

Autistic Women and Girls

Resources for Professionals

Introduction

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

Autism has, up until very recently, been believed to be more common in males than in females. There is much greater awareness of girls and women now as our knowledge and understanding grow and evolve. Some 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. Girls and women may present differently than expected. For further information on diagnosis please see the animation and resource on this topic.

Autistic females 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. They may make eye contact, they may talk about friends and relationships and 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'.

What Does This Mean in Practice?

- They are often expected to 'fit in' with the mainstream
- They are constantly challenged to meet other people's expectations
- They may feel they are constantly 'failing' (in their own terms)
- They experience intolerance and marginalisation in the mainstream school setting; in employment contexts; in society

Autistic females often appear to be coping, but may not be really or only at a cost to their physical and mental welfare leading to:

- anxiety
- exhaustion
- depression
- high risk behaviours
- suicidality

Research Studies

'Where can we be what we are? Experiences of girls with Asperger's Syndrome and anxiety and their mothers' ¹. This research study described experiences of autistic girls not feeling comfortable or at 'home' anywhere; it found the school environment especially is very challenging in many ways.

An international study conducted in 2011-12 found that autistic women have impaired quality of life ². A follow-up to this study based in the UK found that women often feel they can't 'be themselves' and are always presenting a 'mask' to the world.³

Right Click for Women and Girls

An online questionnaire-based survey was distributed through the Scottish Women's Autism Network (SWAN) and other networks. The survey covered many areas of daily living, such as education, health and wellbeing, employment and parenting. Focus groups were also held with women and school-aged girls. The information collected, including many direct quotes, is presented through the Right Click resource.

Outcomes

Autistic females may have difficulties in accessing services for a range of reasons; the historical lack of knowledge and understanding of autism in girls and women can cause barriers for individuals and their families and carers; issues around communication, executive functioning and sensory processing also impact on the individual's ability to access services including:

- diagnosis
- education
- social services
- employment
- healthcare

Difficulties in accessing diagnostic services as well as the social issues associated with autism, including stigma, marginalisation and bullying, can have profound negative effects on individuals, impacting on:

- self-esteem and self-identity
- life trajectory
- life choices
- mental health and physical wellbeing

and creating barriers to accessing education, self-fulfilment, health and social care.

Supporting Autistic Girls and Women

We can:

- recognise that autism affects girls and women, probably far more than was previously thought
- invest in specialist training
- make reasonable adjustments at school, in the workplace, public services and social spaces
- create, develop and emphasise positive narratives of autism, without dismissing the very real challenges and difficulties faced by autistic girls and women
- find role models
- challenge and stretch
- help girls and women develop tools for survival and self-fulfilment
- facilitate peer support
- support them being themselves, in fulfilling their potential as individuals and leading lives as full citizens

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 autism from the perspective of autistic people and professionals.

References

¹ 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

² www.autisminpink.net

³ www.autisminpink.net

Resources

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>

National Autism Project: <http://nationalautismproject.org.uk/the-project>

National Autistic Task Force: <http://nationalautistictaskforce.org.uk/an-independent-guide-to-quality-care-for-autistic-people/>

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