# Characteristics of older autistic adults: A systematic review of literature

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**Abstract**

Autism is a neurodevelopmental condition that affects individuals across their lifetime, though the effects of ageing in older adulthood are poorly understood to date. This systematic review assessed six characteristics in older autistic adults (cognitive functioning, co-occurring difficulties, autism symptom severity, social integration, adaptive functioning, language processing). A total of 41 studies met inclusion criteria, 16 of which included autistic adults with intellectual disability, and three were longitudinal in nature. Findings show differing effects of ageing across the six domains. Factors contributing to discrepancies such as age and IQ differences, methodology, and healthy survivor effect are discussed. The need for more longitudinal studies to investigate changes across developmental stages alongside other limitations, future directions, and clinical implications are discussed.

***Keywords:*** Autism, older adults, characteristics, outcome, prognosis, cognitive, social, comorbid difficulties

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental condition characterised by social communication difficulties and restricted and repetitive behaviours and interests (American Psychiatric Association, 2013) which begin in infancy and persist across the lifespan (Cederlund et al., 2008; Geurts & Vissers, 2012; Howlin et al., 2004). Until recently, psychiatric nosology distinguished between different sub-types of autism, including 'autistic disorder', 'Asperger's syndrome' and 'pervasive developmental disorder not otherwise specified' (PDD-NOS). In 2013, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) subsumed these different categories within the overarching diagnostic entity 'autism spectrum disorder'. In the current review, in line with preferences of many members of the autism community (Kenny et al., 2016), we use identity-first language wherever possible, and use the term autism as a direct synonym for the DSM-5 term 'ASD'.

As a result of changes in the diagnostic criteria and improved knowledge about the heterogeneity of presentation of autism, prevalence estimates for autism have been increasing over the past five decades, with recent estimated prevalence rate reaching 1 in 54 children in the US (Center for Disease Control and Prevention, 2019), which equates to a 37-fold rise from the approximated 5 per 10,000 in the 1960s and 1970s (Newschaffer et al., 2007). Despite autism being a lifelong condition, only a small proportion of studies have been carried out to examine the prognosis of autistic children and adolescents as they grow older, and understanding ageing in autism has been identified as an important priority for both researchers and clinical practitioners (Nicolaidis, 2018; Piven et al., 2011).

To date, only a limited number of studies explored the progress of autistic children and adolescents who entered adulthood (Levy & Perry, 2011; Magiati et al., 2014), these have had mixed findings with regards to the stability and deterioration in social functioning, language skills and cognitive abilities, in contrast to improvements in adaptive functioning and severity of autism symptoms. Inconsistent findings might be due to the use of small and highly heterogeneous samples, and the variability in measures and informants used to evaluate characteristics.

Research exploring autism in late adulthood is even scarcer. It remains largely unknown as to whether the difficulties autistic individuals experience in their childhood and earlier adulthood persist

through to later life. It should be noted that ageing itself may bring about many physical and psychological changes (Beekman et al., 1998; Galluzzi et al., 2008; MacPherson et al., 2002; Wolitzky-Taylor et al., 2010), and having an autism diagnosis might add another layer of complexity to these changes. Currently there are several different hypotheses regarding ageing in autistic adults compared with neurotypical adults. These include proposals that autistic older adults may i) experience similar or *parallel* patterns of age-related decline; ii) are predisposed to more *accelerated* age-related decline, or iii) are *safeguarded* against some aspects of ageing due to biological and cognitive differences (Bathelt et al., 2020; Geurts & Vissers, 2012; Oberman & Pascual-Leone, 2014). Therefore, it is important to gain better insight into the prognosis of individuals with autism in late adulthood so as to develop appropriate psychosocial and support interventions best suited to their unique pattern of age-related changes over time (Davids et al., 2016; Lever & Geurts, 2016b; Patra, 2016).

Previous reviews of the emerging literature on autistic individuals in late adulthood have found some evidence that autistic symptoms (especially behavioural symptoms) are associated with poorer quality of life as well as poorer physical and psychological health and these tend to persist in late adulthood (Mukaetova-Ladinska et al., 2012; Patra, 2016; van Niekerk et al., 2011). These reviews have provided valuable insight into characteristics of older adults with autism and what is required to improve the support and care for this group. They were, however, associated with limitations such as lack of clear study inclusion/exclusion criteria, limited evaluation of the quality of the studies and non-systematic strategies for their literature search.

## Present Review

The current review followed previous research and a recent National Autistic Society Report (2013) in regarding autistic individuals over the age of 50 as older adults (Totsika et al., 2010). Given the importance of understanding the unique needs of older autistic adults, in order to understand their changing needs and ensure they receive appropriate support, an updated and systematic review of the literature is warranted to account for the limitations of the previous reviews, and to evaluate new studies that were published since the latest review in 2016. The present review aimed to explore the characteristics of older autistic adults in the existing literature by examining the

prognosis of this population across six different domains (Magiati et al., 2014): autism symptom severity, cognitive functioning, adaptive functioning, language and communication, social integration and co-occurring difficulties or conditions.

## Methods

### Search strategy

A systematic literature search was conducted in MEDLINE, PsycINFO, and PubMed up to and including 28th May 2020 to identify all the studies relating to characteristics of older autistic adults. Title, abstract and keywords searchers were applied, and an age filter (including middle age (40-60); aged (65 years and older) or very old (age 85 years and older)) was also employed in the search. The search contained the following search terms including variants and synonyms, specified below:

1. Autism (autis* OR Asperger* or ASD)

   AND

2. Older adults/Aging (old* OR elder* OR senior OR ageing)

In order for studies to be identified in the above search, the title or abstract had to contain at least one search term from each of the two groups. Only studies that were written in English and published in peer-reviewed journals were included in the search. The searches on PsycINFO, MEDLINE and PubMed identified 661, 1223, and 5028 records respectively. 651 papers were excluded due to duplication leaving 6261 studies. The titles and abstracts of the identified studies were then screened to see if they were relevant to the topic of the present review. Full texts of papers that were deemed to be relevant were read in detail to determine if they met the inclusion criteria for the review. The bibliography of selected studies was then scanned to identify further relevant studies (See Figure 1 for PRISMA Flowchart).

[INSERT FIGURE 1]

### Inclusion criteria

In order to be eligible for inclusion, studies had to fulfil the following criteria:

i) Clinical participants must have an autism diagnosis

   **OR**

   score above cut-off on an autism screening/diagnostic measure

ii) All participants (clinical or control participants) have to be 50 years old or above

**OR**

the age range of participants included people over the age of 50 and age was used as a predictor of outcome.

iii) A focus on behavioural and/or psychological characteristics of individuals with autism in late adulthood. In other words, studies needed to provide information in at least one of: autism symptom severity; cognitive abilities; adaptive functioning; social outcomes; co-occurring difficulties and disorders; language processing.

iv) Report of quantitative results.

v) Studies must employ at least one quantitative measure of one of the above characteristics to be considered for inclusion.

vi) Studies must be written in English and published in a peer-reviewed journal.

**Article selection**

All titles and abstracts of the 6261 papers were read to decide whether they fulfil the inclusion criteria. 6088 papers were eliminated on the basis of examination of title and abstract alone. The remaining 173 papers were subject to full-text review to decide if they met all the inclusion criteria. The majority of the studies were excluded on the basis that they did not meet the age criterion or did not look at age as a predictor of characteristics. Others were excluded because they did not include any behavioural measures of characteristics or because they were review papers. When there was uncertainty as to whether a paper was eligible for inclusion for the present review, the research supervisor was consulted to decide if the paper fulfilled the inclusion criteria.

A total of 41 papers were included in the review (10 from searching the bibliography of selected papers). The PRISMA flow diagram (Figure 1) illustrates the inclusion and exclusion of papers from the initial search results.

**Critical appraisal**

For all the 41 included studies, the first co-author (INITIALS ANONYMISED FOR REVIEW) measured quality of studies with the quantitative scale of the QualSyst (Kmet et al., 2004). This scale is comprised of 14 items (example items are: method of subject selection is described and

appropriate, appropriate sample size, analysis is described and appropriate) to evaluate quality of quantitative studies with diverse study designs. Each of the 14 QualSyst items is scored as either not been met (0), partially met (1), totally met (2) or not relevant to the article being evaluated (N/A). Not applicable items are not included in the calculation of the summary score. An overall summary score (ranging from 0-1) can be calculated for each study by adding all the relevant item scores together and dividing it by the total possible score (Stott et al., 2017). 1/3 of the included studies were randomly selected to be rated by the first author (INITIALS ANONYMISED FOR REVIEW) to check for inter-rater reliability. Where discrepancies arose, supervision was sought from the senior author to reach a final decision.

## Results

### Designs and sample characteristics

38 of the 41 studies that fulfilled the inclusion criteria for the review were cross-sectional, and three studies were longitudinal (Howlin et al., 2013; Moss et al., 2015, 2017). Sample sizes of the included studies ranged from 17 (Linke et al., 2020) to 6,649 (Rydzewska et al., 2018, 2019) for the autism group, and 18 (Crane et al., 2009) to 3,739,935 (Rydzewska et al., 2018, 2019) for the neurotypical group (NT). A total of sixteen studies included autistic participants with intellectual disability (ID) or with IQ less than 70 in adulthood, and had a wide range in sample size from a very small proportion of overall participant pool (n = 3, 3.3% of overall autism sample, Hwang et al., 2020), to a large proportion of the autism sample (n = 443, 62.2% of overall autism sample, Bishop & Seltzer, 2012). Of the 41 studies, only one study (Tse et al., 2019) provided information about an a priori power calculation, another study discussed the effect of combining data from a number of studies to maximise power (Totsika et al., 2010), two studies were based on the Scottish National Census 2011 data (Rydzewska et al., 2018, 2019), and three studies were based on a longitudinal cohort of participants followed from childhood (Howlin et al., 2013; Moss et al., 2015, 2017). Therefore, it may be that some studies are underpowered due to the small sample size, which can impact both non-significant findings (especially in smaller studies) due to Type II errors, but also lead to potentially significant findings with low reproducibility due to inflated Type I errors.

Tables 1-6 detail the main characteristics of the 41 studies included in the current review broken down by the different domains of focus. Mean age in years for autistic participants ranged from 17 (Minshew & Hobson, 2008) to 65.8 (Geurts et al., 2020), and from 19 (Minshew & Hobson, 2008) to 69.7 (Geurts et al., 2020) for NTs. Out of the 41 included studies, 26 studies had a mean age of less than 50 years for their participants overall and were included in the current review as age was entered as a predictor variable and viewed as a continuum as per the inclusion criteria stated above. Percentage of male participants ranged from 44.57% (Hwang et al., 2020) to 100% (Bastiaansen et al., 2011; Baxter et al., 2019; Geurts et al., 2020; Starkstein et al., 2015; Walsh et al., 2019) for the autism group, and from 20% (Hwang et al., 2020) to 100% (Bastiaansen et al., 2011; Baxter et al., 2019; Geurts et al., 2020; Walsh et al., 2019) for NT group. Mean IQ for the 26 studies without participants with ID ranged from 102 (Linke et al., 2020) to 118.17 (Crane et al., 2009) for autism group, and from 101.5 (Bastiaansen et al., 2011) to 120 (Linke et al., 2020) for NT group. 23 of the 41 studies required participants to have a clinical diagnosis of autism prior to participating in the study, as well as verifying the diagnosis by scoring above cut-off on autism measures (e.g. Autism Diagnostic Observation Schedule (ADOS), Autism Quotient (AQ) etc). The remaining 18 studies had a less stringent inclusion criteria for their autistic participants who only needed to fulfil either one of the two criteria in order to take part in the study.

Of the 25 studies with participants without ID, 10 studies were conducted in the Netherlands, eight in the UK, six in the USA, and one in Australia. Of the 16 studies with participants with ID or have IQ < 70 in adulthood, seven were conducted in the USA, six in the UK, one in Sweden, one in Australia, and one joint between USA and Australia.

**General limitations of studies**

QualSyst (Kmet et al., 2004) was used to evaluate the quality of all the included studies in the review and the overall rating for each study can be found in Tables 1-6. A moderate degree of reliability was found between the two raters' quality appraisal measurement. The average measure intra-class correlation was .83 with a 95% CI [.445, .948], ($F(12, 12) = 5.662$, $p = .003$). 37 of the 41 studies met a more stringent cut-off score of 0.75, indicating excellent quality. Of the remaining 4 studies, 3 studies (Crane et al., 2009; Kern et al., 2007; Wise et al., 2017) were rated just below the

cut-off score (0.73) suggesting good quality, with only one study (Minshew & Hobson, 2008) scored 0.59 meeting a more liberal cut-off score of 0.55, suggesting fair quality. 12 of the 41 studies had a relatively small sample size (i.e., below 40 participants per group). With the exception of the three longitudinal studies following children who received an autism diagnosis in childhood into adulthood (Howlin et al., 2013; Moss et al., 2015, 2017), the cross-sectional nature of the majority of the studies means that no firm conclusion can be drawn on how age-related changes unfold across the lifespan in autistic individuals.

**Characteristics**

Of the six characteristics described in the framework, all were examined in the reviewed studies: co-occurring difficulties or conditions (5 studies without ID; 8 studies with ID); cognitive abilities (10 studies, all without ID); autism symptom severity (7 studies without ID; 3 studies with ID/IQ < 70 in adulthood); social integration and quality of life (1 study without ID; 3 studies with ID/IQ < 70 in adulthood); adaptive functioning (3 studies with ID); and language processing (4 studies without ID). Below is a more detailed discussion of each of the characteristics.

**Co-occurring difficulties or conditions.** A summary of study findings is shown in Table 1. In studies which included participants without ID (Table 1a), one found that having a diagnosis of autism increased the odds of having poorer general health by 5.1 times compared to NT adults, and 66.2% of autistic adults aged 65 years and above reported poorer general health compared to 45.6% of NT adults (Rydzewska et al., 2019). Older autistic adults experienced elevated rates of blindness, deafness, physical disability and other conditions compared to their NT peers (Rydzewska et al., 2018), as well as greater difficulties in motor functioning including strength, flexibility and dexterity and coordination (Linke et al., 2020). For mental health, the most frequent co-occurring conditions were mood and anxiety disorders (Lever & Geurts, 2016b), and one study found an inverted-U shaped curve for anxiety and depression rates rising from adolescence (15-21 years) to early (22-39 years) and middle age (40-64 years) and declining in older (≥65 years) autistic adults (Uljarević et al., 2019). The finding for declining rates of psychiatric co-occurring conditions for older autistic adults relative to their NT peers was corroborated by other studies (Lever & Geurts, 2016b; Rydzewska et al., 2018),

suggesting that autistic older adults may experience greater difficulties in their physical health relative to mental health when compared to NT older adults.

For studies that compared autistic adults with ID to autistic adults without ID (Table 1b), one found that participants with both conditions showed a near significant trend of having greater prevalence of neurological (seizures) (Fortuna et al., 2016), and another found greater gastrointestinal conditions, and lower rates of immune conditions, cardiovascular risk and psychiatric disorders (Bishop-Fitzpatrick & Rubenstein, 2019). The higher rate of neurological conditions may be a risk factor associated with ID more generally, as autistic adults with ID show lower rates of neurological (seizures) conditions compared to adults with ID only (Kats et al., 2013). Greater severity of ID was also associated with greater medication use and support for self-injurious and aggressive behaviours, in addition to neurological conditions in both autistic and non-autistic adults (Kats et al., 2013), suggesting ID may increase older autistic adults' vulnerability to poorer physical health. Other studies which included ageing autistic adults with ID also found increased rates of other physical health conditions (e.g. hypertension, constipation) and reduced ability to live independently (Fortuna et al., 2016), as well as increased rates of Parkinsonism (though symptoms were not associated with IQ suggesting it may be associated with greater difficulties in motor functioning in ageing autistic adults more generally) (Starkstein et al., 2015).

Regarding mental health conditions, one study found that a greater proportion (69.2%) of older autistic adults without co-occurring ID were registered with at least one psychiatric diagnosis (Nylander et al., 2018), with anxiety and affective disorders being the most common (Davis et al., 2011), compared to the broader pool of older autistic adults including those with ID (49.6%) (Nylander et al., 2018). However, a greater proportion of older autistic adults with ID received psychiatric care (73% vs. 56% for autism without ID), and psychotropic drugs (95% vs. 87% for autism without ID), suggesting antipsychotics may be more likely used as a way of managing behaviours for autistic adults with ID (Nylander et al., 2018). One study found that ageing was associated with reduced physical aggression for autistic adults (including those with ID), which coincided with reduced intensive staff supervision and neuroleptic use (Wise et al., 2017). Taken together, the reduced use of neuroleptics in older age may account for the finding that *current* use of

neuroleptics was *not* associated with increased rates of Parkinsonism (Starkstein et al., 2015). However, it is unknown whether *prolonged* use of neuroleptics over autistic individuals' lifetime may contribute to some of the physical health differences observed in ageing autistic adults. One longitudinal follow-up study of autistic adults who were diagnosed in childhood found that neither age or IQ were associated with either total mental health difficulties or social outcomes as reported by informants (Moss et al., 2015). However greater autism symptom severity in adulthood was associated with poorer mental health and poorer social outcomes (Moss et al., 2015).

[INSERT TABLE 1]

**Cognitive abilities.** A summary of findings is shown in Table 2. A range of cognitive abilities were examined across the studies including visual/verbal memory and verbal comprehension, working memory, executive functioning, fluency, processing speed, attention and Theory of Mind. No studies included participants with co-occurring ID.

***Visual/verbal memory and verbal comprehension***. Five studies examined the effect of age and diagnosis related differences in visual and verbal memory (Geurts & Vissers, 2012; Lever & Geurts, 2016a; Powell et al., 2017; Ring et al., 2016; Tse et al., 2019). Visual memory was mostly assessed using the Wechsler Memory Scale-III (WMS-III; Lever & Geurts, 2016a; Tse et al., 2019), with one study using a test of item and relational memory recall through a behavioural task (Ring et al., 2016). For visual memory, conflicting findings of a main effect of diagnosis was noted showing both lower (Tse et al., 2019) and higher (Lever & Geurts, 2016a) performance for autistic adults compared to NTs. The discrepancy may be related to the age of participants, as Lever and Geurts (2016a) noted a decrease in visual memory with increasing age for both autistic and NT adults, and the mean sample age for Tse et al. (2019)'s study was 61 years compared to 47.6 years for Lever and Geurts (2016a)'s study. It may be that the rate of visual memory changes in older age for autistic adults is greater compared to NT peers. Autistic adults also showed relatively poorer performance overall for item and relational memory when assessed using a behavioural task (Ring et al., 2016). Although the direction of causation is unclear, given that NTs showed a strong positive correlation between item and relational task performance, the authors hypothesised that perhaps recall for relational information is poorer for autistic adults which in turn affected their recall for item specific

information (Ring et al., 2016). It should be noted that the only age by diagnostic group interaction was found by Geurts and Vissers (2012), whereby only autistic participants (and not NTs) showed age related differences in visual memory.

Verbal memory was assessed by using Rey Auditory Verbal Learning Test in three studies (Geurts & Vissers, 2012; Lever & Geurts, 2016a; Powell et al., 2017), and verbal comprehension was assessed by the WMS-IV (Tse et al., 2019) in one study. Studies found that autistic adults compared to NTs showed similar levels of verbal comprehension (Tse et al., 2019) though poorer recall verbal memory (Powell et al., 2017). The discrepancy may be related to different domains of verbal memory being studied. Verbal comprehension may tap into crystallised intelligence (Tse et al., 2019) which remain more intact in older age compared to verbal recall memory (Powell et al., 2017). Verbal recall memory may draw upon flexibility and processing speed that rely on fluid intelligence and experience greater cognitive differences in older age. Effect of age was also shown by a number of studies which found that both autistic and NT adults had poorer recall and verbal memory with older age (Geurts & Vissers, 2012; Lever & Geurts, 2016a; Powell et al., 2017). However, no age by diagnosis interactions were noted, and therefore there is no evidence in the studies reviewed to support that age-related differences in verbal memory are specific to autism per se.

***Working memory.*** Working memory (WM) refers to the ability to hold information temporarily so as to enable further processing and manipulation (Baddeley, 2003; Cowan, 2014; Lever et al., 2015). Two studies compared working memory performance between autism and control group (Geurts & Vissers, 2012; Lever et al., 2015). One study used the Spatial Span task from the WMS-III related to visuo-spatial WM (Geurts & Vissers, 2012), and the other used the N-back task (Lever et al., 2015). A main effect of diagnosis was found where autistic participants showed poorer working memory (Geurts & Vissers, 2012) compared to NTs, though autistic participants also showed better performance when there was a greater cognitive load despite having a longer reaction time (Lever et al., 2015). An age by diagnosis interaction found that NTs, not autistic adults, showed a linear decrease in working memory as they aged (Lever et al., 2015). The discrepancy might be due to differences in age, as the mean age for participants in Geurts and Vissers (2012)'s study was 63.6 years, compared to 47.5 years for Lever et al. (2015). It may be that in contrast to the gradual changes

in WM for NTs, there are greater fluctuations and individual differences amongst ageing autistic adults with regards to changes in WM, and differences may occur at an older age compared to NTs.

***Executive functioning and processing speed***. Executive functioning (EF) refers to a range of cognitive functions that are required for complex and goal-directed behaviour (Demetriou et al., 2019). Gradual changes in EF skills are commonly observed as people age (Friedman et al., 2009; Verhaeghen & Cerella, 2002). However, one related aspect of cognitive functioning that may mediate the effects of ageing on EF is processing speed, and decrease in processing speed is a marker of cognitive difficulties associated with ageing (Bunce & Macready, 2005). Processing speed and a range of executive functioning domains were measured across seven studies, including cognitive flexibility, category learning, sequencing and planning (Abbott et al., 2018; Davids et al., 2016; Geurts et al., 2020; Geurts & Vissers, 2012; Lever et al., 2017; Lever & Geurts, 2016a; Powell et al., 2017).

Two studies found that compared to NTs, autistic adults showed poorer category learning, slower processing speed and reduced generativity (Lever & Geurts, 2016a; Powell et al., 2017). However, other studies found that there were no differences in planning, flexibility and processing speed between autistic adults and NT peers (Geurts & Vissers, 2012), and both groups performed similarly on objective measures of EF (Geurts et al., 2020). Nonetheless, autistic adults reported poorer subjective EF (Davids et al., 2016; Geurts et al., 2020), thus highlighting there may be potential inter-rater discrepancies in scoring EF in older autistic adults.

Assessing overall effects of age for both autistic and NT adults, mixed findings also emerged as one study found that older age was associated with better executive control and planning, including aspects of processing speed, reactive flexibility and sequencing (Abbott et al., 2018), another study found that older age was associated with poorer processing speed and flexibility (Powell et al., 2017). A third study suggests that there may be a trade-off between speed and accuracy in performance in older adulthood, as increased reaction time was associated with better accuracy for tasks assessing reactive control (Lever et al., 2017).

Findings related to age by diagnosis interaction were also mixed, as one study found that autistic older adults showed poorer cognitive performance overall including reduced flexibility, and

greater cognitive impairment compared to NTs (Powell et al., 2017), whereas another study did not find any significant interaction for objective measures of EF (Geurts et al., 2020). Comparing study samples, mean sample age differences may again account partially for this discrepancy, as the mean age in the autism sample for Geurts et al. (2020)'s study was 65.8 years, compared to 49 years in the Powell et al. (2017)'s study. Therefore, it may be that autistic adults experience EF difficulties at an earlier age compared to NT peers, though the overall level of EF performance may become more comparable to their NT peers later in older adulthood.

***Theory of mind.*** Only one study examined advanced Theory of Mind (ToM) and found that although NTs showed better ToM performance compared to autistic adults overall, this main effect of group was no longer significant when comparing a subset of participants whose age were above 50 in both groups (Lever & Geurts, 2016a). Although the absence of age by diagnosis interaction means that the study does not warrant support for a faster cognitive changes in ToM amongst NT older adults compared to autistic participants, further research may use a group of participants with mean age ≥50 years to assess whether the absence of ToM difference between the two groups is maintained in much older age.

***Attention.*** Only one study examined attention and found that compared to NTs, older autistic adults tended to make more commission errors on the Sustained Attention to Response Test, though no differences were found with regards to reaction time or response rate for correct answers (Geurts & Vissers, 2012), suggesting selective impaired sustained attention.

[INSERT TABLE 2]

**Autism symptom severity.** A summary of findings is shown in Table 3. Eight studies investigated the effect of ageing on autism symptom severity in autistic older adults without ID (Table 3a). Studies found that compared to NTs, autistic adults showed greater autism symptom severity as measured by the Autism Quotient (AQ) (Happé et al., 2016; Walsh et al., 2019), as well as reduced perspective taking, social cognition and greater personal distress (Lever & Geurts, 2018; Walsh et al., 2019). Autistic adults also showed greater sensory sensitivity (Crane et al., 2009; Lever & Geurts, 2018; Minshew & Hobson, 2008), and greater sensory avoidance as well as reduced sensory seeking behaviours (Crane et al., 2009). However, higher sensory sensitivity was not associated with age

(Minshew & Hobson, 2008), nor with other autism symptoms in autistic adults (Kern et al., 2007). Whilst Lever and Geurts (2018) found that the greatest levels of sensory sensitivity and also attention to detail was found in middle adulthood for autistic participants compared to older age.

When examining ageing by diagnosis interactions, ageing in autistic adults was associated with differences in social skills and social cognition (Lever & Geurts, 2018; Walsh et al., 2019) as well as greater autism symptom severity in general compared to NTs (Happé et al., 2016). One contrasting finding showed that older autistic adults displayed increased activation of mirror neurons during emotion perception suggesting better social adjustment (Bastiaansen et al., 2011). This discrepancy may be accounted by the fact that social adjustment was measured by the Social Functioning Scale which is developed originally for schizophrenia, and has shown low internal consistency amongst autistic participants (Chan et al., 2019), thus there may be validity issues in its use in capturing social functioning in an autism sample by Bastiaansen et al. (2011) compared to the use of more specific measures for autistic traits such as the AQ.

Three studies included autistic participants with ID or had IQ less than 70 (Table 3b). One found that older age was not associated with changes in autism symptom severity (measured by AQ) (Bishop & Seltzer, 2012). However, when controlling for the co-occurrence of ID, a second study found that older age was associated with reduced repetitive, self-injurious, compulsive and ritualistic behaviours, as well as a changes in restricted interests (Esbensen et al., 2009). The effects of IQ and co-occurring ID was examined by both studies which gave rise to seemingly contradictory findings. One showed a positive correlation between IQ and autism symptom severity (Bishop & Seltzer, 2012), and the other found that autistic adults with ID also showed increased repetitive behaviours and fewer age related differences in stereotyped movements compared to autistic adults without ID (Esbensen et al., 2009). Given that a more comprehensive measure of autism symptom severity (Autism Quotient) was used by Bishop and Seltzer (2012), the positive correlation between IQ and AQ may be driven by greater social communication difficulties (or in part by a greater awareness of one's own social communication difficulties when using self-report measures for those without ID), rather than the elevated repetitive behaviours associated with co-occurring ID noted by Esbensen et al. (2009). Furthermore, a third longitudinal study which included some older autistic adults with IQ

less than 70 found that older age was associated with reductions in autism symptom severity (especially reduced restricted and repetitive behaviours) when measured by the Autism Diagnostic Interview-Revised, as well as improved language and mixed social outcomes (Howlin et al., 2013). Therefore, the impact of ageing and intellectual functioning may show differential associations across different aspects of core autism symptom severity and may be subject to reporter bias when comparing self- and other reporter results and warrants further research.

**Social integration and quality of life.** Of the four studies that examined social integration and quality of life in autistic adults, only one study included autistic participants without ID and found that compared to NT participants, older autistic adults reported poorer quality of life (reflected by increase in cognitive and psychological problems) which was not associated with autism symptom severity, age nor intellectual functioning (van Heijst & Geurts, 2015).

Three studies included one or more autistic participants with ID or had IQ less than 70 in adulthood (Howlin et al., 2013; Mason et al., 2019; Moss et al., 2017). Two longitudinal studies which followed a group of autistic children diagnosed in childhood through to adulthood (Howlin et al., 2013; Moss et al., 2017). The first study found that autistic adults showed poor outcomes in relation to education, daily living, employment, and had few reciprocal friendships, and poor social integration outcomes were associated with greater impairment in reciprocal social interaction and lower intellectual functioning (Howlin et al., 2013). The second study found that age was negatively associated with physical quality of life as rated by informants, and greater autism symptom severity in childhood also experienced was associated with poorer physical health satisfaction in adulthood. Furthermore, self-reports from autistic adults also indicated that better social outcomes (including employment, relationships, and independent living) was associated with a higher social quality of life (Moss et al., 2017). Another study found in a sample of autistic adults (one of whom had ID) that those with co-occurring anxiety and/or depression had poorer quality of life compared to adults with no co-occurring diagnoses, and those with both co-occurring conditions had poorer quality of life than those with one condition only (Mason et al., 2019), though the effect of intellectual functioning was not reported. However, quality of life scores were not associated with normative social integration outcomes such as employment, independent living, or peer socialisation (Mason et al., 2019). Taken

together, the studies suggest that the relationship between quality of life and social integration may not be linear amongst autistic older adults, though a conclusion cannot be drawn without a comparison group of non-autistic participants with matching level of intellectual functioning. It may be that greater social integration in a neurotypical world is a significant source of stress and distress for some autistic individuals and thus may not lead to linear improvements in quality of life and warrants further research.

**Adaptive functioning.** All three studies that examined adaptive functioning in older adults included autistic participants with ID or IQ below 70. When assessing the effect of autism diagnosis, one study found that around two thirds of older autistic adults were able to perform all aspects of adaptive daily living (including getting dressed, bathing, exercising, feeding etc) independently, though independence was negatively associated with intellectual functioning (Wise et al., 2019). In a study that compared autistic adults with ID to those with ID only, autistic adults with ID showed lower adaptive functioning, reduced activity level and more behaviour problems (Totsika et al., 2010), suggesting that autism may increase older adults' vulnerability to reduced adaptive functioning above and beyond the effects of intellectual functioning. This was partially supported by the third study which found that only 3.3% of autistic adults (compared to 15% NT adults) met all three criterion for good adaptive functioning when using a more comprehensive measure including social engagement and health (including low disease/disability, better physical/mental functioning and more active engagement with life), and one third of autistic adults (compared to 5% NT adults) met none of the three criterion (Hwang et al., 2020). Having greater levels of autism traits or symptom severity was associated with reduced active engagement with life for both autistic and NT adults (Hwang et al., 2020). Therefore, the studies suggest that co-occurring ID may increase autistic adults' vulnerability to poorer adaptive functioning relative to autistic adults without ID. Autism symptom severity increases autistic adults' vulnerability to poorer adaptive functioning relative to both NT and peers with ID only.

The effect of ageing on adaptive functioning was more mixed. One study found ageing in both autistic adults with ID and NT adults to be associated with reduced active engagement with life (Hwang et al., 2020), and another found that age was not associated with changes in daily adaptive

living skills for older autistic adults with ID (Wise et al., 2019). The third study showed that older autistic adults (≥50 years) with ID displayed fewer behavioural and psychiatric problems compared to younger autistic adults, and received less staff attention (Totsika et al., 2010). Discrepancies may be partially accounted for by differences in living situation and level of support that participants received in their daily lives, as participants living in the community (Hwang et al., 2020) may experience a greater variety of daily living challenges compared to those living in care settings (Totsika et al., 2010; Wise et al., 2019).

**Language processing**. Of the four studies that examined language processing, three assessed phonemic or semantic fluency which tap both executive functioning and language abilities (Baxter et al., 2019; Davids et al., 2016; Geurts & Vissers, 2012). Phonemic fluency refers to naming words that begin with a certain letter of the alphabet, and semantic fluency refers to naming words that belong to a certain category (Shao et al., 2014). Compared to NTs, autistic adults showed both poorer semantic fluency (Baxter et al., 2019; Davids et al., 2016), and phonemic fluency (Geurts & Vissers, 2012). With regards to age, increased general vocabulary (Baxter et al., 2019) and decrease in phonemic fluency (Geurts & Vissers, 2012) were observed across both autistic and NT participants. The only age by diagnosis interactions occurred for phonemic fluency, where one study observed a near significant trend of poorer phonemic fluency in young compared to older autistic participants (Baxter et al., 2019), and another found a significant decrease in phonemic fluency in older age for NT participants compared to autistic participants (Geurts & Vissers, 2012). Therefore, it seems that difficulties with phonemic fluency may be present from a younger age for autistic adults compared to NTs, who experience difficulties in this area later on in life.

One study examined the impact of temporal changes in speech encoding and recall in both autistic and NT adults, and found that both groups showed poorer encoding and recall when the speed of speech was increased, though in autistic adults, those who were older and had greater sensory sensitivity had poorer recall accuracy when speech was faster compared to NTs (Mayer & Heaton, 2014). Therefore, it may be that autistic adults are more vulnerable to age-related effects in speech processing compared to NT peers due to atypical sensory processing.

## Discussion

The present review examined research exploring the characteristics of older autistic adults in relation to six areas: co-occurring difficulties, cognitive functioning, autism symptom severity, social outcomes, adaptive functioning, and language processing. Not all areas received equal attention, and there were relatively fewer studies examining social outcomes, adaptive functioning and language processing in older autistic adults, all of which warrant further research. With the exception of cognitive functioning and language processing, the remaining four domains were examined in both older autistic adults with and without ID. Apart from three longitudinal studies (Howlin et al., 2013; Moss et al., 2015, 2017), and two studies drawing upon population data based on the Scottish Census 2011 (Rydzewska et al., 2018, 2019), the majority of the included studies had relatively smaller sample sizes, were cross-sectional and varied in their approaches in investigating the potential influence of autism in late adulthood, with the majority investigating the effect of age as a continuous variable rather than examining adults above the age of 50 years per se. Therefore, it is difficult to synthesise findings across all the studies and it remains to be explored to what extent current results can be generalised to a wider and more heterogeneous autism population.

Given that three patterns of ageing in autism have been proposed, namely accelerated, parallel and safeguarded against typical patterns of ageing (Bathelt et al., 2020; Geurts & Vissers, 2012; Oberman & Pascual-Leone, 2014), the current findings illustrate a more complex picture rather than adopting any single profile. Cognitive changes showed mixed findings across a range of domains (including visual/verbal memory, executive function, processing speed etc) and some potential reasons accounting for discrepancies due to methodological differences were highlighted in the results. In the absence of longitudinal studies, findings based on cross-sectional design should be treated with caution, and it is important to note that there are few significant age by diagnosis interaction effects suggesting that there is not a uniform ‘double jeopardy’ effect (Geurts & Vissers, 2012; Lever et al., 2015; Lever & Geurts, 2016a; Powell et al., 2017), whereby having a diagnosis of autism increases impact of age on cognition (Geurts & Vissers, 2012). Given the difference in objective and subjective performance in executive function (Davids et al., 2016; Geurts et al., 2020), and only four of the ten studies focussing on cognition included older autistic adults with a mean age above 50 years (Davids et al., 2016; Geurts et al., 2020; Geurts & Vissers, 2012; Tse et al., 2019),

there is a need for more follow-up and longitudinal research of older autistic adults where cognitive performance data can be triangulated from multiple sources to better inform our understanding of this area.

Studies examining co-occurring difficulties in older age have highlighted greater changes in physical health amongst older autistic adults (Linke et al., 2020; Rydzewska et al., 2018, 2019), and especially greater risk for Parkinsonism and neurological conditions (such as seizures) for autistic adults with ID (Fortuna et al., 2016; Kats et al., 2013), though relative prevalence for mental health difficulties such as anxiety and depression may decrease in older adulthood (Rydzewska et al., 2018; Uljarevic et al., 2016). Given the lack of longitudinal studies, it is unclear what factors may underlie differences in physical and mental health conditions in older age. Perhaps a lifetime of increased mental health difficulties and neuroleptic use may have contributed towards some of the physical health differences observed in older autistic adults (Nylander et al., 2018). There may also be added effects of prolonged disadvantaged access to healthcare resources tailored to suit the needs of autistic adults which result in greater health disparities over one's lifetime and poorer physical health outcome in older adulthood (Bishop-Fitzpatrick & Kind, 2017; Nicolaidis, 2012; Woolfenden et al., 2012).

The effect of finding reduced mental health difficulties for older autistic adults compared to their younger counterparts (Rydzewska et al., 2019) is somewhat jarring when compared to a study by Croen et al. (2015) which included a more diverse sample of autistic adults aged 18+, and found elevated rates of co-occurring psychiatric conditions (especially in autistic women compared to men) including a five-fold increase in diagnosed suicide attempts in autistic adults compared to the control group. However, it should be noted that this study did not explicitly explore the effects of ageing as a predictor of outcome, though age was controlled in analyses suggesting that the elevated rates of psychiatric conditions may be present across all developmental stages. The null effect of age as a predictor of mental health in older autistic adults was also supported by results from one longitudinal follow-up study which found that only autism symptom severity in adulthood (and not age or cognitive functioning) was associated with poorer mental health (Moss et al., 2015). However, given that only 81 of the 1507 (around 5%) of autistic participants in the Croen et al. (2015) study were aged 55 and above, compared to 1405 of the 6649 autistic participants in the Rydzewska et al. (2019)

study, the latter may have had increased power when specifically detecting more nuanced age effects for autistic participants in older adulthood.

Changes associated with autism symptom severity, social integration and adaptive functioning also showed mixed results. One factor which may have influenced the uneven profile observed in age related changes in autism symptom severity is co-occurring ID, as it may be that there are greater changes in social skills and social cognition for autistic adults without ID (Happé et al., 2016; Lever & Geurts, 2018; Walsh et al., 2019), compared to reduced restricted and repetitive patterns of behaviours and interests for autistic adults with ID (Esbensen et al., 2009). However, there may be other additional factors at play that may interact with autism symptom severity and ID, such as one's living situation (whether in the community or in care homes), as well as potential 'healthy survivor effect', the latter referring to the increased likelihood of those who have better adaptive living skills and are more engaged with society to reach an older age (Totsika et al., 2010). For example, two studies found that autistic adults with ID showed little changes in their daily living skills (Totsika et al., 2010; Wise et al., 2019) in contrast to another that showed reduced active engagement with society as an effect of age (Hwang et al., 2020). Given that the majority of participants for the first two studies came from care homes, it may be that older autistic adults with ID may be able to independently maintain most of their daily living tasks within care home settings, though find it more challenging to engage with a greater variety of daily living tasks and become socially integrated when living in the community, where quantity and quality of support may also vary (Hwang et al., 2020). In addition, the 'healthy survivor effect' may have meant that fewer older adults with poorer daily living skills and social engagement skills were less likely to be included in the studies, thus leading to a positive bias and overestimate of such skills due to participant selection bias (Totsika et al., 2010).

One seminal study by Howlin et al. (2013) was of a longitudinal nature and followed-up children who were diagnosed in childhood in their adulthood, where 60 of the 90 original participants took part. Although the authors noted no differences in childhood non-verbal IQ and diagnostic confirmation (based on ADI-R) between those who took part in the study versus who did not or were lost to contact, it is unclear whether there may have been differences in their level of cognitive,

adaptive and social functioning in adulthood that may have contributed towards their decision or ability to take part in the study, and thus may still potentially be subjected to possible 'healthy survivor effect'. Those who were followed-up in adulthood had relatively poor adult social integration outcomes when assessed from multiple domains (including education, autonomy in daily living, employment, relationship quality), which was in turn negatively associated with IQ in adulthood and positively associated with social interaction impairment. The poor social integration outcome is especially noteworthy in light of reduced autism symptom severity in adulthood, and none of the participants had intellectual disability during childhood (all had nonverbal IQ in the average range). Beyond social integration, another longitudinal study by Moss et al. (2017) examined quality of life in 52 autistic adults who were diagnosed as children. Autistic adults who displayed higher levels of restricted and repetitive behaviours during childhood reported lower quality of life in adulthood. Informants also noted that older age for autistic adults was associated with poorer physical quality of life. Therefore, the longitudinal studies highlight that autism symptom severity and cognitive functioning can change over an autistic individual's lifetime, and measurements from childhood and adulthood can jointly inform social integration and quality of life of autistic adults from a developmental perspective.

**Clinical implications**

Despite the lifelong and developmental nature of autism, it is striking that very limited research has been carried out to examine the characteristics of autistic adults in later life, especially when examining characteristics such as social integration, adaptive functioning, and language processing, and only 16 of the 41 studies included autistic adults with ID or had an IQ below 70 in adulthood. There is a pressing need to address these gaps in the literature so as to provide a comprehensive understanding of how aging impacts on functioning in older autistic adults with and without ID and enable the development of support and services that meet the unique needs of this ageing population. For example, if there are different developmental patterns in different cognitive domains, healthcare professionals can possibly help autistic individuals draw on their cognitive strengths to compensate for the domains in which they experience relative weakness.

Furthermore, there is some limited evidence in the current review to suggest that older autistic adults may experience greater difficulties with physical health relative to mental health. These findings have significant implications for service planning as they help to inform services of the changing support needs that autistic individuals may require across different life stages. The lack of clear association between social integration outcomes and quality of life also warrants further research, and the current studies which included such measures mostly focused on either health related quality of life (van Heijst & Geurts, 2015), or more objective measures such as education and employment (Howlin et al., 2013; Mason et al., 2019). Only one study included an evaluation of quality of close relationships and friendships (Howlin et al., 2013), though this was completed by parents and carer for more than half of the sample. One measure specifically tailored to assessing quality of life in autistic individuals is the Autism-Specific Quality of Life items developed by McConachie et al. (2018), which include aspects of social functioning (such as perceived support from others, quality of friendships), access to healthcare services, quality of reasonable adaptations based on autism specific needs and autism identity, and have received good validity in a large diverse sample of autistic adults in the UK. The use of autism specific quality of life measures in older autistic adults, as well as triangulation of subjective and objective ratings across more diverse range of quality of life indicators (including domains such as control, autonomy, self-realisation and pleasure) should be adopted by future research (Hyde et al., 2003; Wikman et al., 2011).

## Limitations and future directions

The present review suffers from some limitations which complicate the interpretation of the results. Of note, this review originally aimed to only look at studies that examined characteristics in older autistic adults (over the age of 50). However, as there is a dearth of studies with discrete groups of older autistic adults over the age of 50, the review also included studies with a wider age range within their samples that included individuals over the age of 50, which looked at age as a predictor of relevant characteristics. The number of over 50s included in such studies were not always transparent. Hence, this made it difficult to ascertain how important their findings were in understanding autism in late adulthood. In addition, of the 16 studies that chose to include autistic adults with ID, only two studies included a comparison group of adults with ID only (Kats et al., 2013; Totsika et al., 2010),

thus making it difficult to know to what extent differences in ageing effects were specific to the diagnosis of autism as opposed to ID more generally. Furthermore, the variation in approaches for assessing different characteristics in autistic adults posed a challenge to the integration of results in the systematic review. Unpublished articles or grey literature were also not searched and may potentially leave a risk of publication bias.

Only three studies in the current review (Howlin et al., 2013; Moss et al., 2015, 2017) adopted a longitudinal approach to investigate the impact of ageing in autistic individuals. Although a promising first step, there is a greater need for future studies to adopt a longitudinal design wherever possible in order to examine the potential differences in the ageing trajectories between autistic individuals with and without ID, when compared to both NT peers as well as individuals with ID only. Moreover, it is important to take into account how potential 'healthy survivor effect' may have influenced findings from both cross-sectional and longitudinal studies, and may have interacted with practical challenges around recruitment for autistic adults aged 50 years and older, especially those with ID and other co-occurring mental and physical health conditions. Segerstrom et al. (2016) noted that differential mortality associated with life satisfaction and quality of life became especially evident for adults in their 70s and 80s, such that those who had poorer life satisfaction and quality had greater mortality risk and were less likely to be sampled in research studies. This sampling bias led to an inflated trajectory in the elevation of quality of life ratings in older adulthood amongst those who were sampled, beyond that predicted by developmental changes.

Possible 'survivor effect' should be carefully considered when interpreting findings such as reduced mental health difficulties in older autistic adults reviewed in the current systematic review (Rydzewska et al., 2018; Uljarevic et al., 2016), given that the lifetime prevalence for co-occurring mental health conditions amongst autistic individuals is greater than in the general population (Lai et al., 2019). Findings from cross-sectional studies offer limited insight into how co-occurring conditions may have impacted autistic individuals' development across their lifetime prior to entering older adulthood. Such questions may be addressed by longitudinal studies through estimating to what extent potential childhood and other developmental, medical and environmental factors may have influenced study retention status and follow-up success, and their impact on the validity and reliability

of the study outcomes. Therefore, future studies examining ageing in autism should carefully consider the impact of 'healthy survivor effect' on their sampling method and consider the wider generalisability of their findings to autistic adults across the spectrum.

Furthermore, other future directions have been highlighted throughout the review, such as the need to have more discrete groups of older adults above the age of 50 to examine autism in older adulthood more specifically, and gathering data from multiple informants as well as objective measures to better triangulate and understand where discrepancies across studies may arise. Closer attention should also be paid to the selection of participants to minimise the healthy survivor effect wherever possible, and clearly acknowledge and discuss the implications of this effect when there may be selection bias present.

## Conflict of Interest

On behalf of all authors, the corresponding authors state that there is no conflict of interest.

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Table 1. Summary of studies describing co-occurring difficulties in ageing autistic adults (n = 13).

a) Studies including participants without co-occurring intellectual disability (n = 5).

| **Author (Year), Country** | **Diagnosis (criteria; measure)** | **N (Male)** | **Age (years) (M, SD); IQ (M, SD)** | **Measure(s)** | **Main Findings** | **QualSyst score** |
|---|---|---|---|---|---|---|
| Linke et al. (2020; USA) | ASD: Prior clinical diagnosis (DSM-5); ADOS-2<br><br>IQ: WASI-II | ASD: 17 (14)<br><br>NT: 19 (18) | ASD: 49.7 (6.6); IQ = 102 (24)<br><br>NT: 50.4 (6.3); IQ = 120 (11) | *Motor skills / balance:* BMAT | **ASD (vs. NT):** ↓motor function (total, manual dexterity, coordination, strength and flexibility) | 0.77 (17/22) |
| Rydzewska et al. (2019; UK) | ASD: Prior clinical diagnosis as reported on Scottish Census 2011 | ASD: 6649 (4610)<br><55 yrs: 5244 (3760)<br>≥55 yrs: 1405 (850)<br><br>w/o ASD: 3739935 (1776845)<br><55 yrs: 2183593 (1114283)<br>≥55 yrs: 1556342 (709811) | N/A | *Health:* How is your health in general? | **ASD (vs. NT):** ↓general health (OR = 5.1 in predicting poor health)<br>**Older age:** Greater % of poor general health (ASD/NT (%): 37.9/7.6 at 25-34 yrs; 66.2/45.6 at 65+ yrs)<br>**Age X Diagnosis:** Poorer general health in autism at older age. | 0.95 (21/22) |
| Uljarević et al. (2019; Australia) | ASD: Prior clinical diagnosis; AQ-Short | ASD: 255 (151)<br>15-21 yrs: 77<br>22-39 yrs: 97<br>40-64 yrs: 70<br>≥65 yrs: 11 | ASD: 33.52 (14.98) | *Anxiety:* DSM-5 GAD<br>*Depression:* PHQ-9 | **Age groups:** no diff on depression/anxiety cut-offs; meeting both cut-off for anxiety and depression: adolescence (24.3%), early adulthood (29%), middle age (31.3%), old age (18.2%)<br>**Greater autism symptoms:** ↑anxiety, ↑depression | 0.81 (18/22) |

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|---|---|---|---|---|---|---|
| Rydzewkska et al. (2018; UK) | ASD: Prior clinical diagnosis as reported on Scottish Census 2011 | ASD: 6649 (4610)<br><55 years: 5244 (3760)<br>≥55 years: 1405 (850)<br><br>w/o ASD: 3739935 (1776845)<br><55 years: 2183593 (1114283)<br>≥55 years: 1556342 (709811) | N/A | *Comorbid conditions:* Do you have any of the following conditions which have lasted, or are expected to last at least 12 months? (deafness/partial hearing loss; blindness/partial sight loss; learning disability, physical disability, long-term illness, mental health etc) | **ASD (vs. no ASD):** ↑deafness/partial hearing loss; ↑blindness/partial sight loss; ↑intellectual disabilities; ↑mental health conditions; ↑physical disability; ↑other condition.<br>**Older age:** ↑blindness, ↑deafness, ↑physical disability, ↑other condition; >55 years = ↓intellectual disabilities (survivor effect); >65 years = ↓mental health conditions<br>**Age X Diagnosis:** Older age (ASD) = ↑blindness, ↑deafness, ↑physical disability, ↑other condition; no diff in intellectual disabilities / mental health conditions. | 0.95 (21/22) |
| Lever et al. (2016; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV); ADOS (Module 4)<br><br>IQ: WAIS-III | Part 1:<br>ASD: 172 (116)<br>NT: 172 (97)<br><br>Part 2:<br>ASD: 138 (96)<br>NT: 170 (97) | Part 1:<br>ASD: 46.7<br>NT = 46<br><br>Part 2:<br>ASD = 46.5; IQ = 113.8<br>NT = 45.9; IQ = 113.3 | *Psychiatric co-occurring symptoms*: SCL-90-R<br>*Psychiatric co-occurring disorders:* MINI-Plus, ADHD Rating Scale<br>*Risk factors:* AQ, ADOS, WAIS-III, MMSE, ISCO | **ASD (vs. NT):** ↑Psychiatric co-occurring symptoms/disorders (most common: mood/anxiety disorders);<br>**Age X Diagnosis:** Older age (ASD) = ↓Psychiatric co-occurring symptoms/disorders | 0.95 (21/22) |

b) Studies including participants with intellectual disability (n = 8).

| **Author (Year), Country** | **Diagnosis (criteria; measure)** | **N (Male)** | **Age (years) (M, SD); IQ (M, SD)** | **Measure(s)** | **Main Findings** | **QualSyst score** |
|---|---|---|---|---|---|---|
| Bishop-Fitzpatrick et al. (2019; UK) | ASD: Prior clinical diagnosis (ICD-9)<br><br>ID: Clinical diagnosis (ICD-9) | ASD w ID: 64 (40)<br><br>ASD w/o ID: 79 (58) | ASD w ID: 54.9 (10.1)<br><br>ASD w/o ID: 50.4 (8.6) | *Physical and mental health conditions:* service claims from Medicaid records | **ASD w ID (vs. w/o ID) (*near sig trends*):** ↑neurologic disorders (epilepsy), ↑gastrointestinal disorders, ↓immune conditions; ↓cardiovascular risk; ↓psychiatric disorders (anxiety). | 0.95 (21/22) |

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| Nylander et al. (2018; Sweden) | ASD: Prior clinical diagnosis (ICD-10) | ASD w ID: 140<br>ASD w other conditions: 116<br>ASD w/o ID: 345 | 55 - 96 years | *Health:* Records from National Register | Psychiatric care and diagnoses:<br>**Overall:** 49.6% w ≥1 psychiatric diagnosis, 19.6% w mood disorder diagnosis; 63.4% contact w specialised psychiatric care; 25% had been in-patients<br>**ASD w/o ID:** 69.2% w ≥1 psychiatric diagnosis, 10.8% w affective disorder diagnosis, 56% psychiatric care, 87% receive ≥1 psychotropic drug<br>**ASD w ID:** 73% psychiatric care, 95% receive ≥1 psychotropic drug | 0.94 (17/18) |
| Wise et al. (2017; USA) | ASD: Prior clinical diagnosis (DSM-5) | All ASD: 74 (61)<br><br>ASD ≥50: 40 (31)<br><br>ASD < 50: 34 (30) | All ASD: 49.9 (10.4); IQ (n: 39) = 61.2<br><br>≥50 yrs: 57.8 (6.4)<br><50 yrs: 40.8 (6.01)<br><br>ASD w ID: 55.6(9.2)<br>ASD w/o ID: 54.6 (11.8) | *Language / ID:* clinician judgement<br>*Medical history, hospitalisation etc:* medical records<br>*Behavioural and neuropsychiatric symptoms (BNPS):* psychological records | **All:** 70% w GI disorder; 23% w seizure disorder, BMI: 43% overweight, 25% obese, 75% show physical aggression towards others<br>**Older age:** ↓rates of diabetes, ↓neuroleptic use, ↓intensive staff supervision, ↓physical aggression | 0.73 (16/22) |
| Fortuna et al. (2016; USA) | ASD: Prior clinical diagnosis (DSM-IV) | ASD: 255 (192)<br>40 years: 72 (≥60 years : 12) | ASD: 33.6; IQ (n = 141) 128 w LD<br>≥40 yrs: 48.8 | *Health status:* RHSS (demographics, general health status, medical conditions, functional status, health services utilisation) | **ASD (vs. gen population):** ↑neurologic disorder (seizure; migraine); ↓substance use (tobacco, alcohol); ↓Sexually transmitted disease (>40 years)<br>**Age (>40 years vs. 18-29 years):** ↑seizure, ↑constipation, ↑hypertension, ↑hyperlipidaemia, ↑hypothyroidism, ↑urinary incontinence, ↓ADHD, ↓independent daily functioning (eating, dressing, bathing, walking) | 0.82 (18/22) |

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|---|---|---|---|---|---|---|
| Moss et al. (2015; UK) | ASD: Prior clinical diagnosis (ICD 9/10), confirmed using ADI/ADI-R<br><br>IQ: Childhood (best estimate = Wechsler, Raven's, Leiter, Merrill Palmer); Adulthood (best estimate = VABS) | ASD: 58 (48) | ASD: 43.3 (9.1); IQ = 69.7 (34.3)<br>Childhood assessment: 6.7 (2.2); IQ = 88.7 (14.8) | Social outcomes: FHS<br>Mental health throughout adulthood: FHS, ADI-R (self-injurious behaviour)<br>Current mental health: self-report measures – GHQ-12, Y-BOCS, BAI-II, BDI, ASRS-v1.1 | **Older age:** not associated with total mental health or social outcome scores (informant ratings)<br>Greater autism symptom severity (adulthood): ↓mental health, ↓social outcomes<br>No effect of IQ on total mental health | 0.86 (19/22) |
| Starkstein et al. (2015; USA/Australia) | ASD: Prior clinical diagnosis (DSM-5)<br><br>IQ: Medical records; WASI / Shipley-2 Scale / VABS | Study 1:<br>ASD: 19 (19)<br><br>Study 2<br>ASD: 37 (32) | Study 1:<br>ASD: 57 (6.7); 79% IQ ≤80<br><br>Study 2:<br>ASD: 51.2(8.5); 95% IQ ≤80 | Study 1:<br>*Motor signs:* UPDRS<br><br>Study 2:<br>*Motor signs:* MDS-UPDRS | Study 1:<br>Parkinsonism (16% met diagnostic criteria): 22% bradykinesia; 16% resting tremor; 32% rigidity; 15% postural instability<br>No effect of IQ / current use of neuroleptics<br><br>Study 2:<br>Parkinsonism (32% met diagnostic criteria): 46% bradykinesia, 19% resting tremor; 19% rigidity; 19% postural instability<br>No effect of IQ / current use of neuroleptics | 0.86 (19/22) |

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|---|---|---|---|---|---|---|
| Kats et al. (2013; USA) | ASD: Prior clinical diagnosis (DSM-IV) | 2009 - 2010:<br>ASD w ID: 438 (319)<br>ID: 3441 (2532)<br><br>2010 - 2011:<br>ASD w ID: 298 (224)<br>ID: 3963 (2137) | 2009 - 2010:<br>ASD w ID: 42 (8)<br>ID: 45 (8)<br><br>2010 - 2011:<br>ASD w ID: 41 (8)<br>ID: 44 (8) | *Health:* Records from National Core Indicators Consumer Survey | 2009-2010:<br>**ASD w ID (vs. ID only):** ↑medication and support for behavioural problems (50% ASD, 25% ID); ↓physical disability (5% ASD; 10% ID); ↓neurological/seizure disorder (20% ASD; 25% ID)<br>**↑ID:** ↑medication and support for behaviour/self-injury, seizure/neurological conditions.<br>**↑ID (ID only, no vision/physical disability):** ↑medication and support for disruptive behaviour<br><br>2010-2011 (replication):<br>**↑ID:** ↑medication for behaviours, seizure/neurological conditions<br>**↑ID (ID only, no vision/physical disability):** ↑disruptive/destructive behaviour | 0.83 (15/18) |
| Davis III et al. (2011; USA) | ASD/ID: Prior clinical diagnosis (DSM-IV-TR; ICD-10) | All ASD: 131 (109)<br>Toddler: 40 (31)<br>Child: 30 (17)<br>Young Adult: 27 (17)<br>Adult: 27 (16) | Toddler:<br>1.64 (0.4)<br>Child:<br>8.47 (3.7)<br>Young adult: 40.7 (7.38)<br>Adult: 54.64 (4.99) | *Comorbidities:* BISCUIT-Part 2 (Infant/Toddlers), ASD-CC (Child), ASD-CA (Young adult/adult)<br>*Only 5 items that showed overlap across all measures for anxiety were analysed. | **Older age (controlling for ID):** ↓difficulty and impairment with being easily upset (Adult vs. child/toddlers)<br>**Anxiety:** ↑toddler to child; ↓child to young adult; ↑young adult to adult | 0.77 (17/22) |

*Note.* ↑ = Greater; ↓ = Lower; ADHD = Attention Deficit Hyperactivity Disorder; ADOS = Autism Diagnostic Observation Schedule; ADI(-R) = Autism Diagnostic Interview (-Revised); AQ = Autism Quotient; ASD = Autism Spectrum Disorder; ASD-CA = Autism Spectrum Disorder – Comorbidity for Adults; ASD-CC = Autism Spectrum Disorder – Comorbidity for Children; ASRS-v1.1 = ADHD Self-Report Scale; BAI-II = Beck Anxiety Inventory-II; BDI = Beck Depression Inventory; BISCUIT-Part 2 = Baby and Infant Screen for Children with aUtIsm Traits – Part 2; BMAT = Bruininks Motor Ability Test; DSM = Diagnostic Statistical Manual; FHS = Family History Schedule; GAD = Generalised Anxiety Disorder; GHQ-12 = General Health Questionnaire-12; ICD = International Classification of Diseases; ID = Intellectual Disability; ISCO = International Standard Classification of Occupations; MDS-UPDRS = Movement Disorders Society-unified Parkinson's Disease Rating Scale; MINI-Plus = Mini International Neuropsychiatric Interview Plus; MMSE = Mini Mental State Examination; NT = Neurotypical; PHQ-9 = Patient Health Questionnaire-9; RHSS = Rochester Health Status Survey; SCL-90-R = Symptom Checklist-90-Revised; UPDRS = Unified Parkinson's Disease Rating Scale; VABS = Vineland Adaptive Behaviour Scale; w = with, w/o = without; WAIS = Wechsler Adult Intelligence Scale; WASI = Wechsler Abbreviated Scale of Intelligence; Y-BOCS = Yale-Brown Obsessive Compulsive Scale.

Table 2. Summary of studies describing cognitive functioning in ageing autistic adults (n = 10).

| Author (Year), Country | Diagnosis (criteria; measure) | N (Male) | Age (years) (M, SD); IQ (M, SD) | Measure(s) | Main Findings | QualSyst score |
|---|---|---|---|---|---|---|

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|---|---|---|---|---|---|---|
| Geurts et al. (2020; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV); AQ<br><br>IQ: WAIS-IV | ASD: 50 (50)<br><br>NT: 51 (51) | ASD: 65.8 (5.6); IQ = 110.7 (12.2)<br><br>NT: 69.7 (5.6); IQ = 110.7 (12.5) | *Objective EF ratings:*<br>*Planning:* DKEFS Tower, BADS Zoo Map<br>*Cognitive flexibility:* WCST<br>*General IQ, processing speed, working memory:* WAIS-IV (Processing Speed Index - symbol search and coding, Working Memory Index - including digit span, arithmetic)<br>*Subjective EF rating:* BRIEF | **ASD (vs. NT):** objective EF: ASD = NT; subjective EF: ASD < NT (positive correlation between self/observer ratings)<br>**Age X Diagnosis:** objective EF: ASD = NT | 0.82 (18/22) |
| Tse et al. (2019; UK) | ASD: Prior clinical diagnosis (DSM-5; DSM-III)<br><br>IQ: WAIS-IV | ASD: 28 (22)<br><br>NT: 27 (9) | ASD: 61; IQ = 113.39 (18.11)<br><br>NT: 63; IQ = 118.89 (11.59) | *Autism traits:* AQ<br>*Intellectual abilities:* WAIS-IV<br>*Memory abilities:* WMS-IV | **ASD (vs. NT):** ↓processing speed; ↓visual working memory; no diff in verbal comprehension | 0.91 (20/22) |
| Abbott et al. (2018; UK) | ASD: Clinical diagnosis (ICD-10) and ASD traits (AQ, EQ, SQ)<br><br>IQ: proxy by WAIS subtests (average range) | ASD: 134 (97) | ASD = 31.14 (11.94); IQ ≥ 70 | *Executive control:* Digit symbol subtest (WAIS-III/IV)<br>*Working memory:* Digit span subtest (WAIS)<br>*Initiation/Reasoning*: Hayling & Brixton tests<br>*Sequencing:* trails A/B (AITB)<br>*Planning:* Zoo map and Key search subtests (BADS) | **ASD traits:** ↑AQ, ↑SQ, ↓EQ = ↑Mean executive functioning scores.<br>**Older age:** ↑executive control (digit symbol), ↑planning (Trails A/B) (both measures are related to processing speed, reactive flexibility, and sequencing of performance) | 0.91 (20/22) |
| Lever et al. (2017; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV); ADOS (Module 4); AQ<br><br>IQ: WAIS-III | ASD: 118 (83)<br><br>NT: 160 (91) | ASD: 47.6 (14.9); IQ = 114.8 (16.9)<br><br>NT: 46.1 (16.5); IQ = 114 (16.5) | *Interference control:* Simons Task | **ASD (vs. NT):** ↑Reaction time (RT) & Accuracy for reactive control (RC) for congruent & incongruent trials; no diff for proactive control<br>**Older age:** ↑RT & Accuracy for RC on incongruent trials; ↑RT for congruent trials<br>**Age X Diagnosis**: no diff | 0.91 (20/22) |

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|---|---|---|---|---|---|---|
| Powell et al. (2017; USA) | ASD: Prior clinical diagnosis; ADOS-2 (Module 4); SRS-2<br><br>IQ: WASI | ASD: 29 (24)<br><br>NT: 30 (23) | ASD: 49 (11.7); FSIQ = 113.2 (9.5)<br><br>NT: 48.7 (12.1); FSIQ = 113.1 (10.2) | *Category learning:* WJ-CF<br>*Processing speed and cognitive flexibility:* TMT (D-KEFS)<br>*Explicit memory (immediate free recall and recognition memory):* RAVLT<br>*Cognitive impairment:* MoCA | **ASD (vs. NT):** ↓free recall, ↓category learning, ↓processing speed<br>**Older age:** ↓recall, ↓speed, ↓flexibility<br>**Age X Diagnosis:** Older age (ASD) = ↓cognitive performance overall; ↓ flexibility; ↑ cognitive impairment | 0.91 (20/22) |
| Davids et al. (2016; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV/DSM-5); ADOS<br><br>IQ: WAIS-IV-NL | ASD: 36 (30)<br><br>NT: 36 (30) | ASD: 58.6 (7.8); IQ = 106.3 (18.4)<br><br>NT: 59.4 (8.3); IQ = 107.1 (15.6) | *Autistic traits/ASD symptoms:* SRS-A<br>*Subjective EF:* BRIEF-A<br>*Objective EF:* TL-D, BADS (Zoo maps), COWAT | **ASD (vs. NT):** ↓subjective EF: shifting, emotional control, self-monitoring, initiation, working memory and planning/organising); no diff on objective EF<br>**Older age:** ↓semantic fluency<br>**Age X Diagnosis:** no diff | 0.95 (21/22) |
| Lever et al. (2016; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV); ADOS (Module 4)<br><br>IQ: WAIS-III | ASD: 118 (83)<br><br>NT: 118 (83) | ASD: 47.6 (14.9); IQ = 114.8 (16.9)<br><br>NT: 47.7 (15.4); IQ = 114.3 (15.3) | *Visual memory:* WMS-III<br>*Verbal memory:* RAVLT<br>*Generativity and semantic memory:* COWAT, GIT<br>*ToM:* Faux Pas test<br>*Self-report of memory:* CFQ | In the over 50s:<br>**ASD (vs. NT):** ↑visual memory, ↓generativity, similar ToM<br>**Older age:** ↓visual and verbal memory<br>**Age X Diagnosis:** no diff | 0.91 (20/22) |
| Ring et al. (2016; UK) | ASD: Clinical diagnosis (DSM-iV-TR); ADOS<br><br>IQ: WAIS-III | ASD: 18 (13)<br><br>NT: 18 (14) | ASD: 42.78 (11.8); IQ = 108 (17.9)<br><br>NT: 43.48 (13); IQ = 109 (17.2) | *Memory:* paradigm by Konkel et al. (2008); trials included item test, location test, associative test, order test (all with repeated and manipulated trials) | **ASD (vs. NT):** ↓performance overall (at chance in the *order* and *associative* tasks, ↑false alarm rate); NT > ASD on positive correlations across tasks<br>**Age X Diagnosis:** ↓recognition rate for *order* task in NT (not ASD) | 0.73 (16/22) |
| Lever et al. (2015; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV); ADOS (Module-4)<br><br>IQ: WAIS-III | ASD: 111 (79)<br><br>NT: 164 (93) | ASD: 47.5 (15); IQ = 115.2 (16.9)<br><br>NT: 46 (16.5); IQ = 113.3 (16.7) | *Working memory:* N-back | **ASD (vs. NT**): ↑RT, ↑performance at increased load (non-linear)<br>**Age X Diagnosis:** Older age (NT) = ↓working memory (linear trajectory) | 0.86 (19/22) |

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|---|---|---|---|---|---|---|
| Geurts et al. (2012; The Netherlands) | ASD: Prior clinical diagnosis; SRS<br><br>IQ: DART | ASD: 23 (18)<br><br>NT: 23 (18) | ASD = 63.6 (7.5); IQ = 109.5 (10.3)<br><br>NT: 63.7 (8.1); IQ = 109.8 (7.9) | *Processing Speed:* Digit symbol-copy (WAIS-III)<br>*Attention:* SART<br>*Working memory:* Spatial Span (WMS-III)<br>*Cognitive Flexibility:* MCST, TMT<br>*Planning:* ToL-DX<br>*Fluency:* COWAT<br>*Visual memory:* Visual reproduction (WMS-III)<br>*Verbal memory:* RAVLT | **ASD (vs. NT):** ↑commission errors (attention); ↓ working memory; ↓ fluency, no diff on planning, flexibility, processing speed<br>**Older age:** ↓ fluency; ↓ verbal memory;<br>**Age X Diagnosis:** Older age (NT) = ↓ fluency (than ASD); Older age (ASD) = ↓ visual memory (than NT) | 0.82 (18/22) |

*Note.* ↑ = Greater; ↓ = Lower; ADOS = Autism Diagnostic Observation Schedule; AITB = Army Individual Test Battery; AQ = Autism Quotient; ASD = Autism Spectrum Disorder; BADS = Behavioural Assessment of Dysexecutive Syndrome; BRIEF(-A) = Behaviour Rating Inventory of Executive Functioning(-Adults); CFQ = Cognitive Failures Questionnaire; COWAT = Controlled Oral Word Association Test; D-KEFS = Delis-Kaplan Executive Function System; DSM = Diagnostic Statistical Manual; EF = Executive Function; EQ = Empathy Quotient; ICD = International Classification of Diseases; MCST = Modified Card Sorting Test; MoCA = Montreal Cognitive Assessment; NT = Neurotypical; RAVLT = Rey Auditory Verbal Learning Test; SART = Sustained Attention to Response Test; SQ = Systemising Quotient; SRS(-A) = Social Responsiveness Scale(-Adult); TL-D = Tower of London (Dutch); TMT = Trail Making Test; WAIS = Wechsler Adult Intelligence Scale; WASI = Wechsler Abbreviated Scale of Intelligence; WJ-CF = Woodcock-Johnson Concept Formation Test; WMS = Wechsler Memory Scale.

Table 3. Summary of studies describing autism symptom severity in ageing autistic adults (n = 10).

a) Studies including participants without intellectual disability (n = 7).

| **Author (Year), Country** | **Diagnosis (criteria; measure)** | **N (Male)** | **Age (years) (M, SD); IQ (M, SD)** | **Measure(s)** | **Main Findings** | **QualSyst score** |
|---|---|---|---|---|---|---|
| Walsh et al. (2019; USA) | ASD: Prior clinical diagnosis; ADOS-2 | ASD: 49 (49)<br>Young adult (YA): 24<br>Middle-age (MA): 25<br><br>NT: 36 (36)<br>Young adult (YA): 15<br>Middle-age (MA): 21 | ASD YA: 21.1 (2.3); IQ = 104.6 (14.4)<br>ASD MA: 53 (8.8); IQ = 109.6 (15)<br><br>NT YA: 20.9 (2.4); IQ = 111.8 (13.1)<br>NT MA: 49.7 (6.9); IQ = 111 (13.5) | *Social communication/Autism traits:* SRS-2<br>*Executive function*: ToL | **ASD (vs. NT):** no diff on SRS-2; ↓social cognition (↑SRS-2 score) correlated with ↓EF (↑ToL total moves)<br>**Older age (ASD):** ↓Social Cognition; no diff on SRS-2 Total score | 0.77 (17/22) |

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|---|---|---|---|---|---|---|
| Lever et al. (2018; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV) | ASD: 237 (163)<br><br>NT: 198 (109) | ASD: 46 (13.8); IQ = 113.1 (17.7)<br><br>NT: 45.6 (16.4); IQ = 112.6 (17.3) | *Autism symptoms/traits:* AQ<br>*Cognitive and emotional attitude towards interpersonal situations:* IRI<br>*Sensory sensitivity:* SSQ | **ASD (vs. NT):** ↑AQ, ↑sensory sensitivity; ↓ perspective taking and fantasy; ↑ personal distress<br>**Age X Diagnosis:** Older age (ASD) (peak in middle adulthood) = ↑AQ (total, attention to detail), ↑sensory sensitivity; Older age (no peak) = ↑AQ (social skills); Older age (NT) = no change | 0.82 (18/22) |
| Happé et al (2016; UK) | ASD: Clinical diagnosis by multidisciplinary clinical professionals | ASD: 100 (75)<br><br>Non-ASD: 46 (37) | ASD: 30.02 (10.77); IQ ≥70<br><br>Non-ASD: 37.20 (14.36); IQ ≥70 | *Demographic information:* education/employment, family history etc.<br>*Autistic traits:* AQ, EQ, SQ<br>*Neuropsychological assessments:* WAIS-III | **ASD (vs. non-ASD):** ↑AQ; no diff in EQ, SQ, comorbidity, employment; cognitive functioning (digit span, block design, similarities, vocabulary, matrix reasoning, arithmetic)<br>**Age X Diagnosis:** Older age (ASD) = ↑autism symptom severity (AQ, SQ, diff between SQ/EQ); ↑digit span; ↑block design | 0.86 (19/22) |
| Bastiaansen et al. (2011; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV); ADOS<br><br>IQ: GIT 2 | ASD: 21 (21)<br><br>NT: 21 (21) | ASD = 30.6 (10.09); IQ = 102.5 (14.81)<br><br>NT = 30.5 (9.85); IQ = 101.5 (17.4) | *Social adjustment:* SFS; ADOS-Social domain (ASD only)<br>*Mirror mechanisms:* Observation of dynamic facial expressions | **ASD (vs. NT):** ↓ social functioning (SFS); similar mirror neuron activation during observation of dynamic facial emotional expressions<br>**Age X Diagnosis:** Older age (ASD) = ↑activation of mirror neurons during emotion perception, ↑social adjustment | 0.77 (17/22) |
| Crane et al. (2009; UK) | ASD: Prior clinical diagnosis (DSM-IV/ICD-10; AQ<br><br>IQ: WASI | ASD: 18 (10)<br><br>NT: 18 (10) | ASD: 41.78 (15.24); IQ = 118.17 (10.74)<br><br>NT: 39.5 (13.27); IQ = 111.78 (11.17) | *Sensory profile:* AASP | **ASD (vs. NT):** ↑sensory sensitivity; ↑low registration; ↑sensation avoidance; ↓sensation seeking; 17/18 ASD participants showed extreme levels of sensory dysfunction; no sig correlation between autistic traits and sensory processing<br>**Age X Diagnosis:** no diff<br>**IQ X Diagnosis:** ASD: ↑performance IQ = ↓low registration, ↓sensory sensitivity, ↓sensation avoidance | 0.73 (16/22) |
| Minshew et al. (2008; USA) | ASD: ADI-R; ADOS-G | ASD: 60 (51)<br><br>NT: 61 (49) | ASD: 17 (10); IQ = 110 (12)<br><br>NT: 19 (8); IQ = 112 (8) | *Sensory profile:* SSQ<br>*Neurologic sensory perceptual measures:* LNNBTF; RKSPE | **ASD (vs. NT):** self/parent report: ↑sensory sensitivity (tactile, low pain/temperature; other); ↑errors on fingertip writing and wrist shape drawing perception.<br>**Older age:** not correlated with sensory sensitivity | 0.59 (13/22) |

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|---|---|---|---|---|---|---|
| Kern et al. (2007; USA) | ASD: Prior clinical diagnosis (DSM-IV) | ASD: 104 (79) | ASD: 19.92 (11.42) | *Autism symptom severity:* CARS<br>*Sensory profile:* SP | **Age:** Children (3-12 years) - ↑autism symptoms = ↓sensory processing (auditory, visual, touch, oral, multisensory) at low/high thresholds; no correlation in adolescents (13-25 years) or adults (>25 years) | 0.73 (16/22) |

b) Studies including participants with intellectual disability or IQ < 70 in adulthood (n = 3).

| **Author (Year), Country** | **Diagnosis (criteria; measure)** | **N (Male)** | **Age (years) (M, SD); IQ (M, SD)** | **Measure(s)** | **Main Findings** | **QualSyst score** |
|---|---|---|---|---|---|---|

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|---|---|---|---|---|---|---|
| Howlin et al. (2013; UK)* | ASD: Prior clinical diagnosis (ICD-9/10), reconfirmed using ADI/ADI-R<br><br>IQ: childhood (WISC = best estimate); adulthood (WAIS-R/WAIS-III = best estimate) | ASD: 60 (49) | ASD: 44.17 (9.33) (average time for follow-up: 37.5 (9.17) years)<br>IQ = 87.2 (19.8) | *Language:* ADI-R language item<br>*Social outcomes:* FHS | **Diagnosis confirmation:** all met ≥2 core domain on ADI-R<br>**Older age**: ↓autism symptom severity (↓restricted/repetitive behaviours); no diff on IQ; ↑language; mixed social outcome | 0.95 (21/22) |
| Bishop et al. (2012; USA) | ASD: Prior clinical diagnosis and ADI-R | ASD: 65 (49); 14 had IQ <70 | ASD: 24.97 (8.22); IQ = 89.61 (24.23) | *Autism symptom severity:* AQ; ADI-R<br>*Verbal/Non-verbal/General intelligence:* WRIT<br>*Adaptive behaviours:* Vineland Screener | **Older age:** not associated with AQ<br>**Greater autism symptom severity (AQ):** ↑IQ (~3 points higher on AQ for adults with IQ ≥85); not associated with adaptive behaviours or ADI-R | 0.82 (18/22) |
| Esbensen et al. (2009; USA) | ASD: SCQ, ADI-R, CARS, ADOS, DSM-IV checklist | ASD: 712 (568) | ASD: 19.6 (12); 62.2% w ID | *Restricted and repetitive behaviours:* RBS-R | **Olderage (controlling for ID):** ↓repetitive behaviours (including ↓stereotyped movements (steepest attenuation slope), ↓self-injurious behaviours, ↓compulsive behaviours, ↓ritualistic/sameness behaviours, ↓restricted interests (steepest attenuation slope))<br>**ASD w ID (vs. w/o ID):** ↑repetitive behaviours (including ↑stereotyped movements, ↑self-injurious behaviours)<br>**Age X ID:** ASD w ID had ↓ age-related diff in stereotyped movements than ASD only | 0.86 (19/22) |

*Note.* *Includes participants with IQ < 70 in adulthood, though all had IQ ≥ 70 during childhood. ↑ = Greater; ↓ = Lower; AASP = Adult/Adolescent Sensory Profile; ADI-R = Autism Diagnostic Interview – Revised; ADOS = Autism Diagnostic Observation Schedule; AQ = Autism Quotient; ASD = Autism Spectrum Disorder; CARS = Childhood Autism Rating Scale; DSM = Diagnostic Statistical Manual; EQ = Empathy Quotient; FHS = Family History Scale; GIT = Groninger Intelligence Test; ICD = International Classification of Diseases; ID = Intellectual Disability; IRI = Interpersonal Reactivity Index; LNNBTF = Luria-Nebraska Neuropsychological Battery Tactile Functions; NT = Neurotypical; RBS-R = Repetitive Behaviour Scale – Revised; RKSPE = Reitan-Klove Sensory Perceptual Examination; SCQ = Social Communication Questionnaire; SFS = Social Functioning Scale; SP = Sensory Profile; SRS-2 = Social Responsiveness Scale-2; SSQ = Sensory Sensitivity Quotient; ToL = Tower of London; w = with, w/o = without; WAIS = Wechsler Adult Intelligence Scale; WASI = Wechsler Abbreviated Scale of Intelligence; WRIT = Wide Range Intelligence Test.

Table 4. Summary of studies describing social integration and quality of life in ageing autistic adults (n = 3).

| Author (Year), Country | Diagnosis (criteria; measure) | N (Male) | Age (years) (M, SD); IQ (M, SD) | Measure(s) | Main Findings | QualSyst score |
|---|---|---|---|---|---|---|
| Van Heijist et al. (2015; The Netherlands) | ASD: Prior clinical diagnosis; SRS-A<br><br>IQ: DART | ASD: 24 (19)<br><br>NT: 24 (18) | ASD = 63.7 (7.4); IQ = 109.5 (10.3)<br><br>NT: 63.5 (8); IQ = 109.6 (7.8) | *Quality of life:* RAND-36<br>Psychological problems: SCL-90<br>*Cognitive problems:* CFQ | **ASD (vs. NT):** ↓ QoL (not predicted by symptom severity, age, IQ), ↑ cognitive problems, ↑ psychological problems | 0.86 (19/22) |
| Mason et al. (2019; UK)* | ASD: Prior clinical diagnosis | ASD: 69 (48) (1 w ID) | ASD: 56.4 (7.15) | *Demographics:* ASC-UK registration questionnaire (diagnosis, everyday life, employment/education; level of support; health records etc)<br>*Depression and anxiety:* HADS<br>*Quality of life:* WHOQoL-BREF | **↑Anxiety OR Depression (vs. normal):** ↓QoL (physical, psychological, environmental); no diff on Social QoL<br>**↑Anxiety AND Depression (vs. normal):** ↓QoL (all domains)<br>**↑Anxiety AND Depression (vs. one diagnosis):** ↓QoL (physical, psychological)<br>QoL scores not correlated with participation in normative outcomes (employment; peer socialisation; independent living) | 0.82 (18/22) |
| Moss et al. (2017)* | ASD: Prior clinical diagnosis using ADI; confirmed using ADI_R<br><br>IQ: WAIS-III | ASD: 52 (43) | ASD: 47.9 (9.5); IQ = 69.9 (32.4)<br><br>Childhood assessment: 6.3 (2.1); IQ = 89.3 (14.4) | Quality of life: WHOQoL-BREF<br>Social and mental health outcomes: FHS | **Older age:** ↓physical quality of life (informant rated)<br>**↑ Autism symptom severity (childhood)**: ↓physical health satisfaction<br>↑ Social outcomes (adulthood – self-report): **↑**social quality of life | 0.86 (19/22) |
| Howlin et al. (2013; UK)* | ASD: Prior clinical diagnosis (ICD-9/10), reconfirmed using ADI/ADI-R<br><br>IQ: childhood | ASD: 60 (49) | ASD: 44.17 (9.33) (average time for follow-up: 37.5 (9.17) years)<br>IQ = 87.2 (19.8) | *Language:* ADI-R language item<br>*Social outcomes:* FHS | **↓Outcome quality:** ↑Reciprocal social interaction impairment; ↓IQ<br>**Overall adult social outcomes:** ↓education (72% no formal qualifications); ↓autonomy in daily living (87% not fully independent); ↓ employment (55% never worked/long-term employed); ↓close reciprocal | 0.95 (21/22) |

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| | (WISC = best estimate); adulthood (WAIS-R/WAIS-III = best estimate) | | | | friendship (63% never any peer relationships; 77% no reciprocal relationships > 1 month) | |

*Note.* *Includes participant with intellectual disabilities or IQ < 70 in adulthood. ↑ = Greater; ↓ = Lower; ADI = Autism Diagnostic Interview; ASC-UK = Autism Spectrum Cohort – UK; ASD = Autism Spectrum Disorder; CFQ = Cognitive Failures Questionnaire; DART = Dutch Adult Reading Test; FHS = Family History Scale; HADS = Hospital Anxiety and Depression Scale; ICD = International Classification of Diseases; ID = Intellectual Disability; NT = Neurotypical; QoL = Quality of Life; RAND-36 = Research and Development – 36; SCL-90 = Symptom Checklist-90; SRS-A = Social Responsiveness Scale – Adult; w = with; WAIS = Wechsler Abbreviated Scale of Intelligence; WHOQoL-BREF = World Health Organisation Quality of Life; WISC = Wechsler Intelligence Scale for Children.

Table 5. Studies describing adaptive functioning in ageing autistic adults (n = 4).

| **Author (Year), Country** | **Diagnosis (criteria; measure)** | **N (Male)** | **Age (years) (M, SD); IQ (M, SD)** | **Measure(s)** | **Main Findings** | **QualSyst score** |
|---|---|---|---|---|---|---|
| Wise et al. (2019; USA)* | ASD: Prior clinical diagnosis (DSM-5) | ASD: 74 (61)<br>≥50 years: 40<br>with ID: 62 | ASD: 49.9<br>IQ (n = 39) = 61.17 (20.62) | *Functioning:* ADL; IADL<br>*Overall medical health:* GMHR | **Functioning:** ≥1/3 performed all ADL (w or w/o prompts; correlated with ↑general health); 2/3 independent in ≥50% of daily tasks<br>**Older age:** No change in daily functioning<br>**↑ID severity:** ↑dependence in ≥1 basic ADL; ↓employment in retail/warehouse/farm<br>FSIQ and ADLs - non-linear, best performance for IQ 55-65; 79% w IQ > 60 and 15% w IQ < 60 fully independent in ADL. | 0.77 (17.22) |
| Hwang et al. (2018; Australia)* | ASD: Prior diagnosis; AQ-28 | ASD: 92 (41)<br><br>NT: 60 (12) | ASD: 51.7; 3.3% had ID<br><br>NT: 53.7; 1.7% had ID | *Records from ALSAA<br>*Disease/disability:* medical records; WHO and NHMRCA guidelines for alcohol consumption<br>*Physical/mental functioning:* WADLS; SF-12; WHO-DAS 2<br>*Active engagement with life:* activity level and contact with family/friends | **ASD (vs. NT):** 3.3% ASD (NT: 15%) found to be ageing well by all 3 criterion; 66.3% ASD (95% NT) met ≥1 criteria; 33.7% ASD (5% NT) met 0 criteria; ↓maintenance of physical/mental health.<br>**Greater autism traits / autism symptom severity:** ↓active engagement with life<br>**Older age:** ↓active engagement with life | 0.81 (18/22) |

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|---|---|---|---|---|---|---|
| Totsika et al. (2010; UK)* | ASD: DAS (DSM-III-R) | ASD w ID (≥50 yrs): 87 (49)<br><br>ASD w ID (18-49 yrs): 194 (97)<br><br>ID (≥50 yrs): 195 (105) | ASD w ID (≥50 yrs): 59.1 (8.6)<br><br>ASD w ID (18-49 yrs): 35.9 (8.5)<br><br>ID (≥50 yrs): 61.3 (9) | *Adaptive skills:* ABS-RC:2<br>Behaviour problems: ABC<br>*Psychiatric status:* PAS-ADD<br>*Quality of Life:* IPDL | **ASD w ID (vs. ID):** ↓adaptive functioning, ↑behaviour problems, ↓activity level (non-sig when matched to ID only group on adaptive functioning)<br>**Age (ASD w ID 18-49 years vs ≥50 years):** ↓behaviour problems; ↓proportion of psychiatric cases; ↓staff attention | 0.95 (21/22) |

*Note.* *Includes participants with intellectual disabilities. ↑ = Greater; ↓ = Lower; ABC = Aberrant Behaviour Checklist; ABS-RC:2 = Adaptive Behaviour Scale Part One; ADL = Katz Index of Independence in Activities of Daily Living; ALSAA = Australian Longitudinal Study of Adults with Autism; AQ-28 = Autism Quotient-28; ASD = Autism Spectrum Disorder; DAS = Disability Assessment Schedule; DSM = Diagnostic Statistical Manual; FSIQ = Full Scale IQ; GMHR = General Medical Health Rating; IADL = Lawton-Brody Instrumental Activities of Daily Living Scale; ID = Intellectual Disability; IPDL = Index of Participation in Domestic Life; NHMRCA = National Health and Medical Research Council of Australia; NT = Neurotypical; SF-12 = Short-Form 12; PAS-ADD = Psychiatric Assessment Schedule for Adults with Developmental Disabilities; w = with; WADLS = Waisman Activities of Daily Living Scale; WHO = World Health Organisation.

Table 6. Study describing language processing in ageing autistic adults (n = 4).

| **Author (Year; Country)** | **Diagnosis (criteria; measure)** | **N (Male)** | **Age (years) (M, SD); IQ (M, SD)** | **Measure(s)** | **Main Findings** | **QualSyst score** |
|---|---|---|---|---|---|---|
| Baxter et al. (2019; USA) | ASD: Prior clinical diagnosis (DSM-5); ADOS-2 (Module 4)<br><br>IQ: KBIT-2 | ASD:<br>Young: 21 (21)<br>Middle-age: 24 (24)<br><br>NT:<br>Young: 14 (14)<br>Middle-age: 20 (20) | ASD:<br>Young: 21 (3); IQ = 105.33 (13.5)<br>Middle-age: 53 (8); IQ = 106 (17.93)<br><br>NT:<br>Young: 21 (3); IQ = 107.21 (12.68)<br>Middle-age: 50 (7); IQ = 112.5 (12.79) | *Phonemic fluency:* COWAT<br>*Semantic fluency:* Animal Naming<br>*Verbal processing speed:* Stroop word reading trial<br>*Nonverbal processing speed:* Trail making<br>*General verbal knowledge:* WAIS-III Vocab subtest | **ASD (vs. NT):** ↓semantic fluency; ↓verbal and ↓non-verbal processing speed<br>**Older age:** ↑general vocabulary<br>**Age X Diagnosis:** ↓phonemic fluency in young ASD (near significant trend) | 0.82 (18/22) |

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|---|---|---|---|---|---|---|
| †Davids et al. (2016; The Netherlands) | ASD: Prior clinical diagnosis (DSM-IV/DSM-5); ADOS<br><br>IQ: WAIS-IV-NL | ASD: 36 (30)<br><br>NT: 36 (30) | ASD: 58.6 (7.8); IQ = 106.3 (18.4)<br><br>NT: 59.4 (8.3); IQ = 107.1 (15.6) | *Autistic traits/ASD symptoms:* SRS-A<br>*Phonemic fluency:* shortened COWAT<br>*Semantic fluency:* animal naming | **Older age:** ↓semantic fluency<br>**Age X Diagnosis:** no diff | |
| Mayer et al. (2014; UK) | ASD: Prior clinical diagnosis; ADOS (module 4)<br><br>IQ: WASI | ASD: 19 (15)<br><br>NT: 19 (15) | ASD = 40.23 (11.33); IQ = 113.37 (15.27)<br><br>NT = 38.32 (9.05); IQ = 118.95 (10.84) | *Receptive vocabulary:* PPVT<br>*Working memory:* backwards digit span (WAIS-IV)<br>*Language difficulties:* CC-SR<br>*Sensory difficulties:* SP<br>*Speech test*: experimental stimuli using 30*15 word sentences played at 3 different speeds | **ASD (vs. NT):** ↑recall time for ASD during moderate speed compared to fast speed; both groups had ↓ encoding/recall in fast speed<br>**Age X Diagnosis:** Older age and ↑sensory sensitivity (ASD) = ↓accuracy in fast speed | 0.77 (17/22) |
| †Geurts et al. (2012; The Netherlands) | ASD: Prior clinical diagnosis; SRS<br><br>IQ: DART | ASD: 23 (18)<br><br>NT: 23 (18) | ASD = 63.6 (7.5); IQ = 109.5 (10.3)<br><br>NT: 63.7 (8.1); IQ = 109.8 (7.9) | *Phonemic Fluency:* adapted COWAT | **ASD (vs. NT):** ↓phonemic fluency<br>**↑Age:** ↓phonemic fluency<br>**Age X Diagnosis:** ↑age in NT = ↓phonemic fluency (than ASD) | 0.82 (18/22) |

*Note*. †Only language related findings reported here (see Table 2 for full summary). ↑ = Greater; ↓ = Lower; ASD = Autism Spectrum Disorder; ADOS = Autism Diagnostic Observation Schedule; CC-SR = Communication Checklist-Self Report; COWAT = Controlled Oral Word Association Test; DSM = Diagnostic Statistical Manual; KBIT-2 = Kaufman Brief Intelligence Test 2nd Edition; NT = Neurotypical; PPVT = Peabody Picture Vocabulary Test; SP = Sensory Profile; WAIS = Wechsler Adult Intelligence Scale; WASI = Wechsler Abbreviated Scale of Intellig