Online support for autistic women and girls

The Right Click for Women and Girls programme was developed to provide support, information and inspiration for autistic women and girls, their parents and carers, and the professionals who may be involved in their diagnosis or ongoing support. It is an online programme which is free to access and has been supported by the Scottish Government via the Scottish Strategy for Autism funding.

The idea for the programme arose during the Scottish Strategy for Autism research seminar series at Strathclyde University in 2014 when Catriona Steward presented PhD research that focused on girls with Asperger’s and anxiety (Stewart, 2012). Underpinning that research was the goal of making this previously invisible population visible, giving autistic women and girls a voice and in turn listening to them. Scottish Autism wanted to develop this further, to offer a practical resource for women and girls underpinned by research.

Programme aims

The Right Click programme has been built around themes and issues identified through a number of routes, the rational for which and methods involved are outlined below.

Our first goal centred on information:

- gathering information
- adding to the knowledge-base
- highlighting areas of importance where perhaps more research can be done
- providing resources
The other goal, ‘Inspiration’, was in response to increasing concerns about issues of stigma and negative language around autism and how these things impact on self-esteem, life-choices and individual outcomes (Snow, 2013) (Humphrey & Lewis, 2008).

What was core was that the project should be grounded in experiences of autistic women and that the resource would be

- supportive
- positive and life-enhancing
- outcome-oriented.

The project involved autistic women and girls from the start via the Scottish Women’s Autism Network (SWAN), and built on previous research conducted by Scottish Autism.

**Developing the programme**

We used a mixture of methods. An online 28 item questionnaire was shared via various networks, and focus groups were conducted – our contributors ranged in age from 15 to 70 years. What was created was a wealth of numerical and rich text data, with a combination of quantitative and qualitative data analysis.

The quantitative survey data largely served to identify some of the challenges, problems and areas of concern involved in being an autistic woman or girl. These are crucially important as a start in highlighting where there should be further research and most importantly, resources allocated.

For example, difficulties in accessing health care for women across the board, but specifically antenatal services. Challenges in the experiences of giving birth and anxieties around post-natal support were all identified.

What the qualitative data, on the other hand, has served to illuminate is the ‘whole picture’ aspect of autism in women and girls:

- individual strengths, needs and assets
- humour
- love for their children (where they are mothers)
- insight
- aspirations and achievements, as well as difficulties.
The clearest emerging picture is of a population who, because they have been largely, perhaps not ‘hidden’, but certainly under-recognised, need much greater awareness of their needs and crucially, not just awareness but understanding and support. In every area identified the key message was one of need for increased knowledge in professionals, and better understanding and acceptance within the community at large.

Information and inspiration

The Right Click programme for women and girls is innovative and unique in a number of ways. It includes many interviews with and presentations by autistic individuals such as Sarah Hendrickx, Lana Grant and Dr Wenn Lawson. It offers advice and information on some of the more prosaic but important and often problematic aspects of daily life for women and girls on the spectrum including:

- diagnosis
- employment
- general and sexual health
- work-life balance
- managing anxiety
- eating issues
- parenting
- education.

More research is under way and we will be including more practical skills items and interviews with autistic women and professionals. There are plans for a range of new areas identified over the course of the first year, for example more information for younger women and girls.

There are also local, national and international conference and symposium presentations arising, including opportunities to take the Right Click into a wider arena such as the International Conference on Advances in Women’s Studies, Toronto, 2017. Central to the Right Click Women and Girls programme has been an ongoing process of review and assessment, and it will continue to be built around input from autistic women and girls who are the source of our inspiration!

References

Stewart C. 2012 ‘Where can we be what we are?’: The experiences of girls with Asperger syndrome and their mothers, Good Autism Practice, 13, 1, 2012 pp 40-48

Humphrey, N. & Lewis, S. 2008 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools, Autism, 2008; 12; pp23-46