

AUTISM IN PINK



Recognizing needs of Women with Autism¹ Needs and Recommendations Lifelong Learning Programme

¹ The term autism is being used in this document to include all autism spectrum conditions or disorders.



Illustration: Irene Rodríguez Manero

ABOUT AUTISM

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours. More than 1 in 100 people in the Europe have autism. Autism was first identified in the 1940s and therefore the first generation of children to be diagnosed is only now moving into older age. The United States and Australia have developed specific plans and considers Autism to be an important public health concern.

+ Info:

Combating Autism Act: <http://www.gao.gov/assets/660/652356.pdf>

Autism State Plan Victoria:

http://www.dhs.vic.gov.au/data/assets/pdf_file/0003/660882/autism_state_plan_2009.pdf

ABOUT AUTISM & women

Center for disease control and prevention published on march 2014, last data about prevalence studies. This surveillance study identified 1 in 68 children (1 in 42 boys and 1 in 189 girls) as having autism spectrum disorder (ASD).

Gender theorists have shown that autistic traits are often culturally coded as masculine rather than feminine, but this is not always the case. Some women with autism experience a profound sense of distance and difference from both the majority of male people with autism and the predominant stereotypes of femininity. Females tend to be underdiagnosed because of the tendency of the practitioners best placed to pick up on possible autism tending to associate it with males. Also, diagnostic tests reflect knowledge of men with autism, as opposed to women. In addition, women tend to have the ability to “camouflage” or “mask” their difficulties to the extent that people don’t realise these difficulties exist.

+ Info:

Cowhey, Sharon P. (2005) *Going Through the Motions: Coping with Autism*. Publish America: Baltimore.

Gerland, Gunilla (2003) *A Real Person: Life on the Outside*. Souvenir Press: London.

Grandin, Temple (1996) *Thinking in Pictures: And Other Reports From My Life With Autism*. New York: Vintage Books.

http://www.cdc.gov/ncbddd/autism/states/comm_report_autism_2014.pdf

ABOUT AUTISM in PINK

The AUTISM IN PINK project is an innovative project funded under the EU Lifelong Learning Programme (LLP) between four European autism organisations which has been set up to carry out research into autism in women. It has been looking into the prevalence of autism amongst women in the participating countries, and assessing the competences and needs of women with autism, in order to provide support and education both for women on the spectrum and for their parents, carers and teachers, as well as social care and health professionals.

+ Info: Autism in Pink website: <http://autisminpink.net/>



This document

The present document exposes the needs and recommended actions in policies to assure the equality and the rights of women with Autism Spectrum Condition in Europe. It specifically focuses on educational and health approaches towards treatment, awareness and empowerment of women with autism.

The European Union, the United Nations and the Council of Europe are also actively engaged in fostering gender equality and promoting the role of women from an economic perspective, a social inclusion perspective, an anti-discrimination perspective and a human rights perspective.

Documents and platforms for women with disabilities that could be used to target the needs and rights of women with autism:

- 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union
- UN Commission on the Status of Women

Needs and Recommendations

Diagnosis

Diagnosis can help people with autism to access the services and support they need and it can help them understand themselves better. It can help their family and friends to understand them too. But women with autism in particular can find it harder to get a diagnosis.

Autism is diagnosed around four times more often in boys than in girls. The gap between men and women is now beginning to be understood; there are factors that are unique to girls, girls are more likely to be misdiagnosed. The fact is that this has led historically to a gender-based discrimination against women and girls with autism in many different areas. There is no medical diagnostic test available for autism, and as a result, doctors consider a person's behaviour and childhood development to make a clinical diagnosis. But there is actually an important focus on behaviour observed in males, assuming that this behaviour is common to females with autism as well.

There are large numbers of women with autism who have been overlooked or misdiagnosed due to:

- Females are better able to adapt to, or compensate for, aspects of autism symptomatology than are males, who are more likely to externalise their problems.
- Professionals are less familiar with their profile. This discrimination by health professionals and the late diagnosis affects their access to health services

Needs	Recommended Actions
<p>Specific screening and epidemiological data about autism.</p> <p>More knowledge and understanding about Autism and specifically women with autism</p> <p>Promote access to early <i>identification</i> and <i>intervention</i> that can greatly improve a child's trajectory in life.</p>	<p>Healthcare professionals working in Paediatrics, mental health and education should be trained in autism and specifically in how to identify women with autism.</p> <p>Organising diagnostic assessment and early intervention services to maximise individual and family outcomes</p>

Education

There are still many barriers in the education of females with autism. The lack of specific support, proposals that promote accessibility to the curriculum and misunderstanding of the system, are some of the main difficulties.

Needs	Recommended Actions
<p>Either intentionally or unconsciously, they “<i>mask</i>” their communication or social limitations, so girls’ difficulties are often unnoticed by the teacher.</p> <p>The traditional procedures and methodology in education is not adjusted to neurocognitive style often found in women with autism.</p> <p>Intelligence and areas of strength such as visuo-spatial, vocabulary or eidetic memory tend to mask their needs in structure and hyper selectivity</p> <p>Most women with autism experienced <i>isolation</i> and <i>bullying</i> in schools</p> <p>Educational spaces tend to present a vast mixture of sensory stimuli which can be overwhelming and over-stimulating for people with autism, thus presenting a possible barrier to effective education</p> <p>Lack in legislation about accessibility to education in autism</p>	<p>Promote the development of studies that provide specific screening tools of autism in women</p> <p>Develop teachers training programmes</p> <p>Ensure that women and girls with autism have an equal access to both primary and secondary education</p> <p>Specific legislation to cover the flexibility required regarding the range of educational options and curriculum</p> <p>Specific teams of experts and centres to assure the knowledge and sensitivity to work appropriately with children with autism.</p> <p>Include specific actions against bullying in women with autism.</p>

Violence/Harassment

Girls and women with autism have greater emotional difficulties compared to boys. Attempts to help women with autism feel safe should recognize the need to negotiate alienation in their own way.

- They tend to set their expectations very low because they think they will not be loved and thus their idea of romanticism is more profound. As a result they may gravitate towards abusive people.
- They are more vulnerable to any kind of abuse, because of their lack of understanding social intentions and their lack of ability to identify abuse and non-explicit forms of violence.
- Their lack of communication skills, low self-esteem and emotional dependence makes them more vulnerable to abusers.
- Women with autism are particularly at risk of grooming and bullying online, where they spend much of their social life.

Needs	Recommended Actions
<p>There has been an increase in cyber-bullying, including trolling and stalking, and physical bullying of young people; women with autism are particularly vulnerable</p> <p>There is a lack of research and statistics on the bullying and violence towards people with autism</p> <p>There is still a stigma about autism in all Europe</p> <p>There are several non-evidenced based treatments and therapies that assure us of cures and miracle benefits</p>	<p>It is crucial to promote awareness-raising campaigns on the challenges faced by women with autism.</p> <p>Establish specific laws against bullying and abuse taking into account the vulnerability and difficulties identified for women with autism across all of Europe.</p> <p>Establish specific laws to investigate non evidenced practice that assures cures to autism</p> <p>End all forms of violence against women and girls with autism by using normative instruments to impact the rights of women with autism, including measures to end physical and sexual violence experienced by women with autism.</p> <p>Ensure they have access to justice/survivor services.</p> <p>Ensure these women to have the capacity to make choices about their (sexual) rights.</p> <p>Develop a more systematic understanding of the female presentation of autism</p>

Work and employment

Women with autism have greater difficulties in gaining employment due to:

- Personal factors: negative self-perception, lack of social skills to face an interview, lack of training or education, passive attitude, mental rigidity, need for a structure, smaller social network.
- Social factors: social prejudice of the employers, “typically female occupations” does not fit her features; their diagnosis limits their capacity to actively seek employment.
- Discrepancy between expectations based on their own cognitive and educational achievements and access to quality employment.

Needs	Recommended Actions
<p>Difficulty in accessing guided and vocational training which is adjusted to their particular needs</p> <p>The Higher Education system is based on collaboration and cooperative working and flexibility in competencies, while the strengths in autism tend to be hyper specialization and well-structured jobs</p> <p>Lack of awareness from employers</p> <p>Risk of poverty because of autism and because of being a women</p>	<p>Create Government assistance for business owners to employ them, taking into account gender and autism.</p> <p>Create specific programmes to increase skills of women with autism.</p> <p>Raise the subject of problems of women with autism in discussions with national parliaments so that Member States are encouraged to include their empowerment as a key element in the national strategies that seek to improve their overall condition.</p> <p>Promote a more integrated approach in the national strategies to combine education and employment areas.</p> <p>Raise awareness amongst professionals involved in early identification and diagnosis</p> <p>Develop policies to ensure a deeper assessment, better understanding of real needs, and more appropriate support, (for example set an autism expert in each institution).</p>

Equality/ Inclusion in the Community

There are some other factors contributing to the gender gap in autism:

- Invisibility of women with autism in the work on women, and community spaces and activities, because of overwhelming and non-accessible spaces.
- Lack of empowerment and development of the capabilities of women and girls with autism including in leadership and their participation in the decision-making process in political, economic and social spheres.

Needs	Recommended Actions
<p>Social Networks and support groups to assure their participation in the community</p> <p>Accessibility to leisure programs that have specialist training in autism</p> <p>Support to participate in daily life activities understanding and dealing with overwhelming stimulus</p>	<p>Include measures to impact the rights of women with autism and to achieve gender equality.</p> <p>Foster gender equality as a key objective and gender mainstreaming as a general approach.</p> <p>Promote awareness of the general population to reduce the stigma and stereotypes that might be associated with autism</p> <p>Provide specific actions plan and training about autism to community connectors, supporters and volunteers.</p>