

[Editorial for Special Issue on ‘Women and Girls on the Autism Spectrum’]

## **Towards sex- and gender-informed autism research**

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There is a burgeoning interest, amongst autistic people and their families, clinicians, researchers and the general public, in the characteristics and experiences of girls and women on the autism spectrum. To a large extent this has been driven by a growing awareness that autistic females are under-recognised (Loomes et al., 2017). They are more likely than equivalent males to be diagnosed late, or not at all (Dworzynsky et al., 2012; Russell et al., 2011). As a result they are at greater risk of missing out on the understanding and support that can stem from an autism diagnosis. To address this inequity, a subdiscipline of autism research has sprung up, aimed at elucidating the nature of sex and gender differences on the autism spectrum, and how these impact upon the life chances of autistic girls and women (Lai et al., 2015). This special issue of *Autism*, which includes studies from 10 countries across four continents, was designed to showcase the exciting range of work within this subdiscipline, with a particular emphasis on work of direct clinical relevance. It is designed to point towards the future, by presenting studies that have taken fresh approaches to elucidating the moderating roles of sex and gender on the autism spectrum.

Duvekot and colleagues (2017) offer important new insights into the nature of the diagnostic bias against females. They screened for autism in children presenting to general child and adolescent mental health services, using the Social Responsiveness Scale, Second Edition (SRS-2), and then conducted a thorough autism assessment

with those who screened positive. Amongst the screen positive children, the male-to-female ratio was 2.6:1, whereas amongst those who, after comprehensive assessment, received a full autism diagnosis it was higher, at 3.7:1. One interpretation of this finding is that females with high levels of autistic difficulties, as measured by the SRS-2, are less likely than equivalent males, to meet autism diagnostic criteria clinically even if they undergo an autism assessment that meets current standards for best practice. This could arise from a nosological problem, whereby our current conceptualisation of autism fails to encompass important female-typical manifestations of autism. Further, there may also be a diagnostic challenge to the timely recognition of autism in females; for example, contemporary assessment methods may lack sensitivity to parts of the female autism phenotype (Lai et al., 2015). These challenges may explain why in current diagnostic practice, girls and women often need to present with more concurrent behavioural, developmental or mental health issues for an autism diagnosis would be made, compared to their male counterparts (Dworzynsky et al., 2012; Duvekot et al., 2017).

Several studies in this special issue help us better understand what is driving the under-recognition of autism in females. Frazier and Hardan (2017) employed sophisticated psychometric analytic techniques, including those based on item response theory, to investigate the nature of sex/gender differences on standardised measures of autism symptomatology. They provide the most conclusive evidence to date that, compared to autistic boys, autistic girls score lower on measures of focused restricted interests. Most importantly, they found evidence supporting measurement equivalence and similar symptom structure on the Autism Diagnostic Interview-Revised (ADI-R) and SRS items across males and females; Grove and colleagues

(2017) show similar findings on the Autism Spectrum Quotient-Short Form. Together these studies provide the first empirical evidence that reported sex/gender differences in autism characteristics are due to true differences in the mean levels of the construct being assessed, rather than a result of different constructs being measured. This measured mean level difference may directly impact upon diagnosis, as Duvekot and colleagues (2017) found that repetitive and stereotyped behaviour (RSB), including restricted interests, was a better indicator of autism diagnosis in boys than in girls.

The finding that on average autistic females score lower on measures of RSB than do autistic males raises a question crucial to the study of sex and gender differences in autism; namely, whether current instruments adequately capture all manifestations of autism in females. After all, all autism measures were designed and validated using predominantly male samples. Both Frazier and Hardan (2017) and Duvekot and colleagues (2017) raise the possibility that current measures may not be capturing female-typical RSBs, and suggest that these may be expressed differently in girls and women.

The idea that there are important qualitative sex/gender differences in RSB and beyond is supported by other studies in this special issue. Halladay and colleagues (2017) report the first study to examine clinicians' perspectives on male-female differences in autism characteristics. They found that clinicians notice more differences in the RSB domain than in the social-communication domain, particularly during school age and adolescence. They also point out that sex and gender differences in autism observed by clinicians may fall outside of the psychiatric diagnostic criteria for autism, and such differences can vary by developmental stages.

Sutherland and colleagues (2017) discovered that, compared to autistic boys, autistic girls had more special interests that fit traditional gender stereotypes, for example an intense focus on animals or dancing. Such gender-normative interests may go unremarked by clinicians, and thus not be scored as an autistic behaviour during assessments, contributing to the lower RSB scores of autistic girls and women.

Mussey and colleagues (2017), in their investigation of a large clinical sample, provide further evidence that the so-called gold-standard measures for autism may be underestimating symptom severity in females. They discovered that, whereas autistic boys and girls score similarly on the Childhood Autism Rating Scale (CARS), the girls scored lower on the Autism Diagnostic Observation Schedule, Generic (ADOS-G). The clear implication is that the ADOS, the most widely used direct observational tool for diagnosing autism, may be less sensitive to female autistic difficulties than to male ones.

Sex and gender can further moderate the presentation of autism in aspects not measured by 'gold standard' autism measures. Hull and colleagues (2017), using systematic review and meta-analysis, identify that male-female differences in autism (that are different from neurotypical male-female differences) may exist in the domains of executive function, empathising and systemising traits, internalising and externalising symptoms, and play behaviours; this has also been examined by Pisula and colleagues (2017) in this issue.

We can conclude that researchers must choose their measures carefully when seeking to understand the characteristics of autistic girls and women. This notion is re-

enforced by several studies in this special issue that went beyond the use of standardised diagnostic tools, employing novel measures that tap key constructs. Backer van Ommeren and colleagues (2017) use a sensitive and ecologically valid paradigm, the Interactive Drawing Test, to measure social reciprocity. In so doing they were able to tease out strengths and difficulties of autistic girls that would have been invisible had they used cruder, ordinary diagnostic measures. Little and colleagues (2017) used a coding frame to categorise verbatim caregiver concerns about their child when presenting to an autism assessment service. They found that caregiver concerns about their child's social interaction were predictive of a subsequent autism diagnosis for boys, but not girls. Pre-diagnosis, autistic girls may have on average fewer, or less obvious, perceived social interaction difficulties than autistic boys.

Further evidence for important sex and gender differences in social functioning comes from a methodologically innovative, ground-breaking study by Dean and colleagues (2017), investigating behaviour in the school playground. Using a sophisticated and rigorous mixed-methods approach, this research demonstrated that the social difficulties of autistic girls were more 'camouflaged' than those of autistic boys. Autistic boys were more likely to be overtly socially isolated in the playground, whereas autistic girls tended to be amongst peers, weaving in and out of groups, even if they were not actively socially engaged. It is easy to see how this difference could impact upon identification of autistic girls at school. In the same vein, Lai and colleagues (2017) took another approach to describe 'camouflaging' using standardized tools in autism research. They operationalised camouflaging as the discrepancy between (1) interpersonal behavioural presentation and (2) self-reported

autistic traits and objectively measured social cognitive abilities, and found that autistic women on-average showed a higher level of camouflaging than autistic men. Nevertheless, the extent of camouflaging varies substantially in both male and female groups in their study. Beyond individual characteristics, Dean and colleagues (2017) make another point of fundamental importance, that camouflaging reflects features not just of the individual, but also of the environment. They point out that ‘the female social landscape’, characterised by fluid social groupings, provides a social *milieu* for girl’s camouflaging.

The need to place sex and gender differences in autism, and their impact, in an environmental context is eloquently made by two qualitative studies in this special issue. These show us that, when we seek to understand the experiences of autistic women, we need to consider how autism intersects with wider environmental factors such as social support, gender expectations, socio-economic status and cultural definitions of what constitutes ‘normal’ behaviour for a female (Webster & Garvis, 2017; Kanfischer et al., 2017). Further, the qualitative analysis of Webster and Garvis (2017) provides an important reminder of something that has been so often overlooked and underplayed in discourses about autism: like neurotypical people, autistic people live lives that include successes as well as difficulties.

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