Autism in Pink

Five million people in Europe have Autism\(^1\). Many experience difficulty getting a diagnosis and for some time there was a belief that there were about five times as many boys and men with autism than girls and women. There have been few studies devoted to women with autism, however it is now more widely accepted that women with autism are more at risk of being diagnosed late, being misdiagnosed, or not being diagnosed at all. In the field of EU projects this population is specifically considered one of the more neglected target groups - the EU disability strategy for 2010-2020 aims to improve the economic and social situation of people with disabilities empowering their full and equal participation in education, employment, use of services and facilities, and in life in general.

The ‘Autism in Pink’ project was an EU Lifelong Learning Programme funded partnership between four European organisations led by the National Autistic Society. The main purpose of the project was to contribute to the greater social inclusion of a vulnerable group - young women with Autism - and to provide them with key knowledge and skills to improve the quality of their lives.

Research workshops

Embracing the phrase “Nothing about us, without us” the project gathered a group of 10-12 women with autism in four countries. The volunteers met regularly at structured workshops facilitated by a researcher. The approach was to assess their existing quality of life using standardised instruments primarily the Personal Wellbeing Index – Adult \(^2\), and secondarily Comprehensive Quality of Life Scale – Adult \(^3\). These are both compatible with EU statements on quality of life and were within the range of technical competence and resources of the partner organisations to administer. Using a framework ensured that the workshops had structure and

\(^1\) Use of the word ‘autism’ refers to all people on the spectrum including Asperger syndrome

\(^2\) Personal Wellbeing Index (PWI) Cummins 2005

\(^3\) Comprehensive Quality of Life Scale – Adult (ComQol)
enabled discussion on a wide range of topics. The PWI was selected as the primary tool because it was easily adapted to suit the requirements of the different groups, whilst still producing results that could be analysed and compared.

The women in the different partner countries showed a range of experiences. But overall, there were some particular points that stood out:

- The consequences of autism still tending to be associated with men impacts the lives of women with autism in many ways, ranging from difficulties in getting a diagnosis, to difficulties in their basic human rights being upheld.

- It is essential that the public becomes more aware of ‘Masking’, which appears to take place more in women with autism than men. The qualitative research showed that many of the participants go to great lengths to compensate for and cover up some of their autistic characteristics by suppressing them, mimicking other people, and using logic rather than instinct to work out social situations. This means that people are not aware of the difficulties that they might be experiencing, or of the reality of the need for appropriate support. It also means that women with autism are constantly putting a lot of extra energy into their interactions, which is exhausting.

- There is a need for society to be more understanding, accepting and supportive, and to be more aware of autism. But at the same time we need to treat people with autism as individuals, each with their own value to contribute.

- The reality is that people with autism tend to have a ‘spikey’ profile of strengths and areas of need, so being stronger or weaker in one area does not necessarily indicate corresponding strength or weakness in others.

- the need for further gender specific study

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The workshops in themselves provided valuable opportunities for the women to meet. The PWI framework used to define the structure was particularly successful, with participants gaining more from their attendance than they’d experienced in support groups. In addition to making friends and feeling less alone, they supported each other whilst gaining a greater understanding about themselves and discussing workable solutions to some of the issues they face on a daily basis.

**Case studies from the group**

**Emily** only received a diagnosis of autism three years ago, after spending most of her life feeling different from others but not understanding why. She attributes her late diagnosis to a lack of understanding of the way that autism affects females.

Like most people with autism, Emily struggles with social situations and says she feels "a bit like an alien", even when she's surrounded by loved ones. Emily said: “There are lots of stereotypes surrounding autism which can make it difficult for others to understand how the condition affects me as an individual and as a woman.”

“The project was a great way of coming to terms with my diagnosis and learning how it affects men and women differently. But more than this, it was a chance to meet a group of women who have been through similar experiences and to learn coping strategies from them. Due to my social anxieties I find it really difficult to fit in and don’t have many people close to me aside from my partner and family so the group gave me a real sense of belonging. We’ve all kept in contact and have now formed a type of support group to help each other.”

**Laura** only received a diagnosis of autism at the age of 25, after spending most of her life feeling different from others but not understanding why. She attributes her late diagnosis to the lack of understanding of the way that autism manifests itself in females.

Laura said: “While my autism diagnosis eventually helped me to understand the way I am, it was initially very confusing as I didn’t recognise many of the traditional characteristics in myself. I now realise this was because autism affects males and females differently and can be harder to diagnose in women and girls.”

“The project was great on a personal level as it introduced me to other women who had been through similar experiences. Not only did this help me to develop strategies to deal with some of the difficulties I face, particularly around social situations, it also helped me make some new friends.”

**Feedback**

The overwhelming feedback from group who volunteered for the project was that it had been beneficial for them; they had found the group supportive and learnt a lot from sharing experiences and strategies. Most felt that they had learnt more about autism and more about themselves as individuals, and that they had gained confidence and assertiveness from attending the workshops. They enjoyed meeting other women on the autism spectrum, and felt
less isolated, less alone, more a part of something bigger than themselves. The women felt pleased to be able to contribute to the project, and felt that their contributions would go some way towards raising awareness and helping others.

As the women benefitted from each other and the project, so did the project benefit from the women.

Find out more

- See [autisminpink.net](http://autisminpink.net) for the eBook *Breaking the Silence (contains the personal stories of some of the women who took part in the project)*, research reports, presentations from the project’s International Conference and Study Trip to Brussels to meet MEPs and other project outputs
- Watch the 35 minute [Autism in Pink documentary](http://www.youtube.com/watch?v=Autism_in_Pink) available on YouTube
- Visit [NAS Women and Girls Conference](http://www.nas.org.uk) (9 October 2014) where Senior Researcher Sylvia Kenyon, and one of the women participants, Kerry Lound, will be speaking about the project.

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