

**An investigation of the relationship between functional  
impairment and autistic traits in a clinical population**

Rebecca Varrall

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University College London

## **Abstract**

**Aims:** Based on theories of dimensionality and fractionation of the autistic triad, this study investigates the role of autistic traits in adaptive functioning. The suitability of current diagnostic thresholds and classification criteria are explored with particular interest in partial and mild sub-threshold autistic presentations.

**Method:** Seventy-two young people (mean age = 11.03 years), referred for assessment at a specialist autism spectrum disorder (ASD) clinic were administered the Vinelands Adaptive Behaviour Scales; parent report and direct observational measures of autistic symptomatology; intelligence tests; and the Repetitive Behaviour Scale-Revised. Participants were initially compared according to diagnostic group. Correlational and regression models were then used to investigate relationships between IQ, autistic symptomatology and adaptive functioning.

**Results:** Compared to population norms, adaptive functioning was impaired in all diagnostic groups. Compared to Asperger's disorder (n=25) and pervasive developmental disorder-not otherwise specified (n=10), the autistic disorder (n=24) and broader autism phenotype (n=13) groups showed the greatest difficulties. IQ and parent-reported reciprocal social interaction impairments were predictive of adaptive functioning difficulties in this clinical sample. Agreement between parent-report and direct observational measures of autistic symptomatology was low.

**Conclusion:** Partial and sub threshold presentations show significant adaptive functioning disabilities at comparable levels to diagnoses with full triad of impairments. Further prospective studies are required to account for and explore intervention and longitudinal trajectories.

## **Introduction**

The Pervasive Developmental Disorders (PDD) constitute five neurodevelopmental disorders characterised by delays in development of basic functioning. The most widely recognised of the PDDs are described in the DSM-IV-TR (American Psychiatric Association [APA], 2000) as autistic disorder (AD), Asperger's disorder (AspD) and pervasive developmental disorder-not otherwise specified (PDD-NOS). These three disorders are more commonly known as Autistic Spectrum Disorders (ASD) and are characterised by the 'autistic triad': (a) impairments in social interaction; (b) impairments in communication; and (c) the presence of repetitive and stereotyped behaviours (RSB). These behavioural impairments reflect the features first identified by Kanner in 1943 and the presence or absence of these symptoms still forms the basis for the diagnostic manuals DSM-IV-TR (APA, 2000) and ICD-10 (World Health Organisation [WHO], 1993). Nevertheless, the way in which ASDs are conceptualised continues to evolve and two paradigm shifts within the field have recently called into question the current nosological conventions. It is the clinical implication of these paradigm shifts that will form the basis of the current study.

The first shift has been to understand AD, PDD-NOS and AspD as lying on a spectrum of severity, with AD exhibiting the most severe autistic symptomatology. This dimensional conceptualisation was the result of research which challenged the traditional view that the diagnoses were discrete, qualitatively different categories. Instead it was shown in studies both of relatives of autistic people (Piven, Palmer, Jacohbi, Childress, Arndt, 1997) and the general public (Constantino & Todd, 2003; Constantino, Przybeck, Friesen & Todd, 2000) that the autistic symptomatology triad could be considered as dimensional traits with a clinical sub-section at the extreme end

of the continuum. Seminal research by Constantino & Todd (2003) consolidated the shift towards perceiving ASDs on a spectrum of severity. Using a large community sample of the normal population to explore the nature of the autistic triad, the research demonstrated clear evidence that autistic traits, as measured using the Social Responsiveness Scale (Constantino et al., 2003) were seen in a normal population, and not confined to those with a ASD diagnoses. The dimensional conceptualisation of autism has had implications for research and clinical practice by developing an understanding of both typical and atypical development, monitoring the effects of intervention and in explaining ASD to non-professionals (Constantino, 2009).

A second significant development in the field has been acknowledging the possibility of fractionation of the autistic triad (Happé & Ronald, 2008; Happé, Ronald & Plomin, 2006). Previously, ASDs have largely been considered as unitary disorders, with the symptoms of the autistic triad assumed to co-occur at an above chance level, reflecting their common aetiology. However, there is a growing literature from genetics, neuroimaging, factor analysis and neurocognitive domains to indicate that the triad of impairments are not uniformly seen together and may not be the result of the same underlying cause (Happé & Ronald, 2008; Happé, Ronald & Plomin, 2006; Mandy & Skuse, 2008; Ronald et al., 2005; Ronald et al., 2006a; Ronald, Happé, Price, Baron-Cohen & Plomin, 2006b). Studies in both the community (Ronald et al., 2005; 2006 a & b) and clinical ASD samples (Boomsma, Van Lang, De Jonge, De Bildt, Van Engeland & Minderaa, 2008) have shown the three traits are not highly correlated. It is therefore argued that the triad of impairments constituting an ASD may exist for historical rather than empirical reasons. There are relatively few studies where the concept of fractionation and clustering of symptoms can be examined in detail as inclusion criteria

generally exclude the possible participation of individuals with impairments in only one or two domains of the triad. Often population studies examining autistic symptoms at a behavioural level have selection criteria requiring an ASD and as a result necessitate the presence of three areas of impairments. The focus is therefore usually on differences between diagnoses rather than the extent to which symptoms cluster or not (Happé & Ronald, 2008). Ronald et al. (2005) attempted to overcome this inherent circularity using a community sample of 3000 twin sets. The study found low to moderate correlations between the three domains on a phenotypic and genetic level, and concluded that the three domains are all independent. An alternative perspective argues for two dimensions of impairment, with social and communication domains representing one factor and RSB a separate one. The two dimensional approach to understanding the impairments is supported by Mandy & Skuse (2008) who provide a review of factor analytic studies which demonstrate separate social-communication and RSB dimensions within ASD groups.

Despite being represented by a single dimension in DSM-IV-TR, individual domains of the autistic triad have been fractionated further. Recent interest in the area of RSB domain has resulted in an understanding that the range of behaviours can loosely be classified into 'lower level' repetitive sensory motor behaviour such as rocking and unusual sensory interests; and 'higher level' insistence on sameness including rituals and narrow interests (Turner, 1999). Factor analysis investigations into RSB subtypes has led to the division of RSBs into concepts ranging from two to five factors depending on measure and analyses used (Mirenda et al., 2010; Lam & Aman, 2007; Szatmari et al., 2006). The multiple subtypes reflect the broad heterogeneity of behaviours which are currently encompassed in the one-dimensional RSB domain.

The development in understanding of dimensional and fractionated autistic traits helps to explain clinical presentations which do not fit the autism prototype either due to mild sub-threshold traits, or partial presentation of the triad. The most pertinent example is the controversial PDD-NOS diagnosis which is estimated to be as common as both AD and AspD combined and therefore regularly seen in clinical settings (Volkmar, State & Klin, 2009; Baird, Siminoff, Pickles, Chandler, Loucas, Meldrum, 2006; Chakrabarti & Fombonne, 2005). PDD-NOS is diagnosed when an individual does not present with impairments in all areas of the autistic triad, and as a result it is widely considered to be a less severe form of AD (Matson & Boisjoli, 2006; APA, 2000). A lack of reliable diagnostic criteria with limited specificity and empirical support has led to poor clinician agreement and limited diagnostic validity for the diagnosis (Witwer & Lecavalier, 2008; Paul et al., 2004; Szatmari, 2000; Mahoney et al., 1998). Studies investigating the symptom clustering in partial presentations have indicated that high proportions of PDD-NOS individuals exhibit impairments in the Social and Communication domains of the autistic triad and are lacking the third domain of RSB (Mandy, Charman, Gilmour & Skuse, 2011; Walker et al., 2004; Tanguay, Robertson & Derrick, 1998).

The relatives of individuals diagnosed with ASDs can exhibit mild autistic traits which do not reach threshold for current diagnostic criteria. The impairments are assumed to be the result of a genetic heritability of autistic symptoms and the presentation is collectively known as 'broader autism phenotype' (BAP). Interestingly, studies investigating the presentation of symptoms in BAP have found that relatives often show only one or two of the autistic domains which supports the concept of fractionation of the triad (Happé & Ronald, 2008; Piven et al., 1997). In particular,

social and communication impairments were at a higher rate than RSBs which suggest different influences over the behavioural symptoms (Piven et al., 1997).

Combining the theoretical knowledge of dimensional and fractionated traits with the clinical reality of partial presentations and mild traits raises two significant areas for investigation regarding the suitability of the current diagnostic thresholds and criteria. Firstly the distinction of diagnostic thresholds suggests that individuals above a cut-off are qualitatively different in presentation to those below the threshold who are not perceived to have the same difficulties (Cantwell, 1996). Research in partial presentations or mild traits has shown however, that individuals not only exhibit noticeable autistic trait impairments, but also experience considerable difficulties in other areas of functioning such as psychopathology, long-term independence and relationships (Skuse et al. 2009; Happé & Ronald, 2008; Szatmari et al., 2000). The second question examines the diagnostic criteria necessary to receive an AD or AspD diagnosis. There is an emerging literature exploring the role and relative importance of different autistic traits in presentation, which is warranted given the evidence for fractionation (e.g. Mandy et al., 2011). As individuals with partial presentation or mild traits experience noticeable impairments then it seems necessary to investigate whether the three ASD traits each impact differently on variables such as adaptive functioning, quality of life or psychopathology. This concept has been explored for the clinical diagnosis Oppositional Defiant Disorder where three separate dimensions have been identified. The differential predictive ability of each dimension for a range of psychiatric disorders has supported this conceptualisation of distinct dimensions and had implications for understanding clinical needs in a developmental model (Stringaris & Goodman, 2009).

Adaptive functioning provides a clinically relevant picture of what issues an individual faces on a daily basis and their ability to function independently in terms of communication skills, relating to other people and self-help skills (Tomanik, Pearson, Loveland, Lane, Shaw, 2007). It offers a valuable framework within which to investigate the questions raised of where the diagnostic cut-offs lie and the differential role of the triad of autistic symptoms. Comparing diagnostic groups for adaptive functioning levels provides information regarding suitability of diagnostic thresholds. Similar levels of functional disability would suggest that current thresholds are inappropriate. Secondly, investigating the relationship between the separate autistic traits and adaptive functioning may add to the current understanding of partial and mild presentations. The knowledge that adaptive functioning is impaired in individuals with ASD and contributes in a number of facets including research, intervention planning, comprehensive assessment and improving diagnostic accuracy in classification makes it a useful variable to explore (Perry, Flanagan, Geier, Freeman, 2009; Tomanik, et al., 2007; Szatmari et al., 2006; Liss et al., 2001; Filipek et al., 1999; Volkmar, Sparrow, Goudreau, Cicchetti, Paul & Cohen, 1987).

Circularity is a methodological concern when studying autistic symptomatology and adaptive functioning, as the measures may be perceived as assessing the same constructs and therefore map directly onto one another. However, by using the WHO (1980) definitions of disability and impairment it is possible to distinguish between the two dimensions. Autistic symptomatology is understood to be the result of a neurodevelopmental disorder therefore leading to impairments which can in turn limit capability resulting in disability; whereas loss of adaptive functioning can directly be considered a disability as an individual's everyday capabilities are limited. Research



investigating the structure of the two variables has used factor analysis to confirm that they are two distinct domains (Szatmari et al., 2002).

Studies comparing adaptive functioning in different ASD diagnoses provide the opportunity to examine whether the current thresholds are set appropriately or appear arbitrary given that the traits are dimensional. To date findings have been inconsistent, with some studies suggesting that individuals with more severe levels of autistic symptomatology have greater levels of disability in adaptive functioning (Gillham, Carter, Volkmar, Sparrow, 2000) and others demonstrating that they have equivalent disability levels despite differing levels of autistic symptomatology. Perry et al. (2009) found no differences in the adaptive functioning profile between groups of children under 6 yrs old with either AD or PDD-NOS despite the AD group having more severe autistic symptoms. The study used matched groups for age and IQ, which are two variables shown to impact on adaptive functioning. However, it was highlighted that the PDD-NOS group was possibly not a representative sample. A second study comparing children with PDD-NOS or AD similarly found few differences between the two groups, all of which seemed to reflect a deficit on the part of children with AD in verbal expression (Paul et al., 2004). Walker et al. (2004) compared groups of children with AD, AspD and PDD-NOS. The PDD-NOS group showed least autistic symptomatology yet equivalent levels of adaptive functioning impairments to the AspD group. The PDD-NOS group did demonstrate significantly better functioning than the AD group. What is clear from the literature is that there is difficulty knowing where to place the thresholds between those with a full 'specified' ASD diagnoses and those who have an 'unspecified' label. A small number of reported studies highlight the possibility that the current system does not encompass all necessary cases as there appear to be sub-

threshold individuals who are not qualitatively different in terms of adaptive functioning disabilities.

Investigation of the impact of separate autistic traits on adaptive functioning has been approached by examining the relationship between the two variables. Correlational studies have shown a general consensus that the two variables are somewhat negatively correlated, with lower levels of autistic symptomatology related to higher levels of adaptive skills. However the strength of correlations found has varied considerably from small (Klin, Saulnier, Sparrow, Cicchetti, Volkmar & Lord, 2007) to large (Perry et al., 2009; Liss et al., 2001). The mixed findings may partially be explained by sample sizes, with larger samples providing greater power (e.g. Klin et al., 2007), diversity of measures used, although these were all clinician-rated; age of the cohorts and finally by cognitive level which is a significant predictor of adaptive functioning, particularly in low IQ individuals (Liss, 2001). One study by Perry et al. (2009) has investigated how autistic symptom severity as measured by the Childhood Autism Rating Scale (CARS; Schopler et al., 1980) could contribute to adaptive functioning measured by the The Vineland Adaptive Behaviour Scales (VABS; Sparrow, Cicchetti & Balla, 2005; Sparrow, Balla, & Cicchetti, 1984). The analysis found that a modest amount of variance in VABS Socialisation and Daily living domains was accounted for by autistic symptoms. However, autistic symptomatology was not split into the triad to examine unique contribution and as such does not contribute to fractionation theory.

A limited number of studies have investigated the relationship between RSB subtypes specifically and adaptive functioning and have found a negative correlation between the variables. The strongest relationship has most commonly been seen for the subtype described as 'restricted and stereotyped behaviours', indicating that lower

adaptive functioning individuals tend to have higher levels of repetitive sensory and motor behaviours (Mirenda et al., 2010; Szatmari et al., 2006). Regression analyses by Szatmari et al. (2006) using a two subtype explanation of RSBs showed that the VABS Communication domain significantly predicted the Insistence on Sameness subtype and VABS Daily Living domain predicted the Repetitive Sensory Motor Behaviour subtype. These findings suggest that there is merit in detailed examination of autistic traits as a way to further understand individual presentations and adaptive functioning disabilities.

In summary, whilst it is increasingly believed that autistic traits are dimensional and fractionable, the current literature on adaptive functioning provides little consistent evidence to justify or explain the current thresholds or the necessary diagnostic criteria. It is evident that individuals with partial or mild presentations who do not receive a full ASD diagnosis are nevertheless significantly impaired, which therefore suggests that further clarification and exploration is required.

The aim of this study is to elucidate the clinical implications for individuals with either sub-threshold or partial presentations of ASD traits. This study examines a sample of school aged children and adolescents using the VABS-II measure of adaptive functioning (Sparrow, Cicchetti & Balla, 2005). The sample has not been selected based on ASD diagnosis in an attempt to reduce inherent circularity seen in studies where participants require the triad of symptoms above a certain threshold of severity to receive a diagnosis. Instead, the intention is to obtain a wide range of trait presentation regardless of the individual diagnosis. The first aim of the study is to compare adaptive functioning in individuals with a full diagnosis of AD or AspD with those with partial presentation or milder traits as labelled PDD-NOS and BAP. In doing so I aimed to test whether the current threshold between 'full' and partial ASD presentations is clinically

justified. The second aim of the study is to specifically explore each element of the autistic triad and its relationship and unique contribution to adaptive functioning. This was designed to further understand the role of partial triad presentations within the autism spectrum. I also aimed to carry out exploratory analyses to assess the relationship between distinct subtypes of RSB and adaptive function.

### **Research Questions**

1. Do individuals with the full triad of autistic impairments have distinct adaptive functioning abilities compared to those with partial or sub threshold presentations?
2. Do the separate autistic traits of the triad demonstrate a different impact on adaptive functioning when controlling for IQ?
3. How do distinct subtypes of repetitive behaviour impact on adaptive functioning when controlling for IQ?

### **Method**

#### **Design and Procedure**

Participants were referrals to a specialist ASD assessment and research service for children and adolescents in London, UK. As part of routine ASD assessment, data were collected from families by the clinic team for measures of IQ, severity of autistic traits and adaptive functioning through direct observation, parental and teacher report. I completed the VABS measure of adaptive functioning with caregivers, which was their first point of clinical interaction with the clinic. Caregivers were then interviewed using the 3Di to ascertain early history and current symptomatology, and children were

administered the ADOS and IQ testing (see description below for test details). Following assessment, invitation to participate in the study was extended to all eligible families from the assessment and research service. Consenting families were sent information regarding the study with consent forms and a measure of repetitive behaviour to be completed by the primary caregiver (see Appendix 1). Participants were asked to either bring the completed form and consent and assent forms to clinic or return in freepost envelope. Primary caregivers and participants were asked to consent and assent respectively to the use of the repetitive behaviour measure data collected which was then stored for analysis.

Following completion of the assessment, participants and families returned to clinic for feedback. Clinical classification decisions were based on DSM-IV-TR criteria and were made during discussion between experienced multidisciplinary clinicians, drawing on findings from the measures in the comprehensive assessment. Diagnoses of AD, AspD and PDD-NOS were made according to the diagnostic criteria outlined in DSM-IV-TR. BAP was assigned when individuals did not meet threshold for ASD diagnoses but were observed to demonstrate autistic traits with some functional impairment. The use of a complete assessment including standardised measures with consensus between expert clinicians is considered 'gold standard' in the field (Mahoney et al., 1998).

### **Participants and setting**

Participants were seventy-two referrals to the service between June 2010 and February 2011. Data were collected by a team of experienced psychiatrists and clinical

psychologists. The age of participants ranged from 6yrs to 16yrs (M=11.03, SD=2.26) and participants were predominantly male (n = 57/72, 79.2%). The clinic specialises in assessing children with normal-range or high intelligence; however the sample full scale IQ ranged from 47- 126 (M= 83.06, SD=19.32). See Table 1 for sample characteristics.

Table 1.

*Sample characteristics*

Variable	Total sample (n=72)	AD (n=24; %=33.3)	AspD (n=25; %=34.7)	PDD-NOS (n=10; %=13.9)	BAP (n=13; %=18.1)	Sig.
Age (M/SD)	11.03 (2.26)	10.75 (2.81)	10.96 (2.03)	11.50 (1.58)	11.31 (2.14)	ns
Gender						ns
Male (%)	57 (79.2)	19 (33.3)	20 (35.1)	10 (17.5)	8 (14.1)	
Female (%)	15 (20.8)	5 (33.3)	5 (33.3)	5 (33.3)	0	
FSIQ	83.06 (19.32)	79.58 (18.87)	86.8 (20.93)	87.10 (18.89)	79.15 (17.29)	ns

*Note.* AD = autistic disorder; AspD = Asperger’s disorder; PDD-NOS = pervasive developmental disorder-not otherwise specified; BAP = broader autism phenotype; FSIQ = full scale IQ

All participants met the following inclusion criteria: (a) all fluent in English language; (b) aged between 6 and 16 years (middle childhood to late adolescence) which reflected the diversity of cases seen in the service. This age range offered the largest comparable data set for participants, as individuals younger than 6 years received different cognitive tests and the extended version of the VABS. Exclusion from the study was only if the clinical team had significant doubts about the parental report for example in suspected cases of fabricated induced illness. However, this was not seen in any cases. Participants were included regardless of the assessment conclusions around an ASD diagnosis as the study focused on the relationship of dimensionally-measured autistic traits with adaptive functioning rather than diagnostic categories.

Ethical approval for the study was granted after review by the Royal Free NHS Ethics Committee (see Appendix 2). For the most part, data used in the current study were collected routinely as part of the gold standard PDD assessment and therefore use in research was under a case note review policy. Informed consent from the caregiver and assent from the young person were required for the completion of an additional repetitive behaviour questionnaire and use of the data for research purposes.

### **Sample size**

Power analysis to suggest the sample size for the study used a multiple regression model. Using the 'G\*Power 3' computer program (Faul, Erdfelder, Lang and Buchner, 2007), effect sizes have been informed by previous research by Liss et al. (2001) where authors carried out correlations between adaptive functioning (measured by VABS) and autistic symptomatology (measured by the Wing Autism Diagnostic Interview Checklist; Wing, 1985). The correlations resulted in large effect sizes ranging from 0.6 for Daily Living & Socialisation to 0.8 for Communication with Repetitive Behaviours. Using the large effect size (0.8) predicted from previous research and allowing for a regression model with 5 predictors, and specifying alpha at 5%, and desired power at 80%, the sample size suggested is 32. Considering that this research has used a different measure for autistic symptomatology, a conservative analysis was carried out using a medium effect size to predict R-squared change between blocks. This suggested a sample size of 68.

## **Measures and Administration**

The following measures were used in the present study as indices of adaptive behaviour, autistic symptoms, cognitive development and repetitive behaviour. All measures were administered by trained professionals during routine clinical assessment for diagnostic or research purposes except for the measure of repetitive behavior which was additional for this study.

### ***The Vineland Adaptive Behaviour Scales Second Edition - Parent / Caregiver Form (VABS II)***

The VABS II (Sparrow, Cicchetti & Balla, 2005) is a measure of adaptive functioning in four specific domains which each contain sub-domains: Communication (Receptive, Expressive and Written), Daily Living Skills (Personal, Domestic and Community), Socialisation (Interpersonal Relationships, Play and Leisure Time and Coping Skills) and Motor Skills (Gross and Fine, only applicable for children under 6 years therefore not collected for this study). It expresses overall functioning in the Adaptive Behaviour Composite (ABC) score. Higher scores on the VABS signify greater functioning ability and standard scores follow the usual psychometric convention of mean = 100 and SD=15. The VABS II is a nationally standardised semi-structured instrument completed by either the teacher or primary caregiver. This study used parental assessments of adaptive skills using the VABS-II which I completed via telephone.

Previous research has identified the VABS as a useful tool for assessing adaptive behaviour development in individuals with ASD (Klin et al., 2007; Liss et al., 2001;



Perry et al., 2009; Tomanik et al., 2007; Volkmar et al., 1987). Issues of circularity have not been highlighted despite the conceptual overlap between domains of Social and Communication in both the ASD triad of impairments and the VABS adaptive functioning domains. There is both genetic and phenotypic evidence to suggest that autistic symptoms and adaptive functioning can be considered as two independent factors (Szatmari et al., 2002; Szatmari et al. 2000). Research using the VABS with other disorders not linked with autism confirms that the VABS measures a construct independent of the autism triad (de Bildt, Kraijer, Sytema, Minderaa, 2005). The Daily Living skills domain of the VABS in particular appears to be measuring a construct not seen in measures of core ASD symptoms.

### ***The Developmental, Dimensional and Diagnostic Interview (3Di)-short version***

Participants were assessed using the 3Di short version (3Di-sv; Santosh, et al., 2009; Skuse et al., 2004). This is a validated, semi-structured computerised interview of 53 items based on the longer 3Di version (Skuse et al., 2004) and the Autism Diagnostic Interview-Revised algorithms (ADI-R; Lord, Rutter, & LeCouteur, 1994), which are carried out with parents of children with a suspected ASD. Like the ADI-R, the 3Di-sv uses ICD-10 (WHO, 1993) and DSM-IV (APA, 1994) diagnostic guidelines for autistic spectrum disorders. The 3Di-sv takes a developmental history and a selection of questions which contribute to diagnostic algorithms to provide scores in the three domains of Social interaction, Communication and Repetitive & Stereotyped Behaviours. There are thresholds provided for each domain, above all of which the presentation is considered 'abnormal'. The measure has good internal reliability with

Cronbach's alphas ranging from .81 - .94 and strong (diagnostic) agreement with the 3Di long form (all rs .92). It shows good overall agreement with the ADI-R algorithm (Santosh et al., 2004).

### ***The Autism Diagnostic Observation Schedule (ADOS)***

The ADOS (Lord et al., 2000) is a standardised, well-established semi structured observational assessment which measures social interaction, communication, repetitive behaviours and imagination for individuals with suspected ASD. The tasks include constructional and turn-taking activities, imitation, the ability to tell a story, imaginative toy play, gesture and conversational skills to evaluate a child's individual behaviour. It comprises four modules tailored to an individual's language ability and is based on DSM-IV and ICD-10 criteria. The algorithm uses selective social communication and reciprocal social interaction scores to generate a total score for each domain. Thresholds for AD, ASD or non-ASD are reported at different levels for each module. Higher scores signify greater disability; therefore elevated scores are in the autism spectrum or autism diagnostic range, depending on the severity/frequency of the behaviours displayed. The ADOS does not assess developmental history and does not score RSBs. By itself it does not yield an ASD diagnosis as RSBs are a necessary part of diagnosis and it is therefore used in conjunction with other measures. In this study the ADOS algorithm scores were obtained from video-recordings, administered by psychologists at masters level and above, supervised by research clinical psychologists. Participants were administered either module 2 (n=2), module 3 (n=55) or module 4 (n=15). In the current study, raw

scores were converted into percentages of the scale maximum to allow for comparison of algorithm scores across modules.

### ***Standardised cognitive measures of intelligence***

A number of standardised tests with established psychometric properties were used to evaluate intellectual skills. These included: Wechsler Intelligence Scale for Children: Third Edition (Wechsler, Golombok & Rust, 1991; n=68), the Wechsler Preschool and Primary Scale Intelligence: Third edition (Wechsler, 2002; n=1), the Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999; n=2), and the British Ability Scales (Elliot, Smith & McCulloch, 1996; n=1). Summary variables were computed from these scores for Full Scale IQ (FSIQ), standardised to have a mean of 100 and a deviation of 15.

### ***Repetitive Behaviour Scale – Revised (RBS-R)***

The RBS-R (Bodfish, Symons, Lewis 1999) is an empirically derived clinical rating scale for measuring the presence and severity of restricted and repetitive behaviours commonly seen in individuals with ASD (see Appendix 3). The scale consists of 43 items separated into six conceptually derived behavioural checklists which describe a set of discrete, observable topographies of repetitive behaviour (Stereotyped Behaviour, Self-Injurious Behaviour, Compulsive Behaviour, Routine Behaviour, Sameness Behaviour, and Restricted Behaviour). Each of the checklists has been shown to have acceptable levels of reliability and validity when used to measure repetitive behaviours associated with developmental disabilities and mental retardation. High

scores on the measure indicate greater levels of repetitive behaviours. In order to reduce risk of type I errors in data analysis, the RBS-R items were separated into three factors rather than six (Compulsive Ritualistic Sameness Behaviours; Self Injurious Behaviours; Restricted Stereotyped Behaviours). A recent study validating the RBS-R measure in individuals with ASD found a three factor model was preferable on the basis of fit statistics (Mirenda et al., 2010). Parents of the child/adolescent undergoing assessment completed the brief questionnaire specifically for this study (n=43).

### **Data analysis**

Data were analysed using SPSS-PC software (version 18). All variables were inspected for normality. Assumptions of normality were violated for VABS scores on all domains, three subdomains of ADOS and one on 3Di; therefore data were transformed using a logarithm transformation and secondly a square root transformation. Neither transformation analysis was effective in achieving normality so non-parametric Mann Whitney U analyses, Chi-square and Kruksal-Wallis analyses were used for comparison of data between respondent groups, and Spearman analyses were used for correlations. Given the presence of non-normally distributed variables, for multiple regression models assumptions concerning linearity, multicollinearity and homoscedasticity were rigorously inspected.

## Results

### Preliminary assessment of data

The data were initially explored to ascertain the distribution of adaptive functioning scores and autistic traits and the relationship between the two measures of autistic traits and IQ. Figures 1 to 7 show the distribution of autistic symptomatology scores as measured by the ADOS and the 3Di. All histograms show a continuous distribution of traits with no obvious bimodal presentations.

Table 2 shows the relationship between the two measures of autistic symptomatology and IQ. The 3Di is a parent report measure and ADOS is a clinician observer report. Although the two standardised measures are meant to be evaluating the same concepts there is only one significant correlation. This suggests that they are in fact measuring different constructs which is important for analysis in the rest of the study. There were no significant correlations between IQ and the 3Di. The ADOS Imagination and Social Interaction domains showed significant negative relationships with IQ suggesting that as IQ increases these traits will decrease in severity.

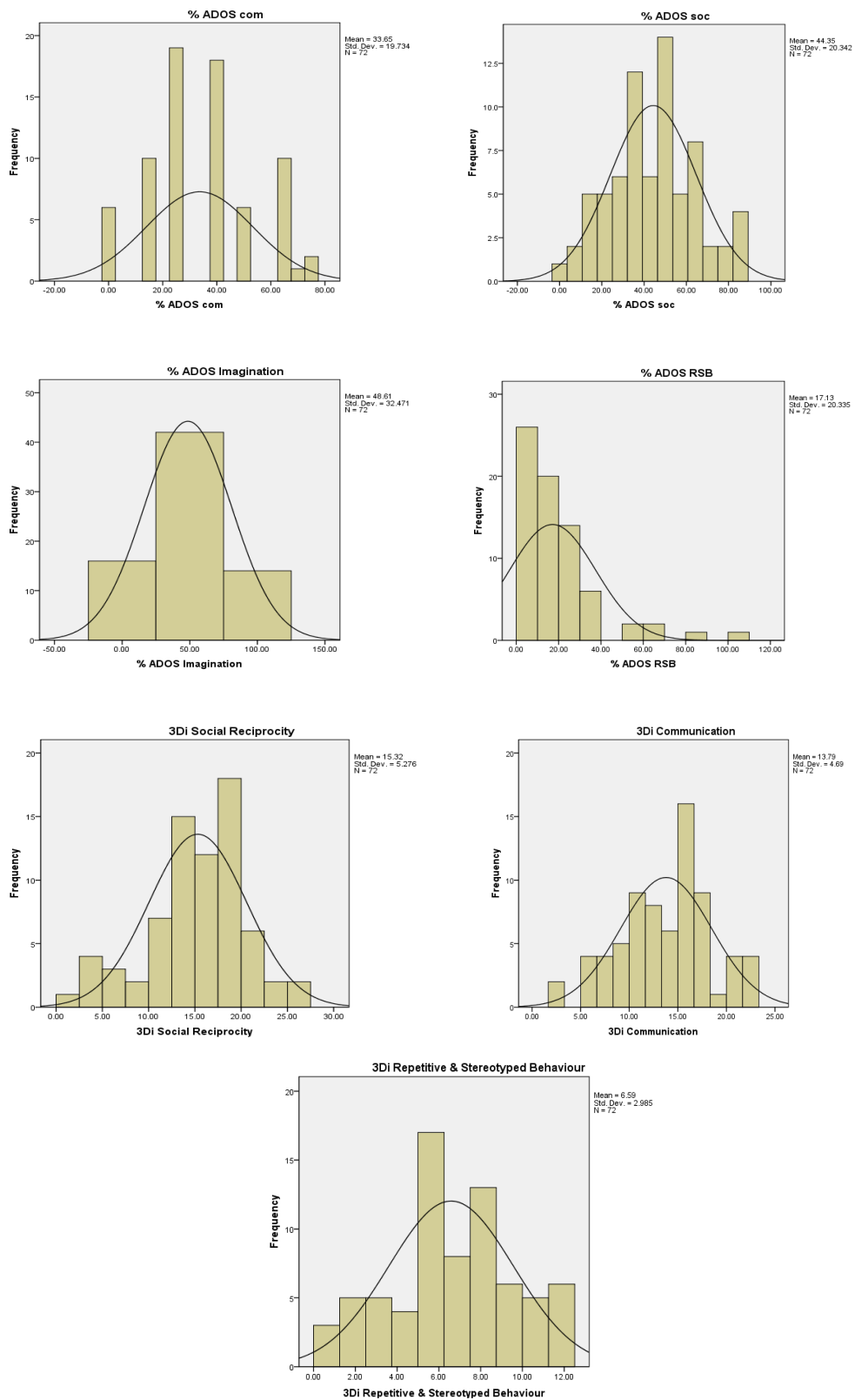
Table 2

*Correlations between IQ and the 3Di and ADOS Measures of Autistic Symptomatology*

	1	2	3	4	5	6	7	8
1. 3Di Social Reciprocity	1	.64**	.33**	.09	.14	.14	.02	-.02
2. 3Di Communication	-	1	.26*	-.01	-.03	.24*	.20	-.08
3. 3Di RSB	-	-	1	.05	.11	-.11	.08	.06
4. ADOS Social Interaction	-	-	-	1	.60**	.15	.06	-.23*
5. ADOS Communication	-	-	-	-	1	.05	.11	-.21
6. ADOS Imagination	-	-	-	-	-	1	.03	-.31**
7. ADOS RSB	-	-	-	-	-	-	1	.11
8. IQ	-	-	-	-	-	-	-	1

\* Correlation is significant at the 0.05 level (2-tailed)

\*\* Correlation is significant at the 0.01 level (2-tailed)



Figs 1-7  
*Distribution of autistic traits in the sample*

Table 3 presents data about significant disabilities and impairments seen in this sample of children and adolescents. Scores for VABS, ADOS and 3Di are reported for the total sample and by diagnostic group. Diagnostic groups are based on decisions made by the clinic following comprehensive assessment using standardised measures and agreement between expert clinicians. The BAP group included participants who were not given a diagnosis of AD, AspD or PDD-NOS yet all showed autistic traits. Of the 13 participants assigned to this group twelve received no clinical diagnosis and one received an ADHD diagnosis.

Examining the adaptive functioning scores for the sample showed that the total composite score (ABC) was in the Low range (<70) compared to population norms (VABS:  $M = 100$ ,  $SD=15$ ) showing that there were considerable disabilities within this sample. The majority of participants scored within the Low and Moderately Low range (88.9%), and the remainder were within the Adequate range with no scores in Moderately High or High range. Of the three domains of adaptive functioning, Socialisation scores appear to be the most impaired and were over one standard deviation below FSIQ.

ADOS algorithm scores combined results for Module 2 (n=2), Module 3 (n=55) and Module 4 (n=15). The two participants who received module 2 were both diagnosed with AD; therefore thresholds shown are for Modules 3 and 4. Algorithm scores for both the Social and Communication domains of the ADOS were above threshold for all groups except in the BAP group which is expected given that they did not receive an ASD diagnosis. Highest scores, signifying greater impairment, were seen in the AD group which were significantly greater than AspD, PDD-NOS and BAP groups. This pattern was seen in the Imagination and RSB domains as well although groups were not

significantly different. There were no significant differences between groups for 3Di scores and all groups were above threshold suggesting clinical levels of impairment. The BAP group had lowest scores in Social and Communication domains suggesting least impairment of the groups. However, the PDD-NOS group had lower levels in the RSB domain.



Table 3

*Sample Characteristics: VABS Standard Scores, ADOS Domains and 3Di Domains*

Variable	Total sample (n=72)	AD (n=24; %=33.3)	AspD (n=25; %=34.7)	PDD-NOS (n=10; %=13.9)	BAP (n=13; %=18.1)	Sig.	Post hoc
<b>VABS<sup>a</sup></b>							
Communication	72.08 (12.14)	68.08 (8.12)	76.89 (12.79)	77.60 (14.70)	66.00 (10.55)	<.01	AD & BAP < AspD & PDD-NOS
Daily living	71.65 (14.50)	67.50 (12.37)	78.2 (15.37)	75.10 (14.22)	64.08 (11.39)	<.01	AD & BAP < AspD BAP < PDD-NOS
Socialisation	65.13 (17.24)	59.50 (9.70)	70.96 (18.54)	69.80 (19.37)	60.69 (20.86)	ns	
ABC	68.38 (12.78)	63.96 (7.54)	73.76 (13.63)	72.90 (14.63)	62.69 (13.21)	<.01	AD & BAP < AspD BAP < PDD-NOS
<b>ADOS<sup>b</sup></b>							
RSI	6.21 (2.85)	7.88 (2.40)	6.36 (2.46)	5.50 (2.07)	3.38 (2.63)	<.01	AD>AspD & PDD-NOS & BAP AspD & PDD-NOS> BAP
Communication	2.72 (1.63)	3.75 (1.65)	2.56 (1.19)	2.50 (1.58)	1.31 (1.18)	<.01	AD>AspD & PDD-NOS & BAP AspD>BAP
Imagination	0.97 (.65)	1.08 (.58)	.96 (.73)	.70 (.48)	1.00 (.71)	ns	
RSB	1.36 (1.62)	1.71 (1.81)	1.44 (1.78)	1.20 (1.14)	.69 (1.11)	ns	
<b>3Di<sup>c</sup></b>							
RSI	15.32 (5.28)	16.96 (4.19)	14.41 (5.51)	15.17 (5.36)	14.16 (6.34)	ns	
Communication	13.79 (4.69)	14.50 (3.33)	14.00 (5.42)	13.73 (4.18)	12.15 (5.75)	ns	
RSB	6.59 (2.99)	7.23 (2.85)	6.69 (2.64)	5.70 (3.30)	5.88 (3.61)	ns	

*Notes:* AD = Autistic Disorder; AspD = Asperger's Disorder; PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified; BAP = Broader Autism Phenotype; RSI = Reciprocal Social Interaction; RSB = Repetitive and Stereotyped Behaviours

<sup>a</sup> VABS standard scores (mean = 100; *SD* = 15).

<sup>b</sup> ADOS algorithm scores: Reciprocal social interaction clinical threshold = 4; Communication clinical threshold = 2

<sup>c</sup> 3Di: Reciprocal Social Interaction clinical threshold = 11.5; Communication clinical threshold = 8; RSB clinical threshold = 5.5

### **Research question 1: Comparison of adaptive functioning between diagnostic and sub-threshold groups**

The first research question compared diagnostic groups on VABS domains and subdomains. Comparing the adaptive functioning domain scores between diagnostic groups showed the AD group had significantly lower adaptive functioning scores (i.e. greater disability) than the AspD group on Communication and Daily Living domains and ABC scores (see Table 3). The AD group also showed significantly lower scores on the Communication domain than the PDD-NOS group. The BAP group had significantly lower scores than both AspD and PDD-NOS groups on Communication, Daily living and ABC scores. There were no differences between the BAP and AD groups indicating that they had similar levels of functional disability. Similarly, the AspD and PDD-NOS group had no significant differences, although levels were still impaired relative to population norms. Interestingly there were no differences noted between any diagnostic groups on the Socialisation domain.

The initial plan was to compare two groups, one with the full triad of impairments (AD and AspD diagnoses) against a second with partial presentations (PDD-NOS or non-ASD). However, results from preliminary group comparisons identified significant differences between the AD and AspD groups and PDD-NOS and BAP groups (see Table 3). Therefore, regardless of the constraints of the small power from each group, it was decided that the groups would remain separate for further analysis. Kruskal-Wallis analyses were used to compare diagnostic groups on the VABS domains (Table 4). These diagnostic groups were based on three different methods. Firstly using the overall clinician consensus decision; secondly, diagnosis based on the

ADOS algorithm which separated participants into three groups to compare AD, ASD and Non-ASD; and finally the 3Di separated participants into two groups of above or below threshold which required impairments in all three domains.

The clinician consensus diagnosis revealed a complex pattern with the most striking finding being the lack of difference between groups in the Socialisation domain compared to significant differences between groups on the Communication and Daily Living domains and ABC. In the subdomains, differences between groups were mainly seen for those relating to communication including the Expressive and Written communication, the Communication daily living domain and the Coping Skills subdomains. In each of these, the BAP group demonstrated the lowest ranking, suggesting greatest impairment, which was most similar to the AD group. Overall there were very few differences in adaptive functioning seen between groups on the ADOS algorithm and 3Di diagnostic constructs. The ADOS algorithm thresholds showed a significant difference only for the Personal daily living domain, with a significant difference between higher scores in ASD group and lower non-ASD groups. The 3Di diagnostic thresholds found differences on the Socialisation domain and subdomains, except for Play & Leisure. Significant differences favouring higher scores in non-ASD group suggest that they have higher levels of adaptive functioning than the ASD group. Findings have to be interpreted with caution as the comparisons are between small sample sizes therefore there is an elevated risk of type one errors. It is also important to note that ADOS algorithm diagnostic thresholds are based on social and communication impairments and as a result are only measuring severity on partial presentations.

Table 4

*Rankings to compare diagnostic subtypes on VABS domains and subdomains*

	Clinic diagnosis					ADOS diagnosis				3Di diagnosis		
	AD (n=24)	AspD (n=25)	PDD- NOS (n=10)	BAP (n=13)	Sig.	AD (n=24)	ASD (n=25)	Non- ASD (n=23)	Sig.	AD/AspD (n=48)	PDD-NOS/ Non-ASD (n=24)	Sig.
VABS												
<b>Communication domain</b>	<b>30.13</b>	<b>45.14</b>	<b>46.10</b>	<b>24.27</b>	<b>&lt;.05</b>	<b>36.65</b>	<b>39.58</b>	<b>33.00</b>	<b>ns</b>	<b>36.39</b>	<b>36.73</b>	<b>ns</b>
Receptive Communication	33.92	42.42	41.35	26.15	ns	37.65	38.94	32.65	ns	35.71	38.08	ns
Expressive communication	28.50	44.88	47.50	26.69	<.01	34.88	39.54	34.89	ns	35.51	38.48	ns
Written communication	32.04	43.70	43.90	25.19	<.05	35.85	37.26	36.35	ns	37.58	34.33	ns
<b>Daily Living Domain</b>	<b>30.08</b>	<b>45.70</b>	<b>44.20</b>	<b>24.73</b>	<b>&lt;.01</b>	<b>33.50</b>	<b>43.34</b>	<b>32.20</b>	<b>ns</b>	<b>35.74</b>	<b>38.02</b>	<b>ns</b>
Personal daily living	33.44	42.12	41.30	27.65	ns	33.00	44.54	31.41	<.05	34.49	40.52	ns
Domestic daily living	33.33	43.52	37.95	27.73	ns	37.13	38.38	33.80	ns	36.14	37.23	ns
Communication daily living	28.65	47.18	42.25	26.04	<.01	33.90	40.36	35.02	ns	37.45	34.60	ns
<b>Social Domain</b>	<b>31.40</b>	<b>43.04</b>	<b>43.35</b>	<b>28.08</b>	<b>ns</b>	<b>36.08</b>	<b>41.50</b>	<b>31.50</b>	<b>ns</b>	<b>31.85</b>	<b>45.79</b>	<b>&lt;.01</b>
Interpersonal social	32.38	43.64	35.35	31.27	ns	37.31	39.98	31.87	ns	32.56	44.38	<.05
Play and leisure	31.75	42.86	42.45	28.50	ns	33.60	41.54	34.04	ns	33.23	43.04	ns
Coping skills	30.92	44.20	44.15	26.12	<.05	36.98	40.94	31.17	ns	31.31	46.88	<.01
<b>Adaptive Behaviour Composite</b>	<b>30.52</b>	<b>45.52</b>	<b>44.15</b>	<b>24.31</b>	<b>&lt;.01</b>	<b>35.19</b>	<b>42.26</b>	<b>31.61</b>	<b>ns</b>	<b>34.43</b>	<b>40.65</b>	<b>ns</b>

*Notes:* AD = Autistic Disorder; AspD = Asperger's Disorder; PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified; BAP = Broader Autism Phenotype; ASD = Autistic Spectrum Disorders

## **Research question 2: Relationship between adaptive functioning and separate domains of autistic symptomatology**

The second research question examined the relationship between individual autistic traits on adaptive functioning. This was initially observed through correlations between subdomain and domain scores for VABS and domain scores for autistic symptomatology as measured by the ADOS and 3Di. Results of correlations between VABS and the ADOS variables are presented in Table 5. Findings showed very few significant correlations and reflected an overall low level of association between the two variables. Three significant negative correlations were seen for the Imagination subdomain of the ADOS which were unexpected. They suggested that greater impairments in imagination and creativity (as indicated by a higher score) were associated with better adaptive functioning in the Communication domain, Expressive communication subdomain and Personal daily living subdomain. These have to be interpreted with caution given the risk of type one errors in multiple comparisons.

Table 5

*Correlations between VABS Domain, Subdomain and Composite Scores and ADOS Domain Scores*

	ADOS			RSB
	Communication	Reciprocal Social Interaction	Imagination / Creativity	
<b>VABS</b>				
<b>Communication domain</b>	.14	-.04	-.25*	-.06
Receptive Communication	.20	.03	-.20	.00
Expressive communication	.00	-.12	-.29*	-.01
Written communication	.07	-.13	-.20	-.13
<b>Daily Living Domain</b>	.08	-.12	-.16	-.05
Personal daily living	.03	-.11	-.24*	-.03
Domestic daily living	.16	-.01	-.02	-.09
Communication daily living	.01	-.17	-.19	-.01
<b>Social Domain</b>	.12	-.10	-.13	-.03
Interpersonal social	.13	-.08	-.07	-.07
Play and leisure	.04	-.15	-.15	.01
Coping skills	.15	-.04	-.13	-.02
<b>Adaptive Behaviour Composite</b>	.13	-.09	-.18	-.05

*Note. ADOS scores are % scores rather than raw scores so as to combine modules*

\* Correlation is significant at the 0.05 level (2-tailed)

Results in Table 6 demonstrate the relationship between VABS and 3Di scores. All correlations were negative and showed a stronger level of association than seen between VABS and ADOS, although at most the correlations were moderate. The 3Di Social and Communication traits showed similar patterns of significant correlations with most of the VABS Communication and Daily Living subdomains, and all of the Socialisation subdomains. The highest correlation was between Social reciprocity and VABS Socialisation domain ( $r = -.53$ ). Both Social and Communication autistic traits were significantly correlated with ABC VABS scores ( $p < 0.01$ ) indicating that higher levels of overall functioning are related to lower levels of autistic symptomatology. The RSB autistic trait was also correlated with the Socialisation domain and ABC, however

these were weaker. The RSB trait did not correlate with any aspects of the VABS Communication domain and subdomains, and only the Daily Living domain.

Table 6

*Correlations between VABS Domain, Subdomain and Composite Scores and 3Di Domain Scores*

VABS	3Di		
	Social Reciprocity	Communication	RSB
<b>Communication Domain</b>	-.21	-.29*	-.17
Receptive Communication	-.26*	-.21	-.11
Expressive communication	-.28*	-.34**	-.20
Written communication	.01	-.10	-.07
<b>Daily Living Domain</b>	-.34**	-.29*	-.24*
Personal daily living	-.35**	-.34**	-.20
Domestic daily living	-.21	-.19	-.19
Communication daily living	-.26*	-.18	-.17
<b>Social Domain</b>	-.53**	-.45**	-.30**
Interpersonal social	-.46**	-.37**	-.25*
Play and leisure	-.50**	-.43**	-.28*
Coping skills	-.49**	-.38**	-.30**
<b>Adaptive Behaviour Composite</b>	-.41**	-.36**	-.26*

\* Correlation is significant at the 0.05 level (2-tailed)

\*\* Correlation is significant at the 0.01 level (2-tailed)

Hierarchical multiple regression analyses were used to determine which autistic traits independently predicted adaptive functioning after controlling for the influence of IQ. Independent variables were entered in two blocks: (i) IQ was inserted first as research suggests that IQ has a significant relationship with adaptive functioning; (ii) autistic trait domains were entered into block two. In this way it was possible to examine the predictive ability of autistic traits variables controlling for the effect of IQ. This multiple regression analysis was repeated for each of the VABS subdomains and using autistic traits measured by ADOS and then by 3Di.

Using the ADOS measure of autistic traits, the predictors were IQ, Social, Communication, Imagination and Repetitive behaviours (Table 7). As revealed by a comparison of standardised regression coefficients, IQ exerted a significant effect on all domains of adaptive functioning except Socialisation domain. Only the VABS ABC model showed significant change with the addition of autistic traits entered in the second block. This appears to be largely due to the influence of the Communication trait which significantly predicted the ABC score. Unexpectedly, the correlation is positive, suggesting that as Communication became more impaired then adaptive functioning would also increase.

Table 7

*Regression Results For IQ and ADOS Predictors of Adaptive Behaviour*

	VABS			
	ABC	Communication	Daily Living	Socialisation
IQ	.32**	.37**	.35**	.20
ADOS Communication	.33*	.33*	.27	.27
ADOS Social	-.25	-.19	-.20	-.24
ADOS Imagination	.04	-.11	.01	-.03
ADOS RSB	-.09	-.01	-.13	-.07
R <sup>2</sup> Δ between 2 blocks	.09*	.08	.05	.05
R <sup>2</sup> of full model	.17	.22	.15	.09

*Note.* Standardised β reported

\* Significant at the 0.05 level (2-tailed)

\*\* Significant at the 0.01 level (2-tailed)

The second set of regression analyses using the 3Di as measure of autistic traits suggested a greater impact of autistic symptomatology on adaptive functioning as shown in Table 8. Results showed that the change in the squared multiple correlation was significant for all domains and ABC scores of the VABS. The largest variance explained was 41% of the Socialisation domain of adaptive functioning. This largely appears to be



due to the 3Di Social reciprocity variable which significantly predicts social adaptive functioning. The significant change in model for the VABS ABC score is also likely to be driven by the 3Di social reciprocity variable. Once again, IQ exerted a significant effect on all VABS domains, suggesting that IQ significantly predicts adaptive functioning in a range of domains. The positive results show that higher IQ is related to greater adaptive functioning levels.

Table 8

*Regression Results For IQ and 3Di Predictors of Adaptive Behaviour*

	VABS			
	ABC	Communication	Daily Living	Socialisation
IQ	.31**	.38**	.33**	.20*
3Di Social Reciprocity	-.41**	-.28	-.31*	-.45**
3Di Communication	-.08	-.05	-.00	-.11
3Di RSB	-.14	-.12	-.15	-.13
R <sup>2</sup> between 2 blocks	.30**	.14**	.15**	.41**
R <sup>2</sup> of full model	.39	.28	.25	.45

*Note.* Standardised  $\beta$  reported

\* Significant at the 0.05 level (2-tailed)

\*\* Significant at the 0.01 level (2-tailed)

### **Research question 3: Relationship between adaptive functioning and subtypes of repetitive behaviour**

A final set of multiple regression analyses were carried out to investigate the role RSBs play in adaptive functioning using results from RBS-R questionnaires. Analyses between those who returned the RBS-R questionnaires (n=43) and those who did not (n=29) did not identify any significant differences between groups in terms of ADOS scores, 3Di scores, age, gender or IQ. Based on the three factor model suggested by

Mirenda et al. (2010) for the RBS-R (Bodfish et al., 1999), IQ was entered in first step of the multiple regression, with the three factors entered into the following step (Compulsive Ritualistic Sameness Behaviours; Self Injurious Behaviours; Restricted Stereotyped Behaviours). IQ proved to be a significant predictor for all domains of the VABS, except for Socialisation adaptive functioning domain. The only significant change in models once the RBS variables were included was seen in the analysis of Socialisation VABS domain. Overall, the findings suggested that RSB variables showed little predictive ability for adaptive functioning however they need to be interpreted with caution due to reduced number of participants which can increase the risk of type two errors.

Table 9

*Regression Results For IQ and RSB Predictors of Adaptive Behaviour (n=43)*

	VABS			
	ABC	Communication	Daily Living	Socialisation
IQ	.31*	.37**	.33*	.19
RBS-R SIB	-.08	-.01	-.22	.05
RBS-R CRSB	-.03	.04	.08	-.19
RBS-R RSB	-.31	-.30	-.21	-.31
R <sup>2</sup> Δ between 2 blocks	.15	.08	.13	.19*
R <sup>2</sup> of full model	.24	.22	.23	.23

*Note: SIB* self injurious behaviours, *CRSB* compulsive ritualistic sameness behaviour, *RSB* restricted stereotyped behaviours. Standardised β reported.

\* Significant at the 0.05 level (2-tailed)

## **Discussion**

The objective of this paper was to examine the role of autistic traits in adaptive functioning using the VABS and two measures of autistic symptomatology. Based on the ideas that autistic traits are dimensional and can be fractionated, the study explored the current thresholds of the ASD diagnoses and the diagnostic symptom clusters which are required. This was done by comparing diagnostic groups in levels of adaptive functioning. Then using a trait-based approach, the study examined the relationship of adaptive functioning and autistic symptomatology through correlations and multiple regressions. Finally, the RSB domain of the autistic triad was further sub-divided to explore the relationship with adaptive functioning.

## **Sample Description**

Fundamentally, this study outlined the prevalence of autistic traits and adaptive functioning skills in a clinic sample. The group consisted of participants aged 6-16 years where the FSIQ ranged from 47 to 126. The range of IQ from moderate learning disabilities to superior was unexpected as the clinic is a specialist service for assessing normal to high functioning young people, and all participants were in mainstream education. In the total sample, autistic traits were seen above threshold on 3Di and ADOS measures. The most severe traits were largely seen in the AD group followed by the AspD, PDD-NOS and BAP group which is expected based on current diagnostic criteria (APA, 2000) and dimensional understanding (Volkmar et al., 2009; Constantino & Todd, 2003). The distribution of the autistic traits showed no distinct cut-offs, as evidenced by lack of bimodality, also supporting a continuous dimensional

conceptualisation (Constantino & Todd, 2003). Significant differences were seen between diagnostic groups for the Social and Communication domains of the ADOS with AD demonstrating most severe impairments. There were no further differences found on the ADOS or 3Di between any groups with full or partial presentations.

All diagnostic groups showed adaptive functioning impairments on the VABS, with the majority of participants in the Low range of adaptive functioning compared to population norms. The results showed an adaptive functioning profile with most marked impairments seen in the Social domain followed by Daily Living domain and finally the Communication domain with least impairment. Although not an expected profile, this does fit with findings from research using the same measures (Klin et al., 2007). Ultimately, results demonstrate the deficits in real life skills which children with autistic traits in this sample experience. The discrepancy between cognitive functioning and adaptive functioning is not as large as seen in previous research (Klin et al., 2007) which likely reflects the greater range in FSIQ and that not all participants received an ASD diagnosis.

### **Comparison of adaptive functioning between diagnostic and sub-threshold groups**

This study builds upon previous research that has compared adaptive functioning in individuals with different autistic diagnoses using the VABS. The findings showed a complex picture which differed depending on diagnostic classification system. There was partial support for past literature which identified limited differences in adaptive functioning between diagnostic groups despite differing levels of autistic impairments using the ADOS algorithm and 3Di thresholds (Perry et al., 2009; Paul et al., 2004;

Walker et al., 2004). However, when groups were separated according to clinician consensus diagnosis there were more gradients of severity demonstrated. The AD group showed significantly greater impairment compared to other ASDs, which was at a similar level to the BAP group. The AspD and PDD-NOS groups showed similar levels of impairment. Differences between groups were found in subdomains predominantly relating to communication and language skills. Interestingly, for the adaptive functioning Socialisation domain, all diagnostic groups were equally impaired suggesting that this is a defining feature of the cohort. The use of clinician consensus diagnosis compared to solely relying on standardised instruments seems to offer greater clinical value. The two standardised measures identified fewer groups based on autistic traits, and had significant comparisons which differed between the two measures.

Clinically, it appears that children who are sub-threshold for diagnoses of AD and AspD are still demonstrating significant difficulties on day to day functioning and yet they are being missed by the existing diagnostic criteria. In particular, the BAP group demonstrated a similar level of adaptive disabilities to the AD group. One possibility is that these participants did in fact have an ASD diagnoses and were missed. This is unlikely given the comprehensive assessment and lower levels of autistic traits. There are other factors which may explain why the BAP group showed such considerable levels of functional impairment; however age and IQ were matched between groups and it is unlikely to be due to co-morbidity as twelve of the thirteen participants in the BAP group did not receive an alternative diagnosis. It is possible that participants with a clinical diagnosis may have been receiving treatment or intervention already which has improved their adaptive functioning, whereas those with BAP have not. This was not accounted for in the study and requires further investigation. An

alternative perspective may be that the adaptive functioning impairments are not the result of a pathological issue within the young person such as ASD. Instead, the adaptive disabilities may rather reflect an attachment disorder or wider systemic issue which is not being captured by the measures used in this study. Prognostic studies may help to elucidate this interesting finding, and further exploration into wider systemic issues is warranted.

### **Relationship between adaptive functioning and autistic symptomatology**

Based on the idea of fractionation, the study investigated whether the separate autistic traits differentially impacted on adaptive functioning. The two variables demonstrated a negative relationship with weak to moderate correlations predominantly in the social and communication domains, which supports findings from past research (Klin et al., 2007). These findings between the two factors of autistic symptomatology and adaptive functioning suggest that although they share a similar conceptualisation of Social and Communication impairments, they can be considered as relatively separate dimensions.

The results appeared to be impacted by methodological issues concerning the measure of autistic symptomatology used. When using the ADOS to measure symptomatology there were few significant findings suggesting the variables were relatively independent and autistic symptomatology was not a good predictor of adaptive functioning. Significant correlations were only found for the Imagination trait, which may reflect the impact of the limited range of the trait on correlational statistics. In comparison, using the 3Di found many significant negative correlations, particularly between 3Di Social and Communication traits and VABS scores, and strong predictive ability of the Social reciprocity interaction trait. The lack of significant correlations

between the two measures and the discrepancies seen in results throughout demonstrated that agreement between the ADOS and 3Di was low. This may reflect the focus of each measure as the ADOS is conducted in a single observation within the clinic whereas the 3Di relies on a parent interview looking at behaviour across time and contexts. The emphasis on presentation within a specific time frame as opposed to an assessment of developmental history may result in different outcomes based on the child's performance. The findings may also be explained by shared method variance as both the 3Di and VABS are parent report measures. However, if this were the case, then it could be hypothesised that all correlations between the 3Di and VABS measures would be significant which was not shown. The findings therefore suggest that parental report was varied and likely reflects the young person's skills accurately.

It is not possible to say from the findings in this study whether one measure is more accurate than the other but indicates that further investigation is needed and could be particularly useful in identifying which measures demonstrate particular validity for specific cohorts such as high or low functioning samples. Correlations between the two autistic measures and FSIQ showed the 3Di to be more independent from IQ. This may have implications for the 3Di as a better measure of autistic traits. The discrepancy between measures ultimately does reflect the importance of using a multidimensional assessment and clinician consensus.

The regression analyses supported the understanding that IQ is a significant predictor for adaptive functioning particularly for Communication and Daily Living domains and less so for the Socialisation domain, which corresponds with past research (Klin et al., 2007; Liss et al., 2001). There was minimal predictive ability of adaptive functioning by autistic traits including the RSB domain which was explored

independently. The exception to this was the parent report social reciprocity interaction which was a significant predictor of adaptive functioning. The equivalent severity of social adaptive functioning disabilities across all diagnostic groups, and the predictive ability of social reciprocity interaction suggests that social impairments are a defining feature of this cohort. The idea that social deficits are at the core of ASD diagnoses is supported in past literature (Constantino et al., 2003; Buitelaar et al., 1999) and has clinical implications for intervention and treatment.

### **Clinical implications**

The findings from this investigation are pertinent given the suggested changes for the new DSM-5 in 2013 (APA, 2011). The revisions for DSM-5 propose that AD, AspD and PDD-NOS are to be subsumed under the category 'Autism Spectrum Disorder', which removes the arguably arbitrary categories for diagnosis. The second proposed change regards the threshold for the new diagnostic category. Proposed diagnostic criteria require two RSB behaviours rather than the current one, and the suggestion is that the threshold has been raised therefore fewer people are likely to receive the new diagnosis (APA, 2011; Mattilia et al., 2011). The findings in the current study support the introduction of a single category, as based on adaptive functioning it would be difficult to justify and validate separate diagnoses, particularly between AspD and PDD-NOS. The concern from these findings for the proposed DSM-5 is with regards to an increased threshold in order to reach diagnosis. This would discount the large number of individuals who show significant adaptive disabilities yet lack severity or diversity in autistic symptoms to reach threshold for a triad diagnosis. PDD-NOS and



BAP individuals will not be included under the DSM-5 proposals and yet this study showed that the groups had similar profiles of adaptive disability to AspD and AD respectively. The proposed emphasis on requiring RSB behaviours in particular is concerning based on these findings, as this trait appears to have less clinical relevance than the social impairments.

The proposed DSM-5 changes fail to consider the possible contribution of a more dimensional approach to diagnosis through the use of variables such as adaptive functioning and cognitive functioning to help specify particular areas of impairment. Instead diagnosis is based on autistic symptom patterns which follow the same model as the current DSM-IV-TR (APA, 2000). Szatmari (2000) has suggested that the current classification is 'deeply unsatisfying' (p. 731) and instead suggests incorporating a two dimensional approach which includes one dimension with autistic symptoms and a second dimension of functioning measured by functional abilities. This would allow for individuals to be diagnosed on qualitative differences in functioning presentation, as well as quantitative autistic traits. If this two dimensional concept was applied to the findings from this study it is clear that individuals with partial or mild presentations would score highly on adaptive functioning disabilities and have their difficulties recognised. The finding in this study that autistic symptomatology and adaptive functioning are relatively independent variables provides support for using this two dimensional approach to classification. It adds to work using factor analysis which identified two dimensions accounting for phenotypic variation in ASD (Szatmari et al., 2002), and in genetic research which suggests two underlying mechanisms for the variables (Szatmari et al., 2000).

The clinical relevance for this investigation is evident for both accessing resources and intervention. Greater understanding of adaptability and disability in individuals exhibiting specific core autistic traits may allow for more targeted resources. Currently, children who do not reach full AD or AspD diagnoses struggle to receive appropriate, clear intervention plans and adequate support, and often difficulties in everyday life can be misattributed (Constantino et al., 2000; Mills, 2009; Skuse et al., 2009). A crucial aim of this study was to explore whether these individuals with sub-threshold autistic presentations, either due to mild traits or partial presentation, are clinically distinct and have different needs from individuals with the full triad of impairments. Evidently from this research, there are individuals with partial or sub-threshold presentations who have significant disabilities of comparable severity to those with AD and AspD, and therefore require support. This echoes findings from other studies where sub-threshold populations have also been associated with an elevated risk of behavioural problems (Skuse et al., 2009). Based on the findings from this study, it would be recommended that access to resources is based on adaptive functioning needs as well as autistic symptomatology. With regards to ASD presentations, resources should be trait-led rather than diagnosis-led. Undoubtedly this brings with it issues for screening and funding larger populations including individuals who are currently considered sub-threshold. However it provides support for on-going debate in the development of clinical interventions.

Adaptive functioning is clearly impaired in this sample of individuals with ASD traits and gives weight to the need for intervention at this level. National guidelines for ASD treatment programmes are currently under construction (NICE, 2011), although to date intervention programmes have often focused on the reduction of autistic

symptomatology (Klin et al., 2007). Given that the relationship between autistic symptomatology and adaptive functioning was inconsistent, and that the amount of variance in adaptive functioning predicted by autistic trait severity was minimal, it is possible that the two variables should be conceived at least partially as independent domains. Therefore interventions which are aimed at targeting the development of adaptive skills may be necessary, as those focusing solely on autistic behaviours may not be sufficient to improve adaptive functioning as well. This may be particularly salient for individuals with low IQ where past research has shown adaptive functioning and autistic symptomatology to have weaker correlations (Liss et al., 2001). In terms of specific domains to target during intervention, adaptive social functioning showed the greatest impairments of the three domains for all diagnostic groups. There was significant predictive ability of social functioning by the 3Di Social reciprocity trait, and the social VABS domain showed the only significant change in understanding variance once RSBs were accounted for. Interventions targeting social reciprocity skills or reducing socially inappropriate RSBs may help to reduce impairments in adaptive social skills.

### **Future work**

As described earlier when considering the functional disabilities seen in the BAP cohort, it was noted that current or previous intervention and treatments were not accounted for within the study. It is possible that this may have influenced both autistic symptomatology presentation as well as adaptive functioning in all diagnostic groups during assessment. Future studies could try to quantify and account for this, for example

by assessing educational system and support, previous assessments and learning disabilities.

With regards to findings in the BAP group, it would be helpful to further investigate the variables which are affecting levels of adaptive functioning. Potentially this may involve a systemic assessment focusing more widely on the child's environment.

This study has used a cross-sectional design and therefore caution has been required to not draw causal inferences. Future projects could further investigate differential relationships between autistic traits and adaptive functioning as well as other variables in longitudinal designs. This would be of interest to assess developmental trajectories and check the stability of the predictors such as IQ and social reciprocity, as well as to investigate the effects of intervention. It is possible that the relationship between the two variables may change over time as expectations of adaptive functioning skills alter with age and developmental stage. This reflects the idea that an individual's diagnosis can change over time depending on developmental expectations, skills and deficits (Mills, 2009; Szatmari, 2000). It requires flexibility and adaptation both from professionals and families to support the individual and assess and match intervention appropriately.

The impact of using different measures for the same constructs is evident in this study. The use of the ADOS and 3Di on the same sample resulted in noticeable differences and warrants further investigation. The discrepancy between the two measures of autistic symptomatology suggests that there is value in comparing measures with different methodologies in an attempt to improve their validity.

## **Limitations of research**

There are a few limitations in this study which are related to the sample used. Although the sample size was larger than that suggested by the power calculation, there were small numbers in each diagnostic group which reduced the power for group comparisons. Despite this, significant findings were still evident which demonstrates the importance of the findings. Given that the sample is from a specialist assessment clinic rather than population-based, it is possible that the generalisability of the results could be compromised.. Additionally, the clinic setting makes it likely that participants may have been receiving a variety of treatment interventions and support within the community e.g. special educational needs plans in school. The different interventions were not assessed or accounted for in this study which may have affected overall adaptive functioning level.

The RBS-R questionnaire required participants to return the forms and resulted in a response rate of 59.7%. There is the possibility that results for the RSB regression analyses are biased as a result of this. Families participating in this section may be caregivers who feel their child has particularly severe difficulties and be active in responding. Alternatively it may reflect individual differences in families such as their organisational abilities involved in completing administration tasks. However, it is likely that the subsample was representative of the broader sample based on analyses showing no significant difference between groups for autistic symptomatology or demographic data.

## **Conclusion**

As the first study to try to differentiate the relationship between autistic traits and adaptive functioning using a trait based approach, findings have highlighted the difficulties faced by individuals with social communication difficulties that are below the accepted threshold for an ASD diagnosis. The study suggests that the current thresholds do not encompass all that they should as individuals with BAP showed equivalent levels of adaptive impairment to AD in groups matched for age and IQ. In terms of the role of specific autistic traits to understand adaptive functioning, there is evidence for social reciprocity as a predictor, but little support for communication or RSB traits suggesting that the variables of autistic traits and adaptive functioning are largely independent. However, the study did support IQ as a significant predictor of adaptive functioning. Methodological issues were highlighted through the use of two measures of autistic symptomatology which had low agreement. At a clinical level the overall findings suggest that the proposed changes to DSM-5 will continue to exclude individuals who have partial presentations. These individuals have been shown to have clinical needs on a par with individuals with the full triad, and therefore this study supports the need for trait-focused resources and interventions so as not to miss them again.

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## **Appendix 1: Information and consent forms**



## **Adaptive functioning in young people with and without an autism spectrum disorder**

You and your child are being invited to take part in a research project about the relationship between adaptive functioning and autism spectrum disorders (ASDs). Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it involves. Please take time to read the following information carefully.

Please do get in touch if there is anything that is not clear, or if you would like more information (see below for contact details). Take your time to decide whether or not you wish to take part.

### What is the purpose of the study?

People with ASDs are known to have difficulties with adaptive functioning – these are the everyday activities in socialising, communicating and daily activities. It is thought that difficulties are seen in all different ASD diagnoses like autism, Asperger’s syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) despite the level of autistic symptoms.

We are interested in looking at the ways in which someone’s autistic symptoms affect the way they get on in a range of daily activities.

The study is being carried out as part of a doctoral training in Clinical Psychology being undertaken by the principal researcher.

### Why has my child been chosen to take part in the study?

Your child has been referred for assessment at .... As a result of this, we know that your child would be eligible to take part in the study. We hope to involve around 70 children who are being seen at the ... Clinic.

### Do we have to take part?

No – it is up to you and your child to decide whether or not to take part. If you do decide to take part, you are both free to pull out of the research at any time, without giving a reason. Your decisions about taking part will have no effect on the standard of care your child will receive from the clinic.

### What will happen to my child and me if we agree to take part?

If you and your child decide that you would like to take part, we will ask for the following:

- You, as the parent or guardian, needs to fill in a questionnaire about your child. This is about certain behaviours and characteristics that some children show. It takes about 15 minutes to complete the questionnaire. Once completed, we would ask you to bring the questionnaire into ... when you attend the clinic.
- You and your child need to consent to your child’s data being used in the research. The data will be collected from the assessment at the ... Clinic.

Are there risks involved in taking part?

We do not expect there to be any risks to taking part in the study as it involves completion of a brief questionnaire by you, the parent or guardian.

What are the possible benefits of taking part?

Whilst there are no direct benefits in taking part, it is hoped that participating families will feel good will from being part of a research project. We also hope that by providing a better understanding of the relationship between autistic traits and everyday life skills that the study will help professionals when diagnosing children in the future. On finishing the study, we can send you a summary of our findings.

What happens to the information collected?

All information collected and analysed during the study will be kept strictly confidential. Instead of using your name, we use a code to label the information you give us. A list of names and their codes will be kept separately and securely, so that only the principle researcher can access it. Completed questionnaires will be kept in a locked, secure cabinet. The study will be written up and published as a research paper, but the individuals who took part will not be identifiable from this.

What if something goes wrong?

We do not expect any problems, but we are obliged to tell you the following: If something goes wrong there are no special compensation arrangements available. In the event of any negligence, you may have grounds for legal action but you may have to pay for it. Regardless of this, if you do have any complaints or worries about the study, the usual National Health Service complaints mechanisms would be available to you.

Ethical Review

Royal Free NHS Trust Ethics Committee has reviewed this study.

Want to find out more?

If anything written above is unclear to you, or you or your child would like to find out more, please do not hesitate to get in touch with the project's principal researcher, Rebecca Varrall. You can contact her on ....

## **Everyday functioning in young people with and without an autism spectrum disorder**

We would like to invite you to take part in a research project. The aim of the project is to find out how having difficulties in getting on with people, or having your own specific interests might affect other areas of your life. We feel it is important to get a good understanding of how these may link in order to better support young people in the future.

In order for you to decide whether you would like to participate, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and be sure that you understand it. If you have any questions, or if you would like further information, please do not hesitate to contact us (see contact details at the end). Please take time to think about whether you are happy to participate. If you would like to take part in this study, we ask that you sign the assent form to show you agree.

### Why have I been asked to take part?

You will be going to see some doctors and psychologists at .... Because of this, we know that you are just the sort of person we want to talk to for our research. We are hoping to find around 70 children who have been to ....

### Do I have to take part?

No – it is up to you whether you take part or not. We have sent your parent or guardian some information about the research project as well. Perhaps you should talk with them about taking part. There is no hurry – you should take your time to decide.

If you decide to take part, and then change your mind later that's OK, and you don't have to tell us why you wanted to stop. Whatever you decide about taking part, it won't change anything that happens to you in hospital.

### What will I do if I take part in the research?

If you do want to take part, here's what will happen:

- We will ask your parent or guardian to answer a list of questions. These will ask whether you have any habits or particular interests. We want your parent or guardian to answer the questions in writing and then bring them in to us when you come to ....
- If you do agree to take part, it will mean that the person who is organising the project will have a look at all of your results after your meeting at ....

Are there any risks?

We don't think there are any risks in taking part in the research. The only person who will have to do anything is your parent/guardian who will fill out some questions for us.

Are there any benefits?

We expect that some young people will be pleased to know they are part of a research project. Also, the things we learn from the research could be useful and may help other children in future.

What if something goes wrong?

We do not expect anything will go wrong, but if it does we will talk to your parents or guardian about what to do.

What will happen to the results of the project?

We hope to write a report so that other people can learn from our research. Your name will not appear in the report. You are more than welcome to get a copy of the report once it is completed.

Thank you for helping us. If you have any questions or worries about the study you can telephone or email the person who is running the research. Her name is Rebecca Varrall. Her telephone number is ....

Royal Free NHS Trust Ethics Committee has reviewed this study

## **Everyday activities of young people with and without difficulties in getting on with people and particular interests**

You are being asked to take part in a research project. Please read this information sheet, as it tells you why we are doing this project, and what you would have to do if you do decide to take part.

### What is research?

Research is a way of finding out new things about the world and the people who live in it. This research project aims to find out about what everyday activities young people can do.

### Why have I been asked to take part?

You are going to be seeing some doctors and psychologists at .... Because of this, we know that you are just the sort of person we want for our research. We are hoping to find around 70 children who have been to ....

### Do I have to take part?

No – it is up to you whether you take part or not. We have sent your parent or guardian some information about the research project too. Perhaps you should talk with them about taking part. There is no hurry – you should take your time to decide.

If you decide to take part, and then change your mind later that's OK, and you don't have to tell us why you wanted to stop. Whatever you decide about taking part, it won't change anything that happens to you in hospital.

### What will I do if I take part in the research?

If you do want to take part, here's what will happen:

- We will ask your parent or guardian to answer a list of questions. These will ask whether you have any particular interests. We want your parent or guardian to answer the questions in writing and then bring them in to us when you come to ....
- If you do agree to take part, it will mean that the person who is organising the project will use what we learn about you from your visit to ....

### Is there anything dangerous?

We don't think there is anything dangerous about taking part in the research. The only person who will have to do anything is your parent/guardian who will fill out some questions for us.

Will it be good to take part?

We expect that some children will find it fun to know they are part of a research project. Also, the things we learn from the research could be useful and may help other children in future.

What if something goes wrong?

We do not expect anything will go wrong, but if it does we will talk to your parents or guardian about what to do.

What will happen to the results of the research?

We hope to write a report so that other people can learn from our research. Your name will not appear in the report.

Thank you for helping us. If you have any questions or worries about the study you can telephone or email the person who is running the research. Her name is Rebecca Varrall. Her telephone number is ....

Royal Free NHS Trust Ethics Committee has reviewed this study

## CONSENT FORM FOR PARENTS OR GUARDIANS

Title: Adaptive functioning in young people with and without an autism spectrum disorder

**Participant ID Number:**

**Date:**

You and your child have been asked to take part in a research study. The researcher running the study is responsible for explaining the project to you before you give consent. Please ask the researcher any questions you may have about this project, before you decide whether you wish to participate.

		Please tick if you agree
<b>1</b>	<b>I confirm that I have read and understood the information sheet (version 2) for the above study and have had the opportunity to ask questions.</b>	
<b>2</b>	<b>I confirm that I have had sufficient time to consider whether or not I want my child and me to be included in the study.</b>	
<b>3</b>	<b>I understand that my child's and my participation is voluntary and that we are free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.</b>	
<b>4</b>	<b>I understand that information collected when my child is assessed at ... may be looked at and used in data analysis by Rebecca Varrall. I give permission for this.</b>	
<b>5</b>	<b>I agree for my child and me to take part in the study</b>	

Name of participant	Date	Signature

Comments or concerns during the study:

If you have any complaints about the way in which this research project has been or is being conducted, please, in the first instance, discuss them with the researcher **Rebecca Varrall – ... (Tel)**. If the problems are not resolved, or you wish to comment in any other way, please contact the Research Governance Co-ordinator ...: (name), either by email (...) or phone (...). Please quote the project number at the top of this form.

ASSENT FORM FOR YOUNG PERSON

Title: Adaptive functioning in young people with and without an autism spectrum disorder

**Participant ID Number:**

**Date:**

You and your parent/guardian have been asked to take part in a project. The person organising the study must explain about the project before you agree to take part. Please ask the person in charge of the project any questions you like about this project before you decide whether to join in.

		<b>Please tick if you agree</b>
<b>1</b>	<b>I have read and understood the information sheet (version 1/2) and have asked any questions I wanted to.</b>	
<b>2</b>	<b>I have had enough time to decide if I want to take part in the project.</b>	
<b>3</b>	<b>I understand that I only need to take part if I want to and that I am free to stop doing the project at any time, without having to give a reason.</b>	
<b>4</b>	<b>I understand that the person doing the research (Rebecca Varrall) may look at my hospital notes if they need to. This is OK if my Parent or Guardian lets them.</b>	
<b>5</b>	<b>I agree to take part in this project</b>	

Name of participant	Date	Signature

Comments or concerns during the study:

If you have any complaints about the way in which this research project has been or is being conducted, please, in the first instance, discuss them with the researcher **Rebecca Varrall –...(tel)**. If the problems are not resolved, or you wish to comment in any other way, please contact the Research Governance Co-ordinator for ...: (name), either by email (...) or phone (...). Please quote the project number at the top of this form.



**Appendix 2: Ethics confirmation letter**



**National Research Ethics Service**

**North West London REC 2**

Royal Free Hospital NHS Trust  
Royal Free Hospital  
South House, Block A  
Pond Street  
London  
NW3 2QG

Telephone:  
Facsimile:

17 June 2010

Miss Rebecca Varrall  
Trainee Clinical Psychologist

Dear Miss Varrall

**Study Title:** An investigation of the relationship between functional impairment and autistic traits in a clinical population  
**REC reference number:** 10/H0720/27  
**Protocol number:**

Thank you for your letter of 7<sup>th</sup> June 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
REC application		
Protocol	1	03 March 2010
Investigator CV		03 March 2010
Participant Information Sheet: 6 - 12 Years	1	03 March 2010
Participant Consent Form: Guardian	1	03 March 2010
Participant Consent Form: Child Assent	1	03 March 2010
Letter from Statistician		
Referees or other scientific critique report		
Questionnaire: Validated: Repetitive Behaviour Scale		
Supervisor CV: Dr Mandy		03 March 2010
Participant Information Sheet: Young People (12-16)	2	
Participant Information Sheet: Parent/Guardian	2	
Response to Request for Further Information		

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
  
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

<b>10/H0720/27</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely



**Dr Michael Pegg**  
Chair

Email: [Thomas.mcquillan@royalfree.nhs.uk](mailto:Thomas.mcquillan@royalfree.nhs.uk)

Enclosures: "After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL- AR2 for other studies]  
Copy to: Dr William Mandy, Great Ormond Street Hospital for Children NHS Trust

### **Appendix 3: Repetitive Behaviour Scale – Revised**

**Repetitive Behaviour Scale – Revised (Bodfish, Symons, Lewis 1999)**

**REPETITIVE BEHAVIOUR SCALE - Revised (RBS-R)**

Study ID#: \_\_\_\_\_

Date of Birth: \_\_\_/\_\_\_/\_\_\_

Gender: female      male

Today's Date: \_\_\_/\_\_\_/\_\_\_

Completed by (please circle): Mother      Father      Other (please specify) \_\_\_\_\_

**Instructions:**

Please rate your child's behaviour by reading each of the items listed and then choosing the score that best describes how much of a problem the item is for your child. Be sure to read and score all items listed.

Consider each item in Two Ways:

- 1) Make your ratings based on your **current** observations and interactions with the person. Use the definitions in the box given below to score each item:

0 = behaviour does not occur  
 1 = behaviour occurs and is a mild problem  
 2 = behaviour occurs and is a moderate problem  
 3 = behaviour occurs and is a severe problem

- 2) Make another rating based on whether you have **ever** observed this behaviour in your child in the past, using the following definitions to score each item:

0 = behaviour was never observed in the past  
 1 = behaviour was observed in the past

When deciding on a score for each item, consider: (a) how frequently the behaviour occurs (e.g. weekly versus hourly), (b) how difficult it is to interrupt the behaviour (e.g. can be easily redirected versus becomes distressed if interrupted) and (c) how much the behaviour interferes with ongoing events (e.g. easy to ignore versus very disruptive).

**I. Stereotyped Behaviour Subscale**

(DEFINITION: apparently purposeless movements or actions that are repeated in a similar manner)

1	WHOLE BODY (Body rocking, Body swaying)	Current:	0	1	2	3
		Ever:	0	1		
2	HEAD (Rolls head, Nods head, Turns head)	Current:	0	1	2	3
		Ever:	0	1		
3	HAND/FINGER (Flaps hands, Wiggles or flicks fingers, Claps hands, Waves or shakes hand or arm)	Current:	0	1	2	3
		Ever:	0	1		
4	LOCOMOTION (Turns in circles, Whirls, Jumps, Bounces)	Current:	0	1	2	3
		Ever:	0	1		
5	OBJECT USAGE (Spins or twirls objects, Twiddles or slaps or throws	Current:	0	1	2	3

	objects, Lets objects fall out of hands)	Ever:	0	1		
6	SENSORY (Covers eyes, Looks closely or gazes at hands or objects, Covers ears, Smells or sniffs items, Rubs surfaces)	Current:	0	1	2	3
		Ever:	0	1		

## II. Self-Injurious Behaviour Subscale

(DEFINITION: movement or actions that have the potential to cause redness, bruising, or other injury to the body, and that are repeated in a similar manner)

7	HITS SELF WITH BODY PART (Hits or slaps head, face, or other body area)	Current:	0	1	2	3
		Ever:	0	1		
8	HITS SELF AGAINST SURFACE OR OBJECT (Hits or bangs head or other body part on table, floor or other surface)	Current:	0	1	2	3
		Ever:	0	1		
9	HITS SELF WITH OBJECT (Hits or bangs head or other body area with objects)	Current:	0	1	2	3
		Ever:	0	1		
10	BITES SELF (Bites hand, wrist, arm, lips or tongue)	Current:	0	1	2	3
		Ever:	0	1		
11	PULLS (Pulls hair or skin)	Current:	0	1	2	3
		Ever:	0	1		
12	RUBS OR SCRATCHES SELF (Rubs or scratches marks on arms, leg, face or torso)	Current:	0	1	2	3
		Ever:	0	1		
13	INSERTS FINGER OR OBJECT (Eye-poking, Ear-poking)	Current:	0	1	2	3
		Ever:	0	1		
14	SKIN PICKING (Picks at skin on face, hands, arms, legs or torso)	Current:	0	1	2	3
		Ever:	0	1		

## III. Compulsive Behaviour Subscale

(DEFINITION: behaviour that is repeated and is performed according to a rule, or involves things being done "just so")

15	ARRANGING / ORDERING (Arranges certain objects in a particular pattern or place; Need for things to be even or symmetrical)	Current:	0	1	2	3
		Ever:	0	1		
16	COMPLETENESS (Must have doors opened or closed; Takes all items out of a container or area)	Current:	0	1	2	3
		Ever:	0	1		
17	WASHING / CLEANING (Excessively cleans certain body parts; Picks at lint or loose threads)	Current:	0	1	2	3
		Ever:	0	1		
18	CHECKING (Repeatedly checks doors, windows, drawers, appliances, clocks, locks, etc.)	Current:	0	1	2	3
		Ever:	0	1		
19	COUNTING (Counts items or objects; Counts to a certain number or in a certain way)	Current:	0	1	2	3
		Ever:	0	1		
20	HOARDING/SAVING (Collects, hoards or hides specific items)	Current:	0	1	2	3
		Ever:	0	1		
21	REPEATING (Need to repeat routine events; In / out door, up / down from chair, clothing on/off)	Current:	0	1	2	3
		Ever:	0	1		
22	TOUCH / TAP (Need to touch, tap, or rub items, surfaces, or people)	Current:	0	1	2	3
		Ever:	0	1		

### Current:

0 = behaviour does not occur

1 = behaviour occurs and is a mild problem

### Ever:

0 = behaviour was never observed in the past

1 = behaviour was observed in the past

2 = behaviour occurs and is a moderate problem  
 3 = behaviour occurs and is a severe problem

#### IV. Ritualistic Behaviour Subscale

(DEFINITION: performing activities of daily living in a similar manner)

23	EATING / MEALTIME (Strongly prefers/insists on eating/ drinking only certain things; Eats or drinks items in a set order; Insists that meal related items are arranged in a certain way)	Current:	0	1	2	3
		Ever:	0	1		
24	SLEEPING / BEDTIME (Insists on certain pre-bedtime routines; Arranges items in room "just so" prior to bedtime; Insists that certain items be present with him/her during sleep; Insists that another person be present prior to or during sleep)	Current:	0	1	2	3
		Ever:	0	1		
25	SELF-CARE - BATHROOM AND DRESSING (Insists on specific order of activities or tasks related to using the bathroom, to washing, showering, bathing or dressing; Arranges items in a certain way in the bathroom or insists that bathroom items not be moved; Insists on wearing certain clothing items)	Current:	0	1	2	3
		Ever:	0	1		
26	TRAVEL / TRANSPORTATION (Insists on taking certain routes/paths; Must sit in specific location in vehicles; Insists that certain items be present during travel, e.g., toy or material; Insists on seeing or touching certain things or places during travel such as a sign or store)	Current:	0	1	2	3
		Ever:	0	1		
27	PLAY / LEISURE (Insists on certain play activities; Follows a rigid routine during play / leisure; Insists that certain items be present/available during play/leisure; Insists that other persons do certain things during play)	Current:	0	1	2	3
		Ever:	0	1		
28	COMMUNICATION / SOCIAL INTERACTIONS (Repeats same topic(s) during social interactions; Repetitive questioning; Insists on certain topics of conversation; Insists that others say certain things or respond in certain ways during interactions)	Current:	0	1	2	3
		Ever:	0	1		

#### V. Sameness Behaviour Subscale

(DEFINITION: resistance to change, insisting that things stay the same)

29	Insists that things remain in the same place(s) (e.g. toys, supplies, furniture, pictures, etc.)	Current:	0	1	2	3
		Ever:	0	1		
30	Objects to visiting new places	Current:	0	1	2	3
		Ever:	0	1		
31	Becomes upset if interrupted in what he/she is doing	Current:	0	1	2	3
		Ever:	0	1		
32	Insists on walking in a particular pattern (e.g., straight line)	Current:	0	1	2	3
		Ever:	0	1		
33	Insists on sitting at the same place	Current:	0	1	2	3
		Ever:	0	1		
34	Dislikes changes in appearance or behaviour of the people around him/her	Current:	0	1	2	3
		Ever:	0	1		

#### V. Sameness Behaviour Subscale cont....

(DEFINITION: resistance to change, insisting that things stay the same)

35	Insists on using a particular door	Current:	0	1	2	3
		Ever:	0	1		
36	Likes the same CD, tape, record or piece of music played continually; Likes same movie / video or part of movie / video	Current:	0	1	2	3
		Ever:	0	1		
37	Resists changing activities; Difficulty with transitions	Current:	0	1	2	3
		Ever:	0	1		
38	Insists on same routine, household, school or work schedule everyday	Current:	0	1	2	3
		Ever:	0	1		
39	Insists that specific things take place at specific times	Current:	0	1	2	3
		Ever:	0	1		

#### VI. Restricted Behaviour Subscale

(DEFINITION: Limited range of focus, interest or activity)

40	Fascination, preoccupation with one subject or activity (e.g., trains, computers, weather, dinosaurs)	Current:	0	1	2	3
		Ever:	0	1		
41	Strongly attached to one specific object	Current:	0	1	2	3
		Ever:	0	1		
42	Preoccupation with part(s) of object rather than the whole object (e.g., buttons on clothes, wheels on toy cars)	Current:	0	1	2	3
		Ever:	0	1		
43	Fascination, preoccupation with movement / things that move (e.g., fans, clocks)	Current:	0	1	2	3
		Ever:	0	1		

**Thank you for completing this questionnaire!**

#### References:

Bodfish, J.W., Symons, F.J., Parker, D.E., & Lewis, M.H. (2000). Varieties of repetitive behavior in autism. *Journal of Autism and Developmental Disabilities*, 30, 237-243.

Bodfish, J.W., Symons, F.J., Lewis, M.H. (1999). *The Repetitive Behavior Scale*. Western Carolina Center Research Reports.