

Autistic Women and Girls

Resources for Professionals

Diagnosis

These resources have been collated from information collected through an online questionnaire, focus groups, interviews with individual practitioners and autistic women, and other recent research studies. Our aim is to summarise all this information, to present it in a succinct and useful form for busy professionals. Each resource contains a summary of key points, with links to appropriate items within the Right Click programme itself and other resources, from websites, online information and books. If you'd like more information on any of the areas covered, or have a specific enquiry, please contact us at rightclick@scottishautism.org

Girls and women may present differently than expected; sometimes described as being like swans (appearing to glide across the surface of life serenely but paddling frantically under the surface) they may make eye contact, they may talk about friends and relationships, they may appear to have similar interests to their peers. However, look under the surface and they may be working very, very hard to cope, and to 'fit in'.

Background

Our understanding of autism is continuously evolving. Some very common ideas around autism are being overturned by more recent evidence, specifically in relation to girls, for example ideas around prevalence, eye contact, demonstrations of empathy or friendships and other relationships.

There is now greater awareness of spectrum girls and women, with recent evidence pointing towards the following:

- females with normal to high intelligence may be overlooked or misdiagnosed because they do not present the 'typical' picture of autism ¹
- Girls and women may be misdiagnosed with mental health illnesses or disorders ²
- Some girls may not be identified by our current screening instruments ³
- It has been argued the issue isn't with existing diagnostic tools e.g. DISCO (Diagnostic Interview for Social Communication Interview), but in training for professionals, and that more specialist training is required ⁴

Swans

Autistic girls have been described as being like swans, appearing to glide smoothly across the surface of life but paddling desperately under the surface just to keep afloat. Girls may develop the ability to imitate or to mask their difficulties. It is understood that some autistic boys may also mask; it's possible that girls may be better at masking or it may be that social expectations on girls promote the motivation and the tools for masking as a coping strategy. High masking abilities are associated with poor mental health in adulthood.

Girls may internalise their difficulties more, with self-harm, school refusal and high risk behaviours.⁵

There are some very common ideas around autism, which are not correct for many individuals, for example:

- Eye contact

Girls often do make eye contact, although they may be more likely to avert their gaze when under stress or anxious and their gaze may be unusually intense.

- Empathy

There are issues of expression (how, what, when) and interpretation in relation to emotional response and affect. Women report that they can and do experience empathy but there may be a difference between their feelings and how they respond. There may be anxiety about 'getting it wrong' or there may be an inability to immediately process what has been experienced. Women report sometimes feeling 'overwhelmed' by emotions.⁶

- Friendships and other relationships

Girls may describe themselves as having friends. The quality of those friendships may be variable but many do have friends; some will prefer to be friends with boys rather than other girls. Many adult women have partners, are married, are raising (or have raised) a family.

- From the Right Click Survey

"I was lucky to have a GP who researched and referred me to a service who understand the female presentation, I received 3 hours of follow up counselling, very useful."

Summary

1. Age range for diagnosis in our survey is from 6 years to 56 years old
2. Girls and women may present differently than expected: they may make eye contact, they may talk about friends and relationships, they may appear to have similar interests to their peers. However, look under the surface and they may be working very very hard to cope, and to 'fit in'.
3. Girls may internalise their difficulties more, with self-harm, school refusal and high risk behaviours.
4. Mothers of girls and adult women are negatively affected when they are disbelieved on trying to access support and diagnostic assessment for their child or for themselves. Lack of access to professional help has an impact leading to poor self-identity, low self-esteem and mental health issues.
5. The diagnostic process itself may be highly stressful; support and signposting during and post diagnosis can make all the difference to positive outcomes.

To learn more about autism in women and girls, register for our Right Click Women and Girls programme where there are in-depth discussions on diagnosis from the perspective of autistic people and professionals.

References

- ¹ Van Wijngaarden-Cremers, P.J.M 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), pp 627–635
- ² Attwood, T. (2007) *The Complete Guide to Asperger's Syndrome*. Jessica Kingsley
- ³ Westman Andersson, G., Gillberg, C. & Miniscalco, C. (2014). Pre-school children with suspected autism spectrum disorders: Do girls and boys have the same profiles? *Research in Developmental Disabilities*, 34 (1)
- ⁴ Judith Gould, National Autistic Society's conference presentation 2016.
- ⁵ Stewart, C. (2012). 'Where can we be what we are?': the experiences of girls with Asperger's Syndrome and their mothers. *Good Autism Practice Journal*, 13, 1, pp 40-48
- ⁶ Milton, D. (2012). On the ontological status of autism: the 'double empathy problem', *Disability & Society*, 27(6), pp. 883-887

Resources

Scottish Women's Autism Network: www.swanscotland.org

Hendrickx, S. (2015). Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age. Jessica Kingsley

James, L. (2017). Odd Girl Out: An Autistic Women in a Neurotypical World. Pan MacMillan

Simone, R. (2010). Aspergirls. Jessica Kingsley

Sainsbury, C. (2009). Martian in the Playground: Understanding the Schoolchild with Asperger's Syndrome. Sage

Right Click for Women and Girls: www.scottishautism.org/womenandgirls

Spectrum Women: Walking to the beat of Autism <https://www.jkp.com/uk/spectrum-women-1.html>

Colouring Outside the Lines, Edinburgh: Peer support for families of autistic girls
www.colouringoutsidethelines.org

Cynthia Kim: <https://www.musingsofanaspie.com/about/>

Debi Brown website: www.aspiedebi.com

Alis Rowe, The Curly Haired Girl Project: <https://thegirlwiththecurlyhair.co.uk>