *“Seems as if s/he is distracted ‘from within’”* (O’Nions et al 2014a, p763).
- 2) *“Knows what to do or say to upset specific people.”* (O’Nions et al 2014a, p763).
- 3) *“(Lacks) Awareness of own identity.”* (O’Nions et al 2016a, P415).
- 4) *“I am driven by the need to be in charge.”* (Egan et al 2019, p485).

A FEATURE FILM?

An act any person would display to assert their self-agency:

- 1) *“I complain about illness or physical incapacity to avoid a request or demand.”* (Egan et al 2019, p485).
- 2) *“Attempts to negotiate better terms with adults.”* (O’Nions et al 2014a, p763).
- 3) *“Apparently manipulative behaviour.”* (O’Nions et al 2016a, p415).

AVOIDANCE OF DOUBT.

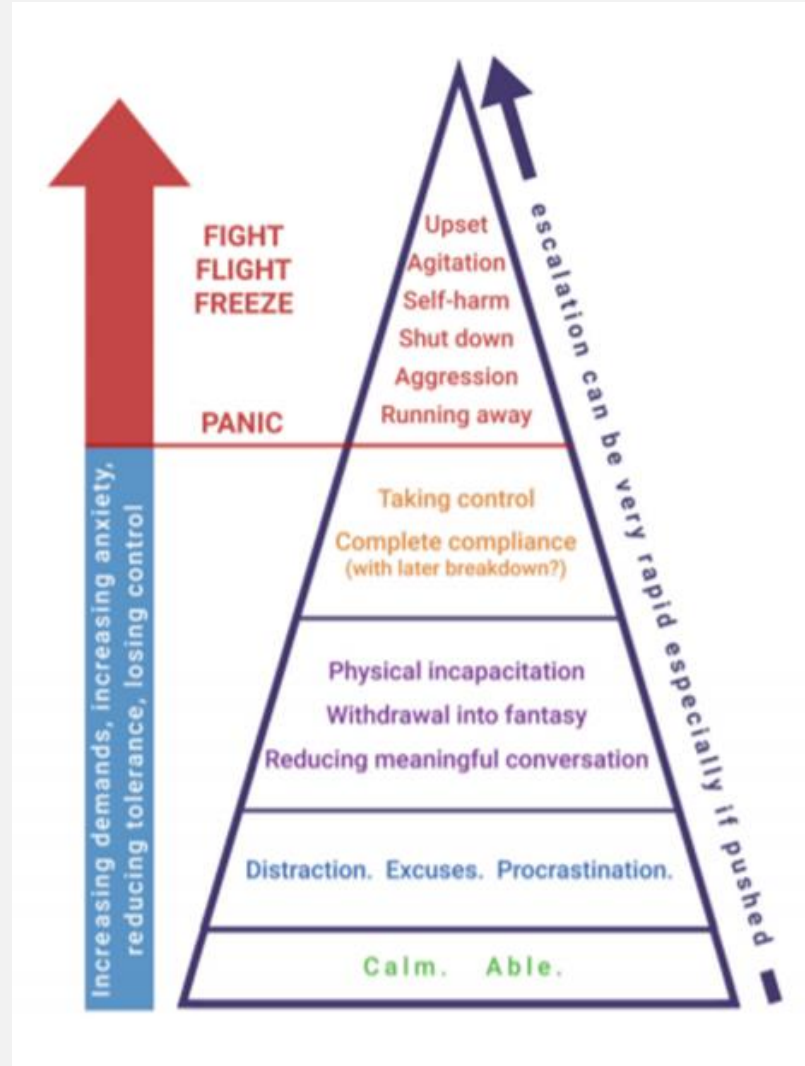
Core DAP Traits.

Anxiety-based Restricted & Repetitive Behaviours & Interests (RRBIs):	Universal.
Avoidance of everyday demands.	Yes
Comfortable in role play & pretence.	No
Consistent mood swings & impulsivity.	No
Frequent & intense actions.	Yes
Social avoidance behaviours.	Yes

Universality of features is based on Newson et al (2003) statistics.

A STRESSFUL SITUATION.

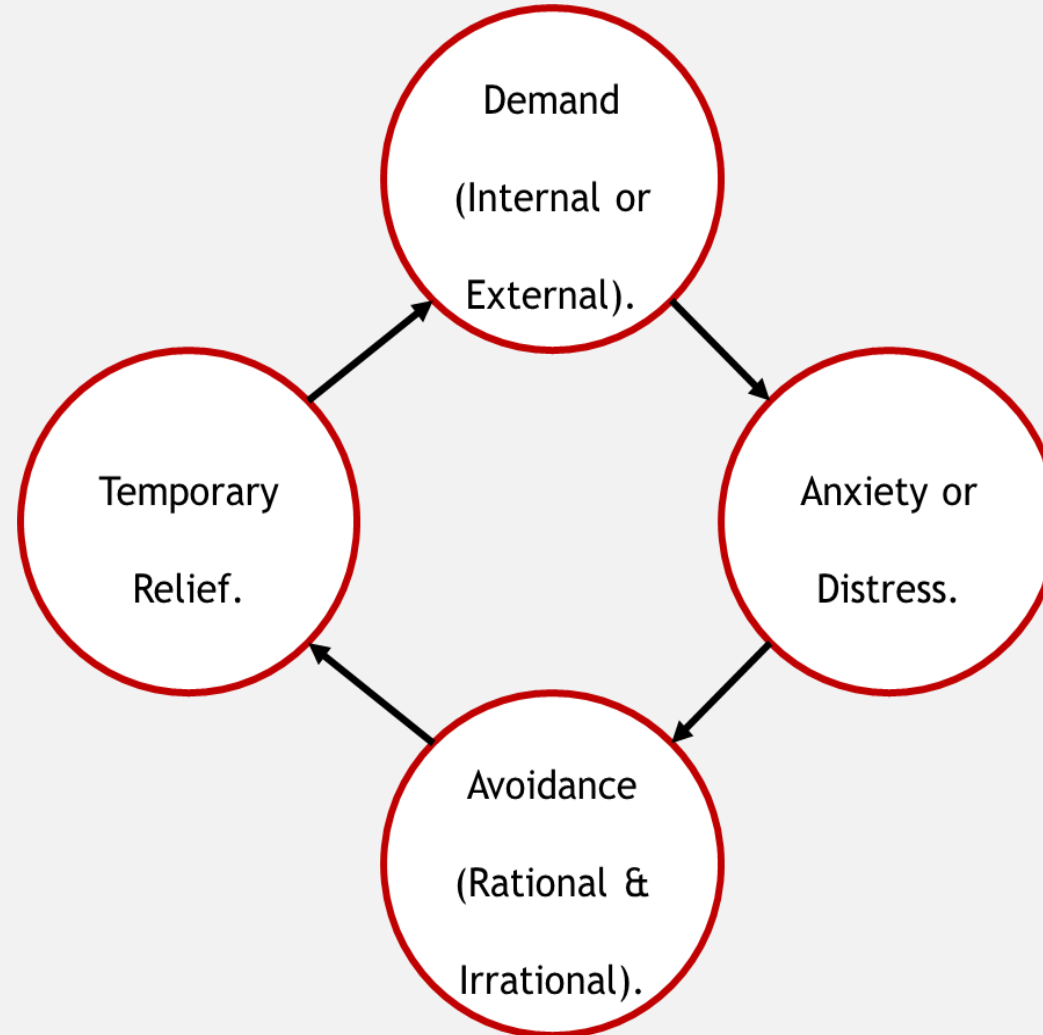
How are demands avoided. (PDA Society 2020, p7).



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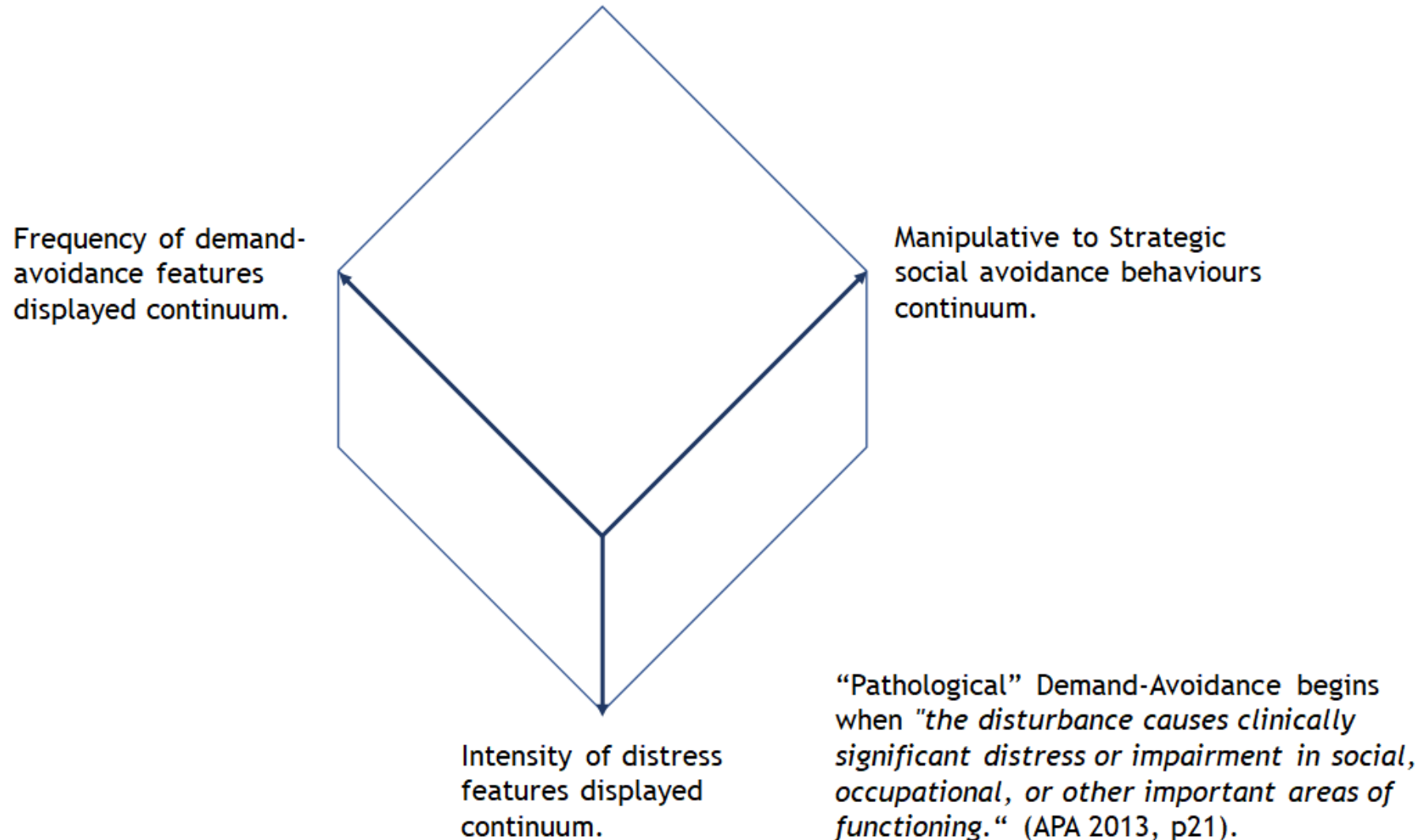
A STRESSFUL SITUATION.

Demand Management Cycle.



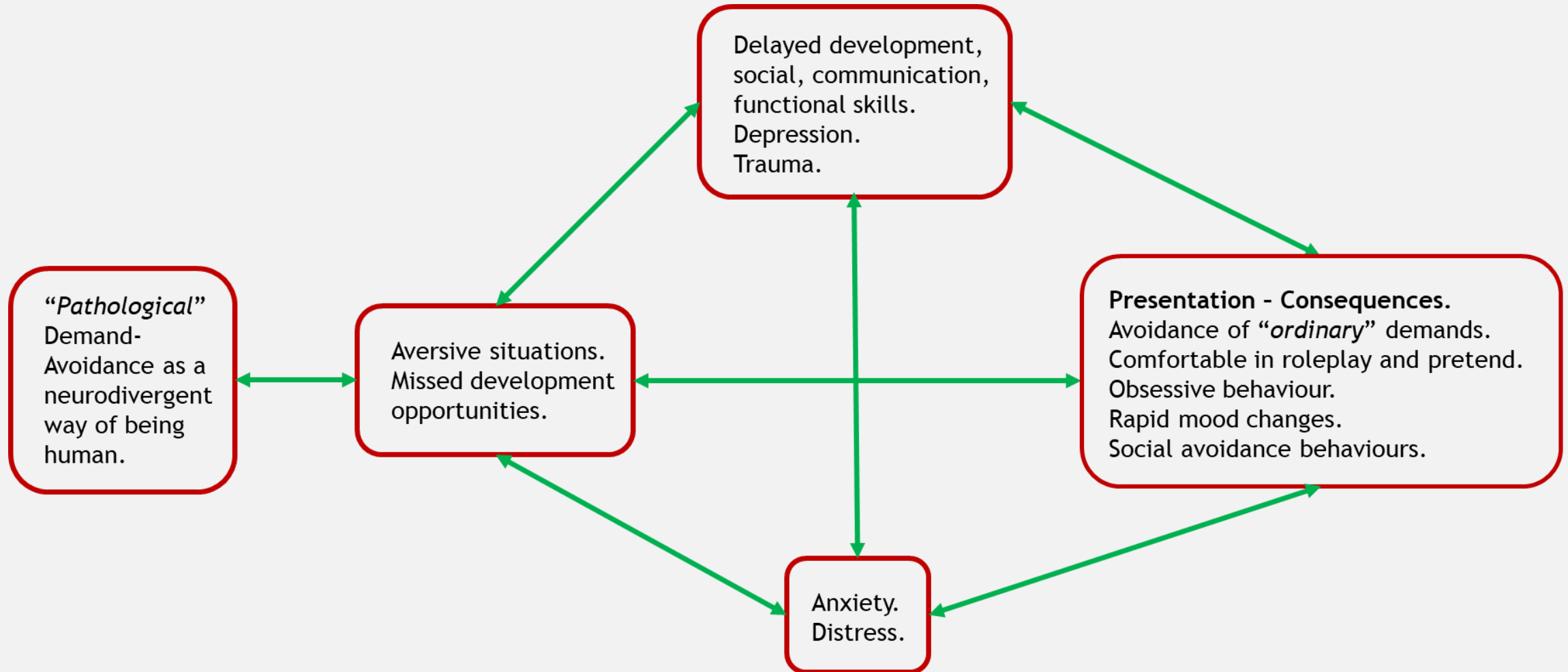
A STRESSFUL SITUATION.

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



A STRESSFUL SITUATION.

A transactional stress developmental model for DAP.



CONTRASTING FORTUNES.

Autism & DAP stereotypes.

Number.	Autism Stereotypes.	DAP Clinical Literature.
1	Absent or delayed roleplay and pretend.	Comfortable in roleplay and fantasy.*
2	Are not sociable.	Are sociable, but it is surface.
3	Delays in social communication and interaction from Theory of mind deficits.	Surface sociability, appears to lack of sense of social identity, pride, or shame.*
4	Dislikes surprises.	Likes novelty.
5	Does not express strong emotions.	Intense emotions and dysregulation.
6	Does not make eye contact.	Makes eye contact.
7	Lacks empathy.	Manipulative demand avoidance behaviours.*
8	Likes routines and structure.	Dislikes routines and structure.*

*Is a reason why it is problematic conceptualising DAP as an ASD.

CONTRASTING FORTUNES.

Autism & DAP stereotypes.

Number.	Autism Stereotypes.	DAP Clinical Literature.
9	Likes routines and structure being imposed upon them.	Has a need for control.
10	Passionate interest with unusual intensity/ focus.	Intense interests are often focused on people.
11	Should use clear and concise language.	Should use complex language to disguise demands.
12	There are many more autistic males, than females.	Female form of autism. Can be equally prevalent in both genders.*
13	Typical autism strategies (often behaviourism based, like Applied Behaviour Analysis) work.	Typical autism strategies (often behaviourism based, like Applied Behaviour Analysis) do not work.*

*Is a reason why it is problematic conceptualising DAP as an ASD.

CONTRASTING FORTUNES.

Autism & Stigma.

- 1) Autistic persons often adversely affected by stigma by stereotypes, judged, and discriminated by others.
- 2) Can internalise stigma, more vulnerable to poorer mental health & low self-esteem.
- 3) Can respond to this by concealment and camouflaging, selective disclosure and self-advocacy, as well as positive reframing and reconstructing identity (Han et al 2021).

CONTRASTING FORTUNES.

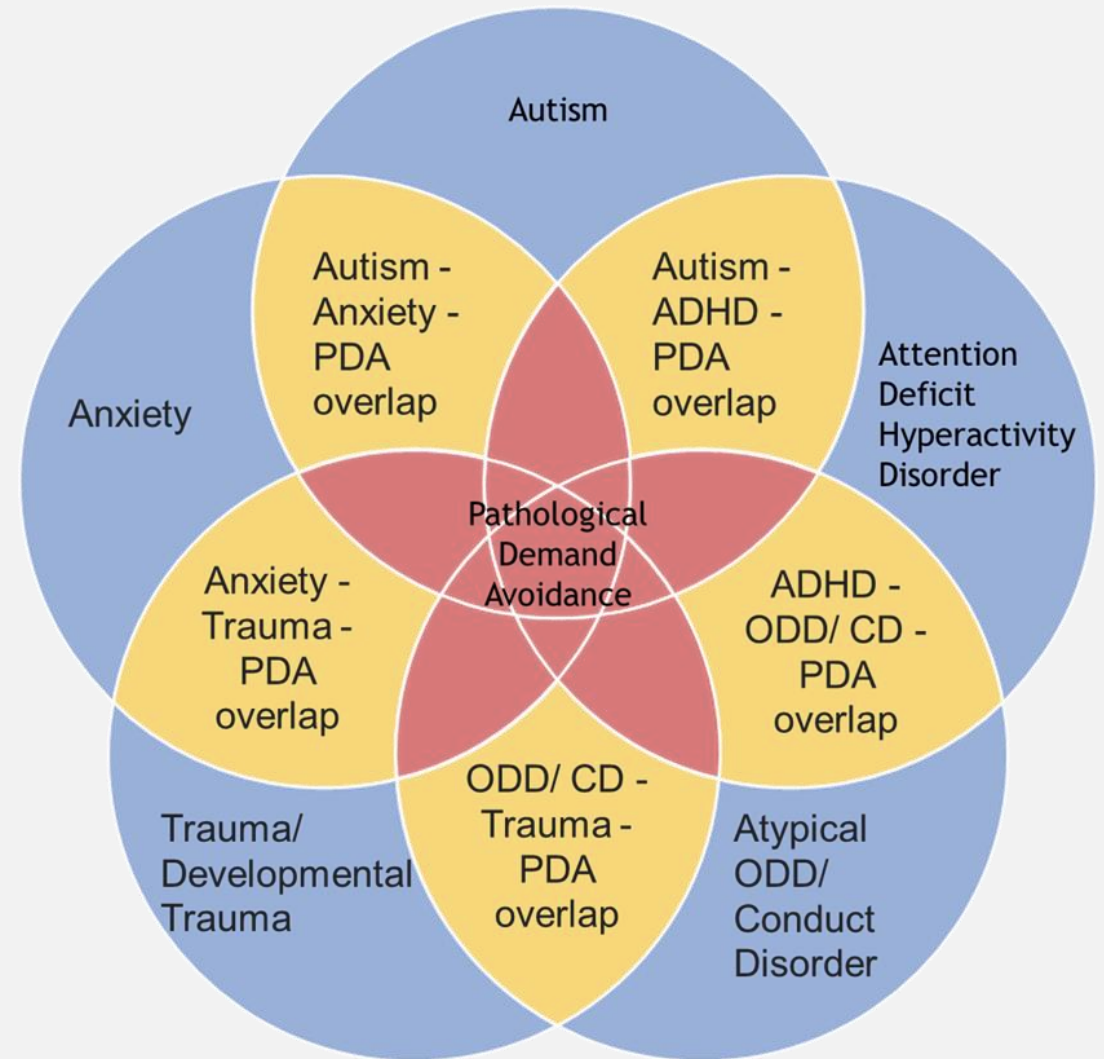
Autism & Stigma.

- 1) Camouflaging is deleterious to autistic wellbeing (Mandy 2019).
- 2) Those not conforming to autism stereotypes are most likely not to receive a dx under DSM-5 criteria (Evers et al 2021).
- 3) DAP features are opposite of many autism stereotypes, it makes it harder for autistic persons to manage their information.

PEAL DISTRICT.

DAP, Gaussian Curves & Spikey Profiles.

- 1) DAP's own spikey profile seems to make it easier for persons to identify with.
- 2) Compounded lack of specificity, generic items on tools, and the several competing diagnostic thresholds & several different behaviour profiles.
- 3) DAP appears easy to identify with.



AVOIDING DEMANDS OF ORDINARY RESEARCH.

Broader issues in autism studies.

- 1) Autistic persons are systemically poorly treated by society (Botha 2021; Woods 2017b).
- 2) Much/ most autism research & practice is poor quality (Bottema-Beutel et al 2021a; Bottema-Beutel et al 2021b; Bottema-Beutel & Crowley 2021; Dawson & Fletcher-Watson 2021a).
- 3) Poor quality research is often associated with poor quality ethics (Dawson & Fletcher-Watson 2021b; Waltz 2007).

FOREVER BLOWING BUBBLES.

DAP's nature makes it easy for anyone to identify with it.

- 1) DAP has no specificity (Christie et al 2012; Christie & Fidler 2015; Garralda 2003; Malik and Baird 2018; Wing 2002; Wing & Gould 2002; Woods 2019).
- 2) Using questionnaires & lacking specific items from using caregiver reports (Lord et al 2018).
- 3) DAP features overlap many accepted constructs & common autism co-occurring conditions; it is easy for one to identify with it, if they wish to.
- 4) Signs of autistic CYP & adults internalizing “*DAP Profile of ASD*” discourse (Cat 2018; Finley 2019; O’Connor & McNicholas 2020; Thompson 2019).

FOREVER BLOWING BUBBLES.

How “*DAP Profile of ASD*” controls autistic persons.

- 1) Autistic persons often high number of co-occurring conditions, 70% at least 1, at least 40% at least 2 or more (Woods 2019).
- 2) Most of autistic persons ill-health is due to minority stress.
- 3) Positive experiences in autistic community can help protect adverse impact of minority stress (Botha 2021).
- 4) One should expect many autistic persons to identify with DAP, & a supportive community would form around “*DAP Profile of ASD*” (Cat 2018; Thompson 2019).
- 5) “*Pervasive Drive for Autonomy*”.
- 6) Which suggests a person is not impaired in neoliberal culture.

A GOOD APPROACH?

Good practice.

- 1) Please can you list strategies that you think are good practice?
- 2) E.g. allowing someone time to process information.

A FIAT PANDA?

AET DAP Strategies (Woods 2019a).

- 1) A specific keyworker & trusted relationship.
- 2) Being flexible & adaptable.
- 3) Indirect praise.
- 4) Letting things go.
- 5) Negotiating by providing choices to pupils.
- 6) Positive relations.
- 7) Thinking aloud.
- 8) Tone of voice.
- 9) Treating anger as communication.
- 10) Use humour.
- 11) Use role play, novelty & various materials.
- 12) Visual communication methods.

A FIAT PANDA?



Helpful approaches for a PDA profile of autism

Conventional support strategies, including those often recommended for ASD, are often ineffective and counter-productive with a PDA profile. In place of structure, routine, firm boundaries, praise, rewards/consequences, is a person-centred approach based on negotiation, collaboration and flexibility.



The PDA PANDA symbolises the need to tailor the environment to meet needs and our P A N D A mnemonic is a simple reminder of helpful approaches.

For more information please visit www.pdasociety.org.uk

Pick battles

- Minimise rules
- Enable some choice & control
- Explain reasons
- Accept that some things can't be done

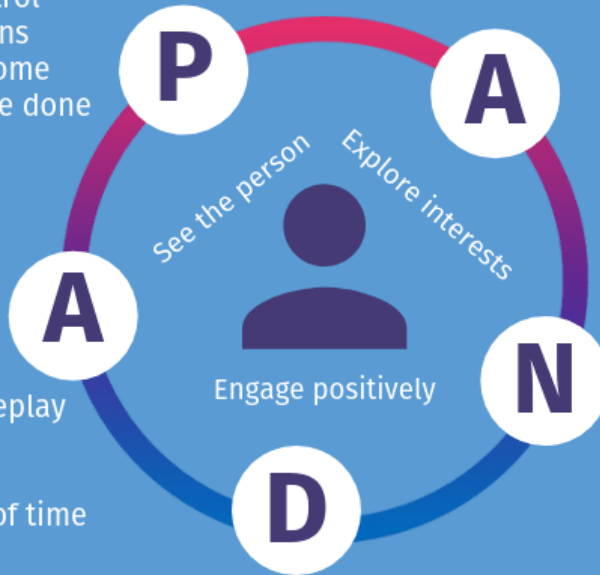
Pick battles
Anxiety management
Negotiation & collaboration
Disguise & manage demands
Adaptation

Anxiety management

- Reduce uncertainty
- Recognise underlying anxiety & social/sensory challenges
- Think ahead
- Treat meltdowns as panic attacks: support throughout & move on

Adaptation

- Try humour, distraction, novelty & roleplay
- Be flexible
- Have a Plan B
- Allow plenty of time



Negotiation & collaboration

- Keep calm
- Proactively collaborate & negotiate to solve challenges
- Fairness & trust are central

Disguise & manage demands

- Word & position requests indirectly
- Constantly monitor tolerance for demands & match demands accordingly
- Doing things together helps

© PDA Society 2019

PANDA Strategies Infographic (PDA Society 2019).

A GOOD APPROACH?

Good practice.

- 1) Please compare your ideal approaches, The SPELL Framework to the DAP strategies?
- 2) You should see that DAP strategies overlap your own list of generic good practice strategies.
- 3) DAP strategies heavily overlap LA Approach, perhaps even a personalised variation of LA Approach.

A MATTER OF PERSPECTIVE.

Should be wary prioritising narrow views on DAP.

- 1) Most would accept Asperger's views on autism was substantially broader than Kanner's.
- 2) Kanner's his drive to establish child psychiatry held back understandings of autism by decades (Silberman 2015).
- 3) *“the best predictor of which autism spectrum diagnosis a person received (Asperger disorder, PDD-NOS, or autistic disorder) was which clinic the individuals went to, rather than any characteristic of the individual.”* (Happé 2011, p541).
- 4) Clinician's bias can be a barrier to identifying autistic females (Lockwood-Estrin et al 2020).

A MATTER OF PERSPECTIVE.

Biased research leads to problematic DAP understandings.

- 1) *“However, identification of mental health problems in autism can be challenging for a number of reasons... Autistic individuals frequently have difficulties conveying information about their emotional states or levels of anxiety... mental health problems may present in atypical or unusual ways... and may not always be easily observable to families, caregivers or clinicians... The types of events or stimuli that can give rise to anxiety may also be different, or more varied, in autistic individuals than in the general population”* (Kildahl et al 2021, p2163).
- 2) DAP probably presents differently in autism vs non-autism.

A MATTER OF PERSPECTIVE.

Biased research leads to problematic DAP understandings.

- 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) Is applicable to basing understanding of DAP on assumption it is a *“Profile of ASD”*.

A MATTER OF PERSPECTIVE.

Biased research leads to problematic DAP understandings.

- 1) *“One of the strengths of the current study was that the data used were collected in 2010 or earlier: for the most part prior to the large peak in interest in PDA and the series of annual conferences on the topic held in the UK. As such, it is likely that clinicians were not particularly ‘on the lookout’ for PDA features in their cases. This meant that it was possible to get an honest and unbiased picture of the features of PDA in this sample.”* (O’Nions et al 2016a, p418).
- 2) Campaigning for DAP as form of autism probably creates source of confirmation bias.
- 3) Only *“DAP Profile of ASD”* supporters know what DAP looks like.

A MATTER OF PERSPECTIVE.



- 1) “*DAP Profile of ASD*” supporters are as biased as anyone else.
- 2) These contributing factors suggest that autism subgroups are a political choice more than anything else.

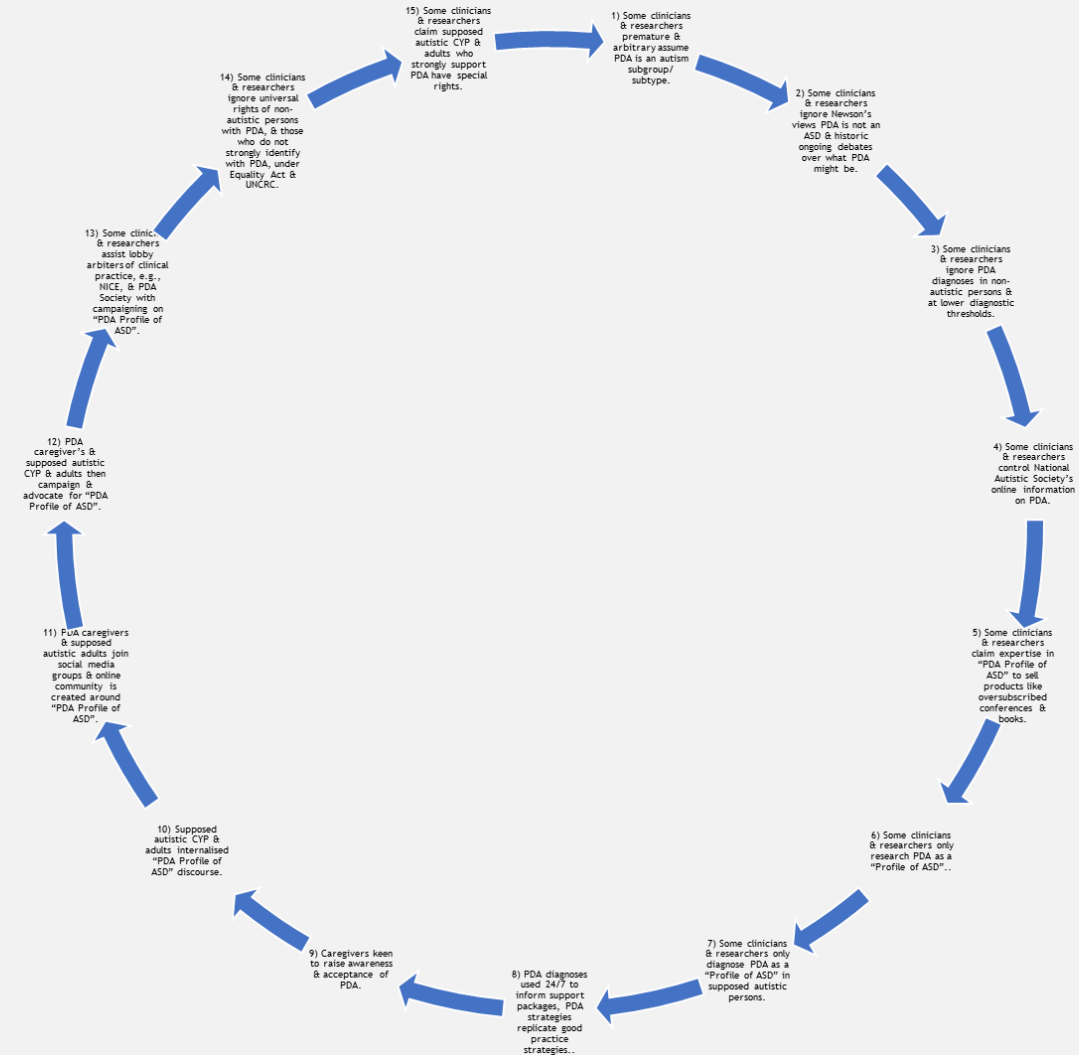
A PERPETUAL MOTION ENGINE?

Propagating “DAP Profile of ASD” cycle components.

Number.	Component in creating demand for “DAP Profile of ASD”.
1	Some clinicians & researchers premature & arbitrary assume PDA is an autism subgroup/ subtype.
2	Some clinicians & researchers ignore Newson’s views PDA is not an ASD & historic ongoing debates over what PDA might be.
3	Some clinicians & researchers ignore PDA diagnoses in non-autistic persons & at lower diagnostic thresholds.
4	Some clinicians & researchers control National Autistic Society’s online information on PDA.
5	Some clinicians & researchers claim expertise in “PDA Profile of ASD” to sell products like oversubscribed conferences & books.
6	Some clinicians & researchers only research PDA as a “Profile of ASD”.
7	Some clinicians & researchers only diagnose PDA as a “Profile of ASD” in supposed autistic persons.
8	PDA diagnoses used 24/7 to inform support packages, PDA strategies replicate good practice strategies.
9	Caregivers keen to raise awareness & acceptance of PDA.
10	Supposed autistic CYP & adults internalised “PDA Profile of ASD” discourse.
11	PDA caregivers & supposed autistic adults join social media groups & online community is created around “PDA Profile of ASD”.
12	PDA caregiver’s & supposed autistic CYP & adults then campaign & advocate for “PDA Profile of ASD”.
13	Some clinicians & researchers assist lobby arbiters of clinical practice, e.g., NICE, & PDA Society with campaigning on “PDA Profile of ASD”.
14	Some clinicians & researchers ignore universal rights of non-autistic persons with PDA, & those who do not strongly identify with PDA, under Equality Act & UNCRC.
15	Some clinicians & researchers claim supposed autistic CYP & adults who strongly support PDA have special rights.

A PERPETUAL MOTION ENGINE?

Propagating “DAP Profile of ASD” cycle.



DAP: As a Social Construct 07th of April 2022.

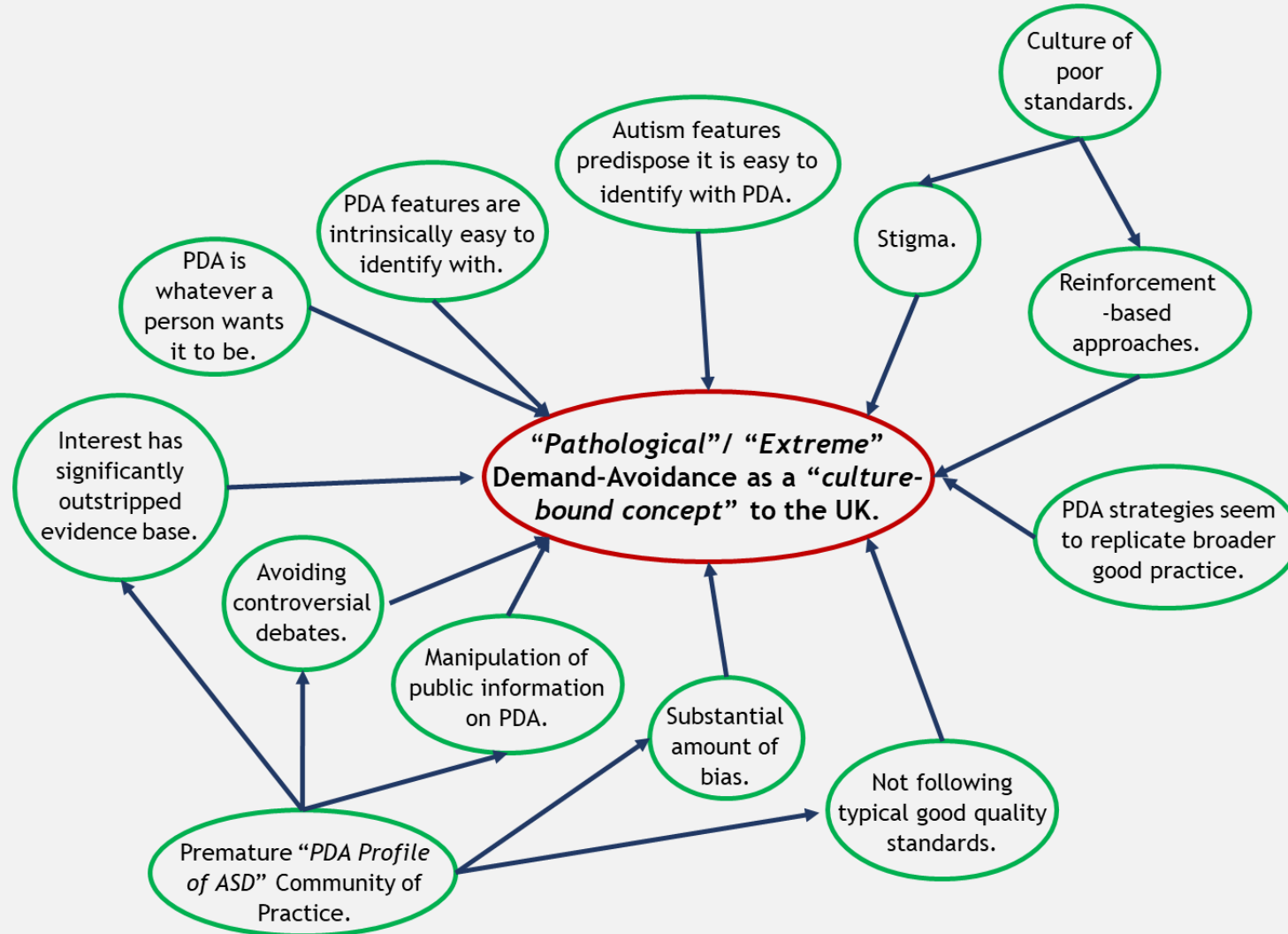
AVOIDING VARIANCE.

Researchers, clinicians & practitioners need to specify
(Conclusion).

- 1) DAP likely a dead impairment category being re-imagined.
- 2) Rare opportunity for examination of how a pseudo-proto impairment category involves in real time.
- 3) How one conceptualizes DAP is based upon personal bias.
- 4) DAP's construction is being affected by cultural factors.
- 5) Yet it seems to represent a tangible way of being human.
- 6) Can map how culture & biology are interacting to create DAP.
- 7) How would you feel about autistic persons creating a Disorder that pathologises your non-compliance in creating an autism friendly world and lack of empathy towards us?

INSERT TEXT.

Why is “DAP Profile of ASD” a “culture-bound concept” in UK?



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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