Tittle: *"Where to live and with whom": research on the right to independent living of people with intellectual difficulties in Spain*

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General description, objectives and theoretical framework:

On an international level, the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) represents a significant step in changing views of disability and a key instrument for advancing social and educational policies and practices (Shogren and Turnbull, 2014). Article 19 of the Convention establishes the right of all persons with disabilities to decide where they want to live and with whom, and to access support that allows them equal access to community resources. However, research shows that people with intellectual difficulties experience many difficulties exercising this right. Research conducted in the international arena over the past two decades indicates that although the community-based support model provides greater opportunities for social inclusion than the institutional model (Mansell et al, 2010), that quality of life improves for people with ID when they are offered support to live in their own community (Chowdhury and Benson, 2011; Young, 2006) and that this is the space in which people with ID usually prefer to live (Deguara et al, 2012; Inclusive Research Network, 2010), an imbalance exists between the support services for independent living (IL) offered to people with ID and their own aspirations and demands. The transition from institutional services towards providing personalized support on a community level is progressing very slowly, and both barriers at the level of training people with disabilities and inadequate support by professionals to help them live as they wish (Abbott and McConkey, 2006; Inclusive Research Network, 2010) are detected. Furthermore, particularities of life cycle may determine both the needs and specific responses to the demands of people with disabilities, meaning that support must be designed in a personalized manner taking into account the stage of life each individual is in (Shaw et al, 2011).

In order to make advances in the approaches to IL proposed by the CRPD, research is needed on barriers to the emancipation of people with ID on different levels and on the support required to help them achieve their life goals at various stages of their life. In this context, the aims of our study were:

1. To identify the challenges facing people in deciding where they want to live and with whom, and in accessing support that allows them equal access to community resources at different stages of their life cycle. These challenges may be in the institutional, political, social, curricular, cultural or family spheres.

2. To identify types of support in the various spheres that help this process.

3. To propose, based on the results obtained from the above, actions to be undertaken in the family and educational spheres, and social policies aimed at ensuring compliance with Article 19 of the CRPD.

The research was carried out in Spain, which ratified the CRPD in 2008 and where a new law (on the rights of people with disabilities and their social inclusion) was enacted in 2013 to articulate support for people with intellectual disabilities in accordance with the proposals of the Convention.

Method:

A qualitative methodology was employed to ascertain the perceptions and views of people with ID, their families and professionals linked to the different services that cater to adults with ID. The study was conducted in three phases. Each phase was designed to obtain information from one of the groups studied; different complementary methods were also used.

Phase 1. Qualitative study of the views of people with ID. Eight focus groups were conducted with self-advocacy groups. In total, 109 self-advocates participated in the groups. The use of focus groups facilitates interaction among participants, debate and comparing experiences (Krueger & Casey 2000). In the particular case of people with ID, focus groups also promote inclusion and empowerment (Kaehne & O'Connell 2010).

Phase 2. Qualitative study on the perceptions and views of families using focus groups. Five focus groups were conducted, with a total of 47 people participating in them.

Phase 3. Study of the perspectives held by professionals. This involved individual interviews with 45 professionals in order to obtain in-depth information regarding their views on the challenges and types of support involved in IL processes. The professionals had a minimum 10 years' experience in the field of study and worked in various support services for people with intellectual disabilities.

Informed consent was requested of all participants. The interviews and focus groups were designed to gather information on the following issues: evaluation of current support options, role of professionals, families and persons with disabilities themselves in defining support needs and deciding on life choices; the role of the organizations providing support for the transition to a community-based model; natural support networks; and perceived challenges in complying with Article 19 of the CRPD.

Interviews and focus groups were transcribed and then analysed using the thematic content analysis technique. Transcripts were analysed by combining structural and descriptive coding processes (Saldaña, 2013) based on a provisional list of codes for the above issues, which were expanded using descriptive codes arising from reading the transcripts. The data for each group (professionals, families and people with ID) were analysed separately. Finally, a triangulation process was conducted between the different groups of respondents.

Expected outcomes

One finding that stands out is people with disabilities demanding greater power in decision-making; although professionals point out that progress has been made in this area, they agree

with people with ID calling for greater empowerment. As for family members, fears regarding the risk of autonomy constitute the biggest barrier to emancipation for people with ID. All three groups agree on the important effect that stigma regarding disability still has on people with ID achieving their personal goals related to IL, value the different types of support provided for IL, such as the figure of personal assistant, and demand that social and educational policies ensure greater flexibility in services that facilitate personalized support.

The method used, which obtains the perceptions of families, professionals and people with disabilities, allows a general and comprehensive overview of the main challenges and factors involved in providing support for the life goals of people with intellectual disabilities. This, in turn, can be drawn on to propose improvement actions aimed at the different groups, as well as changes in organizations' social and educational policies in order to attain compliance with Article 19 of the CRPD.

Due to a methodological approach that analyses in-depth information provided by people with disabilities, professionals and families, this study contributes current and meaningful data on the situation of people with ID with regard to independent living in Spain, where this subject has received little attention from research. It also contributes to the international debate on barriers to compliance with Article 19 of the CRPD, as well as actions that may contribute to the advancement of this right.

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