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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.

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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

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