Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q): Preliminary observations on a trait measure for Pathological Demand Avoidance Elizabeth O'Nions¹, Phil Christie², Judith Gould³, Essi Viding⁴ & Francesca Happé¹

¹ King's College London, MRC Social, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, De Crespigny Park, London, SE5 8AF, UK; ² The Elizabeth Newson Centre, Sutherland House Children's Services (NORSACA), Nottinghamshire, ³ The NAS Lorna Wing Centre for Autism, Bromley, Kent; ⁴ University College London, Developmental Risk & Resilience Unit, Clinical, Educational, and Health Psychology Research Department, Division of Psychology and Language Sciences, London, UK

Short title: Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q)

Journal of Child Psychology and Psychiatry (Association for Child and Adolescent Mental Health and Blackwell Publishing)

Accepted August 2013, available online 7th October 2013. DOI: 10.1111/jcpp.12149

Background: Pathological Demand Avoidance (PDA) is a term increasingly used in the UK to describe children who obsessively resist everyday demands, going to extreme lengths to avoid these. There is debate about its relationship with both autism spectrum disorder (ASD) and oppositional defiant disorder (ODD). Unlike ASD, children with PDA are said to use socially manipulative avoidance strategies; and unlike ODD, they resort to extreme, embarrassing or age-inappropriate behaviour. To date, there has been little research into PDA, and it remains contentious. Currently, there are no questionnaire instruments available to aid consistency in description. This study reports the development and preliminary validation of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q), designed to quantify PDA traits based on parent-reported information.

Methods: The validation study involved data from 326 parents of children aged 5-17 allocated to six groups based on information reported by parents about received diagnoses and behavioural difficulties: (1) typically developing children (N=102), (2) children with ASD *without* disruptive behaviour (N=36), (3) children with ASD *with* disruptive behaviour (N=48), (4) children for whom PDA was suspected by parents (irrespective of other diagnoses) (N=67), (5) children who had, according to parents, been identified as having PDA by a health professional, irrespective of other diagnoses (N=50), and (6) disruptive behaviour or behavioural problems *without* suspected/identified ASD or PDA (N=23).

Results: Though the Strengths and Difficulties Questionnaire (SDQ) did not differentiate PDA from those with ASD plus disruptive behaviour; score on the EDA-Q was significantly higher in PDA than all comparison groups. ROC analysis indicated good sensitivity (.80) and specificity (.85). Across all case groups, females scored higher than males on the EDA-Q. Separate cut-off scores were identified for older and younger age-groups.

Conclusions: Our findings highlight the potential utility of the EDA-Q to assist the identification of this unusual profile for future research.

Keywords: Autism Spectrum Disorder, ASD, Pathological Demand Avoidance, PDA, Pervasive Developmental Disorder, conduct problems, Oppositional Defiant Disorder, ODD, disruptive behaviour.

Introduction

Pathological Demand Avoidance (PDA) is a term used to describe children who display an extremely challenging behavioural profile, central to which appears to be an obsessive resistance to everyday demands and requests, a need to be in control when interacting with others, and a tendency to go to extreme lengths in the service of avoidance and control. Though these children have been likened in some ways to children with autism, and many receive an ASD diagnosis (Newson, Le Marechal, & David, 2003; O'Nions, et al., unpublished observations); they are described as using frequent and varied "socially manipulative" strategies to avoid complying with requests (e.g. diverting the conversation, pretending not to know the answer, adopting a babyish style). In addition, many resort to extreme behaviour apparently intended to shock. Their apparently intact awareness of how to "push people's buttons" suggests a level of social insight that is unusual in children with ASD. On the other hand, children identified as having PDA look somewhat different from most children with conduct disorder/oppositional defiant disorder (henceforth termed 'disruptive behaviour'), in showing little sense of embarrassment, reputation management, or conformity to peer norms. Many resort to behaviour peers view as babyish or personally humiliating, and friendships fail due to controlling behaviour and their extreme response when things don't go their way (Newson et al., 2003).

Recent years have seen increasing interest in PDA in the UK, evidenced by the inclusion of educational guidelines on PDA (Christie, 2007) in the UK-based Autism Education Trust's best practice guidelines, and several over-subscribed conferences on the topic since 2011, jointly run by national and regional UK societies for people with autism. Despite this, there remains controversy about its use as a diagnostic description, particularly given the paucity of research at present. To date, research has explored the qualitative features associated with this profile (Newson, et al., 2003). Using questionnaire measures, we have shown that individuals reported to have been identified as exhibiting the PDA profile have comparable levels of autistic-like traits to individuals with autism spectrum disorder, and comparable levels of anti-social traits to individuals with conduct problems plus callous-unemotional traits, a profile associated with lack of

guilt and empathy (O'Nions, Viding, Greven, Ronald, & Happé, in press; Frick & Ellis, 1999; Viding, Fontaine, & McCrory, 2012). In this study, individuals reported to have been clinically identified as having PDA also exhibited significantly higher levels of emotional symptoms (anxiety) than either of the other clinical groups (O'Nions, et al., in press).

One of the stumbling blocks to further research on these puzzling children is the lack of agreed criteria and measures to quantify aspects of the PDA profile. The term PDA is currently used by some clinicians, although it is not included in current diagnostic manuals. Consistency of the description as it is applied clinically is unknown. Currently, the only available measures are questions tapping PDA incorporated in the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002), and an un-validated descriptive parent interview measure developed by Elizabeth Newson for a follow-up study of PDA in adulthood. We have developed a further interview measure (O'Nions, et al., unpublished observations) based on and extending these two measures. However, interview-based measures require coding of verbal responses from parents or carers by an examiner, so take time and training to administer and score. For the purposes of research and clinical work, it would be helpful to have a questionnaire measure that allowed parents or teachers to provide information quickly and easily about characteristics associated with PDA. Importantly, none of the existing PDA measures has been standardised such that the level of PDA traits can be viewed in the context of normative levels of relevant behaviours in typically developing populations or other disorder groups.

The aim of this study was to develop and test the validity of a new questionnaire measure of extreme demand avoidance, quantifying the extent to which a child displays PDA features. In this preliminary validation study, participants were allocated into groups on the basis of parent reported information about received diagnoses and problem behaviours. To explore the content validity of our measure, we first examined endorsement rates for individual items by parents of children who informed us that their child had been identified as having PDA by a health professional. We then explored how successfully items discriminated PDA from other case groups, resulting in four items being dropped from the final measure. We

then compared total scores for parents of children reported to have PDA to both typically developing children and children from other case groups. We were interested to see whether, based on a parent-report questionnaire, it was possible to distinguish children reported to have been identified as having PDA from those reported to have ASD, disruptive behaviour, or both.

Methods

Development of the "Extreme Demand Avoidance Questionnaire" (EDA-Q)

Item generation & face validation by expert clinicians:

Candidate items were generated based on criteria described by Newson et al., (2003), unpublished material by Newson, plus the PDA items incorporated into the DISCO (Wing et al., 2002). A list of 40 candidate items was developed, covering all aspects of the PDA phenotype. The item list was sent to experienced clinicians (N=10), including J. Gould and P. Christie, and others who had expressed an interest in PDA to the Elizabeth Newson Centre as a result of their contact with children with this profile. All ten were based in the UK, and worked in a range of specialisms and settings (consultant clinical psychologists, N=3; consultant psychiatrists, N=2; paediatricians, N=2; consultant child psychologists, N=2; consultant speech and language therapist, N=1). The majority worked in highly specialist settings, and all bar one estimated they had seen at least ten individuals fitting the PDA profile over the course of their careers. Three had seen more than twenty.

Clinicians were asked, based on their experience, to rate on a likert scale from 0 - 5 how commonly reported each item was in PDA, and how specific the behaviour was to PDA as opposed to other childhood difficulties seen in their practice. They were also encouraged to comment on relevance of items and coverage of the profile. Clinicians' feedback emphasised the need to focus question items on observed behaviour. Disagreement over applicability of questions occurred when they tapped untested cognitive-level hypotheses (e.g. anxiety or social insight). Based on clinicians' recommendations, additional items about early history and receptive verbal and non-verbal communication difficulties were included. Ratings of how common and specific items were to PDA were combined with qualitative feedback and a final 32-item list compiled (See online supplementary Tables S1-S3). Items 1-30 were rated on a 4 point likert scale: "Not true", "Somewhat true", "Mostly true", "Very true". Items 1-28 measured demand avoidance or social manipulation for the purposes of avoidance or controlling interactions (6 items); insensitivity to hierarchy/ praise/ need to manage reputation (6 items); lack of responsibility (3 items); need for control (2 items) emotional lability in response to demands or perceived pressure (4 items); mimicry and role play (4 items); communicative difficulties (2 items), and distractedness (1 item). For items 1-28, parents were asked to rate their child's current behaviour, and for 29 and 30; passivity and floppiness during infancy. The final two items covered the age at which the child began to speak words and phrases, and are not included in the total score.

Parental report validation

Recruitment:

Participants were a volunteer community sample. The study was advertised on a PDA web forum (www.pdacontact.org.uk), and seven other ASD web forums/ web-based membership groups with electronic mailing lists. Forum moderators or main contacts for web-groups were first approached to ask permission before posting of an electronic link to the recruitment page on the NAS website; or in some cases were asked to email the link to their members. Three additional non-ASD web forums were also used to advertise the study, with an emphasis on the need for typically developing control participants. Parents were also asked to forward the link (or indeed paper copies of the questionnaire) to their friends with typically developing children or children with other diagnoses. Questionnaires were also distributed to all attendees of the National Autistic Society PDA conference. In addition, paper or electronic copies of the questionnaire were distributed by teachers at four specialist ASD/ social, emotional and behavioural difficulty schools and three mainstream schools. Recruitment sources yielded the following: NAS PDA conference (N=46), schools (N= 62; 31 mainstream), parent support groups (N=13), web-groups/ forums (PDA/ ASD or non-specialist)/ parent support groups via email (N=186), unknown (N=19). Participants were encouraged to complete

questionnaires for any of their children who fell within the age bracket. As a result, 95 participants had a sibling in the dataset (41 sib-pairs, 3 trios and one set of four). Of note, the typically developing group included 23 unaffected siblings of a child reported to have suspected/ identified PDA, and 10 unaffected siblings of a child in another case group.

Measures:

In the questionnaire booklet, parents were first asked to report on diagnoses their child had received, or diagnoses that they suspected applied to their child. They also indicated whether their child had a statement of special educational needs, and an estimate of their child's intelligence level ("superior", "normal", "mild learning disability" or "severe learning disability").

Participants then completed the Strengths and Difficulties Questionnaire (SDQ), a widely used multidimensional measure of child behaviour problems; with subscales covering conduct problems, emotional symptoms, peer problems, hyperactivity/impulsivity and pro-social behaviour (Goodman, 1997). The SDQ is reported to have good validity and reliability to detect dimensions of impairment associated with behavioural disorders in childhood (Goodman, 2001). Subsequently, participants completed the EDA-Q (32 items). Lastly, an optional question about parental educational status was included as a proxy indicator for socio-economic status.

Participants:

Parents of children aged 5-17 years with or without clinical diagnoses or behavioural difficulties were invited to participate in the study. They were allocated to subgroups based on the child's clinical diagnoses as reported by parents, plus parent ratings of child behaviour (conduct problems and total behavioural difficulties on the SDQ measure) and suspected diagnoses. Atypical cut-offs used on the conduct problems and total behavioural difficulties measures were those identifying the most affected 10% of a general population sample (Goodman, 2001). The method used to allocate participants to sub-groups is illustrated in Figure 1.



Figure 1: Allocation of participants to groups on the basis of diagnostic information as reported by parents (including both diagnoses and suspected diagnoses/ awaiting full assessment) and performance on the Strengths and Difficulties Questionnaire (SDQ). The six participant groups are TD= typically developing; ASD DB-= ASD without disruptive behaviour; ASD DB+= ASD with disruptive behaviour; PDA suspected: PDA suspected by parents; PDA identified: PDA reported to have been identified by a health professional; DB/Behaviour: Disruptive behaviour or behaviour problems. Abbreviations: ODD= oppositional defiant disorder; dx = diagnosis.

As depicted in Figure 1, identified subgroups were (1) typically developing controls (TD; N=102), reported to have no identified or suspected diagnoses, and within typical limits on SDQ behaviour problems and conduct problem subscales; (2) ASD without disruptive behaviour (ASD DB-; N=36, including 6 individuals reported not to have a full clinical ASD diagnosis at the time of the study); (3) ASD with disruptive behaviour (ASD DB+; N=48, including 7 individuals reported not to have a full ASD diagnosis at the time of the study); (4) PDA suspected by parents, irrespective of other diagnoses (PDA suspected; N=67); (5) PDA reported to have been

identified by a health professional (PDA identified; N=50); (6) disruptive behaviour or behavioural problems *without* identified/suspected ASD or PDA (DB/Behaviour; N=23). A decision was made to retain individuals reported not to have received a full clinical diagnosis of ASD at the time of the study in the two autism groups (ASD DB- and ASD DB+), as this often reflected that they were awaiting diagnostic assessments, had a diagnosis suggestive of autism features (e.g. "social and communication difficulties"); or that schools had raised concerns about ASD. Seven individuals who had a diagnosis other than ASD (e.g. ADHD) without high levels of behavioural problems were excluded from the analysis. Those reported to have a non ASD or PDA diagnosis/ suspected diagnosis (e.g. ADHD), and who had high levels of disruptive behaviour or behavioural problems were included in group 6 (DB/Behaviour), but having a diagnosis/ suspected diagnosis was not a necessary criterion for inclusion. For the purpose of the current study, only data from parents who reported their child to have mild or no learning difficulties/intellectual disability were included in the analysis. Group characteristics are detailed in Table 1.

	TD	ASD DB-	ASD DB+	PDA	PDA	DB/
				suspected	identified	Behaviour
Ν	102	36	48	67	50	23
Age (years)	12.48 (3.74)	12.21 (2.79)	12.46 (3.61)	10.06 (2.85)	11.51 (3.23)	10.72 (3.99)
Males (%)	59.8	66.7	81.3	53.7	62.0	82.6
Autism/ASC dx (%)	0	83.3	85.4	52.2	66.0	0
Autism/AS dx/susp	0	100.0	100.0	68.7	68.0	0
(%)						
PDA identified (%)	0	0	0	0	100.0	0
PDA suspected (%)	0	0	0	100.0	0	0
ADHD dx (%)	0	8.3	33.3	22.4	16.3	17.4
ODD dx (%)	0	0	4.2	7.5	10.0	8.7
Abnormal cond (%)	0	0.0	100.0	86.6	84.0	73.9
Other dx (%)	0	22.2	16.7	13.4	14.3	8.7
Clinical dx (%)	0	86.1	91.7	67.2	100	21.7
Suspected dx (%)	0	22.2	31.3	100.0	8.0	26.1
Clinical or suspected	0	100.0	100.0	100.0	100.0	43.5
dx (%)						
Abnormal SDQ (%)	0	58.3	97.9	92.5	90.0	73.9
Superior intel (%)	46.1	22.2	35.4	37.3	46.0	47.8
Normal intel (%)	52.0	27.8	20.8	44.8	34.0	39.1
Mild LD (%)	2.0	50.0	43.8	17.9	20.0	13.0
SEN statement (%)	1.0	61.1	68.1	50.0	69.4	13.6
Parent educational	4.94 (2.15)	4.53 (2.12)	4.52 (2.59)	4.29 (2.23)	4.63 (2.12)	4.76 (2.86)
level						

Table1: Parent-reported characteristics of participants by group. Standard deviations are included in parentheses. Each participant was allocated to one of five groups on the basis of their responses. The six participant groups are: TD= typically developing; ASD DB-= ASD without disruptive behaviour; ASD DB+= ASD with disruptive behaviour; PDA suspected: PDA suspected by parents; PDA identified: PDA reported to have been identified by a health professional; DB/Behaviour: Disruptive behaviour or behaviour problems. Abbreviations: dx = diagnosed; susp = suspected; SEN= Special educational needs; LD = learning difficulties; cond = conduct; intel= intellectual functioning. Dual diagnoses were common amongst participants.

Of note, there were statistically significant differences between the groups for the proportion who had statements of special educational needs (SEN) (whole sample: $\chi^2(5)=114.6$, p<.001; case groups only: $\chi^2(4)=23.75$, p<.001), estimated intelligence/ learning difficulties (whole sample: $\chi^2(10)=61.73$, p<.001; case groups only: $\chi^2(8)=24.80$, p=.002) and gender (whole sample: $\chi^2(5)=13.75$, p=.017; case groups only:

 $\chi^2(4)=12.73$, p=.013). These were not included as covariates in the analysis as they are likely related to group membership. There were no significant differences in parent education level related to group membership (whole sample: F(5, 302)=.72; p>.1; case groups only: F(4, 203)=.32; p>.1). There were significant differences in age across participant groups (whole sample: F(5, 302)= 5.56; p<.001; case groups only: F(4, 203)=4.89; p=.001). As such, analyses were conducted on age-regressed residuals. For ease of interpretation, uncorrected values are presented in tables and figures.

Procedure:

The study information sheet explained that children differ in the extent to which they avoid demands, need to be "in charge" when interacting with others, and react badly when things don't go their way. We explained that a small minority of children display very high levels of these difficulties, often accompanied by subtle difficulties in their social understanding. We said that the aim of the study was to develop a way of measuring how much children display these tendencies, and find out the "normal levels" of these traits and behaviours, and how much they are seen in profiles such as autism and ADHD. The term Pathological Demand Avoidance was not used explicitly in the information sheet to avoid putting-off parents unfamiliar with the term.

Parents were invited to complete the questionnaire via an electronic document, an online questionnaire, or a hard copy. Parents were given the option of completing the questionnaire completely anonymously, or provide contact details to receive further information. To encourage participation, they were also offered the chance to take part in a prize draw.

Ethical approval:

The study was approved by the Psychiatry, Nursing and Midwifery College Research Ethics board, and all participants gave informed consent to take part in the research study.

Analysis:

Analyses of variance (ANOVA) with post-hoc tests using Tukey's Honestly Significant Difference (HSD) were conducted to compare distributions of scores across participant groups, on residuals corrected for age. Uncorrected scores are presented in tables and figures. Assessment of psychometric properties and discriminant validity using Receiver Operating Characteristic (ROC) curve analysis was conducted on raw scores.

Results

The first section describes analyses conducted to support the development of the measure. Specifically, we examine the relevance of items to the PDA phenotype, and the extent to which items successfully discriminate PDA from other case groups.

The second section describes analyses conducted on the final 26-item measure. This includes exploration of (1) concurrent validity, comparing total scores for participant groups on SDQ subscales and the EDA-Q; (2) effects of age, gender, and psychometric properties of the EDA-Q; and (3) how well the measure can discriminates case groups using ROC analysis. We also consider the utility of various cut-offs to detect individuals with a PDA profile from the case groups included here.

Exploring the validity of constituent EDA-Q items in individuals reported to have received a diagnosis of PDA.

Content validity of the EDA-Q items was assessed by exploring item endorsement across individuals reported to have been identified as having PDA. Full details are of item endorsement rates are presented in Table S1. For 17 of the 30 items, more than 75% of parents strongly endorsed the presence of the trait in their child (i.e. responding "Mostly true" or "Very true"). For a further 10 items, between 50 and 74% of the parents did so. Of the three items with lower rates of endorsement, only one item ("Floppy as an infant") was rated "Not true" by over 50% of participants.

Item endorsement rates stratified by group

Item endorsement rates were compared across groups to identify which items best differentiated PDA from case comparison groups. This allowed us to determine whether all items should be retained in the final measure, or whether some could be dropped. Item endorsement stratified by group, expressed as binary

percentage endorsement and mean score for each item are included in Tables S2 and S3. Most items successfully discriminated groups: 15 out of 30 items had a 20-37% higher endorsement rate averaged across PDA groups compared to ASD DB+; and 21 items had a 20-60% higher endorsement rate compared to DB/Behaviour.

To identify the most discriminating items, we took the mean endorsement percentage for the two PDA groups and subtracted endorsement rates for the two closest comparison groups (ASD DB+ and DB/Behaviour). Summing the difference scores for PDA vs. ASD DB+ and PDA vs. DB/Behaviour identified items that were most discriminating in both comparisons. Four items with relatively low discriminative capacity were identified (items 15, 25, 26, 30; <12% difference in endorsement for PDA vs. ASD DB+ and DB/Behaviour combined). The same items were identified when using mean item scores instead of percentage endorsement. These items were dropped, resulting in a final 26-item measure (See Table 2).

		Not true	Some- what true	Mostly true	Very true
1	Obsessively resists and avoids ordinary demands and requests.				
2	Complains about illness or physical incapacity when avoiding a request or demand.				
3	Is driven by the need to be in charge.				
4	Finds everyday pressures (e.g. having to go on a school trip/ visit dentist) intolerably stressful.				
5	Tells other children how they should behave, but does not feel these rules apply to him/herself.				
6	Mimics adult mannerisms and styles (e.g. uses phrases adopted from teacher/parent to tell other children off).				
7	Has difficulty complying with demands unless they are carefully presented.				
8	Takes on roles or characters (from TV/real life) and 'acts them out'.				
9	Shows little shame or embarrassment (e.g. might throw a tantrum in public and not be embarrassed).				
10	Invents fantasy worlds or games and acts them out.				
11	Good at getting round others and making them do as s/he wants.				
12	Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police).				
13	If pressurised to do something, s/he may have a 'meltdown' (e.g. scream, tantrum, hit or kick).				
14	Likes to be told s/he has done a good job				
15	Mood changes very rapidly (e.g. switches from affectionate to angry in an instant).				
16	Knows what to do or say to upset specific people.				
17	Blames or targets a particular person.				
18	Denies behaviour s/he has committed, even when caught red handed.				
19	Seems as if s/he is distracted 'from within'.				
20	Makes an effort to maintain his/her reputation with peers.				
21	Uses outrageous or shocking behaviour to get out of doing something.				
22	Has bouts of extreme emotional responses to small events (e.g. crying/giggling, becoming furious).				
23	Social interaction has to be on his or her own terms.				
24	Prefers to interact with others in an adopted role, or communicate through props/toys.				
25	Attempts to negotiate better terms with adults.				
26	S/he was passive and difficult to engage as an infant				

Table 2: Extreme Demand Avoidance Questionnaire (EDA-Q): 26-item final version. Items 1-26 (apart from 14 and 20) are scored as follows: Not true = 0, Some-what true = 1, Mostly true = 2, Very true = 3. Items 14 and 20 are reverse scored: Not true = 3, Some-what true = 2, Mostly true = 1, Very true = 0. Total possible score for items 1-26 = 78.

Concurrent validity: comparing participant groups on final measure

Having identified the 26 items constituting the final version of the EDA-Q, group-wise comparisons were run on both the SDQ and EDA-Q on age-corrected residuals. Mean raw scores are presented in Table 3. Omnibus ANOVAs are reported for the whole sample (including TD group) and for case groups only. Tukey's HSD were used for post-hoc analysis of group differences.

Strengths and difficulties questionnaire (SDQ) – group differences:

For all SDQ subscales, ANOVAs indicated significant differences related to group (*peer problems* whole sample: F(5,318)=64.17, p<.001, case groups only: F(4,217)=4.92, p=.001; *hyperactivity* whole sample: F(5,318)=50.84, p<.001, case groups only: F(4,217)=2.99, p=.02; *conduct problems* whole sample: F(5,318)=111.83, p<.001, case groups only: F(4,217)=32.29, p<.001; *emotional symptoms* whole sample: F(5,317)=44.90, p<.001, case groups only: F(4,216)=1.14, p>.1; *total difficulties* whole sample: F(5,318)=167.32, p<.001, case groups only: F(4,217)=3.05, p<.001; and *pro-social behaviour* whole sample: F(5,318)=50.03, p<.001, case groups only: F(4,217)=3.42, p=.01) motivating post hoc analyses. Results of post-hoc tests are detailed in and Table 3, where asterisks designate significant differences between PDA and comparison groups. Of note, no SDQ subscales significantly differentiated the two PDA groups. Secondly, neither SDQ total score nor any subscale scores significantly differentiated the PDA groups from ASD DB+.



Figure 2: Mean raw SDQ sub-scale scores by group. *SDQ pro-social subscale was reversed. The six participant groups are TD= typically developing; ASD DB-= ASD without disruptive behaviour; ASD DB+= ASD with disruptive behaviour; PDA suspected: PDA suspected by parents; PDA identified: PDA reported to have been identified by a health professional; DB/Behaviour: Disruptive behaviour or behaviour problems.

	TD	ASD DB-	ASD DB+	PDA	PDA	DB/ Behaviour
				suspected	identified	
SDQ Peer	1.17 (1.51)*	4.97 (2.42)	5.71 (2.20)	6.01 (2.35)	6.06 (2.49)	3.78 (1.87)*
SDQ Hyper	2.07 (2.10)*	5.67 (2.77)	7.47 (2.28)	7.18 (2.47)	6.54 (2.77)	6.80 (2.58)
SDQ Conduct	0.76 (0.88)*	1.65 (1.17)*	5.65 (1.69)	5.96 (2.13)	5.60 (2.30)	4.17 (1.77)*
SDQ Emotional	1.40 (1.48)*	5.17 (3.17)	5.77 (2.68)	6.01 (2.69)	6.36 (2.35)	5.20 (2.84)
SDQ Behaviour	5.40 (3.44)*	17.45 (5.90)*	24.59 (4.67)	25.16 (6.05)	24.56 (5.73)	19.88 (4.50)*
SDQ Pro-social	8.59 (1.81)*	5.50 (2.83)*	3.82 (2.37)	3.97 (2.39)	4.00 (2.20)	5.00 (2.45)
EDA-Q	7.85 (4.41)*	24.80 (14.91)*	42.89 (12.52)*	56.92 (12.67)	56.51 (11.00)	33.94 (12.96)*

Table 3: Means of raw SDQ and EDA-Q scores by group. Standard deviations are detailed in parentheses. Scores followed by an asterisk differed significantly from PDA groups. PDA suspected and PDA identified groups showed no significant differences from each other on any subscale. Of note, the TD group should not be considered representative of the general population, as individuals who exhibited significant behavioural problems were instead allocated to the DB/ Behaviour group.

Extreme Demand Avoidance questionnaire (EDA-Q) – group differences:

An ANOVA indicated significant differences in EDA-Q score related to group (whole sample: F(5,318)=191.21, p<.001; case groups only: F(4, 217)=44.12, p<.001). Post hoc analysis indicated that the PDA identified and PDA suspected groups were reported to exhibit the highest scores, significantly higher than all comparison groups. The ASD DB+ group scored next highest, significantly higher than DB/Behaviour and ASD DB- groups, who did not differ significantly from each other. All case groups scored significantly higher than TD controls (, Table 3). Individuals reported to have behavioural problems as indexed by the SDQ, but no diagnoses, were allocated to the DB/Behaviour group – meaning that the TD participant scores presented here should not be considered representative of variation in the EDA-Q measure as it occurs across the general population.



Figure 3: Raw EDA-Q scores across groups. Boxes represent the lower and upper quartiles, with the horizontal line in the middle reflecting the median value. Whiskers indicate the range of scores, and outliers are identified as crosses. The six participant groups are TD= typically developing; ASD DB-= ASD without disruptive behaviour; ASD DB+= ASD with disruptive behaviour; PDA suspected: PDA suspected by parents;

PDA identified: PDA reported to have been identified by a health professional; DB/Behaviour: Disruptive behaviour or behaviour problems.

Notably, TD controls who were siblings of cases (N=33) scored significantly lower on the EDA-Q than TD controls who were not siblings of cases (N=69) (mean scores 6.45 (SD=4.45) and 8.52 (SD=4.25) respectively; t(100)=3.69, p<.01), potentially indicating a contrast effect. The whole-sample group comparison was re-run with unaffected siblings of cases removed from the TD group, and results were very similar. The only other subscale that differentiated TD controls who were siblings of cases was SDQ emotional symptoms – significantly higher in siblings of cases (mean scores: 2.09 (SD=1.55) and 1.07 (SD=1.34); t(100)=-2.83, p<.01).

Extreme Demand Avoidance questionnaire (EDA-Q) – effects of age and gender:

Due to differences in age across comparison groups, group comparisons were conducted on age-regressed residuals. A significant negative relationship between age and EDA-Q score was detected across the entire sample F(1,322)=26.82, p<.001, r²= 8% suggesting that severity of PDA features decreases with age. The same result was observed when limiting analysis to case groups only.

A univariate ANOVA was used to explore differences in EDA-Q scores related to gender. Across all participants, there was no significant effect of gender (F(1,322)=.01, p>.1). However, restricting analyses to case groups indicated a significant effect of gender on age-corrected residuals (F(1,220)=4.50, p=.04) with females scoring significantly higher than males (raw score for males (N=149): mean=44.38, SD=17.47; females (N=75) mean=50.11; SD=17.26). To explore whether the effect of gender differed across the case groups, a mixed model ANOVA was used to examine a possible group by gender interaction. This did not reach significance, and removed the effect of sex, due to suppressor effects on correlated predictor variables. Group means stratified by gender are presented in Table S4.

Extreme Demand Avoidance questionnaire (EDA-Q) – psychometric properties:

Analysis within the PDA groups indicated a high level of internal consistency for the EDA-Q measure (α =.87), and an even higher level across all case groups (α =.93). For the PDA groups, mean item-total correlation was .45, (range .02 - .62); with only 5 items exhibiting a correlation with total score Spearman's rho < .3 (items

14, 17, 21, 28 and 29). The Spearman-Brown split-half reliability coefficient was .86. Across all case groups, mean item-total correlation was .56 (range .02-.76), with only 3 items exhibiting a correlation with total score Spearman's rho < .3 (items 14, 21 and 29). The Spearman-Brown split-half reliability coefficient was .91.

Principle components analysis (PCA) with an oblimin rotation was conducted to explore dimensionality within the measure. When conducting the analysis across all case groups (N=224), inspection of the scree plot and eigenvalues indicated two viable components (Table S5). The first component accounted for 39% of total variance, with 24 out of 26 items loading onto it. The second component (9% of the total variance) had positive loadings >.3 for items covering role play, pretence, lack of embarrassment and passivity during infancy; but negative loadings >.3 for items covering manipulative behaviour and concern for reputation. When PCA was repeated across all participants (N=326), only the first component was viable (explaining 56% of the total variance, with 24 out of 26 items loading onto it).

Establishing a cut-off for the EDA-Q

Given the availability of groups reported to have non-PDA diagnoses in the sample, it was of interest to explore how successfully the measure could differentiate the PDA from other profiles. To this end, we conducted a ROC curve analysis; combining results from the PDA groups into one group (affected), and ASD DB-, ASD DB+ and DB/Behaviour into a second group (unaffected). We compared the discriminatory performance of the EDA-Q to the SDQ total behavioural difficulties scale using the area under the curve (AUC) index, to examine whether the EDA-Q can better identify PDA compared to a general measure of child behavioural problems. It was also of interest to explore whether a particular cut-off score would maximise the sensitivity and specificity of the measure in a sample similar to ours.



Figure 4: Receiver Operating Characteristic (ROC) curve illustrating sensitivity and specificity for both EDA-Q and the SDQ total behavioural problem scales to identify PDA groups from non-PDA case comparison groups. The reference line illustrates the hypothetical plot were the measures no better than chance at identifying PDA.

Figure 4 illustrates the ROC curve for both EDA-Q and the SDQ total behavioural problems measure. The area under the curve (AUC) value for the EDA-Q was .87 (95% CI: .82 - .92), indicating that it has good discriminatory power. The AUC for the SDQ total behavioural problems measure was lower (.67, 95% CI: .6 - .74). These values suggest that, although the SDQ performs above chance, the EDA-Q provides a superior method to assess the presence of PDA features.

Initial analyses indicated that a cut-off score of 50 maximised both sensitivity (.80, 95% CI: .72-.87) and specificity (.85, 95% CI: .77-.91) to detect individuals at risk of exhibiting PDA characteristics from case comparison groups across the sample. Analyses conducted on males and females separately indicate that this cut-off remained appropriate irrespective of gender, although the sensitivity and specificity values

varied (males: sensitivity = .76, specificity = .84; females: sensitivity = .86, specificity = .88). Analyses conducted separately in children aged above and below 12 years indicated that a cut-off of 45 rather than 50 maximised sensitivity and specificity in older children (age < 12 (cut-off 50): sensitivity = .85, specificity = .81; age \geq 12 (cut-off 45): sensitivity = .88, specificity =.78). Results in subgroups stratified by age and sex supported use of 50 as a cut-off for ages 5-11 years and 45 for 12-17 years.

Discussion

The aim of the present study was to develop a measure to quantify traits associated with PDA as described by Newson et al., (2003) in children, based on information reported by parents. There is a pressing need for further research into PDA, which is increasingly widely used as a diagnostic term in the UK. Individuals with this profile display an extreme level of behavioural impairment, with few or no limits on the lengths to which they will go to avoid or control, and little sense of humiliation or embarrassment. Even those within an ostensible average intellectual ability range are often excluded from special schools (O'Nions et al., unpublished observations). Our findings suggest that the "Extreme Demand Avoidance Questionnaire" differentiates PDA at a group level even from the closest case comparison group (individuals with ASD plus disruptive behaviour). Notably, scores on the Strengths and Difficulties Questionnaire failed to differentiate PDA from ASD DB+, suggesting a clinical need for a new measure to capture the unusual behavioural features characteristic of PDA. Importantly, given the absence of independent clinical assessments on participants, this study can only provide preliminary evidence for validation. Further work is needed to ascertain whether these results hold when full diagnostic assessments are conducted to inform allocation into comparison groups.

The relatively high endorsement rates for EDA-Q items in those reported to have received a PDA diagnosis suggest the measure has good content validity, and comparison of item-endorsement across groups facilitated the refinement of the measure. Using a cut-off score of 50 (for ages 5-11 years) or 45 (for ages 12-17 years), the EDA-Q had relatively strong discriminatory power, with good sensitivity and specificity to detect PDA from other case groups. However, if used in a consecutively referred clinical population, there

may well be more false positives than our findings would indicate, given the possibility that individuals with PDA are less common than those with ASD or disruptive behaviour. With low base rates in the general or even clinical populations, the ratio of true to false positives would increase. However, until suitable measures are used, it is unclear how many children show clinically-impairing problems of demand avoidance.

One challenge for measures designed to identify very specific phenotypes is that behavioural overlap between clinical groups is common. Our findings indicate that many items are endorsed by parents of children reported to have ASD plus disruptive behaviour *and* those with PDA. Our current interest in researching PDA stems from reports and observations that this behaviour has a different quality (e.g. difficult behaviour in ASD may be to achieve a concrete goal or avoid a specific activity, as opposed to persistent avoidance of any requests to maintain control), and fails to respond to the usual ASD approaches. The present questionnaire attempts to tap these subtle differences by measuring the constellation of features that together indicate a profile more consistent with PDA.

Successful differentiation of children reported to have PDA based on EDA-Q score indicates that the measure effectively covers the features of PDA necessary to differentiate it from behaviourally similar profiles at a group level. Endorsement of items removed from the final version of the EDA-Q in the PDA groups suggests these are also relevant to the phenotype, but are less useful in differentiating PDA from other very similar groups. Notably, differentiation of profiles at an individual level is a challenge that a questionnaire can only begin to meet. Diagnostic decisions rely on subtleties that questionnaire-based reports cannot fully tap, and often involve observations and reports from multiple informants, coded by an expert clinician. As such, score on the EDA-Q might be viewed as an indicator of risk and a pointer towards possibly relevant PDA approaches, rather than a diagnostic measure.

Across case groups, we found gender differences associated with the severity of PDA traits, with females scoring higher than males (Table S4). This is consistent with previous reports (Gould & Ashton-Smith, 2011; Kopp & Gillberg, 2011), which have indicated that females with ASD exhibit more PDA characteristics. We

had insufficient data to explore the effect of intellectual disability on EDA-Q scores, or the utility of the measure in this population. Further studies are needed in this area.

We observed that participants within the TD group who were siblings of children in our case groups (including PDA and comparison groups) had significantly lower scores on the EDA-Q, but higher levels of SDQ emotional symptoms. This could indicate a contrast effect, or the impact of living with a sibling with significant behavioural or neurodevelopmental difficulties.

The most significant limitation of this study is that full clinical assessments were not conducted to independently verify diagnoses or suspicions of diagnoses reported by parents. Therefore, it remains possible that participants may not have been correctly grouped. In particular, regarding parents' suspicions of PDA (or lack thereof), we have no information about the basis of this judgement, or how well informed parents were about PDA. Indeed, this likely varied across participants. However, given that PDA is not an official diagnosis, and it is used by some clinicians but not others, limiting the study only to those with a diagnosis, or allocating those suspected of PDA to a non-PDA comparison group would have been problematic. Notably, on all measures, our diagnosed and suspected PDA groups are almost indistinguishable, suggesting that grounds for parental suspicions and clinicians' diagnoses of PDA are very similar. A further limitation is the relatively small number of children exhibiting disruptive behaviour or behaviour problems without ASD features. As such, the discriminatory capacity of this measure in a population with emotional and behavioural difficulties or disruptive behaviour remains uncertain. In short, the present findings should be considered a first step towards the validation of this measure, with further studies needed in well characterised clinical populations.

Conclusions

The present study describes the development and preliminary validation of a trait measure for PDA, a profile characterised by obsessive avoidance of everyday requests and a tendency to go to extreme lengths to subvert these. The EDA-Q was found to successfully differentiate children reported by parents to have been identified as having PDA from comparison groups reported to have other diagnoses or behavioural difficulties. It provides a potentially useful means to quantify PDA traits, to assist in identification and research into this behavioural profile. Future studies should be conducted in population samples to further explore its validity and positive predictive value, taking into account considerations of prevalence, and using information collected via full diagnostic assessments.

Supporting information

Additional Supporting Information is provided along with the online version of this article.

Table S1 Item endorsement among participants
Table S2 (EDA-Q): percentage endorsement of each item by group
Table S3 (EDA-Q): Mean item score by group
Table S4 Mean scores for the EDA-Q stratified by group and gender
Table S5 Component loadings for the Principle Components Analysis

Acknowledgements

Elizabeth O'Nions is supported by an ESRC PhD studentship. Phil Christie receives payment for consultancy and training from voluntary and statutory bodies.

The authors are very grateful to the clinicians who assisted in developing the measure. They are also very grateful to the parents who took part in this study; and to the schools, parent groups and web groups who assisted with recruitment and supported this research.

The authors have declared no competing or potential conflicts of interest.

Correspondence to

Elizabeth O'Nions, King's College London, MRC Social, Genetic & Developmental Psychiatry, Institute of Psychiatry, Denmark Hill, London, SE5 8AF, UK; E-mail: <u>elizabeth.onions@kcl.ac.uk</u>

References

Christie, P. (2007). The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice. *Good Autism Practice (GAP)*.

Frick, P. J., & Ellis, M. (1999). Callous-unemotional traits and subtypes of conduct disorder. *Clinical Child and Family Psychology Review, 2*(3), 149-168.

Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry, 38*, 581-586.

Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(11), 1337-1345.

Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice (GAP), 12*(1), 34-41.

Kopp, S., & Gillberg, C. (2011) The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): an instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities*, *32*(6), 2875-88.

Newson, E., Le Marechal, K., & David, C. (2003). Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Archives of Disease in Childhood, 88*(7), 595-600.

O'Nions, E., Viding, E., Greven, C., Ronald, A., & Happé, F. (in press). Pathological Demand Avoidance (PDA): exploring the behavioural profile. *Autism: The International Journal of Research and Practice*.

Viding, E., Fontaine, N. M., & McCrory, E. J. (2012). Antisocial behaviour in children with and without callousunemotional traits. *Journal of the Royal Society of Medicine*, *105*(5), 195-200.

Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry*, 43(3), 307-325.

Key points

- Pathological Demand Avoidance (PDA) is a relatively new term that is increasingly being used as a clinical description in the UK. Children with PDA display an obsessive need to avoid everyday demands, and try to dominate interactions with others, often using socially shocking behaviour with apparently little sense of what is appropriate for their age.
- The present study describes the development and preliminary validation of a trait measure for PDA: the 'Extreme Demand Avoidance Questionnaire' (EDA-Q). Scores on this measure successfully differentiated individuals reported to have PDA from comparison groups reported to have other diagnoses or behavioural difficulties, including individuals with ASD, disruptive behaviour, or both. The sensitivity and specificity of the measure to identify PDA was good.
- The 26-item EDA-Q provides a potentially useful means to quantify PDA traits. Scores should be considered an indicator of the risk that a child exhibits the PDA profile, rather than a diagnostic indicator. Further studies are needed to validate the measure in a population for whom information from clinical assessments is available.

Supporting information

Table S1: Item endorsement among participants reported to have been identified as having PDA (N=50) on items contributing to the Extreme Demand Avoidance Questionnaire (EDA-Q). Items in italic font are reverse coded in the measure, but item endorsement is presented here as it was reported. Items shaded in grey were removed from the final measure.

	Abbreviated EDA-Q item	% item endorsement in PDA identified grou				
		Not true	Some- what true	Mostly true	Very true	
1	Obsessively resists and avoids ordinary demands	0	6	26	68	
2	Complains about illness when avoiding a request	12	34	26	28	
3	Is driven by the need to be in charge	0	10	12	78	
4	Finds everyday pressures intolerably stressful	2	18	26	54	
5	Tells other children how to behave	2	10	20	68	
6	Mimics adult mannerisms and styles	12	14	22	52	
7	Has difficulty complying unless carefully presented	0	4	18	78	
8	Takes on roles or characters and 'acts them out'	24	32	22	22	
9	Shows little shame or embarrassment	10	18	18	54	
10	Invents fantasy worlds or games	24	26	10	40	
11	Good at getting round others	0	18	32	50	
12	Unaware of differences between self and authority figures	2	14	26	58	
13	If pressurised to do things, may have a 'meltdown'	4	2	14	80	
14	Likes to be told s/he has done a good job	32	42	14	12	
15	Has difficulty reading body language, facial expression	6	42	30	22	
16	Mood changes rapidly	0	8	10	82	
17	Knows what to do or say to upset specific people	8	12	22	58	
18	Blames or targets a particular person	10	12	20	58	
19	Denies behaviour, even when caught red handed	6	18	28	48	
20	Seems as if s/he is distracted 'from within'	10	24	18	47	
21	Makes an effort to maintain reputation	38	31	21	10	
22	Outrageous behaviour to get out of doing something	14	20	24	42	
23	Extreme emotional responses to small events	4	14	16	66	
24	Social interaction has to be on his/her own terms	0	6	18	76	
25	Slow to process or respond to questions/ comments	12	22	18	48	
26	Able to take responsibility for misbehaviour	62	30	2	6	
27	Prefers to interact with others in an adopted role	38	34	24	4	
28	Attempts to negotiate better terms	2	14	20	64	
29	Passive and difficult to engage as an infant	45	14	16	24	
30	Floppy as an infant	86	2	10	2	

Table S2: Extreme Demand Avoidance Questionnaire (EDA-Q): percentage endorsement of each item by group. Items were binary coded (Not true or somewhat true = 0; Mostly true or very true = 1). Items in italic font are reverse coded in the measure, but item endorsement is presented here as it was reported. Items in grey were removed from the final measure. The six participant groups are: TD= typically developing; ASD DB-= ASD without disruptive behaviour; ASD DB+= ASD with disruptive behaviour; PDA susp: PDA suspected by parents; PDA iden: PDA reported to have been identified by a health professional; DB/behav: Disruptive behaviour or behaviour problems.

	Abbreviated EDA-Q item	TD	ASD DB-	ASD DB+	PDA susp	PDA iden	DB/ behav
					5		
1	Obsessively resists and avoids ordinary demands	1	8	58	94	94	57
2	Complains about illness when avoiding a request	0	3	29	58	54	30
3	Is driven by the need to be in charge	2	19	65	93	90	57
4	Finds everyday pressures intolerably stressful	0	28	40	73	80	17
5	Tells other children how to behave	1	14	63	79	88	43
6	Mimics adult mannerisms and styles	4	39	50	76	74	17
7	Has difficulty complying unless carefully presented	0	39	83	93	96	52
8	Takes on roles or characters and 'acts them out'	8	22	33	51	44	26
9	Shows little shame or embarrassment	1	44	77	79	72	52
10	Invents fantasy worlds or games	11	25	29	52	50	43
11	Good at getting round others	9	14	46	82	82	52
12	Unaware of differences between self and authority figures	1	17	60	79	84	35
13	If pressurised to do things, may have a 'meltdown'		31	79	96	94	43
14	Likes to be told s/he has done a good job		81	77	54	26	78
15	Has difficulty reading body language, facial expression	0	56	75	57	52	30
16	Mood changes rapidly	2	36	73	84	92	65
17	Knows what to do or say to upset specific people	10	19	56	78	80	61
18	Blames or targets a particular person	2	19	48	87	78	48
19	Denies behaviour, even when caught red handed	1	19	52	75	76	52
20	Seems as if s/he is distracted 'from within'	2	39	52	70	64	52
21	Makes an effort to maintain reputation	56	28	42	34	30	48
22	Outrageous behaviour to get out of doing something	0	11	33	72	66	26
23	Extreme emotional responses to small events	1	47	65	84	82	70
24	Social interaction has to be on his/her own terms	0	47	88	88	94	48
25	Slow to process or respond to questions/ comments	4	61	69	78	66	65
26	Able to take responsibility for misbehaviour	73	28	10	7	8	22
27	Prefers to interact with others in an adopted role	2	14	19	37	28	13
28	Attempts to negotiate better terms	23	22	54	78	84	57
29	Passive and difficult to engage as an infant	1	33	38	34	40	13
30	Floppy as an infant	0	11	15	13	12	9

Table S3: Extreme Demand Avoidance Questionnaire (EDA-Q): mean item score by group (range 0-3). Items were binary coded (Not true or somewhat true = 0; Mostly true or very true = 1). Items in italic font are reverse coded in the measure, but item endorsement is presented here as it was reported. Items in grey were removed from the final measure. The six participant groups are: TD= typically developing; ASD DB-= ASD without disruptive behaviour; ASD DB+= ASD with disruptive behaviour; PDA susp: PDA suspected by parents; PDA iden: PDA reported to have been identified by a health professional; DB/behav: Disruptive behaviour or behaviour problems.

	Abbreviated EDA-Q item	TD	ASD DB-	ASD DB+	PDA susp	PDA iden	DB/ behav
1	Obsessively resists and avoids ordinary demands	0.1	0.5	1.8	2.6	2.6	1.5
2	Complains about illness when avoiding a request	0.1	0.4	1.2	1.8	1.7	0.9
3	Is driven by the need to be in charge	0.3	0.7	1.9	2.7	2.7	1.7
4	Finds everyday pressures intolerably stressful	0.0	0.8	1.4	2.2	2.3	0.7
5	Tells other children how to behave	0.1	0.7	1.9	2.4	2.5	1.3
6	Mimics adult mannerisms and styles	0.3	1.3	1.7	2.3	2.1	0.8
7	Has difficulty complying unless carefully presented	0.1	1.4	2.4	2.7	2.7	1.7
8	Takes on roles or characters and 'acts them out'	0.3	1.1	1.1	1.7	1.4	0.7
9	Shows little shame or embarrassment	0.1	1.4	2.2	2.4	2.2	1.4
10	Invents fantasy worlds or games	0.4	0.8	1.1	1.7	1.7	1.3
11	Good at getting round others	0.6	0.6	1.5	2.4	2.3	1.6
12	Unaware of differences between self and authority figures	0.1	0.6	1.9	2.4	2.4	1.0
13	If pressurised to do things, may have a 'meltdown'		1.1	2.4	2.8	2.7	1.5
14	Likes to be told s/he has done a good job	2.2	2.4	2.2	1.7	1.1	2.3
15	Has difficulty reading body language, facial expression	0.1	1.9	2.0	1.8	1.7	1.3
16	Mood changes rapidly	0.2	1.1	2.2	2.6	2.7	1.9
17	Knows what to do or say to upset specific people	0.7	0.7	1.8	2.3	2.3	1.9
18	Blames or targets a particular person	0.2	0.8	1.6	2.5	2.3	1.6
19	Denies behaviour, even when caught red handed	0.2	0.7	1.5	2.3	2.2	1.7
20	Seems as if s/he is distracted 'from within'	0.1	1.4	1.5	2.1	2.0	1.6
21	Makes an effort to maintain reputation	1.7	1.1	1.3	1.1	1.0	1.4
22	Outrageous behaviour to get out of doing something	0.0	0.4	1.2	2.2	1.9	0.9
23	Extreme emotional responses to small events	0.2	1.5	2.0	2.6	2.4	1.7
24	Social interaction has to be on his/her own terms	0.2	1.5	2.4	2.6	2.7	1.6
25	Slow to process or respond to questions/ comments	0.3	1.9	2.1	2.3	2.0	1.8
26	Able to take responsibility for misbehaviour	2.0	1.2	0.6	0.4	0.5	0.8
27	Prefers to interact with others in an adopted role	0.0	0.6	0.7	1.3	0.9	0.6
28	Attempts to negotiate better terms	1.0	1.0	1.8	2.3	2.5	1.8
29	Passive and difficult to engage as an infant	0.0	1.2	1.1	1.0	1.2	0.5
30	Floppy as an infant	0.0	0.4	0.4	0.4	0.3	0.4

Table S4: Mean scores for the EDA-Q stratified by group and gender. The six participant groups are: TD= typically developing; ASD DB-= ASD without disruptive behaviour; ASD DB+= ASD with disruptive behaviour; PDA susp: PDA suspected by parents; PDA iden: PDA reported to have been identified by a health professional; DB/behav: Disruptive behaviour or behaviour problems.

	TD	ASD DB-	ASD DB+	PDA suspected	PDA identified	DB/Behaviour
	N _{males} =61	N _{males} =24	N _{males} =39	N _{males} =36	N _{males} =31	N _{males} =19
	N _{females} =41	N _{females} =12	N _{females} =9	N _{females} =31	N _{females} =19	N _{females} =4
Males	8.0 (3.8)	25.0 (15.9)	42.5 (12.5)	55.7 (14.4)	54.9 (11.7)	34.0 (12.7)
Females	7.7 (5.3)	24.4 (13.3)	44.4 (13.2)	58.3 (10.4)	59.2 (9.5)	33.4 (16.3)

Table S5: Component loadings for the Principle Components Analysis (PCA) on items from the EDA-Q conducted in all case groups groups (N= 224). Only loadings >.3 are included in the table. No items have been reverse coded, hence for all items, negative loadings indicate endorsement loading negatively the component.

	1st component (eigenvalue = 10.2) 39% variance	2nd component (eigenvalue = 2.3) 9% variance
Obsessively resists and avoids ordinary demands	.798	
Complains about illness when avoiding a request	.604	
Is driven by the need to be in charge	.792	
Finds everyday pressures intolerably stressful	.657	
Tells other children how to behave	.793	
Mimics adult mannerisms and styles	.649	
Has difficulty complying unless carefully presented	.720	
Takes on roles or characters and 'acts them out'	.469	.629
Shows little shame or embarrassment	.559	.394
Invents fantasy worlds or games	.495	.512
Good at getting round others	.739	
Unaware of differences between self and authority figures	.720	
If pressurised to do things, may have a 'meltdown'	.768	
Likes to be told s/he has done a good job	305	
Mood changes rapidly	.747	
Knows what to do or say to upset specific people	.580	536
Blames or targets a particular person	.678	342
Denies behaviour, even when caught red handed	.628	
Seems as if s/he is distracted 'from within'	.489	
Makes an effort to maintain reputation		524
Outrageous behaviour to get out of doing something	.715	
Extreme emotional responses to small events	.681	
Social interaction has to be on his/her own terms	.729	
Prefers to interact with others in an adopted role	.523	.425
Attempts to negotiate better terms	.552	329
Passive and difficult to engage as an infant		.422