Autistic women and girls: under-recognised, under-researched and under-served

Autistic women and girls are a group neglected within clinical practice and research. Recent reports have suggested that girls and women tend to be diagnosed with ASD later than men, and are more likely to have been misdiagnosed. This is likely due to conceptualisations of ASD being developed on males, a lack of gender sensitive diagnostic assessments, and a subsequent lack of recognition of autism within women and girls among clinicians. As such, one of the aims of this special issue was to stimulate discourse and further research. The editorial board members were delighted by the volume and quality of submissions, and due to this, have decided to host two special issues on this topic, with the second scheduled for the Autumn 2019. It is fantastic to see so many authors focussing on the characteristics and needs of autistic girls and women.

This special issue opens with a poignantly titled paper focussing on “the journey to diagnosis”, with Dori Zener reflecting on the experiences described by her clients, and clinical observations from her practice as a therapist specialising in working with autistic girls and women, who are trying to make positive changes in their lives.

Tharian and colleagues discuss the inclusion of autistic women and girls in works of fiction: books, television, film, theatre and video games. The authors found that while many pieces portrayed characters with traits that are highly recognised within the academic literature, others endorsed outdated myths and stereotypes. The authors feel that responsibly depicting females with ASD within fiction could help develop public awareness and recognition, reduce stigma and increase representation.

Kock and her team describe an innovative qualitative study exploring the intimate relationship experiences of eight autistic women. The research highlighted a number of themes, including dating and sexual experiences and victimisation, the decision regarding whether to disclose their diagnosis, and the challenges and positive aspects of relationships. The authors concluded that post-diagnostic counselling with a specific focus on intimate relationships may be of benefit.

In a reflective piece, Dr Sarah Markham describes her personal experience as an inpatient within a forensic psychiatric setting. Dr Markham eloquently discusses the pathologising of her behaviour in a setting where she was highly dependent on others, and her activities were highly restricted. Key learning points include the need for responsiveness in community health settings when patients are asking for mental health support, the need for increased joint working between clinicians and patients in forensic psychiatric settings, and the need for professionals to receive ASD training. In their invited commentary on this paper, Chaplin and McCarthy further elaborate on the implications of a late ASD diagnosis, note the lack of service provision for women with ASD, and discuss the implications of removing ASD from the remit of the Mental Health Act (1983).

This special issue ends with Clare Allely reporting a thorough systematic review on the empirical literature to date which has focussed on the way in which women and girls with ASD “mask” or “camouflage” their autistic symptoms, and the toll this often takes on emotional and mental health. The paper concludes with a discussion of the potential role of measures which show promise in assessing the extent to which people with ASD mask their symptoms.

The papers in this special edition raise awareness of the wide range of issues being experienced by women and girls with ASD in all aspects of their lives, as well as providing insight into the extraordinary resilience and potential of this under-served group. It is hoped the findings and ideas contained in both the present and scheduled issue will increase the profile of this under-recognised group in clinical practice, and stimulate further research, to achieve positive change and improved outcomes for women and girls with autism.