Autistic women and girls: increasingly recognised, researched and served

This is the second of two special issues focussing on autistic women and girls. Part One, published in March 2019, included a diverse range of papers, including the journey to diagnosis (Zener, 2019), relationships (Kock et al., 2019), mental health comorbidity and forensic involvement (Chaplin and McCarthy, 2019; Markham, 2019), camouflaging (Allely, 2019), and representation within the fictional media (Tharian et al., 2019). The editorial for this issue was entitled “Autistic women and girls: under-recognised, under-researched and under-served” (Chester, 2019) reflecting the additional difficulties faced by females with ASD.

In the current special issue, Zener introduces an innovative therapeutic model, identify needs, validate, educate, strengthen and thrive (INVEST) based on her clinical experiences working as therapist specializing in girls and women with autism. INVEST is a strengths-based therapy approach which teaches autistic women how to thrive in a world that was not designed with them in mind.

Tromans et al. surveyed healthcare professionals about their practice with adult women with autism. The professionals sampled reported feeling less confident in recognising, screening and diagnosing autism in female patients, with many endorsing a wish for additional training in this area. The authors suggested that training programmes should incorporate the specific needs of women with autism in order to promote better outcomes.

Allely conducted a systematic review exploring the female autism phenotype of repetitive behaviours and restricted interests (RBRIs). Allely reported that the RBRIs exhibited by autistic females are not sufficiently captured by most currently diagnostic instruments. As such, clinicians are less likely to identify RBRIs in females as they tend not to be the typical repetitive behaviours commonly associated with ASD.

 RELATEDLY, Nowell et al. examined parent reported sex differences in autistic children’s circumscribed interests. The authors found that boys were more likely to have a primary interest in Physics (e.g. vehicles, physical systems, computers, building), while girls’ most commonly fell into the category of TV (e.g. listening to music, particular shows, tablet watching) or Psychology (e.g. relationships, pretend figures, live action role play). As clinicians’ experience of circumscribed interests is predominantly male-based, the authors suggest that assessments should consider the inclusion of peers vs solitary play, and the degree of functional impairment around the interest, as key to identifying ASD.

Bhullar conducted in depth qualitative interviews with parents of adolescents with ASD in India, who described experiencing stigma, and a lack of social support irrespective of the gender of their child. Despite this, the parents interviewed endorsed a high level of commitment to improving the lives of their children.

Barnard-Brak et al. estimated how many girls may be at risk for ASD, by analysing data from community and clinic based samples, as compared to population estimates. The authors estimated that approximately 39 per cent more girls should be diagnosed with ASD that were not, and that the sex distribution in ASD should be approximately 28 per cent female and 72 per cent male. The authors suggested there may be “a leaky pipeline” within the ASD diagnostic process in the assessment of girls.
Across the two parts of this special issue, a total of 12 papers have been published, by authors working around the world, on a wide range of issues affecting girls and women with ASD. As such, the current editorial has been entitled, "Autistic women and girls: increasingly recognised, researched and served" in recognition of a slowly but surely developing evidence base. While there is a long way to go in terms of redressing the gender imbalance in autism research, it is hoped that these works will go some way to improving outcomes for autistic women and girls in the future.

References