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Gender differences in parent-reported age at diagnosis of children with autism spectrum disorder

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ABSTRACT

Background: Autism spectrum disorders (ASD) are more commonly observed in boys than in girls. There is growing awareness of ASD in girls and recognition that under-diagnosis is common. The current study aimed to investigate any evidence of reduction in the average age at diagnosis for girls by assessing whether: 1) girls' age at diagnosis has reduced, compared to boys', across two age cohorts – children born between 1996–1999 and 2002–2005; 2) age at diagnosis differed between boys and girls diagnosed across childhood; 3) any characteristics are associated with earlier age at diagnosis in girls.

Methods: Data were available from large UK databases of children with ASD: The Database of Children with Autism Spectrum Disorder Living in the North East (http://daslne.org) and the Autism Spectrum Database–UK (www.asd-uk.com).

Results: There was no differential reduction of parent-reported age at diagnosis for girls over time. For children receiving their diagnosis at age ≥60 months, boys received diagnoses an average of one year earlier than did girls (98.2 months, SD = 31.6 vs. 109.1 months, SD = 36.4). For boys and girls, earlier diagnosis was associated with toileting problems and temper problems. Having additional diagnoses (e.g., dyslexia, dyspraxia, and epilepsy) was associated with later diagnosis.

Conclusions: Age at diagnosis has not decreased over time. Girls with ASD are diagnosed later than boys when aged 5 years or older. Health and education professionals would benefit from better understanding factors such as toileting problems, temper problems, and additional diagnoses that could potentially guide early identification of ASD in clinical practice for school-age girls.

1. Introduction

The reported prevalence estimates of autism spectrum disorder (ASD) are always greater in males than females. The male to female ratio is around 4:1 (Baird et al., 2006; CDC, 2014; Fombonne, 2009) in the absence of intellectual impairment (see Rivet & Matson, 2011 for a review). Increased rates of ASD diagnoses in children over the last 15 years or so may be due to the broadening of, and changes to, ASD diagnostic criteria and practice, improved identification, earlier age at diagnosis in the teenage years, and different methodologies used to estimate prevalence (Russell, Collishaw, Golding, Kelly, & Ford, 2015).

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Cognitively able girls may be diagnosed with ASD significantly less frequently and at an older age than boys despite there being no gender differences in the age at which parental concern is expressed (Giarelli et al., 2010). However, with the exception of learning/intellectual disability, there is little evidence to suggest what factors might be associated with earlier age at ASD diagnosis in girls. Indeed, several studies have suggested no gender difference in age at diagnosis (Mussey, Ginn, & Klinger, 2017). In a cross-cohort comparison study, Russell et al. (2015) found no gender difference in age at diagnosis nor differences in gender ratios of diagnosed children aged 7 years assessed in 1998/1999 (n = 96) and 2007/2008 (n = 209). Furthermore, in a large UK cohort study, Brett, Warnell, McConachie, and Parr (2016) found that the average age at diagnosis was 67.3 months for boys and 72.1 months for girls and had not decreased over the decade from 2004 to 2014. Although some children are now diagnosed by age 2 years, Brett and colleagues found no reduction in age at diagnosis for children diagnosed under age 3 years in the UK (Brett et al., 2016). While gender was not a significant influencing factor, earlier age at diagnosis was associated with language regression, lower socioeconomic status, greater degree of support required, greater symptom severity, and greater parental concern about initial symptoms (Brett et al., 2016; Daniels & Mandell, 2014).

There has been growing interest in the identification of ASD in girls, and it is becoming recognised that under-diagnosis or later diagnosis may be common (Dworzynski, Ronald, Bolton, & Happé, 2012; Loomes, Hull, & Mandy, 2017; Van Wijngaarden-Cremers et al., 2014). One way to measure whether there has been better detection of ASD in girls in recent years is to show whether there is evidence of change in the average age at diagnosis for girls. While Brett et al. (2016) assessed factors that influenced age at diagnosis, they did not specifically examine factors that are associated with earlier age at diagnosis independently for boys and girls. Thus, the current study builds on that of Brett et al. (2016) to examine gender differences in parent-reported age at diagnosis in large UK databases of children with ASD.

We had the following aims: First, to assess whether girls' age at diagnosis has reduced, compared to boys', across two age cohorts – children who were born between 1996–1999 and 2002–2005. Changes in diagnostic practices have been shown to have a substantial effect on the increased prevalence of ASD (King & Bearman, 2009). Thus, this separation of birth cohorts was chosen to better control for this potential confound of changes over a decade, so that any evidence of reduced age at diagnosis in girls is less likely to be an artefact of general changes in diagnostic practices. If ASD diagnosis in girls has become more timely, we would expect a differential reduction in age at diagnosis, for girls compared to boys, between the age periods. Second, to investigate whether age at diagnosis differed between boys and girls diagnosed across childhood. We assessed gender differences in age at diagnosis across childhood by grouping the sample at the median age at diagnosis where any differences between boys and girls would most likely be salient (see below). Finally, to examine characteristics that might be associated with earlier age at diagnosis in girls.

2. Methods

Data were available from two large representative UK databases: The Database of children with autism spectrum disorder living in the North East of England (Dasl^{n}e, established in 2003; http://daslne.org) and the Autism Spectrum Database – UK (ASD–UK, established in 2011; www.asd-uk.com). Dasl^{n}e covers six areas around Newcastle upon Tyne, whilst ASD-UK covers the rest of the UK. By 2017, the databases held data from over 4000 families, including information on children's ASD and other medical diagnoses, behaviour problems, and language levels as reported by parents/carers and professionals.

Dasl^{n}e and ASD–UK share similar methodologies and type of data collected. Recruitment has been described previously (Brett et al., 2016; Warnell et al., 2015). Parents/carers are invited to join Dasl^{n}e shortly after their child (aged 2–18 years) receives an ASD diagnosis. For ASD–UK, parents/carers of children with a clinical diagnosis of ASD (aged 2–16 years) are invited to join through heath teams or self-referral.

Children enrolled in Dasl^{n}e and ASD–UK have been shown to be representative of children with ASD living in the North East of England (McConachie et al., 2009) and the rest of the UK (Warnell et al., 2015), respectively. These databases allow analyses based on good statistical power and sampling variation.

Validation of children's ASD diagnoses was examined previously for children enrolled in Dasl^{n}e (McConachie et al., 2009) and both Dasl^{n}e and ASD-UK (Warnell et al., 2015). Corroboration of diagnoses for a random sample of children enrolled in Dasl^{n}e was from information in their medical notes that was checked against questionnaires completed by their clinician. For a further sample, the Autism Diagnostic Observation Schedule-Generalised (Lord et al., 2000) was administered by a research associate and parents completed the Social Communication Questionnaire-Lifetime version (SCQ; Rutter, Bailey, & Lord, 2003) to give some standardised information about the children's ASD characteristics. The SCQ focuses on the child's entire developmental history and provides a total score that is interpreted in relation to specific ASD cut-off points. A score of 15 or greater is an indication of a possible ASD. These checks confirmed that all children met criteria for autism or ASD, or had this diagnosis documented in their medical notes. Parents/carers of children with ASD enrolled in ASD-UK completed the SCQ that has been used previously to investigate the reliability and validity of the parent-reported ASD diagnosis for children enrolled in ASD-UK (Warnell et al., 2015). When a professional report was available about a child, and the SCQ score was below 15, reports were checked for evidence that the child had ASD. However, IQ or language data from this corroboration were not available for use in the current study.

Informed consent was obtained from all participants included in the study. Parents/carers completed a paper or online questionnaire reporting on their child's gender, age at diagnosis, and type of ASD diagnosis within six categories: autism, Asperger syndrome, pervasive developmental disorder-not otherwise specified (PDD-NOS), autism spectrum disorder (ASD), atypical autism, and 'other'. The 'other' category allowed the opportunity for parents to report on any other term that was not listed but which they felt described their child's diagnosis, such as pathological demand avoidance, high-functioning autism, sensory autism etc. The categories were grouped as autism, Asperger syndrome, and 'ASD' that included PDD-NOS, atypical autism, and 'other'. These