

The challenges facing women and girls with autism spectrum disorder in Spain

Cristina Hernández Layna, Marta Plaza Sanz, Ruth Vidriales Fernández, Cristina Gutiérrez Ruiz, Confederación Autismo España

Introduction

In recent years, there has been an increase in scientific and clinical interest in the manifestations of ASD concerning girls and women. The research to date indicates that:

- Diagnostic confirmation is delayed in the case of women, with a higher probability of receiving previous diagnoses of psychiatric disorders (Begger et al., 2013; Egger, 2018). The delay may be due to the fact that existing screening and diagnostic instruments are not sensitive enough to identify the clinical manifestations of ASD in women (Skuse and Mandy, 2015). There also seems to be gender bias in professional practice influencing clinical decision making (Egger, 2018).
- Delay and diagnostic error negatively affect emotional well-being and sense of identity, which can lead to an increase in the risk of stressful or traumatic life experiences (Bargiela, Steward and Mandy, 2016).
- Some personal skills might be more functional or efficient in the case of women, which could result in the masking of nuclear characteristics of ASD (Baron-Cohen, 2002; Gould, 2015; Naser, 2016; Rynkiewicz et al. 2016). Factors explaining these differences and how social roles or demands contribute to them, are unknown.

- Gender identity for women with ASD could be more problematic than for men. In general, they do not identify with the majority of women since their interests are very different (Cooper et al., 2018).
- Women with ASD have a worse perceived health status (Fortuna et al., 2015) and experience high comorbidity with neurological and mental health disorders (Beacher et al., 2012). Besides, they generally receive support later in life than men do, even when their diagnostic is confirmed (Giarelli et al., 2010).
- The underrepresentation of women with ASD in research and clinical practice has resulted in a male bias in understanding the disorder. Certain phenomena have barely been explored, such as gender violence, maternity or expected social roles.

The aim of this study is to analyze the reality of women and girls with ASD in Spain and to contrast it with the results obtained internationally. It intends to explore their life experience and social factors by determining their needs, interests and abilities.

Methodology

- Mixed, quantitative and qualitative design.

Participants:

TOTAL PARTICIPANTS N=244	AUTISTIC PEOPLE n=72					
	Gender		Age in years		Intellectual functioning	
	Female	71 (99%)	Mean	23	Without ID	41 (57%)
					With ID	26 (36%)
	Non-binary	1 (1%)	Range	4-49	Unknown	5 (7%)
OTHER PARTICIPANTS n=172						
Profile	Gender					
	Female	Male				
Family members n=131	108 (82%)	23 (18%)				
Professionals n=38	33 (87%)	5 (13%)				
Expert professionals n=3	3 (100%)	-				

Data collection methods:

QUALITATIVE TECHNIQUES	PROFILE	No.	Persons involved	EXPLORED DIMENSIONS
Needs-detection workshop	Professionals	1	7	• Background and current personal situation
Semi-structured individual and group interviews	Women and girls with ASD	59	59	• Access to diagnosis
	Professionals	13	16	• Competences and skills
	Family members	16	21	• Health
	Expert professionals	3	3	• Education and education history
Focus groups	Family members	16	110	• Employment
	Professionals	2	14	• Friendship and/or affective relationships
Life stories	Women with ASD	13	13	• Sexual and reproductive rights
				• Access and support resources
				• Concerns and priorities for the future

Twenty-three organizations related to the associative movement of people with autism spectrum disorder and their families in Spain have provided access to the participants, represented in 10 Autonomous Communities.

Preliminary results

*A partial analysis of the information collected is offered. It only includes primary dimensions identified by adult women with ASD without associated intellectual disability.

Early identification and diagnosis:

- Diagnosis confirmation is delayed, especially in the case of women who do not have an associated intellectual disability.
- Women receive several diagnoses prior to ASD, contributing to considerable misinformation and anxiety.
- On many occasions, they receive the diagnosis confirmation after a son or daughter receives it as well.
- Women identify the lack of expertise of professional teams of the national health system as the main barrier to access diagnostic confirmation.

Clinical manifestations:

- Women make significant efforts to conceal social difficulties causing high levels of anxiety.

Inclusion and social participation:

- They show a high risk of suffering abuse and violence throughout their lives. Many have been victims of bullying and, in some cases, they have also experienced sexual assault and domestic violence.
- They refer to high rates of discrimination in different areas of their lives and an intense perception of being victims of social exclusion, as well as being "invisible to society."
- They experience limited access to employment and significant difficulties in managing interpersonal labour relations.

Identity and social roles:

- Some women express difficulties or lack of interest in the recognition of their gender identity.
- The lack of coping strategies and skills hinders the development of the role of motherhood and constitutes a significant concern in women who have children.

Support systems and networks:

- There is an absence of specialized resources responding to specific needs of women and girls - physiological changes associated with life cycle: menarche, menopause, maternity, protection against situations of abuse or violence, etc.
- They identify inadequacy of existing support resources for their individual needs. They request an improvement of support alternatives and resources, as well as the increase of knowledge and professional expertise.
- They call for an increase in research and social awareness of ASD in the case of girls and women, in order to improve their situation and quality of life.

Autismo España greatly appreciates the essential and selfless participation of the people and organizations who have volunteered to express their opinions and experience on this project.

