
Autism, Independent living and deinstitutionalization

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Résumé

"In Europe, most people with autism, mainly those with a more severe condition, are institutionalized (Autism Europe 2010). In Portugal, most institutions continue to work according to the medical model of disability (Nogueira, 2019). In 2019, the Portuguese Government created the "Support Model for Independent Living", through a pilot network of 35 "Support Centers for Independent Living". These centres provide a certain number of hours of free personal assistance to people with disabilities who require it. The Portuguese model of Independent Living support is different from the most common models in Europe because it involves a partnership with traditional institutions.

This presentation aims to discuss the role of personal assistance to prevent the institutionalization of autistic people and even their deinstitutionalization. The research is a case study about two support centres for independent living in autism with 35 support recipients (Lisbon Metropolitan Area e Alentejo Region).

We will show data about: i) characterization of support recipients; ii) type of support provided and the number of hours of support per day; iii) changes in their lives after the beginning of the personal assistance support; iv) satisfaction of recipients; v) satisfaction of their families; vi) future expectations; vi) contribution of personal assistance to the prevention of the institutionalization and deinstitutionalization.

Methodologically, several focus groups were carried. We held focus groups with support recipients with autism, their families, and personal assistants. In-depth interviews were also carried out with the coordinators of the independent life support centres. The information obtained was processed using "content analysis".

The results show a very positive impact of personal assistance on the quality of life (four significant areas) and citizen participation of support recipients with autism and their families. However, from the point of view of public policies, the current Portuguese model needs some improvements (internal and external coherence), that can will be in future a credible alternative to the institutionalization."

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