Demographic and cognitive profile of individuals seeking a diagnosis of Autism Spectrum Disorder in adulthood

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Abstract

Little is known about ageing with autism spectrum disorder (ASD). We examined the characteristics of adults referred to a specialist diagnostic centre for assessment of possible ASD, 100 of whom received an ASD diagnosis and 46 did not. Few demographic differences were noted between the groups. Comorbid psychiatric disorders were high in individuals with ASD (58%) and non-ASD (59%). Individuals who received an ASD diagnosis had higher self-rated severity of ASD traits than non-ASD individuals. Within the ASD group, older age was associated with higher ratings of ASD traits and better cognitive performance. One interpretation is that general cognitive ability and the development of coping strategies across the lifespan, do not necessarily reduce ASD traits but may mitigate their effects.

Keywords: Adulthood; ageing; autism spectrum disorders; autism traits; diagnosis; psychiatric comorbidity.

Most research on Autism Spectrum Disorder (ASD) has focused on children and young people, but the majority of people with ASD are adults and there is increasing awareness of the needs of adults and the lack of research on ageing in ASD (Happe and Charlton, 2012; Mukaetova-Ladinska *et al.* 2012; Stuart-Hamilton *et al.* 2009). On current estimates of a 1% prevalence for ASD (Baird *et al.* 2006), the number of adults with ASD aged over 65 will be 155,000 by 2035 in the UK alone (Redden, 2013). Few longitudinal studies exist (Howlin *et al.* 2014), but changes to the diagnostic criteria make it hard to compare adults previously diagnosed in childhood (e.g., by DSM-III criteria) with those receiving diagnosis under the current, generally broader, criteria. In addition, cross-sectional studies have some advantages in terms of both feasibility and representativeness (e.g., freedom from selective attrition).

The increase in both the number of older adults and older adults with ASD, represents a significant change in the population, and will require hither to un-provided services (Dudley and Emery, 2014; Povey *et al.* 2011). It is therefore important to understand the trajectory of well-being, cognitive and social abilities in ASD and the needs of individuals with ASD as they age. Given the fast growing older ASD population, the dearth of research in this area and the slow nature of longitudinal studies, one approach is to use cross-sectional information to examine age-related trajectories in ASD. Although valuable, it is important to note that since the 1940s there have been substantial changes in both diagnostic criteria for and awareness of ASD (Hansen *et al.* 2015; Rutter, 2005). As a result the functional level and independence of individuals receiving an ASD diagnosis has changed dramatically over the past 70 years. Such changes will doubtless effect cross-sectional lifespan studies, therefore it is important to clearly define inclusion and exclusion criteria for participants and exercise caution when drawing conclusions.

A large number of adults are beginning to come forward for first ASD diagnosis in adulthood (Mukaetova-Ladinska *et al.* 2012; Povey *et al.* 2011; Stuart-Hamilton *et al.* 2009). Analysis of the characteristics of these adults provides one source of much-needed information about ASD in older adulthood, albeit with caveats that later-diagnosed samples may be particularly high-functioning or have survived without diagnosis (or with mis-diagnosis) due to particularities of personal qualities or circumstances. Investigating the differentiating characteristics of those individuals who do versus do not receive a diagnosis of ASD, may provide important information on key features for professionals involved in the diagnostic procedure. Information concerning the functional outcomes and comorbidities of individuals who receive an adult diagnosis of ASD will elucidate areas of concern - where ASD may confer an additional risk - which may require monitoring or intervention.

To our knowledge only one study to date has explored the characteristics of individuals seeking a diagnosis of ASD in adulthood. In a retrospective chart review in the Netherlands, of the 125 individuals seeking an ASD diagnosis after age 18 years, 105 (76% male) received a diagnosis of ASD (Geurts and Jansen, 2012). Of those receiving an ASD diagnosis, 34% had evidence of an intellectual disability (compared to 5% in those who did not receive a diagnosis) and 46% had a previous axis 1 diagnosis with high prevalence of mood and anxiety disorders (compared to 75% in those not diagnosed with ASD). Although those receiving a diagnosis of ASD had a high prevalence (53%) of previous contact with mental health services (compared to 20% in non-ASD), and were slightly younger at ASD assessment (ASD mean age=31; non-ASD mean age=35.5), there were few other differences

between the groups in terms of reason for contact with services or number of previous service contacts.

A high prevalence of comorbid psychiatric disorders including depression and anxiety have previously been reported in ASD (Ghaziuddin *et al.* 2002; Gillberg and and Billstedt, 2000), but it is unclear if this changes with age. In a large study of adults with and without ASD across the lifespan, levels of depression and anxiety were found to be high throughout adulthood in ASD compared to a healthy control group, but were on a par with individuals with other psychiatric diagnoses (Lever and Geurts, 2016). When exploring the effect of age on presence of psychiatric symptoms, reported symptoms reduced with older age for both individuals with ASD and typical adults, but this reduction was pronounced in the ASD group (Lever and Geurts, 2016). Higher levels of depression and anxiety symptoms as well as other comorbidities have been associated with presences of more severe ASD traits across the lifespan (Lever and Geurts, 2016), and among young and middle-aged adults (Garcia-Villamisar *et al.* 2015). Depression is common in typical ageing (Steffens *et al.* 2000), and if comorbid conditions such as depression change with age this may also influence severity of ASD traits. Further studies are required to examine the pattern of these associations.

Studies have suggested that symptoms of ASD change with age and may become less severe over time (Howlin *et al.* 2013), although few studies have yet examined later-life. In a lifespan study of adults with ASD (aged 19-79 years old) severity of ASD traits - measured by self-reported (Autism Quotient, AQ) and clinical observation (Autism Diagnostic Observation Schedule) - did not change with age (Lever and Geurts, 2016). However, higher ASD traits were associated with higher self-reported executive function problems among

young and middle-aged adults (Garcia-Villamisar *et al.* 2015). Studies have yet to establish whether ASD traits and comorbidities show the same pattern of change into later-life.

To date, few studies have examined cognition across the lifespan in ASD. One study of adults without intellectual disability, found poorer performance for ASD compared to typical adults on tests of executive function (generativity) and semantic memory, but age-related changes were not observed (Lever and Geurts, 2015). In contrast visual memory measures (where ASD adults performed better than typical adults), demonstrated an (expected) age-related decline in performance for typical adults, whereas ASD adults' performance showed no association with age (Lever and Geurts, 2015). This may suggest that age-related cognitive changes may not show the same pattern in ASD compared to typical adults.

The present study took a cross-sectional approach to examine the characteristics of a sample of adults referred to a specialist ASD diagnostic service. We examined the characteristics of those who received an ASD diagnosis compared to those who did not, to elucidate differences in demographic information, presence of comorbidities, self-report ASD traits and cognitive function. In order to examine ageing with ASD, we also examined association between age and both ASD traits and cognitive function in those with and without an ASD diagnosis. Finally we examined how the characteristics of individuals being referred to the diagnostic service had changed over time.

Methods

Participants

The Autism Diagnostic Research Centre (ADRC) accepts referrals to their adult service for individuals aged over 18 years of age with IQ in the normal range. Referrals are via General Practitioner surgeries (in the UK all individuals are registered with a family doctor General Practitioner surgery), or through Autism Oxford following a pre-assessment interview. Although not a service for those with a learning disability, adults with a previously identified learning disability may be referred to the ADRC but are typically referred on to other services before initial appointment. Where a learning disability is suspected on assessment, IQ is measured and individuals are referred on to appropriate services.

All 255 adults referred to the ADRC service between November 2007 and July 2014 were asked at the time of the assessment whether de-identified data from their assessment could be used for research purposes. 146 adults referred to the service gave written informed consent for data to be used for research purposes. Of these individuals, 100 adults received a diagnosis of ASD, and 46 did not (henceforth referred to as the non-ASD group). The non-ASD group were referred on to other specialist adult services, as appropriate. Characteristics of the ASD and non-ASD groups are shown in Table 1. Four individuals in the ASD group and two in the non-ASD group were found to have a learning disability, and were excluded from some later analyses (ASD n=96; non-ASD n=44).

Assessment

The ADRC diagnostic process includes interview and assessment by an expert team of clinical psychologists, neuropsychologists and psychiatrists with the precise assessment personalised to individual needs. The diagnostic assessment typically lasts a whole day and

includes prior completion of self-report questionnaires, recording demographic information, structured clinical interviews, neuropsychological assessment, and interactions in informal settings (e.g., during lunch). This paper will focus on demographic data, self- report questionnaire data and some limited neuropsychological data.

Demographic information including age, sex, highest education level, employment history, and any family history of developmental or psychiatric disorders was recorded through self and family member report. Individuals completed three self-report questionnaires examining characteristics associated with ASD, the Autism Quotient (AQ; Baron-Cohen *et al.* 2001), the Empathy Quotient (EQ; Baron-Cohen and Wheelwright, 2004), and the Systemising Quotient (SQ; Baron-Cohen *et al.* 2003). The AQ was developed as a brief, self-administered screening tool for autistic traits (Baron-Cohen *et al.* 2001). It has been shown to demonstrate good sensitivity and specificity, as well as being a useful tool for examining ASD traits both within ASD groups and the typical population (Kurita *et al.* 2005; Woodbury-Smith *et al.* 2005). The EQ and SQ were developed as self-report screening tools to examine traits common in ASD, namely the empathy component of social cognition in the EQ, and the drive to analyse and construct rules in the SQ (Baron-Cohen and Wheelwright, 2004; Baron-Cohen *et al.* 2003). The EQ and SQ have been shown to be reliable measures of independent ASD traits (Allison *et al.* 2011; Wheelwright *et al.* 2006). As well as scores on these questionnaires, we report the D-score, the difference between empathising and systemising quotients (Wheelwright *et al.* 2006).

Neuropsychological assessments were tailored to the individual, but most people received the Digit Symbol subtest from the Wechsler Adult Intelligence Scale III or IV (WAIS; Wechsler,

1997; Wechsler, 2008). In addition, approximately half of the sample completed the Vocabulary, Similarities, Arithmetic, Block Design, and Matrix Reasoning subtests of the WAIS.

Statistical Analysis

Differences between ASD and non-ASD groups on demographic information, ASD traits and cognitive function were assessed using ANOVA (for continuous variables) and Chi-square (for categorical variables). Associations between variables of interest and both age and referral rates were examined using Pearson's correlation coefficient or Linear Regression. Effect sizes were calculated using Cohen's d, where d≈.2 is considered "small", d≈.5 is considered "medium", and d≈.8 is considered "large" (Cohen, 1988).

Results

Group Differences between ASD and non-ASD groups

Demographic Information

Demographic information for the ASD and non-ASD groups is shown in Table 1. No group differences were noted between the ASD and non-ASD groups in terms of having a family history of ASD (see Table 1).

Age: Within the ASD group, age was fairly continuously distributed between 18-55 years old, with two older individuals being outliers in the present sample (males aged 63 and 74 years old). Skewness for the whole ASD sample (skewness=1.31) was reduced by removing these

two older outliers (skewness=.746), some analyses are therefore repeated with these individuals excluded. The non-ASD group showed a more normally distributed range of ages from 18-70 years (skewness=0.57). ANOVA demonstrated that individuals in the non-ASD group were older than individuals receiving an ASD diagnosis (see Table 1). This difference remained significant when the ANOVA was repeated excluding the two older ASD outliers ($F=16.39$, $p<.001$).

Sex: Within the group receiving an ASD diagnosis, 25% were female compared to 20% in the non-ASD group. No significant group differences were observed for gender (see Table 1). ANOVA were performed to check for any age-gender confound. No gender differences were observed for age in either group: ASD male mean age =30.99, sd=11.50, ASD female mean age =27.12, sd=7.63 ($F=2.44$, $p=.122$), (with the two older male outliers removed; mean age =29.90, sd=9.63; $F=1.69$, $p=.197$). The non-ASD group had only a small number of females, but again showed no age difference by gender; female mean age =34.88, sd=16.59; male mean age =38.00, sd=14.32 ($F= .295$, $p=.590$).

Employment/Education: Just less than half of each group were either studying or in employment (see Table 1). Twenty-five of individuals in the ASD group (25%) and fifteen of those in the non-ASD (34%) group were in paid employment. This difference was not statistically significant ($X^2=1.24$, $p=.265$). Although this is the proportion of individuals working, few were in full-time employment. Within the ASD group, fifteen individuals were in full-time employment, three were working part-time while studying, and seven were working part-time. For the non-ASD group, ten individuals were working full-time, one

worked part-time while studying, and four worked part-time. None of these frequencies was significantly different by group.

Co-morbidity: Information about comorbid disorders was also recorded, see Table 2. Presence of any psychiatric comorbidity was high, with high rates of depression and anxiety in both groups. No group differences in any comorbid diagnoses were noted between individuals receiving versus not receiving a diagnosis of ASD. It is worth noting that only two individuals with ASD had comorbid epilepsy; one of these individuals had a learning disability and the other had epilepsy possibly associated with alcohol misuse. In both groups, 4% of individuals were found to have a learning disability. As the ADRC service is specifically for adults with IQ in the normal range, these individuals were removed from subsequent analysis.

Self-report symptoms of ASD

Individuals receiving an ASD diagnosis reported significantly higher scores on the AQ measure, compared to individuals who did not receive a diagnosis (AQ, ASD=35.56; non-ASD =31.43), see Table 3. Cohen's effect size value (d=.48) suggested a moderate practical significance. It is worth noting that for both groups these scores are high compared to typical population ratings (AQ=15; Wheelwright *et al.* 2006). No group differences were observed on self-ratings on the EQ, the SQ, or the D-score, see Table 3. The EQ scores for both groups reported here (ASD=19.60; non-ASD =21.68) are lower than previously reported population mean (EQ=44.3; Wheelwright *et al.* 2006). SQ ratings from the two groups (ASD=60.51; non-ASD =56.60) are in line with previous population means (SQ=55.6; Wheelwright *et al.*

2006). For SQ, EQ and D-scores Cohen's effect size values (d≤.20) suggested a small difference. Please note that one individual in the non-ASD group did not complete the SQ, therefore n=43 for the SQ and D-score.

Sex: Sex differences on the self-report scales were explored. For the ASD group, although no significant sex differences were observed, females reported higher scores on the AQ compared to males, see Table 4. No sex differences were observed on any self-report scale in the non-ASD group, but the number of females in this sample was very small (n=8) and results should be treated with caution. For both ASD and non-ASD groups, AQ scores were higher among females and both groups demonstrated moderate Cohen's effect size value (d≥.40).

Cognitive Ability

As previously stated, the ADRC service is specifically for individuals with abilities in the normal range, therefore IQ assessment is not routinely performed and the number of individuals completing subtests on the WAIS was variable. However most individuals completed the Digit Symbol subtest from the WAIS (ASD n=95; non-ASD n=41); no group differences were observed on this measure (ASD mean=8.43, sd=3.31; non-ASD mean=9.29, sd=3.65; F=1.82, p=.179).

Approximately half of each group (ASD n=46-48; non-ASD n=24-25) also completed some or all of the following subtests from the WAIS: Vocabulary, Similarities, Block Design, Matrix Reasoning and Arithmetic. No significant differences between those receiving and not

receiving a diagnosis of ASD were found (all p>.05; results not shown; data available from corresponding author).

Associations with Age in ASD and non-ASD groups

Self-Report Symptoms of ASD

Correlations with age were performed on the ASD sample and repeated excluding the two older outliers, and for the non-ASD group separately. Within the whole ASD group, older age was associated with higher (i.e., more severe) scores on the AQ, SQ and D-score. These results became more robust when excluding the two older outliers, see Table 5. Effect sizes was calculated using Cohen's d, and correlations with age were in the medium range for AQ and D-scores, and high for the SQ score. No such association between age and self-report scales was observed for the non-ASD group, although the Cohen's effect size for the SQ-age correlation was in the moderate range (d=.59). Regression analyses demonstrated that for the ASD group AQ scores increased by 2.19 points with every decade and SQ scores increased 10.4 per decade, see Table 5 and Figure 1 for details. Analyses were reviewed to assure that all associations were linear; linear models best explained the data and no model was more robust using non-linear models.

Cognitive Ability

Associations between available cognitive variables and age were examined for each group separately. For the ASD group, Digit Symbol performance correlated significantly with age (r=.27, p=.008) indicating better performance among older adults; excluding two older outliers does not substantially alter the results (r=.29, p=.005). The correlation between Digit

Symbol and age did not reach significance for the non-ASD group (r=.13, p=.423). Fisher's r statistic was used to assess whether correlations were significantly different between the two groups; age-correlations did not differ significantly (z=0.76, p=.447).

For the ASD group, Block Design correlated significantly with age; older ASD adults demonstrated better performance (r=.29, p=.045; excluding older outliers, r=.30, p=.042) whereas this pattern was not observed for non-ASD adults (r=-.026, p=.901). No significant correlations with age were observed for Vocabulary, Similarities, Matrix Reasoning or Arithmetic in the ASD or non-ASD groups (all p>.05). Age-correlations did not differ significantly between the two groups measured using Fisher's r statistic (p>.05).

Service Referrals

Individuals included in this analysis were referred to the ADRC over a seven year period. In order to assess whether there has been any change in the type of referrals made to the ADRC over time which might affect the present data, correlations were performed using sequentially assigned ID numbers as a proxy for date of assessment, see Table 6 for details. For the whole sample (ASD + non-ASD), age correlated significantly with date of assessment (r=.30, p<.001) indicating that the number of older adults being assessed for ASD diagnosis had increased over the seven year period measured. Among individuals diagnosed with ASD, a positive correlation was noted between when individuals were assessed and age, indicating that in recent years a greater number of older individuals are being referred for diagnosis. Results are shown in Table 6. More recently referred individuals with ASD also reported lower EQ and higher SQ scores, resulting in higher D-scores. No associations between date

of referral and AQ scores were noted for individuals with ASD. For non-ASD individuals, SQ scores correlated significantly with referral date, with more recent referees reporting higher SQ scores. There were no associations between date of diagnosis and Digit Symbol score for either group.

Discussion

This paper describes a group of individuals referred to a specialist ASD diagnostic clinic as adults. A major difference from many other clinics is the low rates of learning disability in this sample (Matson and Shoemaker, 2009; O'Brien and Pearson, 2004). This largely reflects the remit of the ADRC, which does not typically see adults with learning disability. As such, this sample is atypical compared to many clinic-based samples, although it also presents a hither to under-investigated group of individuals with ASD. Within this sample, there were no differences in demographic data or personal and family history between those individuals who received a diagnosis of ASD compared to those who did not. This similarity may reflect some characteristics of this fairly high-functioning sample or reason for referral (in both groups), for example adults seeking a referral after receiving an ASD diagnosis for a child in the family.

It is worth noting that approximately half of the individuals with ASD described here were in employment or education. Despite this, the proportion of individuals in this group working full-time was only 15%, which is equivalent to other surveys of employment in ASD (Bancroft *et al.* 2012; Taylor *et al.* 2015), suggesting that even in this high functioning group there are factors limiting access to employment prior to diagnosis. The rates of

epilepsy among individuals with ASD in this sample are notably lower than rates typically reported in the ASD population. Previous studies have reported epilepsy rates among individuals with ASD of between 5% and 40% (Tuchman and Rapin, 2002). The rate reported here of 2 out of 100 (2%) is more in keeping with rates in the general population (2.9%; U.S. Department of Health and Human Services, 2007) and very low for typical ASD samples. However, the current sample does not include individuals with learning disabilities, and previous studies have suggested that intellectual impairment mediates the association between ASD and epilepsy (Amiet *et al.* 2008). It is worth noting, that of the two individuals with ASD who had epilepsy, one was found to have a learning disability (and was not included in the analysis) and the other had epilepsy possibly associated with alcohol misuse. Epilepsy may be one of the features that brings individuals to earlier clinical attention and hence is less prevalent in a sample specifically selected for late adult diagnosis. Presence of psychiatric comorbidities were common in this group of individuals with ASD (58%) and comparable to other studies (41% in overall sample; 65% in those with mild learning difficulties; Morgan *et al.* 2003). Depression/anxiety were present in approximately one third of this group of individuals with ASD; a similar proportion to that found in a recent study where adults with ASD reported their own experiences of depression and anxiety (Moss *et al.* 2015). In a larger sample including adults with learning disability rates of depression were similar and even higher in those with mild learning disability (46%; Morgan *et al.* 2003).

All individuals referred to the ADRC completed self-report measures of symptoms associated with ASD (AQ, SQ and EQ). AQ scores were significantly higher for those individuals who received an ASD diagnosis compared to those who did not, but no differences were observed on EQ or SQ. It is worth noting that AQ scores for the ASD group reported here (AQ=35) are slightly higher than those reported in other ASD samples (AQ=30; Wilson *et al.* 2014);

whereas the non-ASD mean scores (AQ=31) are notably higher than rates in the typical population (AQ=15; Wheelwright *et al.* 2006) perhaps reflecting the factors that led to ASD being raised as a possible diagnosis for these individuals. For other ASD symptom questionnaires, EQ scores for both the ASD group and the non-ASD group are low compared to previously reported population means (EQ=44.3; Wilson *et al.* 2014) and SQ scores are in-line with the population mean (SQ=55.6; Wilson *et al.* 2014).

Within the ASD group although gender differences on AQ scores do not reach significance, women's ratings (AQ=38) were higher than men's (AQ=35). The effect size for this gender difference is moderate, which suggests that lack of significance may be related to the relatively modest number of women (n=25) compared to men (n=71). No gender differences were observed for EQ or SQ scores within the ASD group. It is worth noting that within this sample, women were at least as likely as men to receive an ASD diagnosis, once they reached ADRC services. In this sample 67% of men and 73% of women assessed received an ASD diagnosis.

Associations with age for self-report autism trait questionnaires were mixed in the ASD group. Older age was associated with higher scores on AQ and SQ measures (although AQ-age correlations did not reach significance when including two older outliers), whereas EQ was not associated with age. The association between age and AQ scores in the ASD group may suggest that autism traits increase with age. Based on the data presented in this paper, AQ scores increase by 2.19 points per decade. Although the comparison group here could not be classified as "typically developing", age-AQ associations are not observed in the non-ASD group. It is worth noting that these high levels of ASD traits in ageing are consistent with a

recent study demonstrating lower theory of mind scores with increasing age in an adult lifespan sample with typical IQ, although theory of mind difficulties were not noted in those aged over fifty (Lever and Geurts, 2015). SQ scores were shown to increase by 10.4 points per decade in the ASD group. The association between SQ (the tendency to analyse and extract rules) and age could be due to either a general age-related change that also occurs in typical developing individuals, or a worsening of ASD traits occurring when ageing with ASD. Perhaps systemising traits increase with age in the typical developing population as well as in ASD; in the non-ASD group the age-SQ correlation shows a trend towards significance and a medium effect size (Cohen's d). Unfortunately, as far as we are aware, data for self-report ASD traits in ageing are limited. An alternative interpretation of the age-SQ correlations is that systemising features become more pronounced in later-life only within the ASD population. However this "worsening" of symptoms does not fit with anecdotal reports of a general improvement in symptoms with age. It may be that *insight* improves with age leading to poorer self-ratings, and it would be interesting to see if others-report of traits changed to the same degree with age. Longitudinal studies are required to investigate these possibilities.

The finding of higher ASD traits in later life is rather surprising as one may expect that "more severe" cases of ASD should be identified by services earlier in life. However, the greater self-rated severity of ASD traits in the older individuals – who are largely high functioning - may be consistent with lifetime development of coping strategies that do not reduce traits but mitigate their effects, thus reducing likelihood/speed of referral to clinical services. It is worth noting that in the ASD group only, older age was associated with better scores on the Digit Symbol and Block Design subtests of the WAIS, demonstrating that older adults had better test performance on tasks that typically decline with increasing age. (No significant

group differences on cognitive measures were observed between the ASD and the non-ASD groups.) Although showing a different pattern of results to here, a recent cross-sectional study has suggested that visual memory performance shows a positive relationship with age in ASD compared to age matched controls (Lever and Geurts, 2015). These results may suggest that higher ability level may be a protective factor and may be one of the reasons why older individuals only now receiving a diagnosis of ASD have managed without service input for so long. However, the cross-sectional associations reported here may also reflect increased awareness of the milder spectrum of ASD in younger individuals, their families and health professionals – i.e. subtle ASD signs are being picked up early (Hansen *et al.* 2015; Rutter, 2005). Alternatively, the increasing severity of ASD symptoms with age may reflect a referral bias, where young adults with mild symptoms (or their parents) may be motivated to seek a diagnosis as a way of accessing support, whereas older adults with mild ASD traits may not.

Unfortunately information describing why these individuals were not identified earlier in life is not available, but the high rates of comorbid psychiatric diagnoses in the ASD group (58%) may be a contributing factor. High rates of ASD traits have been noted among older adults with depression (31% scoring above cut-off on the AQ), compared to lower rates among non-depressed older adults (6.1%), which may suggest ageing alone is not associated with increasing ASD traits (Geurts *et al.* 2016). Comorbidities, especially depression and anxiety, may have masked ASD traits, and earlier misdiagnoses may have delayed referral to appropriate services and diagnosis. Also of note is the association between referral date and age, suggesting that across the period of this service, the age of referees is increasing. Although this may reflect the availability of a diagnostic service for adults with ASD, it may

also reflect the increase in awareness that will allow for older adults with ASD to receive a diagnosis and hopefully, the support they require.

We acknowledge several limitations to this study. Data were collected through a specialist clinical diagnostic service for ASD, where adults are expected to have IQ in the normal range. Thus the sample does not reflect the ASD community as a whole. However, this group of individuals with ASD with IQ in the normal range and not receiving a diagnosis until adulthood have not been previously widely studied. Despite this group being quite homogenous in terms of IQ in the normal range, age effects and group differences were observed, suggesting that such groups can inform research on ageing with ASD. In addition, no typically developing control group was available. The group used here for comparison were themselves referred with suspected ASD, therefore differences between the groups reported here may underestimate differences compared to typical adults. Despite this, significant group differences were observed particularly on autism traits measured by the AQ. It is also possible that a self-selecting bias may affect this data, as only individuals giving consent for their information to be used were included.

Research examining ASD across the lifespan is lacking. In this clinic-based research we describe high functioning individuals receiving a diagnosis of ASD for the first time as adults. Despite the relative "lateness" of the diagnosis, self-report levels of autistic traits (AQ) were high and some traits increased as age increased within the sample. Ability level may be one of the factors that "protects" individuals from receiving a diagnosis earlier in life. Despite all individuals functioning with IQ in the normal range, rates of employment were lower than the population average and in line with rates for the ASD population as a whole.

This may reflect high levels of psychiatric comorbidity (in spite of low levels of epilepsy) even in this high functioning group. Although this study provides valuable information on a little-studied group, it does not allow for the examination of individual differences and change across the lifespan. Future longitudinal studies across the adult lifespan are required to understand the cognitive, social and behavioural changes that occur with ageing in ASD.

Ethical Approval

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. Informed consent was obtained from all individuals included in this study.

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Figure Headings

Figure 1: Scatterplots showing the association between age and both AQ and SQ scores for ASD individuals (green) and non-ASD individuals (blue).

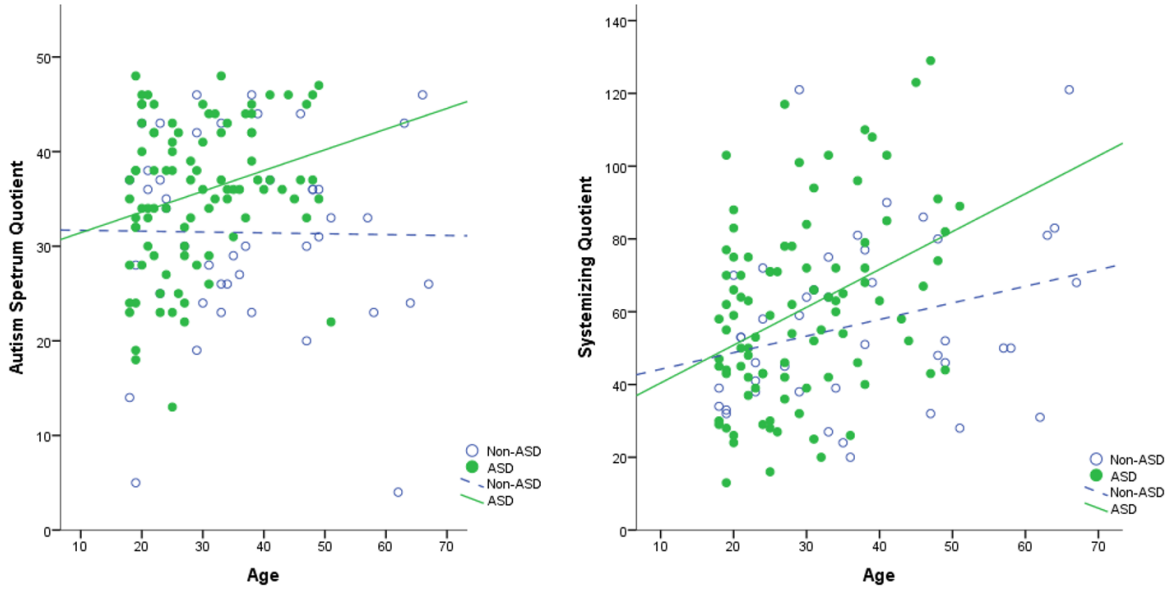

Table 1: Demographic information on individuals receiving versus not receiving an ASD diagnosis and group differences assessed by ANOVA or X^2 as appropriate.

	ASD diagnosis N=100	**Non-ASD N=46**	**Group differences**
Age (mean, sd) Range ǂ	30.02 (10.77) 18-74	37.20 (14.36) 18-67	**F=11.25, p=.001**
Gender % (m,f)	75%,25%	80%, 20%	X^2=.521, p=.470
Highest Educational Level ± (%)			X^2=.6.56, p=.476
No qualifications	9%	6.5%	
GCSE level	30%	22%	
Post-16 qualifications	5%	4%	
A-level	27%	24%	
Diploma	3%	2%	
Degree	13%	24%	
Post- graduate	3%	6.5%	
(Missing data)	(10%)	(10.9%)	
In Employment/ Education* (yes, no, retired)	45%, 42%, 2%	41%, 41%, 2%	X^2=.031, p=.859 (retirees omitted)
Employment details			
None	10%	6.5%	-
None-unable to cope	5%	15%	
Voluntary work	2%	2%	
Working or seeking work	49%	50%	
Studying	21%	9%	
Retired	2%	2%	
(Missing data)	(11%)	(15.2%)	
Family History of ASD (N with ASD diagnosis, no diagnosis)	7, 93	5, 41	X^2=.625, p=.429
Family History			
None	77%	80%	-
ASD diagnosed	7%	11%	
ASD suspected	4%	2%	
Other Dev/Psych	12%	6.5%	

ǂ The age distribution for the ASD group was fairly continuous between 18-55 years old, with two older individuals being outliers (aged 63 and 74). The non-ASD diagnosis group is more normally distributed (skewness=.568) with a continuous age distribution between 18-70 years old.

± GCSE level= GCSE or equivalent (UK school exams taken at age 16); Post-16 qualifications= City & Guilds and other post-GCSE but not equivalent to A-level qualifications; A-level= A-level (UK school exams taken at age 18) or equivalent level 3

qualifications ie BTEC, Access to higher education; Diploma= Higher National Diploma or equivalent; Post-graduate=Masters or PhD level qualification.

* In Employment/Education: yes=employed, studying or volunteering; no=any not currently working or studying including seeking work and given up work due to pressure (excludes retirement); retired=retired from working life (NB retirees are omitted from the statistical analysis due to small N).

Significant results are marked in bold.

Table 2: Comorbidity information on individuals receiving versus not receiving an ASD diagnosis

	ASD diagnosis N=100	**Non-ASD N=46**	**Group differences measured by X^2**
Any Psychiatric Comorbidity (yes)	58%	59%	X^2=.006, p=1.00
Depression (yes)	35%	30%	X^2=.294, p=.707
Anxiety Disorders (yes)	28%	20%	X^2=1.19, p=.312
Other Adult Psychiatric Disorders (yes)	11%	15%	X^2=.518, p=.588
Personality Disorder (yes)	4%	9%	X^2=1.34, p=.261
Learning Disability (yes) ǂ	4%	4%	X^2=.010, p=1.00
Previous Developmental Disorders (yes)	11%	18%	X^2=1.96, p=.197
Epilepsy (n)	2 ±	0	-
Birth Trauma (yes)	5%	2%	X^2=.639, p=.665
Irritable Bowel Syndrome (yes)	7%	0	-

ǂ As identified in the education system or by recent diagnosis (IQ<70).

± One individual had learning difficulties; and one individual has epilepsy thought to be due to alcohol dependence.

Significant results are marked in bold.

Table 3: Mean and standard deviations for Self-report questionnaire data for ASD versus non-ASD diagnosis excluding individuals with learning difficulties.

	ASD diagnosis N=96	**Non-ASD N=44**	**ANOVA for group differences**	**Effect size (Cohen's d)**
AQ	35.56 (7.74)	31.43 (10.11)	**F=7.05, p=.009**	.48 *
EQ	19.60 (10.32)	21.68 (12.02)	F=1.10, p=.296	.19
SQ	60.51 (25.04)	56.60 (23.67)	F=.747, p=.389	.16
D score	.171 (.12)	.147 (.15)	F=1.23, p=.269	.20

Significant results are marked in bold; moderate or higher effect sizes are marked by *

Table 4: Questionnaire data for ASD versus non-ASD diagnosis by gender excluding individuals with learning difficulties; Means (standard deviations)

	ASD diagnosis N=96				**Non-ASD N=44**			
	Males n=71	**Females n=25**	**ANOVA for gender differences**	**Effect size (Cohen's d)**	**Males n=36**	**Females n=8**	**ANOVA for gender differences**	**Effect size (Cohen's d)**
AQ	34.77 (7.94)	37.80 (6.78)	F=2.88, p=.093	.40 *	30.56 (10.44)	35.38 (7.78)	F=1.51, p=.227	.52 *
EQ	20.04 (10.34)	18.36 (10.37)	F=.489, p=.486	.16	22.25 (12.54)	19.13 (9.63)	F=.437, p=.512	.28
SQ	60.83 (25.59)	59.60 (23.88)	F=.044, p=.834	.05	57.20 (25.13)	54.00 (16.84)	F=.117, p=.735	.15
D-score	.17 (.12)	.18 (.11)	F=.056, p=.813		.14 (.13)	.15 (.09)	F=.018, p=.893	.09

Significant results are marked in bold; moderate or higher effect sizes are marked by *

Table 5: Correlations with age for Questionnaire Data by diagnostic group excluding individuals with learning difficulties

	ASD diagnosis – whole sample	**ASD diagnosis – excluding older outliers**	**Non-ASD group**
AQ			
N	96	94	44
Correlation	r=.196, p=.055	**r=.260, p=.012**	r=-.013, p=.933
(Cohen'd effect size)	(d=.40) *	(d=.54) *	(d=.03)
Linear Regression	F=3.77, p=.055	F=6.64, p=.012	F=.007, p=.933
	R^2=.039	R^2=.067	R^2<.001
Unstandardised Beta for Age	Beta=.142	Beta=2.19	Beta=-.009
Change in AQ per decade	1.4	2.2	-.09
EQ			
N	96	94	44
Correlation	r=.018, p=.860	r=.018, p=.863	r=.131, p=.396
(Cohen'd effect size)	(d=.04)	(d=.04)	(d=.26)
Linear Regression	F=.031, p=.860	F=.030, p=.863	F=.737, p=.396
	R^2<.001	R^2<.001	R^2=.017
Unstandardised Beta for Age	Beta=.018	Beta=.020	Beta=.108
Change in EQ per decade	0.2	0.2	1.08
SQ			
N	96	94	44
Correlation	**r=.345, p=.001**	**r=.378, p<.001**	r=.283, p=.066
(Cohen'd effect size)	(d=.74) *	(d=.82) *	(d=.59) *
Linear Regression	F=12.71, p=.001	F=15.35, p<.001	F=3.57, p=.066
	R^2=.119	R^2=14.3	R^2=.080
Unstandardised Beta for Age	Beta=.805	Beta=1.04	Beta=.456
Change in SQ per decade	8.1	10.4	4.6
D-score			
N	96	94	44
Correlation	**r=.239, p=.019**	**r=.264, p=.01**	r=.107, p=.493
(Cohen'd effect size)	(d=.49) *	(d=.55) *	(d=.22)
Linear Regression	F=5.68, p=.019	F=6.89, p=.01	F=.479, p=.493
	R^2=.057	R^2=.070	R^2=.012
Unstandardised Beta for Age	Beta=.003	Beta=.003	Beta=.001
Change in D-score per decade	0	0	0

Significant results are marked in bold; moderate or higher effect sizes are marked by *

Table 6: Referrals over time: Correlations between sequentially assigned ID as a proxy for date of assessment and descriptive variables.

	ASD diagnosis – whole sample				**Non-ASD**			
	n	**r**	**p**	**Effect size (Cohen's d)**	**n**	**r**	**p**	**Effect size (Cohen's d)**
Age	96	r=**.275**	**p=.007**	**.57 ***	44	r=.271	p=.075	.56 *
AQ	96	r=.130	p=.207	.26	44	r=-.164	p=.289	.33
EQ	96	r=**-.272**	p=**.007**	**.57 ***	44	r=.225	p=.141	.46 *
SQ	96	r=**.320**	p=**.002**	**.68 ***	43	r=**.338**	p=**.027**	**.72 ***
D score	96	r=**.382**	**p<.001**	**.83 ***	43	r=.092	p=.556	.19
Digit Symbol	95	r=.111	p=.285	.22	41	r=-.046	p=.775	.09

Significant results are marked in bold; moderate or higher effect sizes are marked by *