

Author: The National Autistic Society
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Autism in Pink EU project concludes with free web resources

Autism in Pink was a project for women with autism funded by the EU and supported by The National Autistic Society in Great Britain (see appendix 1), Lithuania's Edukaciniai Projektai (2), Portugal's Federacao Portuguesa de Autismo (3) and Spain's Autismo Burgos (4).

The project embraced the phrase "nothing about us, without us", gathering a group of women with autism in each country to attend workshops, giving them a unique opportunity to contribute to the materials produced by the project, meet influencers and politicians as well as attending international events to meet the groups from other countries. By taking part in the project's research to produce materials to increase awareness and help others, many of the women volunteers themselves gained more personal insight, increased their confidence and overcame personal challenges.

Dr Wendy Lawson, a psychologist who is also on the autistic spectrum, said in May 2014 on BBC Radio 4's *Woman's Hour*: "There is more awareness. People are realising autism is not a male disposition. I believe it occurs almost equally in girls, as well as boys." (5)

With approximately 700,000 people living with autism in Great Britain (6), four times as many men are diagnosed as women (7). Sylvia Kenyon, a senior researcher from The National Autistic Society, believes this is a pan-European issue and that in each of the countries represented by Autism in Pink, "autism still seems to be thought of as a predominantly male phenomenon".

In an attempt to bring women with autism together, the Autism in Pink project researched the lives of women with autism in the four countries involved. It increased awareness around women with autism and looked at ways to improve knowledge for people who support and work with women with autism.

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The project concluded with a one-day conference in Lisbon, Portugal in May 2014 where women with autism could meet to share their unique experiences. The conference featured talks from Dr Judith Gould and Robyn Steward, a woman with autism and an autism speaker, as well as a musical performance from the APPDA Banda, a Portuguese band including musicians who live with autism.

A personal perspective

Lisa Chu, one of the research participants, remembers the day fondly:

“The participants who chose to speak were all amazing. They came across as very professional and confident. It was a fantastic event and a great way of raising awareness of the issues faced by women with autism, with insights from the women themselves.”

By participating in Autism in Pink, Lisa says: “It meant I could consider carefully the impact autism has had on a range of areas in my life. It has been immensely useful in coming to terms with my diagnosis and identity as a woman with autism. It has helped me to realise how much autism has affected me throughout my life.”

Lisa has lived with low self-esteem and severe depression for 20 years. She has struggled to socialise and organise her life on a daily basis. She has struggled to find an autism diagnosis because she believes “women tend to ‘mask’ or cover up their symptoms by mimicking or compensating in other ways”.

She says: “The current methods used to diagnose autism are skewed towards the male presentation so women with autism are often missed, which has led to lower rates of diagnosis in women.”

How has Autism in Pink helped women with autism?

As Sylvia explains, difficulties common in all of the countries involved in Autism in Pink for women include:

“So-called ‘high-functioning’ women struggle to have their difficulties recognised. They appear so able people find it very difficult to believe they have the difficulties they actually do have.

“Women are able to make it look as if their autism affects them much less than it actually does. This has many implications on their mental and physical health and relationships, and the way other people in all areas of their lives judge them.

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“Society’s tendency to stereotype can be problematic for women with autism because they do not fit neatly into either the stereotype of women, or the stereotype of a person with autism.”

Sylvia believes Autism in Pink was a supported idea as “the project was in line with EU values and the idea everyone is entitled to an equal quality of life”.

“I think the funding was awarded because women with disabilities are known to be particularly vulnerable, and there are very few projects that investigate women with autism specifically.”

Though the Autism in Pink project has formally ended, free resources for both professionals and women with autism are available on the Autism in Pink website. These include *Breaking the Silence*, an e-book, (8) and *The Autism in Pink Documentary* (9). Each resource offers insights from women involved in the project.

For more information about the project visit: www.autisminpink.net

Appendices

- 1 THE NATIONAL AUTISTIC SOCIETY, 2014. *Accept difference. Not indifference.* [online] [viewed 16 June 2014]. Available from: <http://www.autism.org.uk/>
- 2 EDUKACINIAI PROJEKTAI, 2014. *News* [online] [viewed 16 June 2014]. Available from: <http://www.edupro.lt/en/>
- 3 FEDERACAO PORTUGUESA DE AUTISMO, 2014. *Home* [online] [viewed 16 June 2014]. Available from: <http://www.fpda.pt/>
- 4 AUTISMO BURGOS, 2014. *Autismo Burgos* [online] [viewed 16 June 2014]. Available from: <http://www.autismoburgos.es/#>
- 5 BBC, 2014. *Woman’s Hour* [online] [viewed 16 June 2014]. Available from: <http://www.bbc.co.uk/programmes/b042zb4w>
- 6 THE NATIONAL AUTISTIC SOCIETY, 2014. *Statistics: how many people have autism spectrum disorders?* [online] [viewed 16 June 2014]. Available from: <http://www.autism.org.uk/about-autism/myths-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx>
- 7 AUTISM WEST MIDLANDS, 2014. *Women and Girls with Autism* [online] [viewed 16 June 2014]. Available from: <http://www.autismwestmidlands.org.uk/files/autism--women.pdf>
- 8 AUTISM IN PINK, 2014. *Breaking the Silence* [online] [viewed 16 June 2014]. Available from: <http://www.autisminpink.net/>
- 9 AUTISM IN PINK, 2014. *Documentary* [online] [viewed 16 June 2014]. Available from: <http://www.autisminpink.net/>

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