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Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood

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HIGHLIGHTS

- Twenty five adult outcome studies of individuals with ASD were identified.
- Overall, cognitive scores were stable; adaptive skills and ASD symptoms improved.
- Social outcomes were generally poor for many participants.
- Early IQ and language predicted outcomes; but with large individual differences.
- Quality of life and socio-emotional factors should be considered in future work.

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ABSTRACT

Background: Although increasing numbers of children diagnosed with Autism Spectrum Disorders (ASD) are now entering adolescence and adulthood, there is limited research on outcomes post childhood. A systematic review of the existing literature was conducted.
Method: PsycINFO, PubMed, MedLine and CINAHL were systematically searched using keywords related to ASD and adolescent and adult outcomes. Studies of individuals diagnosed with ASD in childhood and followed up into adulthood were identified and reviewed. Only studies with samples sizes >10, mean age at outcome >16 years and at least one previous assessment in childhood (<16 years) were included.
Results: Twenty-five studies meeting criteria were identified. Reported outcomes in adulthood were highly variable across studies. Although social functioning, cognitive ability and language skills remained relatively stable in some studies, others reported deterioration over time. Adaptive functioning tended to improve in most studies. Diagnosis of autism or ASD was generally stable, although severity of autism-related behavioural symptoms was often reported to improve. Childhood IQ and early language ability appeared to be the strongest predictors of later outcome, but few studies examined other early variables associated with adult functioning.
Discussion: Implications of the findings are discussed in relation to methodological challenges in longitudinal outcome research and future research directions.

Contents

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1. Introduction

Prevalence estimates for Autism Spectrum Disorders, a group of complex lifelong neurodevelopmental conditions affecting social interaction, communication and patterns of behaviour and interests, have been rising over recent decades, most likely due to changes in diagnostic criteria and greater awareness of the heterogeneity of the condition (Fombonne, 2009). Just as rates of diagnosis are rising in children, increasing numbers of individuals are also being diagnosed in adolescence or adulthood. However, there is limited research on outcomes post middle childhood. For example, although there is evidence that early, intensive behaviourally and/or developmentally based interventions have at least some short term effects on improving functioning in early or middle childhood (see Kuppens & Onghena, 2012; Magiati, Tay, & Howlin, 2012 for recent reviews), research on the longer term impact of these interventions is extremely limited. There is little research on developmental trajectories over time or on psychosocial interventions for adults (Bishop-Fitzpatrick, Minshew, & Each, 2013; Piven & Rabins, 2011) and generally, services for adults with ASD have been found to be costly (Cimera & Cowan, 2009), scarce and/or inadequate (Bishop-Fitzpatrick et al., 2013; Shattuck et al., 2012). Transition to adulthood is often difficult and stressful for individuals with ASD and their families (Hendricks & Wehman, 2009) and there is a pressing need for better knowledge of trajectories through adolescence and adulthood in order to provide necessary support and resources.

Three reviews of adult outcome studies have been published relatively recently (Henninger & Taylor, 2012; Howlin & Moss, 2012; Levy & Perry, 2011). However, Levy and Perry's (2011) review was descriptive, non-systematic and neither the search process nor inclusion/exclusion criteria were described. Howlin and Moss (2012) systematically reviewed studies on adult outcomes with a clearly described search process, but they reported only overall summary indices/ratings (typically ranging from very poor to very good) for outcomes in independent living, employment, romantic relationships and friendships. Finally, Henninger and Taylor (2012) critically reviewed the ways in which researchers have defined "successful adult outcomes" for individuals with ASD from the earliest to the most recent outcome studies. Their review was comprehensive but, again, not systematic and also focused on global summary ratings of outcome.

The present review aims to extend these earlier reviews by (i) systematically reviewing longitudinal studies from childhood to adulthood; (ii) reporting detailed summary information on childhood characteristics of participants; (iii) summarizing the assessment methods employed in each study to allow a better understanding of how adult outcomes have been measured and the variability between studies; (iv) reporting outcomes for *specific* domains of functioning and behaviour (including cognitive ability, language/communication, adaptive functioning, autism severity and social functioning); (v) including individuals with ASD of all levels of intellectual ability; and (vi) examining and summarizing data on childhood predictors of later outcomes as reported in the included studies.

2. Method

2.1. Search strategy

A systematic search was conducted in PsycINFO and PubMed up to and including 10th April 2013. The search consisted of the following search terms: (autis* or ASD* or Asperger*) AND (adult* or adolescen* or people or individual* or youth* or teenag* or "young people") AND (outcome* or prognosis or follow-up or longitudinal or long-term or predict* or change* or continuit* or trajector*). The asterisk represents truncation, allowing the search to identify different endings of the term. The parentheses group terms together. In the above search, at least one term from each of the three groups had to be present in the title or abstract. The search was limited to original research studies published in English in peer-reviewed journals. The titles and abstracts of the search results were then screened and the relevant papers identified. The same terms were also searched in the title only of the MedLine, CINAHL, EMBASE and Web of Science databases up to and including 10th April 2013, to ensure as far as possible that all relevant studies would be identified. In addition, the earlier reviews by Howlin et al. (2004), Levy and Perry (2011), Howlin and Moss (2012) and Henninger and Taylor (2012) were examined and relevant studies not identified in the search described above were included if they met the inclusion criteria. Because the quality and representativeness of the included studies, as well as the validity and generalizability of findings, can be negatively affected by small sample sizes amongst other factors, case studies or small case series with fewer than 10 participants were not considered. There was no restriction on the IQ ranges of the participants.

2.2. Inclusion criteria

The following inclusion criteria were applied:

(i) Longitudinal study with at least one assessment in childhood or early adolescence and one in later adolescence or adulthood

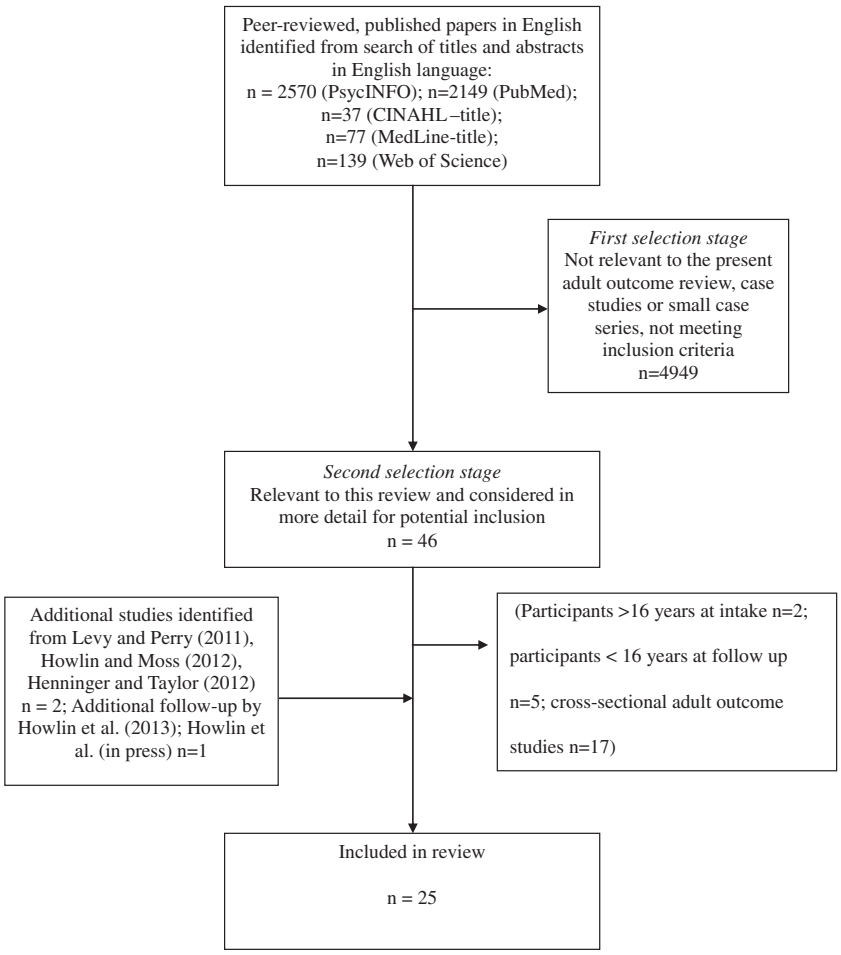

Fig. 1. Summary of the search selection process.

(i.e. cross-sectional adult outcome studies with a single assessment point in adulthood only were not included);

(ii) Mean age of participants at first ("child") assessment <16 years;

(iii) Mean age of participants at adolescent/adult follow-up ≥16 years;

(iv) Professional/clinical diagnosis of autism, infantile autism, ASD, PDD-NOS or Asperger's Syndrome (AS) in childhood using DSM or ICD criteria; or, in the earlier studies conducted in the 60s, individuals with a diagnosis of "infantile psychosis" who were later classified as having autism.

2.3. Search and selection process

The second author carried out the initial searches in the electronic databases. In the first stage of the selection process, all papers whose title or abstract were clearly not relevant to this review were excluded. During this first selection stage, regular meetings between the first and second authors were held to scrutinize the title/abstract of the papers to ensure agreement regarding the papers to be selected for detailed review.

In the second stage of the selection process, all papers with a title or abstract that appeared to be relevant to the review (N = 46) were examined in detail by the first and second authors together to exclude any that were not relevant and/or did not meet the inclusion criteria. The search process is summarized in Fig. 1.

2.4. Included studies' summary/coding procedures

After selecting the studies for inclusion in the review, relevant information and variables from each study were summarized in Tables 1–4. The data tabulated included: demographic and diagnostic information on participants at intake; the measures employed in each study, and the outcomes reported in adulthood (i.e. autism symptomatology; IQ; adaptive behaviour; language/communication; social integration/independence, and other comorbid [medical, behavioural, psychiatric] conditions). Studies from the same cohort with multiple publications are reported as a single entry in the summary tables. This process was conducted by the first and second authors and then reviewed and finalized by the third author.

3. Results

All included studies are summarized in Table 1.

3.1. Study characteristics: participants and measures used

Twenty-five studies meeting criteria were identified.* They were published between 1984 and 2013, with only ten published prior to 2000. Sample sizes ranged from 11 to 725, with a median sample size of 45. Only eight studies had 20 or fewer participants and five had more than 100. Reported diagnoses of the participants included autism,

* The studies by Seltzer, Shattuck and colleagues' research group (i.e. Shattuck et al., 2007; Seltzer & Taylor, 2003; Taylor & Seltzer, 2011) were not included in the present review, as at intake participants in their cohort ranged from 10 to 52 years old, with a mean age of 22 years; 35% of their participants were over 21 years old at intake. Follow-up data were presented for the whole cohort and thus it was not possible to disentangle child from adult participants. Similarly, the follow-up studies by Rutter and colleagues (Lockyer & Rutter, 1970; Rutter & Lockyer, 1967; Rutter et al., 1967) were also excluded, as the mean age at follow up was < 16 years (mean 15.7 years).

Table 1
Summary of Studies Included in Review (N = 25).

Study no.	Author (year)	N (% Males)	Diagnosis	Mean age at initial assessment in years (SD) [range]	Mean age at follow-up in years (SD) [range]	Initial mean IQ in childhood (SD or %) [range]	Measures
1	Howlin, Moss et al. (2013); Howlin, Savage et al. (2013)	60 (81.6%)	Autism (ICD-9 or 10 criteria confirmed with ADI/ADI-R)	6.9 (2.9) [2.9–13]	44.2 (9.4) [29–64]	86.3 (all had NVIQ > 70)	*Autism Severity:* clinical diagnosis. *IQ:* WISC, WPPSI, WAIS, WASI, Raven, Leiter, Merrill Palmer – "best estimate" calculated. *General/social functioning:* VABS, Family History Schedule (FHS) adulthood items.
2	Gillespie-Lynch et al. (2012)	20 (100%)	Autism (first diagnosis DSM-III; DSM-IV at follow-up)	3.9 (1.2)	18.3 (3.6), then 26.6 (3.8)	Developmental quotient: 54.7 (15.5)	*Autism severity:* ADI, ADOS. *Language:* ESCS *Cognitive:* Cattell, Stanford-Binet 3rd *General functioning:* VABS, social outcome
3	Gray et al. (2012)	119 (82.4% male)	Autistic disorder DSM-III-R or IV	8.7 (4.3) [2.8–19.8]	19.2 (4.5) and 24.8 (4.7)	Borderline or average: 27 (22.6%); mild/moderate ID: 75 (63.1%); severe ID: 17 (14.3%)	*Autism severity:* DBC-Autism Screening Algorithm (DBC-ASA) *Emotional & behavioural functioning:* DBC *Social/environmental:* Index of Relative Socioeconomic Disadvantage (IRSD)
4	Anderson et al. (2011)	65 (90% male)	Autism (DSM-IV)	9.78(0.75)	18.1 (0.16)	Not reported/measured	*Autism severity:* ADI-R, ADOS, ABC *Cognitive:* WISC-III, DAS, Mullen *General functioning:* Pubertal Development Scale, other parent-report measures
5	Billstedt et al. (2011); Billstedt et al. (2007); Billstedt et al. (2005)	108 (71.3%)	DSM III-R, DSM-IV, ICD-10 autistic disorder/infantile autism/atypical autism	all <10 years at intake (exact mean age at intake not provided)	25.5 (6.4) [17–40]	<70: 98 (82%) >70: 22 (18%)	*Autism severity:* DISCO *Cognitive:* WAIS-R, WISC-III *General functioning:* VABS, GAF; structured interview with parent/carer about individual's activities and quality of life
6	Liptak et al. (2011)	725 (82%)	Autism diagnosis based on school district classification and confirmed by parents	15.4 [13–17]	19.2 [17–21]	Not reported/measured	Parental and individual interviews from the National Longitudinal Transition Study-2 (US Department of Education)
7	Chowdhury et al. (2010)	34 (97%)	Clinical diagnosis of Autistic disorder (10), Asperger syndrome (15) or PDD-NOS (9) confirmed by ADI-R	4–5 years	22.5 (2.5) [19–28]	Nonverbal IQ: 98.8 (15.7) [72–124]	*Autism severity:* ADI-R, RBS-R
8	Farley et al. (2009)	41 (92.7%)	DSM-III Autism confirmed at follow-up with ADI-R and ADOS; met DSM-IV at follow-up	7.2 (4.1) [3.1–25.9]	32.5 (5.7) [22.3–46.4]	Full Scale IQ (FSIQ): 83.68 (17.56) [36–137]	*Autism severity:* ADI-R, ADOS *Cognitive:* WAIS-R *General functioning:* VABS, overall social functioning
9	Marriage et al. (2009)	45 (82.2%)	ASD (33), ASD and Intellectual Disability (ASD & ID; 12); DSM-III-R or DSM-IV criteria	ASD: 12.4 (3.4) [5–17] ASD & ID: 11 (5.0) [3–17]	21.3 (4.0) [19–37] 21.5 (5.0) [19–30]	12 FSIQ <70	*Autism severity:* ADI-R, ADOS, Child Symptom Inventory, Australian Scale for Asperger's Disorder *General functioning:* Mental status exam, vocational and social history
10	Szatmari et al. (2009)	Autism: 36 (86.1%) AS: 21 (90.5%)	DSM-III-R/DSM-IV Autism or Asperger syndrome using ADI or ADI-R.	Autism: 5.5 (0.98) AS: 5.6 (0.93)	Autism: 17.7 (1.56) AS: 17.6 (1.17)	Autism: 84.5 (16.11) AS: 101.33 (18.02)	*Autism severity:* ADI-R, ABC *Cognitive:* AALPS *Language:* TOLD *General functioning:* VABS
11	Whitehouse, Line et al. (2009); Whitehouse, Watt et al. (2009)	11 (100%)	DSM-IV autism using ADI-R/ADOS	10.2 years (3.2)	21.9 (4.0) [16.1–28.9]	Not reported/measured	*Autism severity:* ADOS-G, ADI-R *Cognitive:* Verbal IQ, WASI *Language:* TROG-E, BPVS-II, ERRNI, York, NEPSY, CC-A, OSCCI, TOWRE, Goldman-Fristoe *General functioning:* parent questionnaire on individual's educational/employment/psychiatric history.
12	Cederlund et al. (2008)	140 (100%)	DSM-III or III-R for Autism (70), Gillberg & Gillberg criteria for AS (70) confirmed with DISCO	Autism group: <10 years (exact mean age not given) AS group: 11.3 (3.8)	Autism: 24.5 (5.4) [16.1–36.1] AS: 21.5 (4.4) [16.0–33.0]	Autism: <70: 70 ≥70: 14 AS: VIQ 107.2 (18.6) PIQ 94.6 (18.7)	*Autism severity:* ASDI, DISCO, HBSS, CARS *Cognitive:* WAIS-III *General functioning:* GAF, VABS

13	Eaves and Ho (2008)	48 (77.1%)	ASD based on DSM-III, III-R or IV criteria; CARS used.	6.8 [3–12]	24.0[19–31]	Verbal IQ >70: 17.4% Non-verbal IQ >50: 61%	*Autism severity:* CARS *Cognitive:* WPPSI, WISC, Bayley or Leiter
14	McGovern and Sigman (2005); Sigman and McGovern (2005)	48 (87.5%)	DSM-III or III-R diagnosis of autism CARS or ABC for half the sample; ADI-R at follow-up	3.9 (1)	19.0 (3.8)	52.2 (13.3)	*Autism severity:* CARS, ABC, ADI-R, ADOS-G *General functioning:* VABS, emotional responsiveness (developed by authors), Peer Play Scale *Cognitive:* Cattell, Stanford-Binet 3rd or 4th, BSID, Mullen *Language:* Reynell, CELF-R, ESCS
15	Howlin et al. (2004)	68 (89.7%)	Autism (based on initial criteria by Rutter, which closely match DSM-IV-TR and ICD-10 criteria, reconfirmed in adulthood with ADI-R).	7.24 (3.10) [3.1–15.66]	29.33 (7.97) [21.16–48.58]	PIQ: 80.21 (19.28) [51–137]	*Cognitive:* WAIS-R, Raven's, Leiter, Merrill-Palmer *Autism severity:* ADI *Language:* BPVS, Neale, Schonell
16	Howlin et al. (2000); Mawhood et al. (2000); Bartak et al. (1975)	19 (100%)	Autism confirmed by ADI and ADOS	7–8 years	23.75 (1.79) [21.25–26.58]	Not reported/measured	*Autism severity:* ADOS, ADI, *General functioning:* VABS, SEF-I *Cognitive:* WAIS-R *Language:* Gray Oral, Edinburgh, Schonell, BPVS, EOWPVT
17	Larsen and Mouridsen (1997)	18 (55.5%)	Initial diagnoses of psychosis up to 1970 were re-examined to establish ICD-10 criteria for Autism (9) or Asperger syndrome (9)	Approx. 8 years old (2–14 years)	38 [32–44]	IQ <70: 4 IQ 71–85: 6 IQ >85: 8	Patients' medical and personal register records
18	Ballaban-Gil et al. (1996)	99 (67%)	Clinical diagnosis of ASD consonant with DSM-IV criteria	6.8 [0.8–20.3]	18.1 [12–29.5]	Severe mental retardation (SMR): 31% Mild mental retardation (MMR): 15% Normal or near-normal: 22% Indeterminate: 28%	Childhood data (medical, language, social, diagnosis) from Tuchman, Rapin & Shinnar (1991) adulthood data from structured interview with parent
19	Piven et al. (1996)	38 (71%)	ADI diagnosis of autism	5 years	17.6 (4.0) [13–28]	Nonverbal IQ: 88.4 (6.1) [67–136]	*Autism severity:* ADI *Cognitive:* WISC-R, Merill-Palmer, Leiter
20	Perez and Sevilla (1993)	17 (82.3%)	DSM-III Autism at intake; no follow-up diagnostic confirmation process described	12.5 (1.7) [10–16]	17.5 (1.7) [15–21]	23.8 (7.8) [15–43]	*Cognitive:* PEP, AAPEP
21	Kobayashi et al. (1992)	197 (84.3%)	Autistic disorder according to DSM-III-R criteria	6.4 (2.8)	21.8 (3.6)	IQ <70: 76.4% IQ ≥70–79: 23.6%	*Cognitive:* Tanaka-Binet, Suzuki-Binet, WISC *Language:* authors' speech ratings *General functioning:* adaptive level, interviews with parents or patients, opinions of medical and other professionals
22	Szatmari et al. (1989)	16 (75%)	DSM-III criteria for autism, ASD, AS	all <6 years (exact mean age not stated)	26.1 [17–34]	92.4 (14.2) [68–118]	*Cognitive:* WAIS-R, Grooved Pegboard, Token Test, WCST, Beery *General functioning:* VABS, structured interview with parent, DICA, author developed social impairment rating scale
23	Gillberg and Steffenburg (1987)	23 (74%)	DSM-III Infantile autism	Mean age not specified, but all seen in childhood and prior to onset of puberty	16–23	SMR: 9 MMR: 8 Normal or slight "subnormal:" 6	*General functioning:* Structured interview and clinical examination
24	Rumsey et al. (1985)	14 (100%)	DSM-III Infantile autism	"early childhood", but exact age not provided	28 (6.8) [18–39]	PIQ: 97.4 [55–129]	*Cognitive:* WAIS *Autism severity:* Psychiatric and parent interviews *General functioning:* VSMS
25	Shirataki et al. (1984)	13 (92.3%)	Infantile autism according to Kanner criteria	5.2 [3–7]	27.8 [22–35]	Not reported/measured	Author developed social and speech rating scales, EEG, CT scans

Table 2
Summary of cognitive, adaptive functioning and communication/language outcomes in adulthood.

Study number	Cognitive/intellectual functioning	Adaptive functioning	Communication/language
1	Mean IQ relatively stable from 85.5 (sd 14.2) to 87.2 (19.8); most participants remained within 1 sd of original score.		57% had functional/echoed phrase speech in childhood compared to 80% in adulthood; only 3 adults (5%) had no speech, compared to 15 (25%) in childhood.
2	Developmental Quotients decreased from 54.7 (T1; mean age 3.9 years) to 44.8 (T3; mean age 18.3 years)	Improvement in VABS daily living and communication skills; little change in social skills; VABS raw scores generally improved (T2 mean = 59.5; T3 = 69.6; T4 = 67.3).	Language age equivalent scores improved (T1 mean 1.7 years at CA 3.9 years; T3 = 5.0 years at mean CA 18.3 years), but remained significantly delayed.
5	IQ shifted downwards (47% initially diagnosed with severe mental retardation; 71% at follow-up).		
6			12% no trouble conversing, the remainder significant trouble or did not converse at all.
8	Large variability in individual IQ change, but average scores stable. Six increased by >1 SD on nonverbal measures; 5 decreased by >1 SD. Seven increased by > 1 SD on verbal IQ, 2 decreased.	VABS ABC in adulthood = 65.0 (SD = 32.8). Mean DLS > socialization and communication scores.	
10		Socialization, communication and daily living VABS scores improved, but flattened out over time at the end of the trajectories observed; AS group > autism group.	
11	NVIQ for ASD group stable over time (101.2 to 103.4).		Language deficits persisted in 5/11 individuals. Parent report indicated structural language problems in ASD group, despite average performance on other tests.
12	Autism group IQ shifted downwards; 25% more had IQ/DQ ≤49 compared to childhood. AS group mean IQ stable.		
13	Mean Verbal and Performance IQs stable over time.		
14	Mean IQ scores stable between early (52.2) and middle childhood (50.8), but declined in young adulthood (46.1).	VABS ABC age equivalent scores improved (57.6 to 73.6); few changes in communication skills. No changes in responding to bids for joint attention.	By young adulthood, 23 (49%) had language age equivalent scores <30 months; 7 (15%) <30 to >47 months; 17(36%) >48 months.
15	PIQ decreased from 80.21 to 75; VIQ scores increased from 61.5 to 69.6.		Language functioning was poor, with a mean BPVS age equivalent of 8.3 years at follow up.
16	VIQ scores improved from 66.6 to 82.3; PIQ scores decreased from 94.3 to 82.8 for the ASD participants.	Autism participants < language group in adult mean VABS socialization SS (46.4 versus 74.2) and DLS (65.1 versus 99.9). No group differences in maladaptive behaviour.	PPVT standard scores increased by a mean of 3.8 points for ASD participants at follow-up. 12/18 participants with ASD with poor language in childhood continued to have poor language, but 6 had good language outcomes.
18	Rates of severe mental retardation stable over time; rates of normal cognitive functioning or mild/moderate MR increased due to large number of "indeterminate" child IQ cases; large individual variability in IQ trajectories in those with known childhood IQ.		Language improved with age, but only 35% and 29% achieved normal or near-normal fluency or comprehension respectively.
21			Overall language developmental levels (based on authors' ratings) improved in adulthood; 16% rich vocabulary, 30.5% could communicate to some extent; 32% could understand but not speak; 9% echolalic speech, 12% no words or vocalizations.
22	6 individuals had FSIQ >100, 5 86–100, 4 71–85, 1 < 70. 8 had gone to college, 7 of those had degrees; all others in SEN classes.	6 scored >100 on the VABS composite, 5 scored 86–100, 1 scored 71–85 and 4 scored <70.	
24	Verbal IQ ranged from severely impaired to average; Performance IQ 55–126.		
25	12/13 classified as severely intellectually disabled. One was mildly retarded, employed, and independent.		Language levels overall stable; 6/13 children made some, but small, improvements.

ASD, AS, and/or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) or, in one of the earlier studies (Larsen & Mouridsen, 1997), infantile or childhood psychosis later established as autism based on ICD-10 criteria. The mean chronological age of the cohorts studied was 7.8 years at initial assessment (range 3.9 years to 15.4 years) and 24.3 years at follow-up (range 17.5–44 years). Methods of data collection and participant recruitment varied (see Table 1). Mean intake IQ in the ten studies that reported this was 79.3 (range 24 to 99), but several studies simply noted the numbers of participants with IQ above or below 70 (see Table 1). Due to the very small number of females included in most studies, there was very little exploration of potential gender differences in adult outcomes, although four studies did examine gender as an outcome predictor (see Table 4). The studies used a wide range of measures to assess autism severity and symptoms, cognitive and language abilities, adaptive behaviour functioning and social participation and outcomes (see Table 1 for a summary and Appendix A for an alphabetical list of all measures employed in the included studies). Many employed standardized measures alongside researcher-developed interviews or other caregiver-informant based assessments.

3.2. Outcomes

Although a number of studies evaluated outcomes across multiple domains, others focused on specific areas, such as intellectual

abilities, adaptive functioning, social outcomes, autism severity or comorbid difficulties. A summary of reported outcomes in cognitive, adaptive behaviour and communication/speech functioning is presented in Table 2; Table 3 summarizes outcomes relating to severity of autism-related symptoms, social integration and independence and comorbid difficulties/disorders in adolescence or adulthood.

3.2.1. Cognitive ability

There was wide variability in cognitive outcomes across and within studies (see Table 2) and several studies reported IQ scores at follow-up only (i.e. Rumsey, Rapoport, & Sceery, 1985; Shirataki et al., 1984; Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989). Of the 11 studies that provided data on *change* in IQ scores over time, two reported a mean decrease in IQ or DQ scores from childhood to adult follow-up (Billstedt, Gillberg, & Gillberg, 2005, 2007; Gillespie-Lynch et al., 2012); in four other cohorts IQ was generally stable over time but often with large individual differences noted (i.e. Eaves & Ho, 2008; Farley et al., 2009; Howlin, Savage, Moss, Tempier & Rutter, 2013; Whitehouse, Watt, Line & Bishop, 2009). Farley et al. (2009), for example, found that although average IQ scores remained unchanged, six of the 41 participants showed IQ increases of at least one standard deviation, while five decreased by a similar amount. Howlin, Savage et al. (2013), too, found that while for the majority of participants IQ remained very stable over four decades, in a minority there was significant decline.

Improvement in mean IQ scores was reported in only two studies. Mawhood, Howlin, and Rutter (2000) reported an average improvement of around one standard deviation in VIQ from childhood to adulthood. Howlin, Goode, Hutton, and Rutter (2004) also found a small (8 point) increase specifically in VIQ, although this cohort excluded any participants with a child nonverbal IQ <50.

In the remaining three studies, great individual variability in IQ change over time was reported. Sigman and McGovern (2005) reported a mixed pattern of change, with mean IQ remaining relatively stable between early and middle childhood, but declining in young adulthood. In Cederlund et al. (2008), IQ was generally stable among participants with a diagnosis of Asperger syndrome, but decreased in the subgroup with a diagnosis of autism. Finally, in the Ballaban-Gil, Rapin, Tuchman, and Shinnar (1996) cohort, severe mental retardation rates were reported to be stable over time, while mild intellectual disabilities or normal cognitive functioning increased, most likely due to the large number of "indeterminate" child IQ cases; nevertheless, the authors also noted that the IQ trajectories of those children with known childhood IQ also varied considerably in adulthood.

3.2.2. Adaptive functioning

As with cognitive ability, there was large individual variability reported in this domain, although adaptive functioning was relatively low at all time points (see Table 2). Information regarding adaptive functioning in adulthood was provided in seven studies, but three of these did not present the data in a format that allowed examination of change over time (i.e. Howlin, Mawhood, & Rutter, 2000; Mawhood et al., 2000; Szatmari et al., 1989). The remaining four studies all reported at least some improvements in overall composite or age equivalent adaptive functioning scores (i.e. Gillespie-Lynch et al., 2012; McGovern & Sigman, 2005; Szatmari et al., 2009) and/or decreases in maladaptive behaviours (i.e. Anderson, Maye, & Lord, 2011). Adult adaptive functioning was reported to be better in the domains of daily living and communication skills than in socialization (i.e. Farley et al., 2009; Gillespie-Lynch et al., 2012; Mawhood et al., 2000; Szatmari et al., 2009).

3.2.3. Language and communication

Ten studies reported data on adult language and communication skills, of which seven examined changes in language from childhood to adulthood (see Table 2). Of these, five reported at least some improvements in adult language test raw, age equivalent, standard or other scores or in speech acquisition compared to childhood (i. e. Ballaban-Gil et al., 1996; Gillespie-Lynch et al., 2012; Howlin, Savage et al., 2013; Kobayashi, Murata, & Yoshinaga, 1992; Mawhood et al., 2000). One earlier study (Shirataki et al., 1984) reported overall stability with some small improvements in some individuals. At the same time, all ten studies reporting adult language data noted wide variability in individual language outcomes and generally poor functional language in adolescence and adulthood (see Table 2). For example, in Gillespie-Lynch et al. (2012), mean adult language age equivalent scores were five years at a chronological age of 18.3 years, an improvement of only around 3.3 years compared to mean childhood scores. Sigman and McGovern (2005) also reported that, at a mean age of 19 years, 49% of their participants had language equivalents below 30 months; only 23% had age equivalent scores above 96 months. Similarly, only 35% of the cohort studied by Ballaban-Gil et al. (1996) achieved normal or near-normal speech fluency or comprehension and only 12% of the 725 adults with ASD in Liptak, Kennedy, and Dosa (2011) were reported to be able to converse fluently.

3.2.4. Diagnostic stability and severity of autism-related behaviour symptomatology

Seventeen studies presented some information on either diagnostic status or severity of ASD core symptoms in adulthood. Generally, diagnostic status (autism or ASD) remained stable over time with few major changes (Billstedt, Gillberg, & Gillberg, 2011; Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Farley et al., 2009; Howlin, Moss et al., 2013; Larsen & Mouridsen, 1997; Piven, Harper, Palmer, & Arndt, 1996; Sigman & McGovern, 2005). Even the few participants who no longer met full diagnostic criteria in adulthood were reported to continue to be very impaired (i.e. Piven et al., 1996) or they met criteria on some, but not all, core ASD diagnostic domains.

Similarly, among the six cohorts for which there were data on *changes* in severity of core autism symptoms over time, all reported some overall improvements in total autism symptom scores (Gray et al., 2012; Howlin, Moss et al., 2013; McGovern & Sigman, 2005) or in *specific* autism core subdomain symptoms [i.e. social interaction (Gillespie-Lynch et al., 2012; Piven et al., 1996); communication (Piven et al., 1996); repetitive and stereotyped behaviours and interests (i.e. Chowdhury, Benson, & Hillier, 2010; Howlin, Moss et al., 2013)]. However, the patterns of change reported varied across studies. For example, Gray et al. (2012) found that individuals with severe intellectual disabilities tended to show an increase in autism symptoms as measured by the DBC-Autism Algorithm. Gillespie-Lynch et al. (2012) reported improvements in ADI-R social interaction scores from 11 to 18 years, with subsequent scores being relatively stable, but there was little change in nonverbal communication and repetitive behaviour domains. Others (e.g. Chowdhury et al., 2010; Howlin, Moss et al., 2013; Howlin, Savage et al., 2013) reported less change in social skills and more improvements in communication and repetitive behaviours. Possible reasons for these discrepancies are explored in the Discussion section. A single study (Gray et al., 2012) reported an increase in autism symptoms in adulthood but this occurred only for those participants with ASD and severe intellectual disabilities.

3.2.5. Social integration and independence

Eighteen studies reported adult outcomes related to social integration and independence, with most research groups utilizing global outcome ratings based on the early studies of adolescents/young adults by Rutter and colleagues (Lockyer & Rutter, 1969, 1970; Rutter, Greenfield, & Lockyer, 1967) and also used by Howlin et al. (2004). These are derived from ratings of friendships, occupational placements and independent living. Composite outcomes were generally divided into "*poor or very poor*" (requiring specialized provisions and high levels of support; no work; little or no autonomy; no friends; few or no acquaintances outside family or residential setting), "*fair*" (some degree

Table 3
Summary of adult outcomes in autism symptomatology, social integration and independence and comorbid difficulties.

Study number	Autism Symptom Severity outcomes	Social Integration and independence outcomes[a]	Comorbid/co-occurring conditions' outcomes
1	All adults re-assessed with ADI-R met diagnostic criteria in at least 2/3 core diagnostic domains, but overall severity scores decreased in total ADI-R and restrictive/repetitive behaviour domain.	72% did not obtain any formal educational qualifications; only 16 (26%) lived independently or in semi-sheltered accommodation; 9 (15%) had professional or skilled non-manual jobs and 8 (13%) had manual jobs; the remaining had voluntary, sheltered or no (55%) jobs; none were married/in long-term relationships; most never had friends; overall, 7% had good outcomes, 10% good, 23% fair, 27% poor and 33% very poor.	
2	ADI-R social interaction improved from T2 to T3, but stable or increased by T4; little change in non-verbal communication and repetitive/stereotyped symptoms.	50% had "poor" social outcomes; the remaining had fair (20%), good (10%) or very good (20%) outcomes.	3/20 seizures; eight on medication for mood or anxiety problems; three for behavioural problems, one for attention, two antipsychotics.
3	Autism symptomatology mean item scores measured by DBC-ASA decreased over time, but increased in those with ASD + severe ID; those with average IQ or mild ID improved the most. DBC social relating subscale did not change much.		Small but significant improvements in emotional and behavioural problems in adulthood, but rates remained high.
4	ASD group more socially withdrawn over time compared to non ASD group.		79% psychotropic medication (ever); irritability decreased over time for autism and non ASD groups. ASD trajectories more heterogeneous than in non-ASD groups. Children with more severe ASD features had greater irritability and hyperactivity scores.
5	All participants met DISCO criteria for autistic disorder or atypical autism at follow-up. Social interaction symptoms remained common (at least 15/20 symptoms in >50% of sample).	38% lived with parents, 49% in group homes, 13% with community-based support or help from relatives. Only 6% supported employment; only one in regular employment; others in special schools or no occupation. Quality of life: very good (18%), good (44%), average (26%), poor (9%), very poor (3%). Overall outcome: very poor (57%; autism = atypical autism), poor (21%), restricted but acceptable (13%), 8% fair.	43% of 108 epilepsy, 31% used anti-epileptic medication; 8 of 108 psychosis and prescribed lithium; one non-psychotic depression; one Tourette's; 23% substantial tics; 50% moderate to severe self-injurious behaviours, 33% hyperactive, 18% extreme violence; 49% major medical problems requiring regular medical attention.
6		82.6% lived with parents; > 50% not met any friends in last year.	
7	Restricted repetitive behaviours improved. 25.4% of those symptomatic at intake were asymptomatic at follow-up.		
8	6 improved to subclinical levels based on the ADOS.	Overall social outcome: very good (24%), good (24%), fair (34%), poor (17%); half in full- or part-time independent paid jobs, 10 (24%) in day programs 7% in supported employment, 5% part-time volunteers, 10% unemployed; 7% (N = 3) married with children.	13/41 depression; four suspected depression; three OCD and nine other anxiety disorders; 4/6 with childhood ADHD continue to be treated as adults; two Tourette's; one schizophrenia; one bipolar disorder; one antisocial personality disorder, intermittent explosive disorder and history of pica.
9		Adult functioning lower for those with ASD + ID childhood diagnosis compared to those with ASD only in education, occupation, independence and social functioning.	25% anxiety disorder in adulthood; 25% depression; in those with ID, one had OCD (8%); in those with ASD only, two (6%) had psychosis, four (12%) substance abuse problems and eight (24%) ADHD.
10	Autistic symptoms in adolescence: AS group < autism group; but developmental trajectories similar.		
11		None in ASD group had close friendships or romantic relationship in adulthood; ASD group < independent than language impairment group;	Three comorbid major depressive disorder and generalized anxiety disorder; one OCD.
12	*Autism:* 43 (81%) still met criteria for autism, 9 atypical autism, 1 ASD; *Atypical autism*: 2/17 still met criteria, 15/17 now met criteria for autistic disorder. *AS:* 59 (84.3%) still met criteria for AS, 3 atypical autism, 8 did not meet criteria for any ASD.	*Autism*: 56% very poor outcomes, the rest fair outcomes; none good overall outcomes. *AS*: 27% good, 47% fair, 23% restricted, 3% poor.	

13		46% had "poor" overall outcome ratings, 15 (32%) fair; 21% good or very good; parent-rated mean QoL was 5.2 on a scale of 1–10.	77% had some psychiatric difficulties; based on parent report, 24 thought to have OCD; 24 anxiety; 10 depression; 3 bipolar disorder; 5 Tourette syndrome; 18 conduct disorder; 3 fragile X syndrome; 1 tuberous sclerosis; 39.5% on prescription drugs for behavioural problems; 9 epilepsy.
14	Parent-reported improvements in social, nonverbal and verbal communication and repetitive/stereotyped behaviours; parent-reported diagnosis very stable. High functioning participants improved more. Parents reported their children were more emotionally responsive to others' distress in adulthood compared to childhood.		
15		Overall social outcome was very good for 12%, good for 10%, fair for 19%, poor for 46% and very poor for 12%.	Ten reported to have epilepsy, six on regular antiepileptic medication.
16	On the ADI, the autism group exhibited more problems in areas including compulsions, stereotyped behaviour, verbal rituals, and unusual sensory interests than language impaired group.	74% of the Autism group had severe social difficulties in composite scores of ability for social acquaintances, quality of friendships, sexual relationships and independence.	
17	Diagnoses generally stable, although more changes in AS group.	*AS group:* 3 = good outcome; 4 = fair; 2 = poor. *Autism group:* 2 = good outcome; 1 = fair; 1 = poor 5 = very poor.	Two participants in Autism group (22%) and one in AS group (11%) developed epileptic seizures. Psychiatric illness high and higher in the autism group (8/9 individuals).
18		Social deficits persisted; only 3% no social deficits. Only one lived independently. 27% employed.	70% behavioural difficulties.
19	Mean composite ADI scores improved (16.7 to 11.0) in communication and socialization (21.0 to 12.1); few changes in ritualistic behaviours; 5/38 no longer met diagnostic criteria, but still impaired.		One seizure disorder.
21	43.2% improved; 31.5% deteriorated on family-rated symptoms and dependency evaluations.	Based on authors' definition, 10.7% had adapted satisfactorily, 16.2% lived almost independently, 26.9% had some odd behaviours, 22.8% could not adapt socially, 23.4% had poor social skills.	36/188 had epilepsy at follow-up (mean onset age 13.3 years).
22	At least 1/3 had positive scores for 7/12 RSSI items measuring nonverbal communication, whereas 1/3 had positive scores for 3/17 items measuring verbal communication impairments. Three had no symptoms.	five lived independently, 10 with parents, one in group home.	Parent reported psychiatric comorbidity: one schizoid; four overanxious; three OCD; 5 > one diagnoses; one paranoid thinking; one hallucinations. Participant reported psychiatric comorbidity: one overanxious; two OCD; two > one disorders; one magical thinking; two paranoid thinking; three hallucinations.
23	8/23 had temporary symptom aggravation (i.e. hyperactivity, aggression, insistence on sameness) in puberty. five showed continued deterioration;	Based on Lotter (1978), 2/23 had very poor outcome, nine poor, eight restricted but acceptable, three fair, one good.	35% had epilepsy at follow up (4 grand mal epilepsy; 2 psychomotor epilepsy); four Fragile X syndrome; two other fragile sites in autism group; one individual with AS had bipolar disorder.
24	Social impairments present in all patients. Motor symptoms also observed in 86%.	Vineland social maturity scale quotients ranged from 30 to 88. All but three participants lived with their parents or in treatment settings.	None met DSM-III criteria for affective disorder, but half showed affective flattening. Half chronic, generalized anxiety. Six caretakers of mostly high-functioning individuals reported aggressive, destructive temper outbursts. Positive symptoms of schizophrenia not reported, but two high functioning individuals reported possibly delusional thoughts.
25		Poor prognosis: 8/13 entirely dependent on others; 3/13 could only minimally care for themselves.	5/13 reported episodes of epileptic seizures.

[a] Outcomes were rated as per Howlin et al. (2004) as "very good" if participants were employed, had friends and had high levels of independence; "good" if employed with support, had friends and could travel independently; "fair" if participant required support in daily living but had some autonomy; "poor" if participant had very limited autonomy; and "very poor" if participant was in long-stay hospitals.

Table 4
Relationships between Childhood Variables and Adolescent/Adult Outcomes by Domain of Childhood Functioning Assessed.

Study number	Childhood Variables				
	Autism Severity	Cognitive functioning	Speech/Language/Communication	Social functioning	Gender
1	Higher ADI scores predicted poorer adult social outcomes.	Higher IQ predicted somewhat better adult outcomes, but contribution smaller than Reciprocal Social Impairment (RSI) ADI (all had childhood NVIQ > 70).	Less language in childhood associated with lower adult IQ scores; poorer language associated to some extent with poorer adult social outcomes, but effects not significant when RSI controlled for.	Higher ADI RSI childhood score (=more impairments) was best predictor of poorer adult outcomes.	
2		Developmental Quotients not associated with adult social functioning outcomes, but predicted adaptive functioning.	Better language and more responses to joint attention predicted better adult adaptive behaviours, social functioning overall ratings and more independence.		Individuals unable to complete standardized assessments in adulthood more likely to be female
3		Severe ID risk factor for more behavioural/ emotional problems in adulthood.			
5		Higher IQ predicted adult autism severity (DISCO ASD algorithm).	Speech before 5 years positively correlated with adult autism severity (DISCO ASD algorithm)		Female gender associated with lower scores on Disruptive behaviour.
8		IQ correlated positively (r = .51) with adult IQ. Improvement in cognitive ability predicted better later social outcomes.			Females somewhat better than males at follow-up based on GAF scores, but not statistically significant. Female gender associated with poorer quality of social interaction.
10		Outcome differences could not be explained by intake non-verbal IQ.	Outcome differences not explained by early language skills' change.		Females more often had epilepsy than males.
13	Less severe CARS scores associated with better overall adult social rating outcomes.	Higher VIQ predicted better overall outcome ratings in adulthood.			
14		Participants with higher childhood IQ made more adaptive behaviour gains. IQ in middle childhood predicted IQ scores in adolescence/ adulthood.	Play, responsiveness to joint attention and requesting behaviours predicted language gains from preschool to young adulthood.	Early peer social engagement was predictive of later adaptive behaviour. Mid-school comforting behaviours predicted adolescents'/adults' response to others' distress.	
15		Childhood PIQ and VIQ correlated positively with adult IQ scores; individuals with childhood PIQ ≥ 70 had significantly better social outcomes.			
17		Normal intelligence predicted better social outcomes.			
18		Higher initial cognitive functioning predicted better progress in language skills.			
20		PEP cognitive performance predicted adult functional communication. PEP eye–hand integration predicted vocational skills, independent functioning and vocational behaviour (APEP).		Imitation in childhood predicted adult interpersonal behaviours.	Self-injurious behaviours more commonly reported in females (65%) than males (34%). Similar but non-significant trend when evaluating those without ID, with 50% females and 23% males showing self-injurious behaviours.
21		IQ at six years positively correlated with adult adaptive level outcomes.	Speech level at/before 6 years correlated with better adult adaptive functioning in males.		
22	Early autistic symptoms did not correlate with later VABS composite scores.		Early deviant language did not correlate significantly with later VABS composite scores.	Early social impairments did not correlate significantly with later VABS composite scores.	IQ of females higher than males when group split into IQ < or > 50, but no sex differences for total IQ.
23		Those with IQ >50 in preschool years had significantly better social outcomes than those <50.	Communicative speech before 6 years of age associated with better social outcomes.		

of independence, some support and supervision but no specialist residential arrangements; no close friends, but some acquaintances), "*good or very good*" (high or good levels of independence, holds job without or with some support; has some close friends and acquaintances). This method of summarizing data for this particular domain is also followed here.

Overall, adult outcomes in social integration and independence were reported to be mainly *poor* or *very poor* (see Table 3), with 50% or more of participants remaining fully or largely dependent on parents or carers and requiring significant support for education, living arrangements and employment (i.e. Billstedt et al., 2005, 2011; Cederlund et al., 2008; Eaves & Ho, 2008; Gillespie-Lynch et al., 2012; Howlin, Moss et al., 2013; Howlin et al., 2004; Rumsey et al., 1985; Shirataki et al., 1984). Individuals with ASD were often socially isolated and had few friendships or romantic relationships (i.e. Howlin, Moss et al., 2013; Liptak et al., 2011; Whitehouse, Watt et al., 2009). Rates of independent living and employment were also low (see Table 3). Social independence outcomes were lower for individuals who also had intellectual disability (Marriage, Wolverton, & Marriage, 2009).

The one study reporting somewhat more favourable social integration/independence outcomes was that of Farley et al. (2009). In that cohort, 20 out of the 41 participants (48%) achieved good or very good outcomes and 34% were rated as "fair". However, in that sample participants were relatively high-functioning (mean childhood Full-Scale IQ = 83.7) and, perhaps more importantly, most were members of the Church of Jesus Christ of Latter Day Saints in Salt Lake City, a community that provides substantial assistance and support in education, occupation and social participation.

3.2.6. Comorbid difficulties and disorders

Sixteen of the 25 studies reviewed provided some information on co-occurring or comorbid medical, behavioural or psychiatric conditions in adulthood, with most studies reporting high rates of co-occurring conditions in adulthood (see Table 3). However, only one research group examined *change* in associated emotional and behavioural problems over time (Gray et al., 2012). In this study, although small improvements were noted, comorbidity rates remained high.

3.3. Childhood predictors of adolescent and adult outcomes

Table 4 summarizes childhood characteristics that have been found to correlate or predict adult outcomes.

3.3.1. Gender

No conclusions can be drawn regarding the possible role of gender in relation to adult outcomes, as there were either very few or no female participants in most studies. Only four studies explored gender as a possible predictor of adult outcomes (see Table 4). Kobayashi et al. (1992) found a trend towards females being more likely to have IQ >50 in adulthood. Ballaban-Gil et al. (1996) found that adult females had more self-injurious behaviours than males, although Gray et al. (2012) reported fewer disruptive behaviours in women than in men in adulthood. In an adult cohort of 31 females and 77 males, Billstedt et al. (2005, 2007, 2011) reported a non-significant trend towards adult females having better general functioning scores, but higher rates of epilepsy and poorer social interaction than adult males. Finally, although gender was not explored as a predictor of outcome, Howlin, Savage et al. (2013) noted that individuals with ASD in her cohort who were unable to complete standardized intellectual assessments in adulthood were more likely to be female.

3.3.2. Childhood IQ

Childhood cognitive ability (e.g. IQ, DQ) was one of the most commonly researched predictor variables and was among the strongest predictors of cognitive ability in adulthood (Cederlund et al., 2008; Farley et al., 2009; Howlin, Savage et al., 2013; Howlin et al., 2004; Sigman & McGovern, 2005). Higher childhood cognitive ability was also associated with less severe autism or maladaptive symptomatology (Billstedt et al., 2007) and better adaptive functioning in adulthood (Billstedt et al., 2007; Gillespie-Lynch et al., 2012; Kobayashi et al., 1992; McGovern & Sigman, 2005; Perez & Sevilla, 1993). A positive association between childhood cognitive ability and social outcomes in adulthood was also reported by five research groups (Eaves & Ho, 2008; Farley et al., 2009; Gillberg & Steffenburg, 1987; Gillespie-Lynch et al., 2012; Larsen & Mouridsen, 1997). Only two studies reported specifically on the relationship between childhood IQ and adult communication and both found a positive relationship (Ballaban-Gil et al., 1996; Perez & Sevilla, 1993).

3.3.3. Childhood severity of autism symptomatology

Only three studies investigated the impact of severity of autism symptoms in childhood on adult outcomes. Howlin, Moss et al. (2013) reported that higher diagnostic ADI scores (indicating more impairments in childhood), especially in Reciprocal Social Interaction (RSI), predicted poorer adult outcomes. Indeed, in that study severity of RSI was an even stronger predictor of outcome than childhood IQ, although all participants had a childhood NVIQ > 70. On the other hand, Szatmari et al. (1989) found no correlation between early autistic symptoms and later adaptive functioning. Szatmari et al. (2009) also failed to find any significant differences in outcome between individuals with a diagnosis of autism (n = 36, mean IQ 84.5) and those with Asperger's syndrome (n = 21, mean IQ 101.3) and the developmental trajectories of both groups were generally similar.

3.3.4. Childhood adaptive functioning

Of the 25 studies included in the present review, none examined the relationship between childhood adaptive functioning and later adult outcomes.

3.3.5. Childhood language and communication

Eight studies explored language/communication/early pre-communication factors as possible predictors of adult outcomes. In five of these, better childhood language or communication skills or speech acquisition before age 5 or 6 were consistently found to be predictors of better adult outcomes. Specifically, earlier play skills, responsiveness to joint attention and requesting behaviours predicted language gains from preschool to young adulthood (Sigman & McGovern, 2005). In some studies, early language skills also predicted adult autism symptoms as measured by the DISCO (Billstedt et al., 2007), later adaptive behaviours (Gillespie-Lynch et al., 2012; Kobayashi et al., 1992) and better social outcomes (Gillberg & Steffenburg, 1987; Gillespie-Lynch et al., 2012). In contrast, Howlin, Savage et al. (2013) found that early language development was not significant in predicting adult outcomes when reciprocal interaction impairments in early childhood (as measured by the ADI-R) were included in the regression analysis. Szatmari et al. (2009, 1989) also found no relationship between early language ability and adaptive behaviour skills in adults.

3.3.6. Childhood social functioning

Only four of the included studies specifically examined social functioning in childhood as a predictor of adult outcomes and findings were mixed due to the variety of variables assessed. McGovern and Sigman (2005) reported that early peer social engagement was predictive of later adaptive functioning, and comforting others when distressed in mid-school years was predictive of adolescent and adult responses to others' distress. Howlin, Moss et al. (2013) found that severity of social deficits in childhood, as measured by the ADI Reciprocal Social Interaction score, was the strongest predictor of later adult outcomes. Perez and Sevilla (1993) found that imitation in childhood predicted interpersonal behaviours in adulthood. In contrast, Szatmari et al. (1989) found

no association between early social impairments and later adaptive functioning.

3.3.7. Childhood co-morbid disorders or conditions

Comorbidities in childhood were not consistently recorded and, if assessed, were reported very differently from study to study. Thus, a systematic summary of rates or types of other conditions/disorders in childhood was not possible. However, the main comorbid problems identified in childhood included epilepsy, challenging behaviours directed towards self or others and psychiatric conditions (mostly anxiety, depression, but also bipolar disorder or childhood psychosis in a very small number of cases).

There was very little exploration of the impact of these factors on adult outcomes, although Gray et al. (2012) reported that childhood behavioural and emotional problems predicted higher rates of these difficulties in adulthood (see Table 4). Howlin, Savage et al. (2013) found that the presence of epilepsy and/or severely challenging behaviour was associated with a significant decline in cognitive functioning from childhood to adulthood. Billstedt et al. (2011) also reported a weak association between early onset epilepsy and poorer social functioning in adulthood and better General Assessment Functioning scores (mean GAF score = 33.2) in the subgroup of those with Fragile X compared to those with other medical comorbidities (mean GAF score = 11.7).

4. Discussion

The present paper systematically reviewed outcomes for adolescents and adults with ASD as reported in longitudinal studies with at least one time point assessment in childhood and another in late adolescence or adulthood. There were large variations in reported outcomes both between and within studies, which also reflects the large individual variability that is characteristic of individuals with ASD (see also Levy & Perry, 2011).

At the same time, there were also some consistent findings. When taken together, findings on intellectual functioning outcomes in adulthood appear relatively consistent, in that IQ scores tend to remain stable or to decrease somewhat over time in the majority of studies with only a few exceptions. In cohorts with higher childhood IQ scores, there appears to be greater IQ stability (e.g. Farley et al., 2009; Howlin, Savage et al., 2013; Whitehouse, Watt et al., 2009). All included studies reported large individual variability in IQ adult scores, but the majority suggest that early childhood IQ has some predictive utility in relation to individuals' future outcomes.

The findings regarding adaptive functioning suggest some improvements in this domain over time, particularly in daily living skills and possibly communication, but less so in socialization skills, with large individual differences and continuing overall impairments. Language also tended to improve over time, but individuals in the studies reviewed continued to experience significant language impairments, particularly in the functional and social aspects of communication. Although autism-related symptoms and behaviours generally improved with age, diagnostic status was mainly stable, with almost all participants continuing to meet at least partial diagnostic criteria for autism or ASD in adulthood (see Table 3).

Inconsistent findings on variables associated with outcome can largely be explained by the small and highly heterogeneous sample sizes, the varying amount of time elapsed between childhood and adulthood assessments and the variability in measures and informants employed to assess these symptoms in the included studies. However, studies published after 2000 tend to report somewhat better outcomes than those published earlier. This may be due to cohort differences in diagnosis, severity of autism and related difficulties, or service and treatment options (Levy & Perry, 2011), with later cohorts likely benefiting more and from an earlier age from advances in diagnosis, treatment and educational provisions (Kabot, Masi, & Segal, 2003). Nevertheless, our findings also suggest that outcomes for more recent cohorts are only slightly better than those reported a few decades ago. Howlin and Moss (2012), too, highlighted that, despite some improvements, more recently reported adult outcomes of individuals with ASD are generally poor. However, the more positive outcomes in the study by Farley et al. (2009) suggest that community support and integration may be a crucial factor in increasing social participation and improving outcomes for individuals with ASD in the future.

Although services and support systems in adulthood were not a focus of the present review, a number of recent studies has highlighted the fact that support needs for adults with ASD and their families are largely unmet (Kogan et al., 2008; Shattuck et al., 2012). Nevertheless, in their study of adult quality of life, Billstedt et al. (2007, 2011) found that this was good or very good for 62% of their participants and poor or very poor for only 12%. Although these ratings were based on caregiver reports, and not information from adults with ASD themselves, increasing emphasis on quality of life and mental and emotional well being is likely to result in better targeted support for the social and emotional needs of adults with ASD.

4.1. Limitations of the present review

The conclusions of this review should be interpreted in light of its limitations. Firstly, in the initial screening stage of the search process, when over 5000 potential studies were identified, we did not specify separately the numbers of studies rejected according to each specific exclusion criterion (i.e. small n; no diagnostic ascertainment; not a follow-up study etc.). In addition, the search process was not repeated by an independent, blind researcher. Instead, the first and second authors worked collaboratively to establish the selection/inclusion process and agreement was reached throughout. Finally, it was difficult to summarize findings and key directions in the existing literature by "weighting" the strength of findings according to study quality. Studies varied widely with respect to cohort selection and size, diagnostic and assessment measures used, assessment reliability, drop-out rates and other methodological characteristics and we could not establish a fair and unbiased way of taking account of all these factors in judging research quality. Rather, our efforts focused on trying to identify consistent patterns and trends amongst the included cohort studies. We did, however, explore whether sample size, initial IQ or age of participants at follow-up were related to general outcome or deterioration/improvement in IQ over time as these data were available for almost all studies. Only two significant associations were identified: studies of smaller cohorts tended to report somewhat better adult outcomes (rho = −.62; p = .02); and overall outcome ratings tended to be higher in cohorts with a higher childhood IQ, although this only approached statistical significance (rho = .54; p = .07).

4.2. Challenges in research into adulthood, implications and recommendations

Despite attempts to standardize measurement methods within and across studies, individual differences amongst people with ASD, differences in child and adult assessments, and changes in diagnostic criteria over time make it difficult to compare findings between individuals and across different time points and studies. Thus, although diagnosis in most of the studies reviewed was based on ICD or DSM criteria, the versions used varied with time. Nevertheless, the core diagnostic domains of impairments in social-communication and the presence of restricted and repetitive behaviours and interests have remained relatively stable across the different classification systems used. In addition, most research groups attempted to re-confirm diagnosis using criteria applicable at the time of follow-up and/or by employing standardized diagnostic tools (see Table 1; see also Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013 for further

reflections on changes in diagnostic criteria in light of the newly published DSM-5).

4.3. Priorities for future research

Moving forward, it will be essential that early child intervention studies (for a review, see Magiati et al., 2012) continue to follow-up their participants into adolescence and adulthood in order to explore which child or environment/intervention factors may improve later developmental trajectories, to what extent and how.

Another area where currently virtually no research exists relates to outcomes, strengths and needs of people with ASD in middle and older adulthood. This clearly needs to become a high research and service priority (see Happe & Charlton, 2012; Piven & Rabins, 2011 for reviews and recommendations for future research agendas on ageing in ASD). Similarly, since most participants in adult cohorts studied to date have been male, greater attention needs to be paid to the outcomes for females with ASD.

Shattuck et al. (2012), Bishop-Fitzpatrick et al. (2013), Taylor and Seltzer (2011) and Henninger and Taylor (2012) recommend that assessment of change and social participation in adulthood should emphasize not just individual abilities, but the social, intervention and policy context as well (see also NICE guidelines for adults with ASD, 2012, for evidence-based recommendations for working and supporting adults with ASD and their families). Very few of the studies included in the present review address such factors.

To conclude, cross-sectional and longitudinal research into adulthood and older age will be crucial in order to provide more appropriate and effective services and support systems for adults with ASD. Systematic investigation, not just of individual characteristics but also of environmental and social factors, and from multiple perspectives, is needed to improve the outlook for future generations of individuals with this condition.

Appendix A. Summary of measures employed in the reviewed studies.

Abbreviation	Measure/test
AAPEP	Adolescent and Adult Psychoeducational Profile
ABC	Autism Behaviour Checklist
Aberrant Behavior Checklist	Aberrant Behavior Checklist
ADI	Autism Diagnostic Interview
ADI-R	Autism Diagnostic Interview—Revised
ADOS-G	Autism Diagnostic Observation Schedule—Generic
AALPS	Arthur Adaptation of the Leiter Performance Scales
ASDI	Asperger Syndrome Diagnostic Interview
ASAD	Australian Scale for Asperger's Disorder
Beery	Beery Visual Motor Integration Test
BPVS	British Picture Vocabulary Scale
BPVS-II	British Vocabulary Picture Scale—Second Edition
BSID	Bayley Scales of Infant Development
CARS	Childhood Autism Rating Scale
CC-A	Communication Checklist—Adult
CELF	Clinical Evaluation of Language Fundaments
CELF-R	Clinical Evaluation of Language Fundaments—Revised
CSI	Child Symptom Inventory
DAS	Differential Abilities Scale
DBC	Developmental Behavior Checklist
DICA	Diagnostic Interview for Children and Adolescents
DISCO-10	Diagnostic Interview for Social and Communicative Disorders
ERT	Edinburgh Reading Test
EOWPVT	Expressive One Word Vocabulary Test
ERRNI	Expression, Reception and Recall of Narrative Instrument
ESCS	Early Social Communication Scale
GAF	Global Assessment of Functioning
Goldman-Fristoe	Goldman–Fristoe Test of Articulation
Gray Oral	Gray Oral Reading Test
Grooved Pegboard	Grooved Pegboard
HBSS	Handicaps, Behaviours, and Skills Schedule
Leiter	Leiter International Performance Scales
Merrill-Palmer	Merrill-Palmer Scales
Mullen	Mullen Scales of Early Learning
Neale	Neale Test of Reading Ability
NEPSY	A Developmental Neuropsychological Assessment
OSCCI	Oxford Study of Children's Communication Impairment spelling test
PDS	Pubertal Development Scale
PPVS	Peabody Picture Vocabulary Scale
PEP	Psychoeducational Profile
Peer Play Scale	Peer Play Scale
Raven's	Raven's Progressive Matrices
RBS-R	Repetitive Behavior Scale—Revised
Reynell	Reynell Scales of Language Ability
Schonell	Schonell Graded Word Spelling Test
SEF-I	Socio-Emotional Functioning Interview
SIB-R	Scales of Independent Behavior—Revised
Stanford-Binet 3rd	Stanford-Binet, 3rd edition
Stanford-Binet 4th	Stanford-Binet, 4th edition
Token Test	The Token Test
TOLD	Test of Language Development
TOWRE	Test of Word Reading Efficiency
TROG-E	Test for Reception of Grammar—Electronic
VABS	Vineland Adaptive Behavior Scales
Vineland Screener	Vineland Screener
VSMS	Vineland Social Maturity Scale
WAIS-III	Wechsler Adult Intelligence Scale—Third Edition
WAIS-R	Wechsler Adult Intelligence Scales—Revised
WASI	Wechsler Abbreviated Scale of Intelligence
WCST	Wisconsin Card Sorting Test
WISC-III	Wechsler Intelligence Scale for Children, Third Edition
WPPSI	Wechsler Preschool and Primary Scale of Intelligence
WRIT	Wide Range Intelligence Test
York	York Adult Assessment

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