

# Women, Girls and the Autism Spectrum

SWAN/ANS Learning Event - 27 April 2015

## Summary of workshop discussions



### Introduction

The learning event included two workshop sessions, one focusing on diagnosis of women and girls on the spectrum and the other focusing on education. Delegates were randomly allocated to three groups for the diagnosis workshop and could choose between groups focusing on primary, secondary or tertiary education for the second workshop.

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?

#### Education for women and girls on the autism spectrum

- what makes for good practice in education for girls and women on the spectrum?
- what are the current constraints on this good practice?
- how could these constraints be overcome?

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.

### **Education workshops**

Discussions in the education workshops were largely positive – there seemed to be a broad consensus on what constitutes good practice in various educational settings and there were lots of suggestions and examples of good practice from individuals, parents and practitioners in all groups.

The core of good practice at both primary and secondary school level is teaching staff who are well-trained and have a good awareness and understanding of autism, how it presents in girls and how to recognise anxiety and other indicators of (lack of) wellbeing in girls on the autistic spectrum.

Delegates emphasised the need for individualised rather than prescriptive support; the need for clarity and consistency; the need to consider pupils’ needs in different settings and through transitions of all kinds; the need for good communication both in school and between home and school; the desirability of small class sizes, specialist support, quiet space.

In the secondary age group, acceptance of difference was felt to be a significant factor and whole school education and awareness of autism considered to be the key to achieving this.

At both secondary and tertiary level, delegates identified peer support, buddying systems and mentoring as beneficial. They suggested that classes in social skills, study skills and life skills should be available (but not mandatory) and support offered in these areas, especially during transitions. They recommended that reasonable accommodations should be offered in areas such as timetabling, time pressured activities, teaching styles, etc.

At tertiary level, delegates again identified the need for in depth training of teaching staff and for individualised support for students. Delegates recommended that needs assessments should be conducted by suitably trained staff, that students should have a named person as a first point of contact for advice and support and that institutions should seek to ensure consistency in this regard.

There was considerable emphasis on the need for support during the transition into tertiary education, especially for those living independently for the first time. Peer support and

mentoring, social, study and life skills support, and opportunities to visit the institution and meet key staff in advance of commencing studies were all suggested as beneficial.

The implementation of good practice is by no means universal. In schools, the main constraint was considered to be a lack of knowledge and understanding of autism, not only among teaching staff but across the whole school community. Delegates were concerned that some teaching staff are not even aware that they need to improve their understanding of autism.

Delegates cited a range of issues which suggest that more training is needed, including lack of recognition that presentation differs in different settings and circumstances; lack of recognition that difficulties and anxieties do not necessarily manifest themselves as challenging behaviours in the classroom; a tendency to focus on behaviour rather than the underlying cause of the behaviour; lack of understanding of the need for downtime and the concept of burnout; lack of consistency of approach across classes and year groups; and the use or tolerance of patronising, negative or ableist language.

Delegates identified a need for better communication between home and school, also the need to recognise parents and indeed pupils as experts and partners.

Delegates acknowledged that many aspects of the school environment can cause anxiety, sensory problems and social difficulties, including bells, uniforms, circulation space, lack of time between classes, periods of unstructured time, lack of quiet space and so on, and that there are constraints on the extent to which these can be adapted to meet the needs of all pupils.

Problems can arise from peer pressure and social stigma, particularly where pupils are seen to be treated differently by staff.

Various staffing constraints were identified, including lack of leadership from senior staff, lack of time to develop individualised approaches or to attend training, and pressures on teachers to meet the additional support needs of many pupils simultaneously.

It was recognised that are underlying resourcing constraints with many of these issues. Much could be achieved with improved awareness amongst staff and more effective use of existing resources, for example through better links with families, structured support mechanisms that are more readily understood by staff and the promotion of examples of good practice. Ultimately, though, more resources are needed for training and support.

Some of the social difficulties might perhaps be addressed by the inclusion of disability rights in the curriculum, the identification of positive role models and improved support to develop social and study skills at all stages in the education system.

In the tertiary sector, the main constraint was considered to be at the level of policy and resourcing. Delegates spoke of policies that are unenforceable or overly simplistic; of

institutions using a tick box approach to policies and services rather than a more person-centred or flexible approach; of policies and recommendations not translating into action.

As ever, lack of awareness of both staff and fellow students was thought to be a significant constraining factor, the implications of which ranged from poorly conducted needs assessments blocking access to appropriate support to lecture slides not being provided in advance of a class to social pressure from peers.

Delegates identified some practical constraints. For example, many courses require group project work which can present additional challenges for those on the autism spectrum. Large class sizes can make it difficult for staff to determine whether someone is struggling. Transport was identified as an issue.

Again, resource constraints underlie many of these issues, but delegates felt that more effective use could be made of existing resources and that many institutions could usefully re-evaluate how they spend their resources in this area. Both general and targeted training is needed for staff – in particular support services could improve their knowledge and understanding of autism as it presents in women.

Delegates called for better signposting of services, a more proactive approach to needs assessment and review, ongoing support throughout the period of study; provision of a range of support including mentoring and buddying. It was suggested that institutions might consider appointing an autism champion.

Delegates emphasised the need for awareness raising across the whole community, partly to address social pressures and partly to ensure that undiagnosed individuals are able to access support if the need arises.

### **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.

#### Feedback from the Event:

'Thank you for organising this. Very useful and enlightening. Inspiring speakers. Good to see people who may not be entirely comfortable presenting being listened to and accepted and encouraged and doing a good job'

'Very interesting event with a good range of attendees. All presentations very informative and made me think'

'I have learned a lot today'

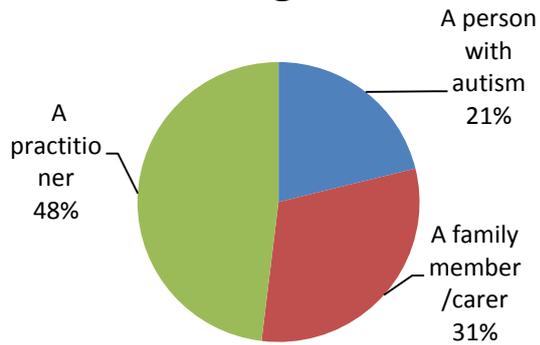
'It was so good to hear real life perspectives in such an open and relaxed format'

'It helped me to understand my daughter who is 15 years old with Asperger's'

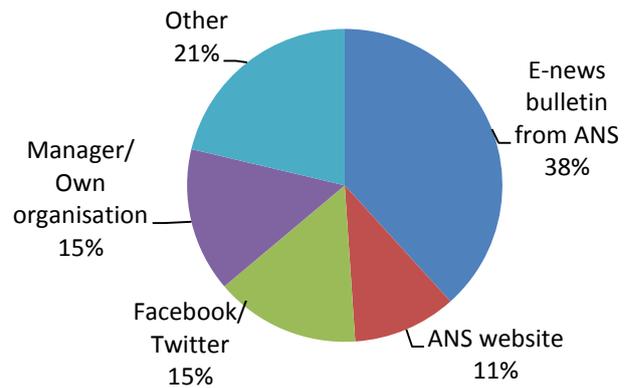
'Extremely valuable hearing first-hand experience'

'Selection of speakers excellent and very interesting'

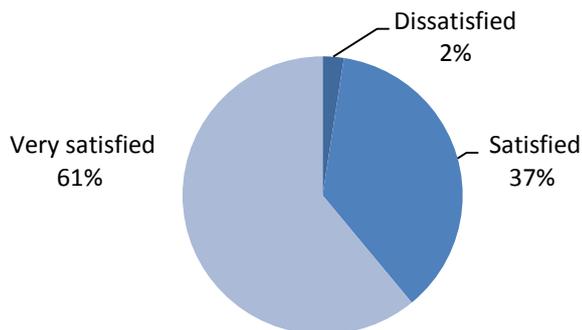
## Delegates



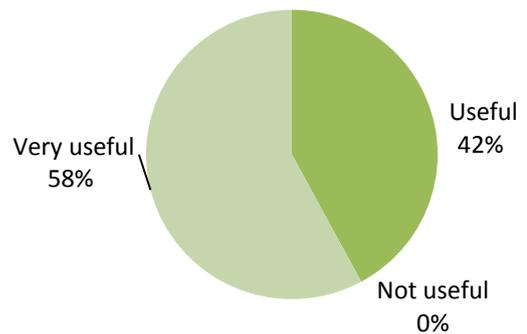
## How did you hear about the event?



## Overall, how satisfied were you with the event?



## How useful did you find the presentations?



## How useful did you find the workshops?

