Author: Lorraine MacAlister
Organisation: Autism Training Consultant, The National Autistic Society
Date of publication: 27 February 2018

NETWORK AUTISM
Where Autism Professionals Connect

Exclusively sponsored by:

AXCIS Education
Leaders in SEND Recruitment

Online support to help diagnose autistic women and girls

The aim of the Women and Girls on the Autism Spectrum module is to support professionals to identify autism in women and girls. It is specifically aimed at diagnosticians, but has been developed in such a way that it should be useful to anyone with an interest in autism, including autistic people, parents, carers and a wide range of other professionals.

It is now recognised from research, clinical practice and anecdotal reports that many undiagnosed autistic females, or those who demonstrate the less traditionally obvious traits of autism, are not recognised. This can result in misdiagnosis, late diagnosis, or those individuals not being diagnosed at all.

This module aims to provide an insight into the potential differences experienced by autistic women and girls. The philosophy of all our online modules is to put the autistic voice at the centre.

While managed by us, this project is being overseen by the National Association of Head Teachers (NAHT) Autism and Girls forum. The forum is an external reference group which was formed to raise awareness of autism in women and girls. The group consists of key people in the field of autism, including researchers, autistic women, education professionals, academics, parents of autistic girls and senior staff from the National Autistic Society.

How it began

In early 2017 we held a focus group with several autistic women. The feedback from these discussions helped format the development work on the module. One of the most important things to come out of this focus group was how vital a diagnosis can be in relation to making sense of who you are as a person.

For this reason we decided to focus on developing a module which would support diagnosticians to better understand autistic female characteristics, and to give them the confidence to diagnose those individuals successfully.

Why are women and girls missed?

It is often said that the differences autistic girls experience are of a more subtle presentation, or may appear so to others. Some autistic women and girls feel that they are masking their autism to try to hide the fact that they feel different. They may copy behaviour from others around them, and can be exhausted by the constant effort to appear similar to other people, or might be unaware they are 'masking' in the first place.

In practice, this can mean that autistic girls have better social integration skills from years of observing and practising. Autistic girls often base their understanding of the world on analytical thinking rather than on intuitive understanding. As Judith Gould (2017) explains:

"they learn social skills through their intellect rather than by instinct or social intuition".

An interactive module

We wanted the module to be interactive in order to make the learning process more engaging, and so worked with a company called Little Man Project to explore what our key principles were and the messages that we needed the module to get across. Little Man Project pulled this together and have built us an interactive module.

The module will enable you to review the potential differences that autistic women and girls might experience from non-autistic females, and from autistic boys and men. The module looks at the historical perspective to try and understand why they may have been missed in the past, and focus on developmental characteristics that you might be able to observe in someone (or yourself).

The module includes several film clips with autistic women and clinicians, giving further insight into different autistic perspectives and advice for clinicians from clinicians. A useful addition are several examples of questions to ask or things to observe, which can all be added to a folder to download at print at the end.

This module has been developed in conjunction with autistic women and leading clinicians. Contributors have included the focus group of autistic women, autistic content writers including Lana Grant, Sarah Hendrickx and Dr Wenn Lawson, and clinicians including Dr Judith Gould.

What we hope the module will achieve

Our aim is to ensure that more autistic women and girls are recognised and diagnosed, enabling them to gain access to the support and understanding they are entitled to. We will measure the impact of the project through a variety of ways, including collating feedback from those who have completed the module and working with professionals and individuals to examine whether we are seeing more women and girls diagnosed.

Author: Lorraine MacAlister
Organisation: Autism Training Consultant, The National Autistic Society
Date of publication: 27 February 2018

One of the most important learning points that we hope people will take from the module is the importance of listening to what autistic girls are telling us and why diagnosis can be so vital in terms of self-esteem, being able to understand yourself and being supported in the right way.

The module which will be launching in March 2018. It has been funded by the Pears Foundation which is enabling us to offer it free for the first year. For more information about the module and how to register your interest, please visit our website.

References

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. Autism, 21(6) pp703-705