

Ageing and ASD: an invisible stage of life

*What are the needs of the protagonists?
Which future challenges will have to be faced?*

Autismo España is a state confederation representing 76 organisations of the third sector promoted by relatives of people with ASD that provide specific and specialized support and services to the attention of people with ASD and their family.

Objectives

- Understand the social reality of ageing of people with ASD in Spain on the basis of the active ageing model (WHO, 2015).
- Become aware of the implications of this stage of life from different perspectives: people with ASD over 40 years of age, relatives, professionals and organisations.
- Identify barriers and facilitators in the promotion of active ageing of people with ASD.
- Enhance specialised support systems that improve the quality of life of people with ASD in advanced age, for an active ageing.

Methodology

This research was conducted following a qualitative approach, by means of literature review, data analysis as well as semi-structured interviews, focus groups, life-histories, etc.

Participation: 21 confederated organisations from 7 different Autonomous Communities.

	Total
Individuals with ASD (over 40 years)	11
Families (mothers, fathers, sisters, brothers)	49
Professionals (confederated organisations)	90
Expert on ageing and disability	1
Total of participants	151

General conclusions

- Early confirmation of the ASD diagnosis is primordial. Early detection and diagnosis are essential to guarantee the access to the relevant support required by the person throughout his/her life, as well as in order to facilitate an active ageing.
- A consensus exists on the necessity to include the available knowledge on ASD to progresses in gerontology, in order to benefit from both fields of expertise.
- Nowadays, ageing of people with ASD is a complex reality to address for themselves as well as for their family and the specialised organisations, while being invisible in many ways to the main social agents.
- In the Spanish context, the existing means of support for people with ASD differ and are scattered. Public policies and planning criteria of support systems directed to this group are very disparate and bring to light sound territorial disparities.
- The momentum of the resources and support to the adult life of people with ASD, is considered as a priority, especially in the ageing process.

- Due to the development and changes in the support systems in order to be better adapted to the needs that imply the ageing process, the training and qualification of professionals is necessary, as well as the incorporation of new profiles.
- Research is essential in improving the means of support necessary to people with ASD while aging. The increase of investigation and specialisation in the professional sector is a shared request from different groups of informants, especially from the group of professional participants.

Autismo España greatly appreciates the strong interest and implication of the confederated organisations that have collaborated to this research, as well as the indispensable and selfless participation of all the people who shared their opinion and point of view for the study.

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