

The Views Of People With Intellectual Disabilities On Their Right To Live Independently: Exploring Barriers, Supports And Suggestions For Improvement.

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General description on research questions, objectives and theoretical framework

This study forms part of a doctoral thesis on the supports and barriers encountered by people with intellectual disabilities (ID) in exercising their right to independent living in Spain. The aim is to explore the views of people with ID regarding obstacles that impede and actions that promote their exercising of this right.

The past forty years have seen important advances in how we understand disability. Disabled people have gone from being problematic individuals who do not meet the standards of normality that govern society to citizens whose physical, social, political and economic environment makes it difficult for them to exercise their rights under the same conditions as other people (Barnes & Mercer, 2010).

Since 2008, the Convention on the Rights of Persons with Disabilities (United Nations, 2006) has been in effect in Spain, Article 19 of which recognizes the right of the individual to decide where and with whom to live and to receive the necessary support to live in an independent and inclusive manner within the community. Although authors like Verdugo et al. (2009) point out that Spaniards with ID experience difficulties in exercising their right to independent living, studies on the situation they face in relation to independent living in Spain are scarce. These authors argue that not being involved in decision-making and a lack of housing alternatives in the community are some of the obstacles that prevent a person from having control over their own life.

On an international level, studies focusing on the opinions of people with ID show that there are still significant barriers to living independently (Inclusion International, 2012). People with ID state that they encounter obstacles when making their own decisions about with whom and where to live (European Agency For Fundamental Rights, 2012). McConkey et al. (2004) point out that in many cases decisions are taken by professionals or family members, who prefer institutional residential services due to the security and stability they offer. In light of this, people with ID denounce the lack of opportunities they have to be heard (McGlaughlin & Gorfin, with Saul, 2004) and call for more choice regarding the degree of independence they wish to live with (Inclusive Research Network, 2010; Deguara et al, 2012).

With regard to housing, people with ID express a preference for ordinary households (McGlaughlin & Gorfin, with Saul, 2004) and their home being close to their family and community services and amenities (McConkey et al, 2004). However, they highlight the lack of any alternatives to the family home which would enable them to live independently within the community (European Agency For Fundamental Rights, 2012). The most common alternative are group homes (Inclusion International, 2012), which do not always offer the person the degree of independence they want (Inclusive Research Network, 2010). Some people with ID

express a preference for personalized support (McGlaughlin & Gorfin, with Saul, 2004). According to McConkey et al. (2013), personalized support acknowledges the person as an individual who has their own preferences and strengths, empowering them to take control of their own lives and the support they receive, and is aimed at ensuring the person lives in the community in an inclusive manner.

Knowing the opinions and views of people with ID regarding their right to independent living has become a prerequisite for developing improvement actions focused on their interests and demands.

Method

A qualitative approach (Denzin & Lincoln, 2003) was adopted for this study. In accordance with the principles of inclusive research (Walmsley & Johnson, 2003), the researchers had the support of an Advisory Council comprising people with ID, who assisted with the literature review, the design of instruments and discussion of the results.

A total of 22 people with ID participated in the study (11 women and 11 men). They were selected with the assistance of professionals from 5 support services applying the criteria of having mild to moderate intellectual disabilities and being aged between 20 and 55. With regard to their employment status, 7 participants worked in ordinary companies, 9 worked in Sheltered Workshops, 4 participated in occupational centers and 2 were unemployed; and with regard to housing, 9 were living in an ordinary home with personalized support, 5 in a group home, 7 with their family and 1 in an ordinary home without support.

The interview was individual, semi-structured and had an average duration of 1 hour 30 minutes. To improve the accessibility of the interview, photographs and visuals of the various issues were selected to show to the interviewees. The interview focused on the following issues: *their personal pathway* (in relation to education and training, employment and housing); *the home* (opinion of their current home, support received and barriers encountered, desired changes and view of potential for change); *participation in the community* (view of their current job, social relations and participation in leisure activities, view of support received and barriers encountered, desired changes and potential for change); *couple relationships* (view of their couple status, support received and barriers encountered, desired changes and potential for change); and *conception of independent living* (definition and understanding of the right to independent living).

The interviews were recorded and transcribed with participants' prior informed consent. A thematic content analysis was then performed based on the transcripts. The following 3 main issues were addressed: attitudes that hinder independent living, person-centered forms of support, and actions for improvement.

Expected outcomes

This study has contributed to determining the views and opinions of people with ID regarding their right to independent living. In relation to obstacles impeding their exercising of this right, people with ID highlight others' attitudes towards them. They consider that their families and professionals often overprotect them to the detriment of their personal goals. They also believe that people with ID experience fear when emancipating themselves from their family and this prevents them from making the leap to achieve their dreams. According to the

interviewees in our study, a lack of support and preparation are some of the causes of their fears and the overprotection they receive from their families.

As for support, people with ID want to be supported in their day-to-day lives without being prevented from developing their own autonomy. They ask to be allowed to make mistakes and learn from them like any adult. The type of residential service the person receives also conditions their independence. Personalized support is valued higher than group homes, as people with ID experience more control over their lives and personal growth with the former. The participants in our study all agreed that whatever the circumstances the person should always receive the unconditional support of their family and professionals should help them to achieve their dreams.

The main actions for improvement proposed by people with ID are a change of attitude by professionals, family members and also people with ID themselves. They also urge administrations to compensate for the inequalities they experience compared to the rest of society in exercising their right to independent living.

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