Northumbria University
NEWCASTLE

University**Library**

Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder

Marion Rutherford[1], Karen McKenzie[2], Tess Johnson[1], Ciara Catchpole[1], Anne O'Hare[3], Iain McClure[4], Kirsty Forsyth[1], Deborah McCartney[1] and Aja Murray[1]

[1] School of Health Sciences, Queen Margaret University, Edinburgh, Scotland, United Kingdom

[2] Northumbria University, Newcastle upon Tyne, England, United Kingdom

[3] Salvesen Mindroom Centre, University of Edinburgh, Edinburgh, Scotland, United Kingdom

[4] Child and Adolescent Psychiatry, NHS Lothian, Edinburgh, Scotland, United Kingdom

Corresponding Author

Marion Rutherford

School of Health Sciences,

Queen Margaret University,

Edinburgh, Scotland, United Kingdom,

EH21 6UU,

Tel: +44 (0)131 474 0000,

Fax: +44 (0)131 474 0001

Email mrutherford@qmu.ac.uk

Abstract

This article reports on gender ratio, age of diagnosis and the duration of assessment procedures in autism spectrum disorder diagnosis in a national study which included all types of clinical services for children and adults. Findings are reported from a retrospective case note analysis undertaken with a representative sample of 150 Scottish children and adults recently diagnosed with autism spectrum disorder. The study reports key findings that the gender ratio in this consecutively referred cohort is lower than anticipated in some age groups and reduces with increasing age. The gender ratio in children, together with the significant difference in the mean age of referral and diagnosis for girls compared to boys, adds evidence of delayed recognition of autism spectrum disorder in younger girls. There was no significant difference in duration of assessment for males and females suggesting that delays in diagnosis of females occur prior to referral for assessment. Implications for practice and research are considered.

Keywords

autism spectrum disorder, diagnosis, females, gender, males

Introduction

Early diagnosis of autism spectrum disorder (ASD) contributes to better outcomes, as a result of timely access to appropriate interventions (Begeer et al., 2013). Delays in diagnosis are common regardless of gender; however, girls with ASD are particularly disadvantaged through under recognition, misdiagnosis or delayed diagnosis (Giarelli et al., 2010; Shattuck et al., 2009). The picture is somewhat different in adults, with recent studies reporting similar mean ages of diagnosis regardless of gender, ranging from 31 to 34.1 years (Geurts and Jansen, 2012; Lehnhardt et al., 2012; Wilson et al., 2013).

Controlling for symptom severity, males are more likely to receive a diagnosis of ASD than females (Russell et al., 2011) and girls are more likely to be diagnosed with an intellectual disability (ID) than ASD (Levy et al., 2010). This is consistent with the idea that girls with an ASD may be under-identified because the disorder is understood to disproportionately affect males and is thus perceived as a 'male disorder' (e.g. Zwaigenbaum et al., 2012). The need for females to display more severe symptomatology to receive a diagnosis of ASD may explain the apparent paradox that in clinically diagnosed samples, females may show more severe ASD traits and comorbid psychopathology than males even though the latter have a greater vulnerability to ASD (e.g. Dworzynski et al., 2012).

The reported gender ratio in ASD varies according to the age and type of population studied. Large-scale studies of children of all intellectual levels commonly report a gender ratio of 3–4 males:1 female (e.g. Shattuck et al., 2009), although greater ratios have been reported by other researchers who both include (e.g. Blumberg et al., 2013) and exclude children with ID (e.g. Mattila et al., 2007). A growing number of well-conducted, large-scale studies with children report greater female representation in clinical cohorts, with gender ratios of 2–5:1 in populations with and without ID (Lai et al., 2015). The nationwide US study (Baio, 2012) reported state-wide gender ratios ranging from 2.6–7:1. Worley et al. (2011) found a gender ratio of 1.16:1 in toddlers, suggesting that closer study of different age groups could be important in understanding of under-diagnosis of ASD in some female groups.

The reported gender ratio in adults ranges between 9 males:1 female (Brugha et al., 2009) and 2–2.4:1(Hofvander et al., 2009). Jensen et al. (2014) studied ASD incidence rates across the lifespan and identified a reduction from 5:1 to 3:1 between 1995 and 2010.

These changing gender ratios may reflect either true differences in prevalence or differences in awareness and recognition of ASD in girls, as well as in diagnostic practice. As recognition of ASD changes, the true gender distribution among individuals with ASD

remains an area worthy of study, and sampling method and cohort selection may have a significant impact on gender ratio found.

There is evidence of variability in practice in the waiting times for diagnosis; Palmer et al. (2011) found only one-third of UK child services had a defined time standard. Of these, less than half met the 17-week timescale from referral to diagnosis. Demographic factors, including gender, may further increase the time taken to complete diagnostic assessment (Siklos and Kearns, 2007).

There are, however, relatively few studies which report on gender differences in the diagnostic assessment process within a representative clinical population of children, adolescents and adults with ASD (Rivet and Matson, 2011) or which examine at which stage of the diagnostic process any putative gender differences may occur – prior to or during the diagnostic process. A longer diagnostic process for females would suggest a need to improve gender-relevant tools and processes for diagnosis. Alternatively, delayed identification prior to referral would highlight a need to raise awareness among referrers about female presentation of ASD.

This study, therefore, aimed to use data from a nationally representative clinical sample to explore whether gender differences existed in relation to the ratio of adults,

young children and adolescents diagnosed with ASD, the age of referral and diagnosis and duration of the diagnostic process.

Methods

Approval for the study was obtained from Caldicott Guardian and Research and Development departments. The study method, which is detailed more fully in McKenzie et al. (2015), included retrospective case note analysis of 150 case notes from 16 diagnostic services. Proportionate stratified random sampling was used to recruit participating services from all services (30 adult and 64 child) in Scotland which routinely assess and diagnose ASD. The final sample of eight adult and eight child services, representative of the Scottish population, was selected following stratification of the eligible diagnostic services on the basis of urban–rural categorisation and randomisation. The sampled services (n = 16) were invited to identify up to 10 most recently diagnosed cases (diagnosed for the first time within the preceding 24 months and not previously diagnosed elsewhere). The sample does not include those assessed and not given a diagnosis.

The sample was also examined in relation to socioeconomic status (SES) using the Scottish Indices of Multiple Deprivation (SIMD) which provides a relative measure of deprivation. Each postcode area is rated from 1–5, where 1 is the most deprived and 5 is the

least deprived. The proportions of SIMD values in the sample were similar to those in the Scottish population, with 60% of the Scottish population and 58% of our sample falling within SIMD categories 2, 3 or 4.

Service provision for diagnostic assessment of ASD in Scotland

Services in Scotland are organised by 14 health board areas. All areas have a child ASD diagnostic service, and 11/14 have an adult service. Referral and assessment practice at the time of recruitment followed paediatric clinical guidelines (Le Couteur et al., 2003; Scottish Intercollegiate Guidelines Network (SIGN), 2007) and quality standards (Scottish Executive, 2006) for adult services. Referrals to child services follow general developmental assessment from a multi-disciplinary team. Referrals for adults arise internally, within ID or Mental Health teams, or externally via General Practitioners or self-referral. ASD diagnostic assessment is largely provided by multi-disciplinary National Health Service (NHS) teams (including a combination of medical, allied health professional, clinical psychology and nursing staff), in the context of wider individualised support and interventions.

Sampled services

Services sampled are described more fully in McKenzie et al. (2015). Child services included Child and Adolescent Mental Health Services (CAMHS) and Paediatrician-led child development services. Child teams averaged 5.2 members (range = 3–9). Adult services included ID, Mental Health services and ASD specialist services and had an average of 2.8 members (range = 1–7).

Services provided case notes for the analysis. A range of diagnostic terms were given, including Autism Spectrum Disorder, Asperger's Syndrome, Atypical Autism, Autism and Childhood Autism. These were combined under the diagnostic term ASD for the purposes of the study. The characteristics of the sample are shown in Table 1. One transgender individual was excluded from subsequent gender analyses.

Table 1. Characteristics of the sample

	Age range of all children (0-9.11yrs) (n=46)	Mean age of female children (0-9.11yrs) (n=7)	Mean age of male children (09.11yrs) (n=39)	Age range of all adolescents (10-18.11yrs) (n=40)	Mean age of female adolescents (10-18.11yrs) (n=12)	Mean age of male adolescents (10-18.11yrs) (n=28)	Age range of adults (19-39.11) (n=47)	Mean age of female adults (19-39.11) (n=15)	Mean age of male adults (19-39.11) (n=32)	Age range of adults 40 + (n=16)	Mean age of females 40+ (n=7)	Mean age of males 40+ (n=9)
Age in years at diagnosis	1.9-9.8	5.7 (SD 1.9)	5.8 (SD 2.2)	10-18.9	15 (SD 2.8)	13.3 (SD 2.7)	19.5-39.5	27.9 (SD 6.5)	27.4 (SD 5.6)	40.9-56.3	47.8 (SD 4.6)	47.7 (SD 5.6)
Intellectual disability present (n)	9	1	8	12	2	10	18	6	12	6	5	1
Missing data*	6	1	6	6	1	6	0	0	0	0	0	0
Diagnosed Psychiatric condition present (n)	2	0	2	14	5	9	14	6	8	4	2	2
Missing data*	13	2	11	11	3	8	19	5	14	8	4	4

*Missing data refers to data which was not stated, missing, or unclear in the data extraction forms

Measures

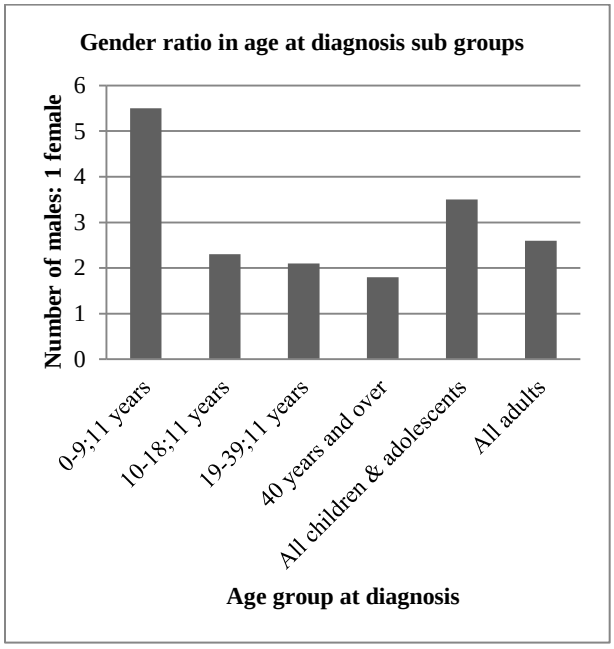
An individual data extraction tool (McKenzie et al., 2015) was developed for use with the 150 cases, together with an associated operational definitions document to increase inter-rater reliability for individual data extraction (Hutchinson et al., 2010). These tools (available from the first author on request) allowed data to be gathered for analysis of the total time from referral to diagnosis shared and the assessment duration. As a proxy for validity of diagnoses, in each case, the tool included a measure of adherence to best practice guidelines. Adherence to guidelines was high across child cases, with a mean adherence score of 16/19 (standard deviation = 1.9) (McKenzie et al., 2015). Given the recency of the publication of guidelines from the National Institute for Health and Clinical Excellence (NICE, 2012) 142, results were indicative of good diagnostic practice in adult cases, where the mean adherence score was 11.9/14 (standard deviation = 1.4) (McKenzie et al., submitted).

Results

Gender ratio

The male to female gender ratio for adults was 1.8:1 (1.2:1 for those with ID and 2.5:1 for those without), and for all children and adolescents (age = 0–18 years), it was 3.5 male:1 female. There was a strong gender bias in the child group with ID (18 males and 3 females); however, the numbers were too small to draw strong conclusions or to provide a meaningful gender ratio for this group. Gender ratio across the sample reduced with increasing age, as shown in Figure 1.

Figure 1. Gender ratio in age at diagnosis sub groups



Adolescents are defined as young people between 10 and 19 years (UNICEF, 2011), and we considered this subgroup in our analysis. Among children and adolescents sampled, 58% (46/86) were aged 0–9, 11 years, and the gender ratio in this group was highest at 5.5:1. Children and adolescents aged 10–18, 11 years, made up 42% (34/86) of those diagnosed in child services. A further six individuals from the adult services cohort were aged 17– 18 years and are included in this analysis on the basis of age. In the 10–18 years group, the gender ratio was 2.3:1. In the 19–39 years age group, the ratio was 2.1:1, and in the over 40 years group, the gender ratio was 1.2:1.

ID

Of those newly diagnosed with ASD in adult services, 38% had ID (26/69), 50% (12/24) were females and 31% 14/45) were males. In child services, 24% (19/80) diagnosed had a stated ID; this was 12% (2/17) of females and 27% (17/63) of males. A series of chi-square tests found no significant association between gender and whether the individual had ID or not for younger children ($\chi 2 = 0.19$, $df = 1$, $p = 0.66$); adolescents ($\chi 2 = 1.95$, $df = 1$, $p = 0.16$) or adults ($\chi 2 = 2.03$, $df = 1$, $p = 0.154$).

Gender differences in age of referral, diagnosis and total duration of assessment Adults.

No significant differences were found between males and females for the mean age of referral ($t(67) = 0.93$, $p = 0.26$), mean age of diagnosis ($t(67) = 0.84$, $p = 0.40$) or in total duration of the diagnostic process ($t(67) = -0.65$, $p = 0.52$).

Children and adolescents.

Significant differences between all children and adolescents were found for age of referral ($t(78) = 2.28$, $p = 0.03$) and diagnosis ($t(77) = 2.09$, $p = 0.04$) with boys being both referred and diagnosed at a younger age (Table 2). No significant gender difference was found for total duration of the diagnostic process ($t(78) = -0.38$, $p = 0.71$). The data for the child and adolescent groups were analysed separately. For children under 10 years, no significant gender differences were found in relation to age of referral ($t(47) = -0.29$, $p = 0.27$), age of diagnosis ($t(47) = -0.42$, $p = 0.68$) or for duration of the diagnostic process ($t(47) = -0.81$, $p = 0.42$). Similarly, no gender differences were found for the adolescent group in relation to age of referral ($t(35) = 1.48$, $p = 0.15$), age of diagnosis ($t(35) = 1.38$, $p = 0.18$) or for duration of the diagnostic process ($t(35) = 1.37$, $p = 0.18$).

Table 2. Mean ages from referral to diagnosis and total duration of diagnostic process for the sample stratified by gender.

Age groups at referral	Gender	Mean age of referral (SD)	Mean age of diagnosis (SD)	Mean total duration of diagnostic assessment (from referral to diagnosis)
Child (0-9.11)	Male (n=47)	5 years 6 months (Range 1.6-9.9, SD 2.4)	6 years 7 months (Range 1.9-11.8, SD 2.9)	350 Days
	Female (n=8)	5 years 5 months (Range 2.3-8.9, SD 2.2)	6 years 3 months (Range 3.3-10.7, SD 6.3)	308 Days
Adolescent (10-18.11)	Male (n=20)	13 years 4 month (Range 10.8-18.2, SD 2.7)	14 years 2 months (Range 10.5-18.6 , SD 2.6)	285 Days
	Female (n=11)	14 years 6 months (Range 10-18.5, SD 2.9)	15 years 4 months (Range 11.1-18.9, SD 2.6)	260 Days
Adult (19-39.11)	Male (n= 32)	26 years 7 months (Range 19-39, SD 5.7)	27 years 4 months (Range 19.5-39.5, SD 5.6)	171 Days
	Female (n=15)	27 years 6 months (Range 19.4-39, SD 6.5)	27 years 9 months (Range 19.5-39.2, SD 6.5)	147 Days
Adult (40+)	Male (n=9)	47 years 3 months (Range 42.1-55.5, SD 5.4)	47 years 7 months (Range 42.4-56.3,SD 5.6)	142 Days
	Female (n=7)	47 years 3 months (Range 40.5-53.8, SD 4.7)	47 years 8 months (Range 40.9-54.4, SD 4.6)	185 Days

Discussion

Despite the increased prevalence of ASD in children and adolescents over recent years, this study found that girls continue to be referred and diagnosed significantly later than boys and that this delay occurs prior to referral for specialist assessment. This finding adds weight to the reported concerns that there is a delayed diagnosis and under-identification of ASD in girls (e.g. Giarelli et al., 2010) with the potential effect of limiting access to specialist support and intervention. Findings provide evidence of the need to direct resources and training about ASD in females, at referrers from health, education and social care services.

Once referred, the duration of the diagnostic process was not significantly different for boys and girls. A high level of adherence to clinical guidelines and policy may contribute to an equal duration of assessment for males and females (McKenzie et al., 2015).

The gender ratio in all children and adolescents (3.5:1) was in keeping with national estimates (see Van Wijngaarden-Cremers et al., 2014) and was highest in the under 10 age group. A further important finding in this study was that gender ratio reduces with increasing age, being smaller for adolescents (2.3:1) than for younger children (5.5:1), thus supporting the camouflage hypothesis (Dworzynski et al., 2012) that it becomes increasingly difficult for girls to mask their symptoms of ASD over time. This evidence of delayed recognition of girls leads us to further consider why this might be the case. Subtle differences in clinical presentation of females are thought to contribute to under-diagnosis of younger girls (Kirkovski et al., 2013), which in turn strengthens the need to better understand the female profile of ASD in children under 10 years of age and to share this effectively with referrers and diagnosticians. The findings also highlight the need to examine female characteristics in an adolescent population because this could be a crucial stage for identification or unmasking of difficulties.

There are few nationwide studies reporting on the diagnosis of ASD in adults but there is some evidence of changing practice over time leading to a greater female representation in recent years (Jensen et al., 2014). This study looking at consecutively referred cases could indicate changing practice and improving identification of females with ASD in adulthood. The adult gender ratio of 1.8:1 found here was similar to that reported by Hofvander et al. (2009) of 2:1. Although it is far lower than the 9:1 ratio found by Brugha et al., 2009), it is important to note the limitations reported in the latter study, including the low survey response rate, the small sample size (n = 19) and the use of a higher cut-off score on standardised assessment, excluding those with milder presentations. The epidemiology of ASD in adults merits further study in light of findings in this study and others.

The study found that, for adults, there was no significant gender effect on age of referral, diagnosis or duration of the diagnostic process. The mean ages of diagnosis for both males (30 years) and females (32 years 6 months) are consistent with other clinical cohort studies (e.g. Geurts and Jansen 2012). While gender may not affect age of diagnosis in adults, late identification and referral for ASD diagnostic assessment remain a significant challenge for many adults.

In this study, 18/70 adults diagnosed were over the age of 40 years (six of whom had ID), with the oldest being aged 55 years, providing clinical evidence for concerns over older adults who remain unidentified and for whom the diagnostic criteria and instruments are undifferentiated (Piven and Rabins, 2011). Given the evidence of gender disparity in children and adolescents, consideration of the effect of gender on presentation in older adults could also be considered.

In this study, the co-occurrence of ID impacted on the gender ratio in adults, with a ratio of 1.2:1 females to males, although there was no overall significant relationship between gender and whether an individual had ID or not. This ratio is consistent with other studies (Scottish Consortium for Learning Disability, 2011). Among adult males, more new ASD diagnoses were given to higher functioning individuals, who may be more likely to receive a later diagnosis (Shattuck et al., 2009). Among women, there were equal numbers with and without ID, which may be explained by historical under-recognition in females with ID (Jensen et al., 2014) who are now being diagnosed with ASD in adulthood in a greater proportion than males with ID. An estimated 4%–40% of those with ID have ASD and 50%–70% of individuals with ASD have ID (Goldin et al., 2014). Similarly, 46% of the adult group diagnosed in adult services in this study had ID. However, only 23% (19/80) diagnosed in child services had a stated ID based on psychometric assessment and only 2/19 were female. Inconsistency in diagnosing ID in practice leading to under-ascertainment of ID is recognised as problematic (McKenzie and Megson, 2012), and this is borne out within our sample.

Implications

These results suggest that under-recognition of adult females with ASD is likely in population studies which find much higher gender ratios. The difference between incidence and prevalence explains some variation in gender ratio across adult studies. In consecutively referred cohorts, there may be a higher likelihood of women being newly diagnosed as adults because they were missed as children, conversely men may be proportionately less represented in the late diagnosed group.

The study found that girls are diagnosed at a later age than boys and that the delay occurs prior to referral for diagnostic assessment, through under-recognition. This indicates a need to raise awareness among potential referrers about the ways in which ASD may present in girls with different symptomatology (Van Wijngaarden-Cremers et al., 2014) and in particular in the adolescent group. Although recent research suggests there are no gender differences in core symptoms of ASD (Begeer et al.,2013; Worley et al., 2011), there is evidence that ASD indicators in girls may be missed because the girls may present with subtle differences to boys with ASD (Hartley and Sikora, 2009) or that there is interpreting bias among parents (Giarelli et al., 2011) affecting recognition. Differences in the presentation of girls (Kopp and Gillberg, 2011) may impact on identification, and therefore, this study suggests that increasing referrer's awareness of female presentation of ASD at different stages has the potential to reduce age of diagnosis of girls.

Once referred, the diagnostic teams deliver an equal experience of diagnosis for girls and boys in terms of duration, a finding not previously reported in the literature but worthy of consideration. The presence of the National Autism Plan time standards (Le Couteur et al., 2003) and high adherence to clinical guidelines (McKenzie et al.,2015) may be contributory factors in duration being the same for boys and girls, suggesting that NHS policy and practice contribute to an equal duration of assessment regardless of gender.

Limitations

The results of the study must be considered within the context of its limitations. The sampling method adopted, while reflecting the general population of Scotland in terms of levels of deprivation and recent clinical practice, by its very nature did not include all those diagnosed

with ASD by all diagnosing services across Scotland. The study only includes those diagnosed and in doing so has not considered gender in the context of those assessed and not given a diagnosis. The results, therefore, will be influenced by the characteristics of those individuals who were sampled.

Acknowledgements

The authors acknowledge Linda Irvine, Strategic Programme Manager, Mental Health and Wellbeing, NHS Lothian.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Scottish Government.

References

Baio J (2012) Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report. Surveillance Summaries* 61(3): 1–19.

Begeer S, Mandell D, Wijnker-Holmes B, et al. (2013) Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders* 43(5): 1151–1156.

Blumberg SJ, Bramlett MD, Kogan MD, et al. (2013) Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011–2012. *National Health Statistics Report* 65: 1–11.

Brugha T, McManus S, Meltzer H, et al. (2009) Autism spectrum disorders in adults living in households throughout England – 2007. Report from the adult psychiatric morbidity survey 2007, NHS Information Centre for Health and Social Care, Leeds, 22 September.

Dworzynski K, Ronad A, Bolton P, et al. (2012) How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry* 51(8): 788–797.

Geurts HM and Jansen MD (2012) A retrospective chart study: the pathway to a diagnosis for adults referred for ASD assessment. *Autism* 16(3): 299–305.

Giarelli E, Wiggins LD, Rice CE, et al. (2010) Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal* 3(2): 107–116.

Goldin RL, Matson JL and Cervantes PE (2014) The effect of intellectual disability on the presence of comorbid symptoms in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders* 8(11): 1552–1556.

Hartley SL and Sikora DM (2009) Sex differences in autism spectrum disorder: an examination of developmental functioning, autistic symptoms, and coexisting behavior problems in toddlers. *Journal of Autism and Developmental Disorders* 39(12): 1715–1722.

Hofvander B, Delorme R, Chaste P, et al. (2009) Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry* 9(1): 35.

Hutchinson A, Coster JE, Cooper KL, et al. (2010) Comparison of case note review methods for evaluating quality and safety in health care. *Health Technology Assessment* 14(10): 1–144.

Jensen CM, Steinhausen HC and Lauritsen MB (2014) Time trends over 16 years in incidence-rates of autism spectrum disorders across the lifespan based on nationwide Danish register data. *Journal of Autism and Developmental Disorders* 44(8): 1808–1818.

Kirkovski M, Enticott PG and Fitzgerald PB (2013) A review of the role of female gender in autism spectrum disorders. *Journal of Autism and Developmental Disorders* 43(11): 2584–2603.

Kopp S and Gillberg C (2011) The Autism Spectrum Screening Questionnaire (ASSQ) – Revised Extended Version (ASSQREV): an instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities* 32(6): 11/20, 2875–2888.

Lai MC, Lombardo MV, Auyeung B, et al. (2015) Sex/gender differences and autism: setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry* 54(1): 11–24.

Le Couteur A, Baird G and Mills R (2003) *National Autism Plan for Children (NAPC)*. London: National Autistic Society.

Lehnhardt FG, Gawronski A, Volpert K, et al. (2012) Psychosocial functioning of adults with late diagnosed autism spectrum disorders-a retrospective study. *Fortschritte der Neurologie-Psychiatrie* 80(2): 88–97.

Levy SE, Giarelli E, Lee LC, et al. (2010) Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental and Behavioral Pediatrics* 31(4): 267–275.

McKenzie K and Megson P (2012) Screening for intellectual disability in children: a review of the literature. *Journal of Applied Research in Intellectual Disabilities* 25(1): 80–87.

McKenzie K, Forsyth K, McClure I, et al. (2015) The relationship between waiting times and 'adherence' to the Scottish Intercollegiate Guidelines Network 98 guideline in autism spectrum disorder diagnostic services in Scotland. *Autism*. Epub ahead of print 1 June. DOI: 10.1177/1362361315586136.

McKenzie K, Rutherford M, Forsyth K, et al. The relationship between adherence to NICE guideline 142 and waiting times within Autism Spectrum Disorder diagnostic services in Scotland. (Submitted to *The Journal of Disability Policy Studies*/under review).

Mattila M, Kielinen M, Jussila K, et al. (2007) An epidemiological and diagnostic study of Asperger syndrome according to four sets of diagnostic criteria. *Journal of the American Academy of Child and Adolescent Psychiatry* 46(5): 636–646.

National Institute for Health and Clinical Excellence (NICE) (2012) *Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum (CG142).* London: NICE.

Palmer E, Ketteridge C, Parr JR, et al. (2011) Autism spectrum disorder diagnostic assessments: improvements since publication of the National Autism Plan for Children. *Archive of Disease in Childhood* 96: 473–475.

Piven J and Rabins P (2011) Autism spectrum disorders in older adults: toward defining a research agenda. *Journal of the American Geriatrics Society* 59(11): 2151–2155.

Rivet TT and Matson JL (2011) Gender differences in core symptomatology in autism spectrum disorders across the lifespan. *Journal of Developmental and Physical Disabilities* 23(5): 399–420.

Russell G, Steer C and Golding J (2011) Social and demographic factors that influence the diagnosis of autistic spectrum disorders. *Social Psychiatry and Psychiatric Epidemiology* 46(12): 1283–1293.

Scottish Consortium for Learning Disability (2011) *Statistics Release: Adults with Learning Disabilities – Implementation of 'The Same as You?' Scotland 2010*. Glasgow: Scottish Consortium for Learning Disability.

Scottish Executive (2006) Quality diagnostic standard. In: *Autistic Spectrum Disorders Needs Assessment Report (2001): Scottish Executive Report on Implementation and Next Steps*. Edinburgh: HMSO. Available at: http://www.gov.scot/Resource/Doc/94715/0022799.PDF

Scottish Intercollegiate Guidelines Network (SIGN) (2007) *Assessment, Diagnosis and Clinical Interventions for Children and Young People with Autism Spectrum Disorders*. Edinburgh: SIGN.

Shattuck PT, Durkin M, Maenner M, et al. (2009) Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry* 48(5): 474–483.

Siklos S and Kearns K (2007) Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities* 28: 9–22.

UNICEF (2011) The state of the world's children 2011 (executive summary) – adolescence: an age of opportunity. Available at: http://www.unicef.org/publications/index_57468.html

Van Wijngaarden-Cremers PJ, Van Eeten E, Groen WB, et al. (2014) Gender and age differences in the core triad of impairments in autism spectrum disorders: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders* 44(3): 627–635.

Wilson CE, Gillan N, Spain D, et al. (2013) Comparison of ICD-10R, DSM-IV-TR and DSM-5 in an adult autism spectrum disorder diagnostic clinic. *Journal of Autism and Developmental Disorders* 43(11): 2515–2525.

Worley JA, Matson JL, Sipes M, et al. (2011) Prevalence of autism spectrum disorders in toddlers receiving early intervention services. *Research in Autism Spectrum Disorders* 5(2): 920–925.

Zwaigenbaum L, Bryson SE, Szatmari P, et al. (2012) Sex differences in children with autism spectrum disorder identified within a high-risk infant cohort. *Journal of Autism and Developmental Disorders* 42(12): 2585–2596.