
“Where to live and with whom”. Barriers to and supports for independent living from the viewpoint of advisors with disabilities.

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RESEARCH REPORT



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Accessible summary

- This report was written by a team of university researchers and an advisory committee working with them composed of people with learning disabilities. They work in Catalonia.
- The report is about where people with learning disabilities would like to live and with whom.
- The report presents the opinions of people with learning disabilities regarding the barriers facing them and the supports they need in order to live as they would like.
- This report also explains what people with learning disabilities ask for in order to be able to live as they would like.
- The report explains how the research was done and how the advisors and researchers worked together to write the report.

Summary (Abstract)

This report was written by a team of researchers who work at the University of Girona and an Advisory Committee that works with them composed of people with learning disabilities. They work in Catalonia (Spain). The report is about where people with learning disabilities would like to live and with whom. The report presents the opinions of people with learning disabilities regarding the barriers facing them and the supports they need in order to live as they would like. It also explains what people with learning disabilities ask for in order to be able to live as they would like. The report explains how the research was done and how the advisors and researchers worked together to write the report.

Keywords

Learning Disabilities, Independent Living, Advisory Committee, Inclusive Research



Who we are

The authors of this report are a **team of researchers** working at the University of Girona and an **Advisory Committee** composed of people with learning disabilities.

- **The university researchers** are part of a research group investigating disability. In 2012 we started a research on the transition to adult life of young people with learning disabilities². We wanted the investigation to explain the real problems facing people with learning disabilities in this process. For this reason, we thought it was important to work together with an Advisory Committee composed of people with learning disabilities so that they could help us in the research process³. After working together for the 2012-13 academic year, the advisors and researchers rated the experience very positively⁴. For this reason, we continued to work together on research. During the 2013-14 academic year, we asked the advisors to work together on research about Independent Living, and they agreed.
- We on **the Advisory Committee** are a group of people who meet with researchers at the university every month. We give ideas and some advice about several issues. During the 2012-13 academic year, we advised the researchers on research into transition to adult life. We gave our opinion and discussed the difficulties we face and the supports we have during the transition to adult life. We made some proposals to overcome these difficulties. During the 2013-14 academic year, there were 12 of us collaborating with the researchers on a research project about independent living. We are different ages and have different experiences. Some of us live with our family, others with home support and some in group homes. We discussed different life models. We gave our opinion about supports and barriers in independent living.

² This research was funded by MINECO (Government of Spain) through project EDU2011-22945, entitled: "The transition to adulthood and working life of young people with learning disabilities from an inclusive perspective: problem identification, good practices and proposal for a plan of action".

³ Working together with an Advisory Committee composed of people with learning disabilities is one of the ways for people with learning disabilities to collaborate in research, as other researchers have explained (Bigby, Frawley & Ramcharan, 2014; Walmsley & Johnson; 2003).

⁴ The research team explained it in the following article: Puyalto et al (2016).



How we wrote this report

Dissemination is essential in making known the results of research. The researchers and advisors worked together to produce this report during the 2014-15 academic year. It was written in the following phases:

1. During a meeting held in January 2015 the advisors, with the support of the researchers, produced a presentation explaining who we are, what we do and the summary of our experience since 2012.⁵
2. With the support of the researchers, the advisors explained the research at a Summer Course (July 2014) and a Conference on Collaborative Research (in May 2015). The audience was composed of professionals, students and researchers. In both cases, the researchers prepared the draft of the presentation. On the basis of this, we then agreed the structure, the images we wanted to use and fragments to comment on. We also made the two presentations together.
3. In April 2015, we prepared a poster explaining our research on independent living. The researchers prepared a proposal with the content structure and we jointly revised the texts on the poster to check that they were easy to understand. We then decided which images we wanted to use. We presented the poster at an international conference.⁶
4. The researchers prepared a first draft of the report based on the presentation document, the poster and the presentations at the Summer Course and at a Conference. The report includes quotes from this material. One of the researchers did some drawings to illustrate the different sections of the report⁷. The advisors and researchers discussed the draft together, agreeing on the content, structure and drawings.
 - a. The advisors were responsible for writing the description of the Advisory Committee (under the “Who we are” section) in the presentation document.
 - b. The Advisory Committee and researchers wrote the “How we did the research” section together, using the poster.
 - c. The researchers were in charge of writing the presentation of the research group under the “Who we are” section. They looked for other

⁵ See document in Advisory Committee and Research Group on Diversity (2015) (http://media.wix.com/ugd/fe33e0_cef4983a75a74812b96b74dd2c76890a.pdf)

⁶ See Fullana et al (2015) (http://media.wix.com/ugd/fe33e0_dfc5afd206934f9fad92a7bf4eda07c5.pdf)

⁷ Drawings were made by Carol Puyaltó, one of the Researchers.

studies for the section “Where to live and with whom”. They also prepared the discussion section by selecting texts from other studies where people with learning disabilities described their views on independent living. Using these texts, and taking into account the results of our own research, the advisors organized the content of the discussion section with the support of the researchers.

5. The researchers prepared the final version of the report, and an English translator translated it into English.



Where to live and with whom

Article 19 of the Convention on the Rights of Persons with Disabilities (UN 2006) states that all persons with disabilities have the right to decide where they want to live and with whom. It also says that they have the right to receive support to participate in the community.

However, research shows that people with learning disabilities have many difficulties exercising this right⁸.

In Spain, people usually receive care in institutions. Most people with disabilities live with their families or in residences or group homes. Alternative services based on the community are not common⁹. There is a need for detailed research on the difficulties and supports people with learning disabilities have so that they can live as they wish. To do this, we must start with their own experiences and opinions.

This report is based on research conducted during the 2013-14 academic year. The title was “Where to live and with whom” and its aim was to take a detailed look at the barriers and supports facing people with learning disabilities who want to lead an independent life.

⁸ See, for example, the studies conducted internationally by Inclusion International (2012) and the European Union Agency for Fundamental Rights (FRA) (2013).

⁹ See Verdugo, Jenaro & Campo (2009)

How we did the research

We did the research in 7 sessions over 9 months during the 2013-14 academic year. In these sessions, participants discussed independent living through various activities: watching fragments of films and documentaries, role playing, analysing case studies, discussion groups and photovoice. Both the University of Girona and MINECO (the Spanish Public Science Foundation) authorized the research. In accordance with the Spanish Psychological Society's ethical guidelines, the participants signed an informed consent document giving their permission to record the meetings. These recordings were later transcribed in full. The researchers took care to use plain language throughout the sessions and in the minutes of each session, as well as to provide accessible materials. Below we briefly describe what we did in each session.



In **Meeting 1** (14th November), the researchers and advisors decided to do research together.

In Meeting 1, we talked about our and others' experiences regarding independent living. A researcher wrote our ideas on a white board.

We considered different options. For example, living with your family is a good option if it is what you want:

“When there is a good relationship with the family it is possible to live together.”

“You can live with your parents and be independent, have your own things and do what you want when you want.”

“Being with the family has more advantages. You can organize yourself better and you're not alone.”

The advisors all agree that what is important is being able to choose and decide how to live:

“An adult person needs their own space”.

“Getting free from your family, with them not protecting us so much and supporting us more so that we can live independently.”

We also need economic resources:

“To be able to go and live in a flat with your partner you need to find work.”

And know how to manage money:

“To be independent you need to know how to manage your personal budget.”



In **Meeting 2** (12th December), we watched fragments of films and videos about different kinds of home support: residences, group homes, independent housing, family house. We discussed these options and agreed that:

- People should choose where to live and with whom
- The professionals working in the homes and group homes should foster the autonomy of the people who live there:

“The professionals should let the others do things or they will never learn.”

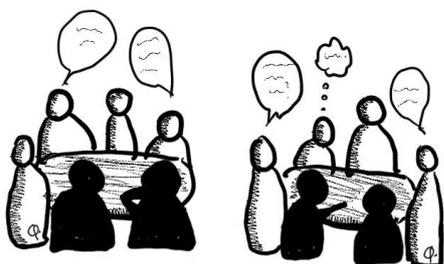
- Receiving support in your own home is greatly appreciated:

“The support person must be qualified to do this job. They must let people with learning disabilities do things for themselves, so they can learn how to do them.”

- How your family brings you up has a very important influence on becoming independent as an adult:

“Parents overprotect a lot”. “They can put obstacles in the way when you want to become independent”.

“It is important to be stimulated from an early age, not to be spoiled. The upbringing you receive from your parents is very important”.



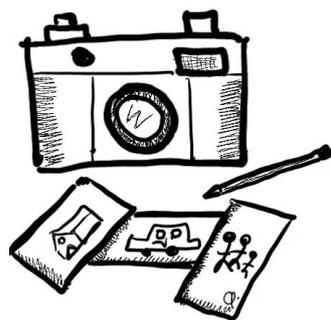
In **Meeting 3** (16th January), we had a discussion in small groups about different cases of people with learning disabilities wanting to live independently.

Two practical cases were presented. Each one explained a situation of someone who wanted to live more independently. One of them lived at home, the other in a group home (see cases and comments in Table 1).

Case	Comments
Case 1. Peter: Living at home <ul style="list-style-type: none">• 32 years old• He lives with his parents• He works part-time in a sausage factory• Peter has decided to explain to his parents that he wants to live independently	<p>“At that age it’s time to leave, his parents have to accept it”</p> <p>“He will need to know how to organize his life because then when his parents aren’t there he’ll know how to live alone”</p>
Case 2. Carol: Living in a group home <ul style="list-style-type: none">• 27 years old• She works in a sheltered workshop• She lives in a group home with 7 people• She wants to have more privacy and choose who to live with	<p>“She’s very young and there are too many people in the flat. She wants privacy. There’s a big difference between living with 7 or with fewer people”</p> <p>“If she’s independent enough and has enough money, she could live in a flat with a support person”</p>

Table 1: Cases and comments

Between Meetings 3 and 4, the Advisory Committee participated in a Training Course on Educational Research. We had some lessons on research from different university lecturers. We learnt how to do interviews, how to carry out focus groups and also to use drawings and photographs to obtain information. We were able to use this knowledge in Meetings 4 and 5.



In **Meeting 4** (29th May), we used pictures and drawings to discuss our ideas about living independently.

Using a focus group, we discussed/debated the barriers to and the supports for independent living (see Table 2: “barriers” and “supports” in next section).

In **Meeting 5** (12th June), we made proposals about things that could improve our independent living project.

We wrote the proposals on a white board and voted on the most relevant for us (see “proposals” in next section).



In **Meeting 6** (19th June) and **Meeting 7** (26th June), we worked together on the presentation for a summer course conference. We did the conference together. More than 30 professionals working in services for people with disabilities attended this conference.

Main contributions from the advisors about Independent Living

As a result of joint discussions throughout the year, we agreed on the main barriers experienced by people with LD to living as they would like. We also agreed on the supports that contribute to helping people with LD achieve their goals for independent living. Table 2 shows the results:

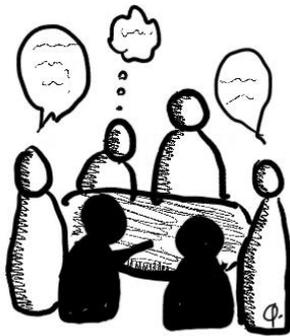
 Barriers	 Supports
<ul style="list-style-type: none"> • Mistrust from people about our potential • Overprotection from families and professionals • Dealing with the daily routine • Fear of leaving the family home • Lack of government financial aid and support to live independently • Sometimes professionals don't help in the right ways • Too much control 	<ul style="list-style-type: none"> • Family support and accompaniment • Receiving training from professionals who help us to be more independent • Support at work • Having enough money • Having friends • Having a partner • Having the opportunity to take decisions • The freedom to choose

Table 2. Results: barriers to and supports for independent living

On the basis of this analysis, the Advisors agreed what measures would help people with learning disabilities to make progress in relation to independent living. These are our proposals:

1. First, we ask for our voices to be heard and taken into account.
2. Second, we ask for opportunities to decide where to live and with whom. And also to create our own family. So we ask:
 - **Politicians** to help us to become independent: financial aid and more opportunities to choose where to live.

- **Our families** to let us take decisions and not protect us so much.
 - **Professionals** to not be afraid to talk to us on this subject. To give us the support we need to lose the fear of deciding.
 - **Professionals** and **researchers** to disseminate more good experiences to provide more knowledge about independent living.
 - Everyone: to let us make mistakes.
3. We all know that everyone is different, we ask that everyone receive support that is tailored to their own needs and wants.



Discussion

To compile this section we reviewed results from other studies on independent living. Below we explain what we found about barriers, supports and what people with learning disabilities want.

Barriers to independent living

In our research, we found that overprotection by families and professionals is a barrier to independent living. This coincides with the findings of various investigations involving the participation of people with learning disabilities (Abbott and McConkey, 2006; European Union Agency for fundamental Rights (FRA), 2012).

Another element that makes independent living difficult is that sometimes professionals do not provide the right kind of support, as explained by Abbot and McConkey (2006), McConkey et al. (2006) and IRN (2010).

Another barrier is the negative attitude towards the potential of people with disabilities. Participants in research by IRN (2010), the European Union Agency for Fundamental Rights (FRA) and McConkey et al (2006) also say this.

In addition, a major barrier hindering emancipation is the lack of self-motivation and confidence people with disabilities sometimes have. McConkey et al. (2006) also consider this issue.

Finally, the Government also puts obstacles because they don't provide enough options to decide where and with whom to live and they don't provide financial resources to help people with disabilities live their lives according to their wishes. This is also the finding of research by the European Union Agency for Fundamental Rights (FRA) 2012 and IRN (2010).

Supports for independent living

Regarding supports for independent living, our study participants think that both families and professionals are needed to provide support for independent living. Like the participants in the study by Abbot and McConkey (2006), we ask families to support people with disabilities to achieve the life projects they want.

The support of professionals is also very important in helping people with disabilities acquire the necessary skills to live in the community. The same result is found in research by Abbott and McConkey (2006), Deguara et al (2012) and McGlaughlin, Gorfin and Saul (2004).

Also, our study participants consider having friends an important support for independent living, as did participants in the research by the European Union Agency for fundamental Rights (FRA) 2012 and IRN (2010).

Receiving support to help freely make decisions about life choices is another finding which is consistent with previous research (Abbot and McConkey, 2006 and IRN, 2010).

Requests



The proposals / requests that we put forward in our research coincide with some recommendations from other studies involving participants with disabilities, whether advisors, researchers or informants.

Firstly, we request that the voices of people with learning disabilities are represented in the community and taken into account by politicians. This request is also made in Abbott and McConkey (2006) and Deguara et al (2012).

We also call for decisive action by the Government, which should help with concrete actions such as providing more houses to live in, grants for disabled people and decent wages that allow emancipation. Participants in the studies by Deguara et al. (2012) and the European Union Agency for Fundamental Rights (FRA) (2012) also called for this.

We ask families to change their attitude towards the potential of people with disabilities, supporting their life choices. This also appears in research by Deguara et al. (2012) and the IRN (2010).

As for professionals, the participants in our study and in research by the IRN (2010) ask them for support to help them lose their fear of making decisions about their lives.

Finally, as proposed in the research by Inclusion International (2012) and the European Union Agency for Fundamental Rights (FRA) (2012), we call for personalized support, tailored to each person's needs and desires and in accordance with what they choose for their life.

As the advisors and researchers in this study, we are satisfied with having worked together on research which may help to identify supports and resources to improve the life experiences of people with disabilities. We are even more satisfied still that this partnership we have established is a step, however small, towards making the words of Deguara et al. (2012: 127) a reality: "It is important that other people see us and value us positively. People should not ignore or pity us. They need to get to know us better and learn that we are like anyone else".

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