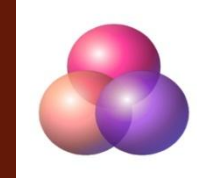


New research ideas and questions about PDA

Overview

- ◆ PDA: much concern, little research
- ◆ Why research PDA?
- ◆ PDA and Autism Spectrum Disorders?
- ◆ Does understanding the basis of ASD help us understand PDA?
- ◆ What underlies demand avoidance?
- ◆ Our current research into PDA



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PDA: much discussed, little researched

- Only one paper published in a clinical/research journal to date

REVIEW

Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders

E Newson, K Le Maréchal, C David

Arch Dis Child 2003;**88**:595-600

- Huge parental concern (web presence)
- Need to raise awareness
- Need for empirical studies



'PDA' little used beyond UK

- ◆ What are these difficulties called elsewhere?
 - 'Oppositional defiant disorder' or 'conduct disorder'?
 - 'reactive attachment disorder'?
 - 'bipolar disorder in childhood'?
 - 'schizoid personality'?
 - 'sheer cussedness'?

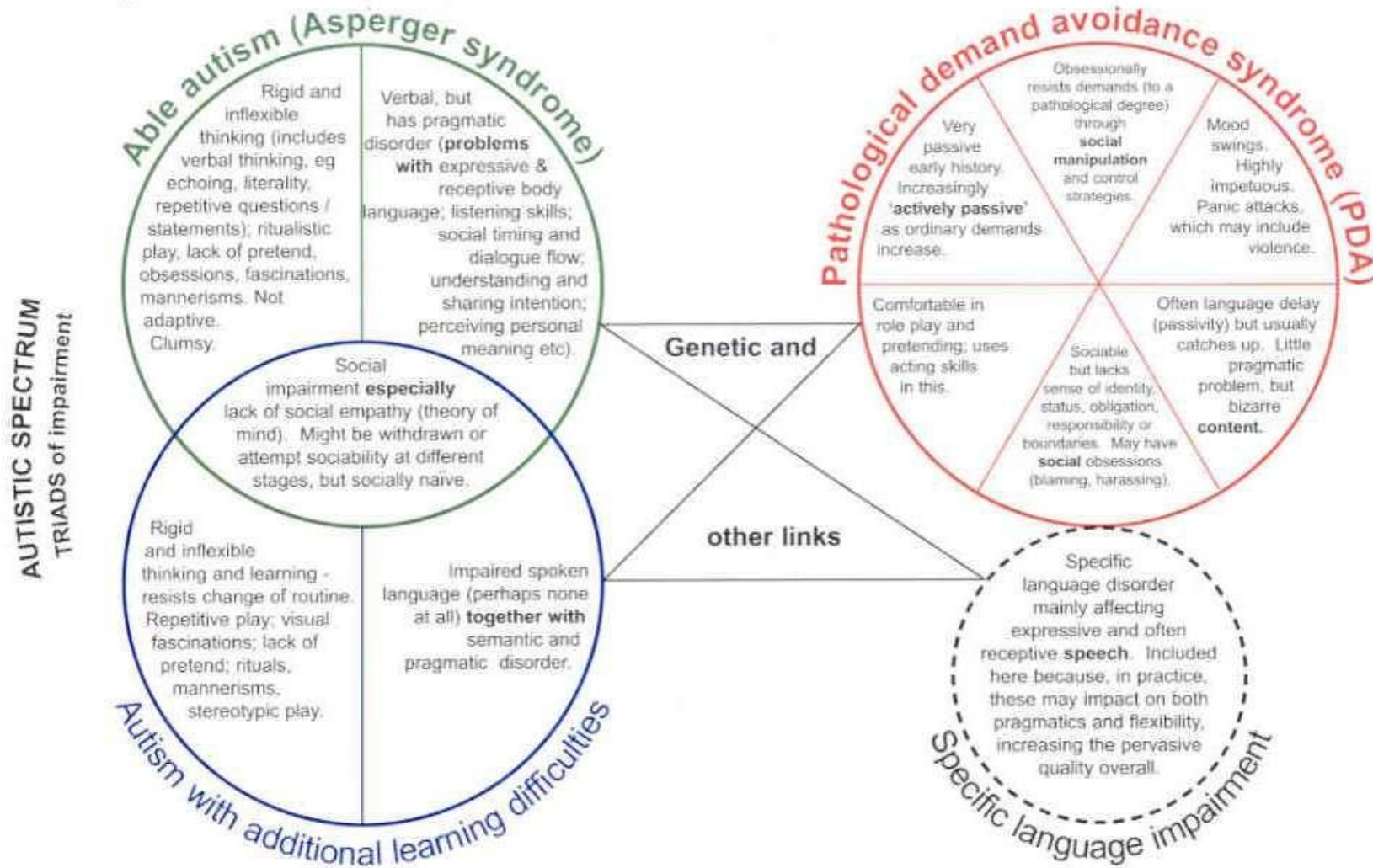
- ◆ *Where* are these young people?
 - ASD clinics?
 - Excluded from school?
 - ???

Why research PDA?

- ◆ Hard to manage for families and schools
- ◆ Typical ASD-suited approaches don't work?
(repetition, routine, reward)
- ◆ Relatively gloomy prognosis in Newson follow-up

THE 'FAMILY' OF PERVASIVE DEVELOPMENTAL DISORDERS

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



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

Elizabeth Newson
1999

PDA and Autism Spectrum Disorders

◆ Similar to ASD?

- Friendship problems
- No embarrassment
- Obsessive traits
- Highly anxious?
- Fail to read social cues?

◆ Different from ASD?

- Gender ratio
- Like pretend and role play
- Nonverbal comm' ok?
- Socially manipulative?
- Don't respond to reward and routine?

Similar behaviour, different reasons?

The Autistic Triad

Social impairments

Triad is *fractionable*...

- 3 traits correlate only moderately
- distinct genetic effects
- isolated deficits seen



Communication impairments

Restricted/ Repetitive Behaviours & Interests

The Autistic Triad: Relevance for PDA?

Social impairments

Pragmatics ok?
Comprehension?

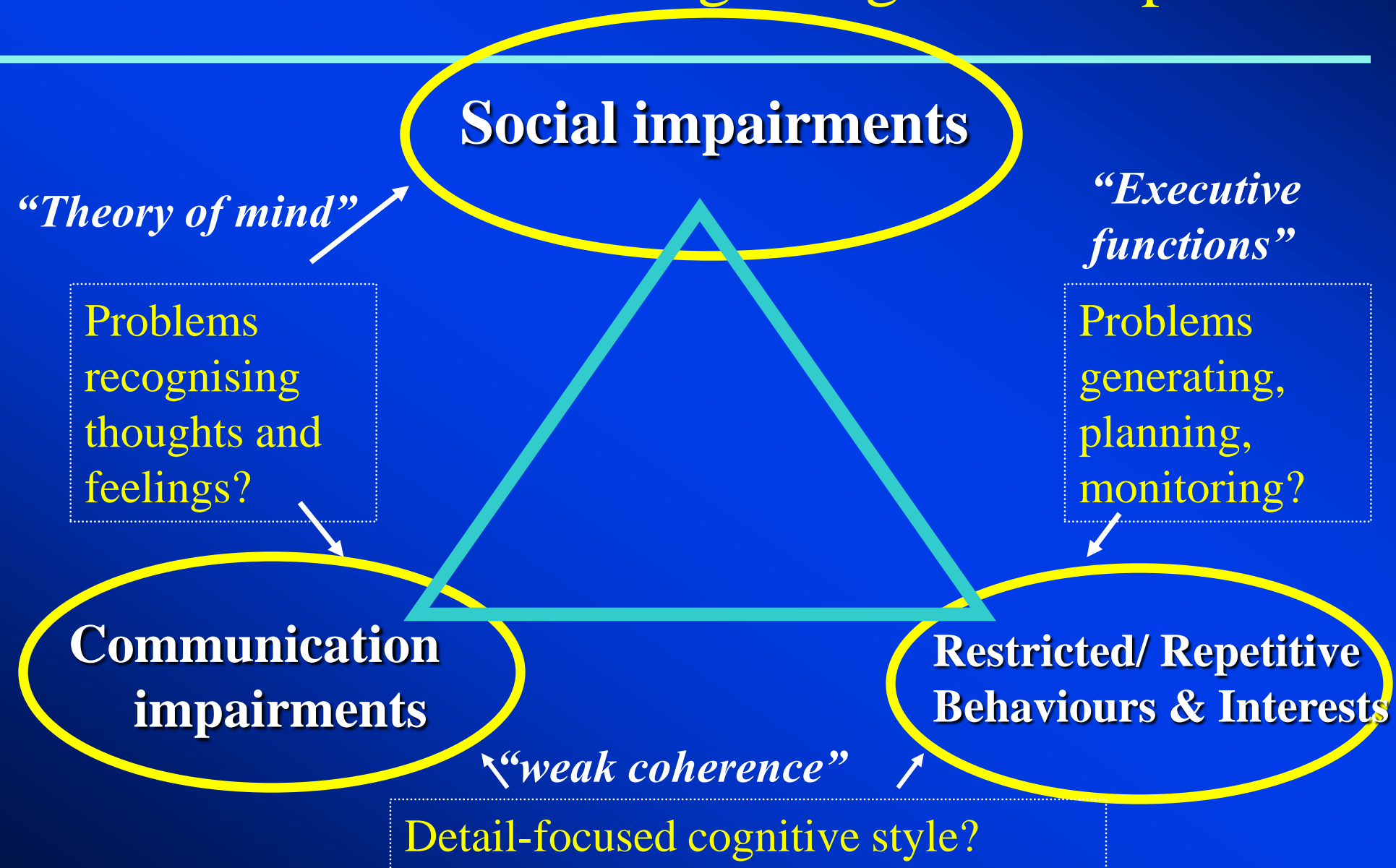


Communication impairments

Restricted/ Repetitive Behaviours & Interests

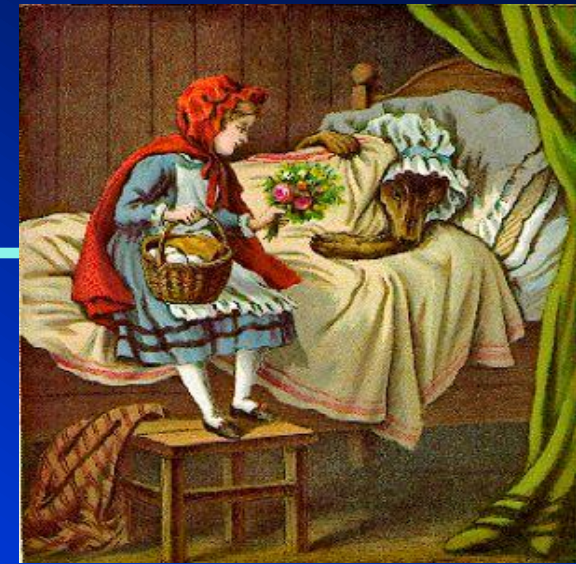
Role play? Fixated on a person? Obsessive DA?

The ASD triad: No single cognitive explanation?



Mind-blindness in ASD

‘Theory of mind’ = recognising others’ thoughts
...putting yourself in another person’s shoes



Tested by ability to attribute a false belief (3 years+)

Manifest in everyday social skills (2 years+)

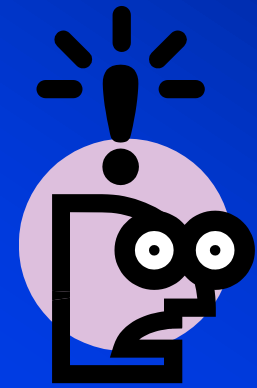
e.g. making secrets, pretend play, lying



‘Mind-blindness’ in ASC e.g.
-social interest but difficulty,
-over-literal understanding,
-don’t use/understand lies, secrets
-lack of social pretend play

Defining criteria for PDA

- ◆ Passive early history
- ◆ Resists and avoids ordinary demands of life
- ◆ Surface sociability
- ◆ Lability of mood
- ◆ Comfortable in role play and pretending
- ◆ Language delay, seems result of passivity
- ◆ Obsessive behaviour
- ◆ Neurological involvement



Understanding vs. Caring

- ◆ ‘Reading minds’ and ‘empathising’ may be distinct abilities
- ◆ Difficulty **knowing** what others are feeling is *not* the same as not **caring** about others’ feelings
- ◆ Most people with ASD *do* care about others’ feelings



Empathy dysfunction in conduct disorder + callous/unemotional

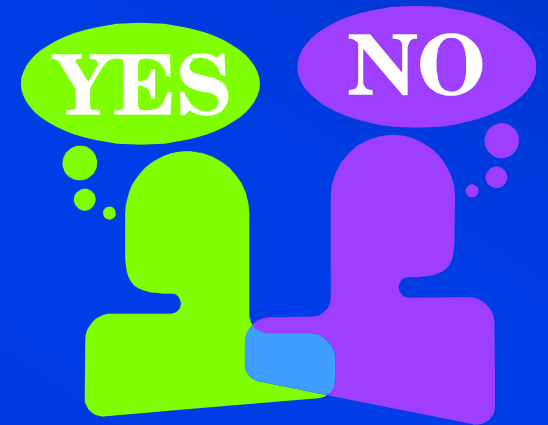


Work by
Essi Viding, UCL
James Blair, NIMH

“I am not quite sure what I would call that expression, but I know that is what people look like just before you stab them”

What might underlie Demand Avoidance?

- ◆ *Why do TD children (generally) comply?*
 - Want to please others? Enjoy positive emotional displays?
 - Care about reputation? Others' views of self matter?
 - Herd instinct; instinctively recognise hierarchy?
- ◆ *Why is complying so hard for children with PDA?*
 - Anxiety → Attempt to control?
 - Identity disorder?
 - Theory of mind + empathy difficulties?
 - No response to positive emotions?



Current research – ongoing work

- ◆ Exploring the behavioural profile in PDA
- ◆ Exploring the cognitive profile in PDA
 - ◆ Explore overlap with ASD – knowing? and conduct problems/callous unemotional traits – caring?
 - ◆ Does PDA represent a “new” cognitive profile?

1. Exploring the behavioural profile

PDA
group
(N=25)

ASD
group
(N=39)

CP/CU
group
(N=28)

- ◆ Measures: Strengths and Difficulties Questionnaire (SDQ), Anti-social Process Screening Device (APSD), Childhood Autism Spectrum Test (CAST)

Findings of study exploring behavioural profile

- ◆ **Severe impairments across multiple behavioural domains.**
- ◆ Peer problems and autistic-like traits comparable to ASD.
- ◆ Anti-social traits/ lack of pro-social behaviour comparable to CP/CU.
- ◆ Significantly higher levels of internalizing/ emotional problems than ASD or CP/CU.

O'Nions, Viding, Greven, Ronald & Happé (submitted)

Research into the PDA cognitive profile

- ◆ Does PDA represent a “new” cognitive profile, or is it just a “multiple hit” of other existing profiles.

- ◆ Need to identify participants for inclusion in research.
 - No standard criteria for assessment of PDA
 - PDA used by some clinicians but not others



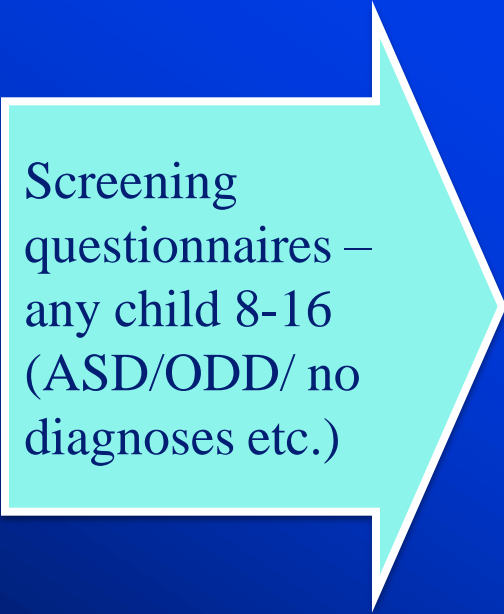
Screening stage

- ◆ Purpose built PDA questionnaire we developed (“EDA-Q”) flags who might display a PDA-like profile.


Example items:

- ◆ Obsessively resists demands and requests.
- ◆ Is driven by the need to be in charge.
- ◆ Shows little shame or embarrassment.
- ◆ Mood changes very rapidly.
- ◆ Uses outrageous or shocking behaviour to get out of doing something.
- ◆ **PLUS SDQ profile: anxiety/ low pro-social/ conduct/ peer problems**
- ◆ *Recruitment: schools/ parent groups/ web forums/ NAS conferences*

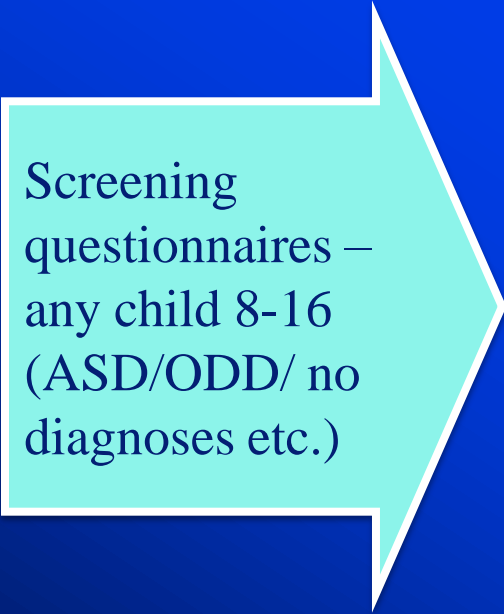
Recruiting participants with a PDA-profile for research



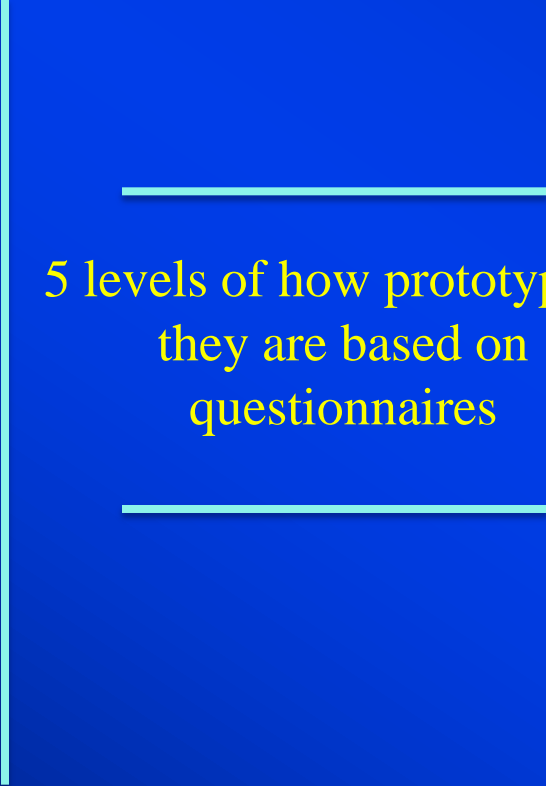
Screening
questionnaires –
any child 8-16
(ASD/ODD/ no
diagnoses etc.)



Recruiting participants with a PDA-profile for research



Screening
questionnaires –
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5 levels of how prototypical
they are based on
questionnaires

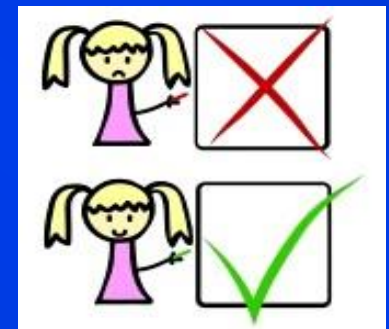
Recruiting participants with a PDA-profile for research

Screening questionnaires – any child 8-16 (ASD/ODD/ no diagnoses etc.)

5 levels of how prototypical they are based on questionnaires

Parent interview (based on DISCO items for PDA)

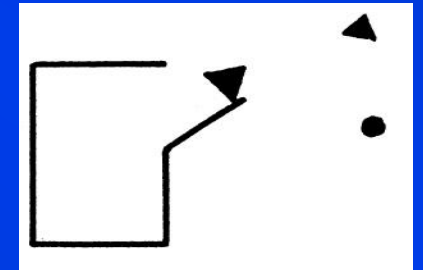
Cognitive testing & behavioural observations



Progress so far...

Cognitive Testing session

- ◆ Observational session based on ADOS (whilst wearing Heart Rate monitor)
- ◆ WASI (HR baseline)
- ◆ Computer based measures:
 - ToM tasks – strange stories & triangles animations task
 - Empathy tasks – self-reported feelings related to vignettes
 - Emotional salience – emotional dot-probe.



What we look for behaviourally in PDA

(some examples – *not a validated measure*):

- ◆ Attempts to cause distraction throughout tasks, tries to change them, negotiates, makes excuses (bizarre or reasonable) etc.
- ◆ Sense the child is always one step ahead
- ◆ Child appears to monitor effect of behaviour on you (e.g. looking at eyes)
- ◆ Social manner seems fake, becomes suddenly uninhibited or over-the-top. No need to regulate behaviour for our benefit.
- ◆ Superficial engagement with conversation tasks, sense the child is palming us off.
- ◆ Adopts a dominant role (e.g. setting limits, interrupting).
- ◆ Appeal to better nature doesn't work/ constraint by social norms unimportant.

Some examples...(girls aged 8-10)

- ◆ Holding her finger over the laptop button to play the next clip – starting it too soon
- ◆ Telling us how many more questions she would answer.
- ◆ Interrupting and talking over us, showing no deference.
- ◆ Using props even when asked not to, answering the phone.
- ◆ Redirecting our questions to her toy.
- ◆ Giving us stickers at the end because we had been nice.

Some examples *cont.*

- ◆ Adopting the manner and behaviour of a much younger child, speaking in a baby voice.
- ◆ At times speaking very loudly in an inappropriate, over-the-top manner, and using very exaggerated expressive gestures.
- ◆ Answers to questions sounded scripted/ copied (e.g. “*It felt like my whole world lit up*”)



Preliminary observations I

- ◆ Behavioural profile (especially demand avoidance) can occur in children with a very clear ASD profile (e.g. throughout display very inappropriate social responses etc.)
 - Even range of strategies: excuses, bargaining, “Why do I have to do this?”, hiding self etc.
- ◆ Can occur in children who show fewer ASD-like features – though social responses can seem superficial or variable.
 - Likely to fall under radar, considered just naughty
 - May be completely disengaged

Preliminary observations II

- ◆ Socially “manipulative”/ provocative behaviour (e.g. dialling 999, urinating on another child’s clothes) can occur on a background of poor ToM
 - Qualitative differences?
- ◆ Extra mentalising in some – attribution of trickery that would require an awareness of double bluff.
 - Attribution of mental states/ animacy to toys/ animals in stories.

Further research

- ◆ Explore links between this profile and other neurodevelopmental disorders (e.g. tics, epilepsy)
- ◆ If you are a parent/know a parent of a child who displays characteristics of PDA, or a typically developing child, please consider taking part.
- ◆ If you are a clinician and are interested in our measures, please get in touch:

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<https://sites.google.com/site/lizonions/>

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All families who have taken part in the research so far!

