

Women, Girls and the Autism Spectrum

SWAN/ANS Learning Event - 27 April 2015

Summary of diagnosis workshop discussions



Introduction

Discussions were structured around a series of questions as follows:

Diagnosis of women and girls on the autism spectrum

- what key things contribute to positive experiences of identification, assessment and diagnosis?
- what are the most important things to have access to post-diagnosis/identification?

Delegates were also asked for examples of good practice.

Notes were taken in each group and delegates were given opportunities to make written contributions to the discussion, both during and after the event. This information has now been collated. This document summarises the discussions, draws out key learning points and highlights some of the things SWAN hopes to take forward.

Diagnosis workshops

Delegates identified a number of factors that contribute to a positive experience of identification, assessment and diagnosis of autism in women and girls, including early identification/diagnosis, the availability and accessibility of clinicians who can diagnose autism and the extent to which practitioners understand autism and how it may present in girls and women.

Delegates emphasised the need for improved understanding of autism in girls and women among all those who may be involved in the diagnostic pathway, not just those responsible for diagnosis, and suggested that specific training is needed across a broad range of healthcare and education roles. Some suggested that such training should be mandatory to ensure a positive experience for all girls and women.

Delegates also emphasised the need for respect. They would like to be listened to and believed, to be trusted as an expert on their own lived experience, either as an autistic individual or as the parent/carer of an autistic individual. They would also like to have access to support and guidance, as an individual or as a family, during the process of assessment and diagnosis.

Post identification/diagnosis, there is an ongoing need for support, although the type of support needed may vary from person to person and over time. Support was considered especially important for teenage girls, particularly with regard to safety and puberty, for adults during post-school transitions, and for parents who are on the autism spectrum themselves.

Delegates felt it important to have clear and easily accessible information on what support is available. Examples of the types of support they would like to see include online access to information about autism, access to learning opportunities and support to develop practical skills and strategies.

Delegates stressed the importance of peer support in various forms. They spoke of the need for acceptance, the knowledge that you aren't alone, that it's okay to be different, the availability of safe space in which to talk to others and share experiences and the role of mentoring, both for the individual and for families.

Delegates also stressed the importance of meaningful inclusion, especially in school, and the need for teachers and employers who are willing to engage, adapt and learn.

A number of barriers to diagnosis were identified and there were several reports of individuals and parents who had had to push hard to get help.

Delegates cited difficulties with accessing the diagnostic process, including the lack of a clear and consistent diagnostic pathway, the patchy availability of diagnostic services and the lack of knowledge of autism and its presentation in girls and women among GPs and others who might refer them for diagnosis.

Delegates also cited barriers within the diagnosis process itself, including a general lack of resources and experience, poor understanding and recognition of how autism presents in older women and the difficulty of obtaining a diagnosis for 'well behaved' girls and those without 'learning difficulties'.

More generally, some delegates had great difficulty with the language and negativity of the deficit model on which medical diagnosis is based.

There was a broad consensus across all groups that the key benefits to diagnosis are in the area of self-identity and understanding – 'confirmation that I am not mad'. Some delegates also felt that a formal diagnosis can lead to support. However, some felt that they don't need a formal diagnosis and that (self-)identification is enough.

Key learning points

A number of themes emerge very strongly from the workshop discussions.

Firstly, there is a pressing need for extensive general awareness raising and also targeted training among health and education practitioners and managers. This applies to autism in general but more particularly to autism as it presents in girls and women at all stages in their lives.

Secondly, peer support is hugely important, both during identification/assessment/diagnosis and on an ongoing basis thereafter. At present, such peer support is not widely available, especially for teenage girls, late-diagnosed women and autistic mothers. There is a pressing need to build capacity for developing and expanding existing SWAN and other peer-support and partnership networks/forums across the country.

Thirdly, there is a pressing need to gather and disseminate the lived experience of girls and women on the autism spectrum as a valid and important form of evidence to inform practice and research. Autistic women have much to say about themselves and want their voices to be heard.

These themes are echoed in the feedback we received on the event itself.

In conclusion, SWAN and Autism Network Scotland perceive there to be a future role for SWAN in three main areas:

- awareness and training regarding autism in girls and women
- peer support for girls and women on the autistic spectrum
- facilitation of information gathering and dissemination regarding the lived experience of girls and women on the autistic spectrum.