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## A community living experience: Views of people with intellectual disability with extensive support needs, families, and professionals

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### ABSTRACT

**Background:** Despite the benefits of community living for people with intellectual disabilities (ID) and extensive support needs, they remain highly institutionalized.

**Aims:** To qualitatively analyze the perceptions of people with ID, including those with extensive support needs, professionals, and family members six months after the implementation of 11 community homes for 47 people in different regions of Spain

**Methods:** Thematic analysis of 77 individual interviews conducted with 13 people with ID, 30 professionals and 34 family members was performed using Nvivo12.

**Results:** Seven themes were found: (1) “the room as I like it”, (2) “sometimes I don’t obey”, (3) “here I do a bit of everything”, (4) “lots of people love me here”, (5) “all thanks to them, who have helped me” (6) “I miss my mom”, and (7) “I’m happy here”.

**Implications:** Transitioning into the community has shown a clear positive change in emotional well-being, opportunities to participate in activities or exercise control over one’s life. Nevertheless, certain restrictions were still present in people’s lives, which significantly limit their right to independent living. While many of these restrictions may disappear, professional practices typical of a medical model can be recreated in services located in the community.

### What this paper adds?

In Spain 32,760 individuals with ID remain institutionalized, and half of them require extensive support.

Perceptions of people with ID about their living environment, especially of those who experience extensive support needs, have been frequently omitted in previous studies.

This paper analyzes the experiences of people with extensive support needs, family members and professionals after the move of 47 people with ID to community homes.

The study takes a rights-based approach to disability, situating the voice of disabled people at the centre of the analysis. The qualitative analysis conducted identified positive experiences in relation to well-being, participation, and control over one’s own life as well as limitations to independent living, such as the recreation of institutional cultures in community-based services. The experiences reported here indicate an overall improvement in people’s lives, however, the voices of people with intellectual disabilities are critical

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to assess any restrictions to full participation in the community and to independent living.

## 1. Introduction

The provision of supports in community settings is associated with important improvements in the quality of life of people with ID (Gómez et al., 2021; Verdugo et al., 2021), such as social inclusion and community participation (e.g., Bigby et al., 2017; Linehan et al., 2015; McConkey et al., 2013), interpersonal relationships (e.g., Duggan & Linehan, 2013; Felce et al., 2008; McConkey et al., 2016; Salmon et al., 2018) or decision-making (e.g., Bigby et al., 2017; Linehan et al., 2015; McConkey et al., 2013, 2016; Sáenz, 2018; Stainton et al., 2011). However, despite the benefits of community living, there has not been a substantial reduction in the number of people with ID who remain institutionalized across Europe in the last decade (Šiška & Beadle-Brown, 2020, 2022). In Spain, although the first steps toward deinstitutionalization have been taken, 32,760 individuals with ID remain institutionalized (Verdugo & Jenaro, 2019), half of whom require extensive support (Verdugo & Navas, 2017).

People with ID who require more intensive support, either because of additional physical or sensory disabilities or because of the presence of other behavioral or mental health disorders (Verdugo & Navas, 2017), frequently experience greater social exclusion and poorer quality of life (Lombardi et al., 2016) as a result of often being forced to live in segregated settings.

The insufficient implementation of deinstitutionalization processes for this group is in part due to the existence of numerous barriers that limit or hinder their inclusion in the community. For example, the mistaken belief that independent living means to live on one's own with complete autonomy (Committee on the Rights of Persons with Disabilities [CRPD], 2017); infantilizing attitudes toward those with greater support needs (Björnsdóttir et al., 2015); and resistance from relatives and professionals when it comes to initiating deinstitutionalization processes for those who require extensive supports (Bowey et al., 2005; Jones & Gallus, 2016; Pallisera et al., 2017). However, living in community settings has been associated with improvements for this group as regards adaptive behavior (Bigby et al., 2012), self-determination (Bigby et al., 2018; Young & Ashman, 2004), interpersonal relationships and participation (Bigby et al., 2012), and overall quality of life (McCarron et al., 2019; Young & Ashman, 2004). In fact, the studies by McCarron et al. (2019) and Young & Ashman (2004) reported that people with ID and greater support needs benefitted more from the transition to community than those whose needs were less intensive.

Given the improvements in personal results that living in the community entails for this group, it is necessary to engage in deinstitutionalization processes, as Spain was urged to do in the latest Report on the Rights of Persons with Disabilities (CRPD, 2019). However, such processes should not be limited to relocating the person to a different sized or elsewhere located service that reproduces the cultural patterns of an institution. To prevent this from happening, it is essential to adequately plan the transition to the community by properly accompanying professionals so that they may provide active support, focused on the person, and relinquish the traditional care role (Bigby et al., 2014; García Iriarte et al., 2016; Hostyn et al., 2011; Netten et al., 2010; Pallisera et al., 2018).

Families also play an important role in deinstitutionalization processes and may become either facilitators or barriers (Pallisera et al., 2017; Puyaltó & Pallisera, 2020). Although research results suggest that families are more satisfied once their relatives are in community settings (Jones & Gallus, 2016; Kozma et al., 2009), they may require additional support to progress from initial opposition to change toward the ultimate satisfaction that comes from their relative living and participating in the community.

The relevance of the role played by professionals and families fostering independent and community living for people with ID has led to a variety of studies on their perceptions regarding deinstitutionalization processes. However, the voices of people with ID are rarely heard, especially when they have extensive support needs (Abbott & McConkey, 2006; Björnsdóttir et al., 2015; Salmon et al., 2018).

Priority should be given to knowing the vision of people with ID as informants of their own lives because their perceptions provide the best descriptions of their quality of life, and it may not coincide with that of professionals and relatives (Chowdhury & Benson, 2011; Verdugo et al., 2014). People with disability should be consulted and allowed to play an active role in decision-making, especially when related to processes aimed at fostering their independence and autonomy (UN, 2006). Moreover, when they are given the chance, they provide solutions that should be taken into account to ensure satisfactory deinstitutionalization processes (Björnsdóttir et al., 2015; Bowey et al., 2005; García Iriarte et al., 2014; Pallisera et al., 2017).

Therefore, the purpose of this study is to qualitatively analyze the perceptions of people with ID, including those with extensive support needs, professionals and relatives six months after initiating a deinstitutionalization process for 47 people in different regions across Spain. Individuals with ID moved to 11 housing units, which were part of a pilot project aimed at generating learning about independent and community living support processes. Throughout this project, seven service providers facilitated people's move into a new community living context, seeking to allow the person to decide, providing any support that might be required, and focusing each relocation on the person and their family's needs. These processes were combined with intensive training for support professionals in methodologies aimed at fostering inclusion in the community, such as active support, positive behavioral support or person-centered planning.

This general aim can be operationalized in the following specific objectives:

- 1) To analyze, from a qualitatively perspective, possible changes in the life conditions of people with ID and their families after transition to community settings.
- 2) To delve into facilitators and barriers to community living.
- 3) To explore factors to be improved in processes aimed at fostering community living.

## 2. Method

Qualitative research is used to gather and understand a variety of perspectives, seeking to establish patterns of what people do or think and examining the implications of such patterns. Besides standing out for their higher ecological validity, qualitative designs can yield unexpected and emerging effects due to the fact that they are focused on learning about people's experiences rather than on testing predetermined hypotheses (Patton, 2015). Qualitative methods are contributing to scientific research on the quality of life of people with ID by taking into account their experience (Beail & Williams, 2014; Smith et al., 2009).

### 2.1. Participants

A total of 77 individual interviews were conducted. This study analyzes the experiences of 13 of the 47 people who moved to the community who, although limited, had enough ability for using spoken language to facilitate their participation in the interviews. Additionally, 30 professionals who supported them and 34 relatives were also interviewed. Out of the potential 47 relatives or legal guardians, only 34 were included, since some declined to participate for a variety of reasons such as a poor relationship with their relative, lack of interest in the study or unavailability.

Regarding participants' characteristics, 64.6 % presented severe or profound intellectual disability; more than half (57.4 %) had another co-occurring disability, and 70.2 % had chronic health conditions. Also, according to participants' medical records prior to their transition, mental health problems were frequent in the sample (44.7 %), being the most prevalent uncooperative behaviors (84.6 %), withdrawal or inattentive behaviors (76.9 %), and disruptive (69.2 %), stereotyped (61.5 %) or socially offensive (61.5 %) behaviors. These percentages are similar to those reported by Verdugo and Navas (2017) in a study carried out in Spain about people with ID and extensive support needs.

#### 2.1.1. People with intellectual disability

The 13 people with disability (7 men and 6 women) were adults between the ages of 23 and 57 ( $M = 42.77$ ;  $SD = 12.29$ ) who had moved six months earlier into a community-based accommodation. Before the move, four of them lived with their families (although they were depended on other disability related services) and the other nine lived in residential institutions (ranging from 10 to 43 places), with a history of institutionalization ranging between 4 and 23 years ( $M = 12.22$ ;  $SD = 7.26$ ). At the time of the data collection, only two people were working in ordinary settings. According to the professionals interviewed, all the participants required extensive support to live in the community, either because of their intellectual disability or because of the existence of physical limitations or mental health or behavioral issues and environmental barriers.

#### 2.1.2. Professionals

The 30 professionals who were interviewed (86.6 % women), with ages between 21 and 53 ( $M = 35.27$ ;  $SD = 9.17$ ), provided support for one or several of the 47 people who initiated the transition to community-based living arrangements. Most of them (93.3 %) were professionals providing direct supports and 25 % were newly hired staff. The majority were trained or had training in positive behavior support (80 %), active support (76.7 %), and person-centered planning (70.0 %).

#### 2.1.3. Families

The ages of the 34 relatives were between 26 and 79 ( $M = 53.32$ ;  $SD = 13.87$ ). Out of these, 17 were parents of the person with disability, 12 were siblings, and the remaining five were other relatives or legal guardians. Eleven families were matched to the 13 people with ID who took part in the study.

### 2.2. Instrument

Since the purpose of moving to the community is to achieve significant changes in participation and quality of life, and because of the need to gather information about the barriers experienced, the following questions were addressed to relatives and professionals (a) "What aspects do you think are especially relevant to achieve (person's name) inclusion in the community?"; (b) "In your opinion, what challenges are you facing along the process?"; (c) "What dimensions of his/her quality of life do you think are being positively influenced after the change of accommodation?".

For people with ID, an open-ended structured interview was designed. This format was chosen to ensure that questions were consistent across different accommodations and thus favor comparability. The preliminary version of this interview was reviewed by an expert in easy-to-read-texts and by a person with ID, both of whom suggested certain changes aimed at ensuring greater cognitive accessibility. Once the changes had been included, the interview was reviewed and validated again. As an example, some of the questions included were "tell me about where you live", "tell me about the rules and timetables at home" or "tell me about the professionals who help you" (see the complete interview in Appendix A).

### 2.3. Procedure

The interviews were conducted by the first author six months after the person's relocation, either at their new accommodation or at the headquarters of the support-providing organization. The interviews were carried out individually with each participant and lasted between half an hour and two hours. The presence of a support professional during the interview to facilitate communication was only

necessary in three cases.

Informed consent was obtained from all participants, consent being also asked to their legal guardians when necessary. Ongoing consent into the study was sought during the entire data collection process as recommended by Maes et al. (2021).

Interviews with relatives and professionals were audio recorded. In the case of people with disability, because of communication difficulties, answers were literally registered on paper during the interview to be later transcribed. All names were replaced with pseudonyms or pronouns, and names of cities, residences or streets were removed.

The procedure described above was approved by the Bioethics Committee of the University of Salamanca (2019).

#### 2.4. Data analysis

An inductive thematic analysis was performed. After reading the information gathered from the interviews and identifying the main topics without trying to fit them into a preliminary coding scheme, the six phases suggested by Braun & Clarke (2006) for processing information in a thematic analysis were used: 1. Become familiar with the data, 2. Generate initial categories or codes, 3. Search for themes, 4. Review themes, 5. Define and name themes, and 6. Produce the final report.

The interviews were conducted, manually transcribed and analyzed by the same person, which allowed greater immersion and understanding of the data (Patton, 2015). Nonetheless, being aware that qualitative research is influenced by the researcher's position, the analyses and codebook were regularly reviewed and discussed with another author (Patton, 2015). The analysis was entirely performed using Nvivo 12 software.

#### 2.5. Researcher's position

The study was carried out adopting a phenomenological approach, which involves learning about participants' experiences and influenced by a human rights model of disability which seeks to place the experience of people with disability at the center. This is why, throughout the results section, priority has been given to the voice of people with disability regarding their experiences when labeling the themes, preserving their own words.

### 3. Results

The interviews with people with disability, professionals and relatives yielded the following seven main themes, which will be developed in the following sections: (1) *"the room as I like it"*, (2) *"sometimes I don't obey"*, (3) *"here I do a bit of everything"*, (4) *"lots of people love me here"*, (5) *"all thanks to them, who have helped me"* (6) *"I miss my mom"* and (7) *"I'm happy here"*.

#### **Theme "the room as I like it"**

One of the main topics drawn from the analysis was the importance of feeling at home in the new accommodation. For the people with disability who took part in this study, the new house needed to be pleasant. One of the characteristics they mentioned was size. However, while professionals and relatives mentioned that it was a smaller house as regarded space or number of places available as a positive aspect, people with disability stated that they liked the new dwelling because it was very large, perhaps because they felt that they had more room for themselves.

"It's a bit cold, but it's large" (Belén, 33 years old, person who formerly lived with her family).

"I think that, at the physical level, being in a smaller house allows him to use the elevator, to use the shower chair longer or whenever he wants to because it's available. That has improved, indeed" (Juan, 21 years old, professional).

In their new dwelling, people with disability had personal space, generally their bedroom, where they could enjoy privacy, as well as keep their things.

"I've got a TV (...) I've got all sorts of stuff (...). And here I can have, look, the room as I like it. There was [at his room in the residential setting] only a poster and two pictures of my family, and look at all I've got here (...) What I like the most is that the center is near" (Ramón, 47 years old, person who had spent five years in several institutions).

The participants spoke about the importance of the house being in a central place with services. Apart from location, families and professionals noted the importance of the surrounding's accessibility, both physical and cognitive, which may be an issue in an ordinary building.

"Access to the flat is a bit difficult, between a lamppost and some gardens, the chair... we find it hard to take her" (Josefa, 79 years old, mother of a person with cerebral palsy).

#### **Theme "Sometimes I don't obey"**

Another topic of great relevance was the freedom to decide and exercise control over their own life.

First, only some of the people with ID affirmed that they had been consulted about the move, although they all expressed that they were happy with the change of residence. Some of the people did not choose their housemates either, which, in some cases, gave rise to difficulties in day-to-day coexistence.

“I don’t want to live with Charo, because she jumps on the chairs. I would like to live on my own and without Rosa because when I’m sick I can’t stand anyone and they don’t let me sleep. But Elena is good” (Laura, 55 years old, person who has lived in a nursing home for 22 years).

After changing their place of residence, most of participants started making more decisions about certain aspects of their lives. They showed less dependence on routines and more freedom to go out and spend their money as they wished. However, certain decisions, especially related to leisure activities in the community, were not always based on individual choice but on group consensus and on the availability of professional support. Although there were improvements in decision-making as compared to their former living environment, there were rules (especially associated with timetables or tasks) that still limited the interviewees’ freedom to live independently.

“Of course... sometimes I don’t obey. Going to bed (...) I always want to stay [awake] a little longer. I have to be at home at a certain time. And if I’m out fishing I don’t want to come back, I want to go on and on because it’s a sport I like a lot (...) And before [in the former living environment] they wouldn’t let me do anything (Daniel, 24 years old, person who has spent six years living in different institutions).

#### **Topic “I do a bit of everything here”**

Both those who used to live with their families and those who lived in an institution used to spend long terms of inactivity before the transition. After moving into the community, people with ID enjoyed more opportunities to learn and develop new abilities, especially those related to household tasks, self-care or social skills, which was reflected in an increased participation in several areas of their lives, including those where they required more intensive support, such as employment.

“I didn’t use to go fishing before, I didn’t leave to go anywhere, I would only sleep. Here I do a bit of everything and I go to the mechanics’ workshop, I mend things, I like it” (Daniel, 24-year-old person who has spent six years living in different institutions).

Professionals and relatives stressed the importance of the person being allowed to choose the activities they were to participate in, of small groups to facilitate participation in leisure activities in the community and of a good selection of accessible activities in the district or city.

“She now goes to work, gets up in the morning, makes her bed, makes coffee and dresses, gets ready. That has definitely improved. She didn’t do it before, now she does. This is a remarkable thing for this person. (...) So I think the city council should provide support to arrange more activities for these people.” (Mamen, 45 years old, mother of a 23-year-old person who formerly lived in the family home).

“Being a smaller group, she is enjoying leisure more because a van or other means of transport can be used for moving around. Before, since there were so many, it was sometimes a bit unfeasible. They would always go to the same places and now she has a wider range of leisure activities.” (Susana, 29 years old, professional working with Isabel).

As regards participation in the community, and since the interviews were conducted in the post-pandemic period, participants mentioned that COVID-19 had negatively impacted their lives due to the reduction of activities and social contact.

“Before, one could go to the bar, now one can’t because of the virus, to have something to eat, meet people and talk face-to-face.” (Dolores, 57-year-old person who has spent seven years in a nursing home).

#### **Theme “Lots of people love me here”**

Inclusion in the community is not limited to taking part in activities and requires sustaining mutual relationships with other people, feeling accepted and loved.

“And I go to mass every Sunday because I get on very well with the priest. Lots of people love me here” (Ramón, 47-year-old person who has spent five years living in institutions).

Relatives and professionals agreed on the importance that the people expand their social circle, but reported that it is sometimes difficult due to society’s negative attitudes, which is why professionals are to play the role of “social connectors”. However, even well-intentioned professionals occasionally displayed patronizing attitudes, taking for granted that they know what is best for people with ID, or even describing as “normal” relationships only those with people without disability.

“I go to visit my friends in the countryside, he comes... I also see that he socially has not only the relationships he has here at the center, because I think that they’re what he desires: normal relationships.” (Elvis, 39-years-old professional working with Daniel).

Finally, some people with disability expressed the importance of privacy and others their desire to live as a couple, even those who were not in a relationship at the time. No professionals took these aspirations into account and only one relative made some comment in this regard that reflected an attitude that denied, as well as the right to live independently, the right to decide over issues related to personal relationships, marriage, family and parenthood, which are covered by article 23 of the CRPD.

“I would like to meet more [people] and find myself a girlfriend and live with her. I would be the happiest man in the world.” (Israel, 54-year-old person who has spent 23 years living in a nursing home).

“Living in a house alone, we don’t think so, with their partner, no. But it would be alright to share with other boys.” (Francisca, 71 years old, mother).

**Theme “All thanks to them, who have helped me”**

The change towards living in the community involved performing many tasks, some of them completely new. In certain cases, people would only require little support to carry out activities that they already knew how to do, while in others the professionals taught them to perform the new activities on their own.

“And I now know everything. I know how to mop the floor, load the dishwasher, hang out the laundry and all sorts of things. And shower, since I didn’t know how to shower. They used to shower me at \*the nursing home\* . I now know how to shower on my own. All thanks to them, who have helped me. Since I had never done it. If it wasn’t for them, I couldn’t do those things.” (Guadalupe, 43-year-old person who has spent four years living in a nursing home).

However, there were families who considered that professionals should perform these basic tasks *for* the people rather than *with* the people. Besides, such families were more focused on emphasizing the importance of support in dietary and hygiene activities, of a more welfare-oriented nature.

“So they feed him, he’s fine. Like a child, while he is fed and clean, he is happy, if you know what I mean.” (Amelia, mother, 75 years old).

Other families had a way of understanding their children’s lives that was the exact opposite. They viewed it as full of possibilities and regarded support as a fundamental aspect to achieving such full-filling life, which is why certain staff continuity was positively valued. The continuity would allow them to understand the interests, preferences and needs of each person.

“It must be sensitive people and, above all, people who respect his likings, his preferences, who know him well and treat him like an adult at all times. When support works, everything else works, both at home and in the community, at the daycare center, everywhere. For me, it’s much more important that he be accompanied by someone who knows how he is and who is willing to have fun with him than the activity itself.” (María Jesús, mother, 59 years old).

Professionals and relatives regarded this type of person-centered support as possible when ratios dropped, but they often considered that there was no funding available. None of the people with disability made any comments in this respect, which could mean that these aspects were not important to them or that they did not participate in decisions related to the selection or management of their support people.

“Almost all the difficulties have to do with economic and funding issues... [At the beginning] It was very hard because support couldn’t be funded 24 h a day.” (Cristina, 28 years old, professional working with Israel).

**Theme “I miss mom”**

Family relationships were important to many of the people with ID who were interviewed. Likewise, professionals stressed the relevance of taking care of family ties in the transition process, since relatives are an important source of emotional and material support. Some relatives and professionals also emphasized the importance of good family-service communication and coordination to better meet the person’s needs. While most families maintained frequent contact with the person, some mentioned that the dwelling’s location, their age or other duties, as well as certain restrictions that still existed in the person’s home (such as visiting hours), prevented them from visiting their relatives as often as they would like to.

“I find it hard to get there by transport and, well, you can’t always go whenever, right? That is, there’s a timetable from 5 to 7 in the afternoon, then, mm, well I can’t go at noon or whatever, I can’t say: well, it suits me better now.” (Josefa, mother, 79 years old).

Some people with ID who had so far lived with their family found separation difficult.

“I miss mom” (Fernando, 38-year-old person who used to live in the family home).

While professionals were aware of this difficulty, many families mentioned that they were the only ones who suffered such separation.

“We thought he would miss his home more (...)the thing is that he sees this as his home, which would be more difficult in a nursing home. So we thought that he would miss us more and he hasn’t, but that’s a great relief” (Ana María, 60 years old, Fernando’s mother).

On the other hand, many of the families experienced fears and concerns at the beginning of the process. Their main concerns were associated with adaptation to change and poor attention due to staff shortage or inexperience. Despite these initial fears and concerns, all the families agreed that the change had been positive both for the person with disability and for the entire family, noting that they were now more at ease and enjoyed a greater quality of life.

“The benefit automatically transfers to the family, when he is fine, the rest of us are fine. Keep in mind that he is a person with behavioral disorders; perhaps the rest of the boys don’t have that. The entire family’s quality of life improves with the relief it brings” (María José, mother, 53 years old).

### Theme “I’m happy here”

After relocation to the new dwellings, there was an improvement in the people’s wellbeing, both physical and emotional. As regards emotional wellbeing, some people mentioned that they were in a better mood and calmer.

“At the nursing home I was worse. I’d go to bed and wouldn’t get out, I didn’t listen to the instructors, I didn’t like the things I did. Twelve years I’ve spent at the nursing home. I’m happy here (...) I’m calmer and less nervous, safer.” (Javier, 56-year-old person who has spent 13 years living in a nursing home).

According to families and professionals, this greater tranquility materialized in a reduction of problematic behaviors, which they find very relevant, since they regarded these behaviors as one of the main obstacles to inclusion. The improvement in wellbeing was sometimes accompanied by benefits at the physical level, improved sleep, lower medication intake and an increase in physical activity.

“I already told you before that she had stopped taking the medication that she used to regularly take, for constipation, for example, because she is physically more active. Insomnia has disappeared. Vitamin D deficiency, we don’t know very well how it is related to all this, but... analytics say so. As for health, we have had to stop giving her a lot of the medication she used to take. She no longer needs it. Wonderful. Rest. She can rest again. She takes a nap after lunch, sleeps right through the night.” (Adriana, 50-year-old professional).

Finally, one family pointed out the still existing barriers for people with intellectual disability to access healthcare services, such as, for example, professionals’ lack of knowledge or long waiting times.

“Doctors in general don’t know much about autism, you must keep explaining, they don’t know what to do, I’m faced with many barriers with that issue [...] I say that he shouldn’t wait because he gets nervous and that causes a problem, but lots of times they don’t take it into account.” (Raquel, mother, 65 years old).

## 4. Discussion

A central aspect of independent living is the ability to choose and exert control over one’s own life (UN, 2006). In this research, after moving into community-based accommodations, participants exhibited an increased participation in decision-making, which is consistent with studies where independent living has been shown to improve self-determination (Bigby et al., 2017; Felce et al., 2008; Linehan et al., 2015; McConkey et al., 2013, 2016; Sáenz, 2018; Stainton et al., 2011), including that of those who have greater support needs (Bigby et al., 2012; McCarron et al., 2019; Young & Ashman, 2004). Nevertheless, such decisions seem to be restricted to certain aspects of their lives, a feature that is characteristic of institutional settings (CRPD, 2017). First of all, some of the people had not decided where or with whom to live. This result, also reported by Salmon et al. (2018), could respond to the fact that many of the people had their legal capacity restricted or removed, their families or legal guardians being, despite the stated in article 12 of the CRPD (UN, 2006), the ones to make this kind of decisions. Given the recent legal reform that was implemented in Spain in 2021, in which restriction or deprivation of legal capacity was replaced by a decision-making support process, it is to be expected and desirable that, in line with the CRPD, people with disability may begin to exercise greater control over these central aspects of their lives.

On the other hand, the results of this study show that control over daily activities is partly conditional on the choices of the cohabiting group or the availability of support. As also observed by Koritsas et al. (2008), the support staff is also limited in terms of offering real opportunities to choose, since there are many issues that do not directly depend on them. Besides, as already stated by Pallisera et al. (2017), it would be necessary to rely on more professional resources to undertake real work for inclusion in the community.

As in the study of Bigby et al. (2012), people’s participation in activities increased, both at home and in the community. Nevertheless, and as also observed by Abbott & McConkey (2006), relatives and professionals noted the need for a broader choice of accessible activities in the community.

Together with participation in activities, the development of reciprocal relationships is also important. Although participants increased their contact with other people in the community, it is still hard for them, because of society’s attitudes, to develop significant relationships, as also noted by Jahoda & Markova (2004). The findings of this and other studies (Bigby & Beadle-Brown, 2016; McConkey & Collins, 2010; Power, 2013) indicate that professionals should act as social connectors to make it easier for people with disability to expand their social circle, which, in most cases, is limited to their housemates and family.

Independent living does not mean being able to do everything autonomously, but choosing, deciding (CRPD, 2017) and relying on adequate support to accomplish it. Understanding this is key to ensuring that people with extensive support needs is not excluded from experiences aimed at promoting community living. As regards the preferences of the people about what such support should consist of, and in line with the findings of previous studies (Bigby & Beadle-Brown, 2016; Garcia Iriarte et al., 2016; Pallisera et al., 2018), the most outstanding are that professionals know them well, listen to them and understand them, have a good relationship, have fun, and that they help them to learn and do things on their own rather than doing the tasks for them. This last aspect is also emphasized by other researchers, who suggest that the role played by professionals should be aimed at support rather than care, which could be achieved using methodologies such as active support (Abbott & McConkey, 2006; Karban et al., 2013; Pallisera et al., 2018).

The results of this study reveal the importance of families as a source of emotional and material support in processes aimed at promoting independent and community living. Some authors note that family relationships may be altered after the change in dwelling due to reasons such as parents’ age or distance between houses (Kozma et al., 2009). In this study, certain families mentioned distance or visiting hours as the main barriers to keeping in touch. Despite this and the fact that some people found the separation difficult at

first, most participants in this study did not mention any weakening impact on their social networks or the feelings of loneliness noted by other authors (Bigby, 2008; García Iriarte et al., 2016; McCarron et al., 2019, 2017).

Transitioning to a dwelling in the community not only has an impact on the life of the person with disability, and it is therefore necessary to work from a family-centered perspective that considers the difficulties that families may experience during such processes. The difficulties mentioned by relatives, which are very similar to those reported in previous studies (Bowey et al., 2005; Jones & Gallus, 2016; García Iriarte et al., 2021; Owen et al., 2015; Pallisera et al., 2018; Roos & Søndena, 2020) were pain because of the separation and concern about aspects that were especially related to support staff or to adapting to the new living environment. Nevertheless, this type of process benefitted the families' quality of life by promoting greater relief and respite, as observed in this and other studies (García Iriarte et al., 2021; Jones & Gallus, 2016).

Whereas the results of previous studies on behavioral disorders and deinstitutionalization are contradictory (Perry et al., 2011), in this project, having a smaller number of people sharing their living space generated a calmer atmosphere that proved beneficial to all the participants, increasing their emotional wellbeing and, according to the professionals, reducing the frequency of challenging behaviors. Future research should explore how community living contributes to reducing problem behaviors with a particular focus on how professional practice contributes to possible changes in these behaviors such as reduction of restrictive practices and increase in positive behavior support, practice leadership or active support in community settings.

Finally, families stressed, as on other occasions (Navas et al., 2019), healthcare professionals' poor knowledge about people with ID and the necessity to increase flexibility in the healthcare services in their community to adapt the provision of care to their needs. These barriers to accessing healthcare in community settings could be an obstacle to deinstitutionalization processes, so future research should explore this aspect further.

One of the strengths of this study is the use of a qualitative approach, which has afforded the possibility of discovering results that were unexpected in this independent living experience (Patton, 2015), such as the limited control that the people have over where they live and whom with, or over certain activities of daily living, but also unexpected positive results after only six months from the relocation, such as reported improvements in physical and emotional wellbeing. Moreover, this study responds to the need to understand the frequently overlooked view of the people with ID with extensive support needs themselves, as well as that of relatives and professionals (Björnsdóttir et al., 2015; Parrilla & Sierra, 2015). Nonetheless, it has certain limitations that should be addressed in future studies. One such limitation is that, while participants with disability had extensive support needs, only those who were capable of minimum speech were interviewed. Future studies should include methods that can also gather the perspective of people with a complete absence of verbal communication using ethnographic or creative approaches that include interaction among the researcher, the person with extensive support needs and other people who may be significant to the latter (Maes et al., 2021; Simmons & Watson, 2015). The variety of situations registered in the study (people coming from the family home or from different types of institutions) could be regarded as another limitation. Nevertheless, this has meant obtaining a broader variety of results that, because of the nature of qualitative design, contribute to the study's richness and quality (Tracy, 2010). Finally, it should not be forgotten that the results were assessed only six months following the move, so it would be convenient to monitor and assess the situation for a longer period using other complementary techniques and measures.

## 5. Conclusions

The findings show a clearly positive change in emotional wellbeing, opportunities to participate in activities or exercise control over one's own life that indicates that living in supported housing inside the community significantly enhances the quality of life of those who have greater support needs.

Despite being positive results, they could be improved, especially in areas such as social inclusion or decision-making over aspects that are generally managed by organizations or families, such as choosing where to live and with whom, or the selection and hiring of support staff. Likewise, certain restrictions that are still present at home such as timetables or monitoring of visits, noticeably limit the right to independent living. It should not be forgotten that the institutionalizing culture can be recreated in smaller services located in the community through professional attitudes and practices (Linehan et al., 2015). It is essential to assess whether these community services really offer the necessary support to meet the aspirations of truly independent living. In this regard, the Quality of Life Supports Model (Gómez et al., 2021; Verdugo et al., 2021) provides a robust and professional theoretical framework for support delivery, person-centered assessment of results, organization transformation and system change that can be used to align a person's support needs with individualized support strategies, and establish parameters for person-centered assessment.

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## CRedit authorship contribution statement

**Laura Esteban:** Writing – original draft, Methodology, Data curation, Formal analysis, Investigation. **Patricia Navas:** Project manager, Conceptualization, Methodology, Data curation, Writing – review & editing, Supervision. **Miguel Ángel Verdugo:** Project Manager, Writing – review & editing, Supervision. **Edurne García Iriarte:** Methodology, Formal analysis, Writing – review & editing. **Victor Arias:** Methodology, Writing – review & editing.



## Declarations of interest

None.

## Data Availability

Data will be made available on request.

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## Appendix A. Interview for people with intellectual disability

Question
Tell me about where you live
Do you like where you live?
What do you dislike about where you live?
Do you like where it is? Why?
Do you like your room? Why?
Did you choose to live in that house?
Would you like to live in a different house? Why?
Do you like the activities that you carry out during the day? Why?
Do you choose the activities you carry out?
Would you like to do other different activities? Which ones?
At home, you live with other people,
Are you happy with them? Why?
Would you like to live with different people? With whom?
Tell me about the rules and timetables at home.
Are you happy with them or not?
Tell me about the workers who help you.
What do you like about the workers who help you?
What do you dislike about the workers who help you?
To carry out activities in your district or city like others do (for example shopping, going to the cinema, going to bars), do you need help?
What do you find hardest?
What things have improved in your life since you've been living in this house?

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