Title: *Being in control*: choice and control of support received in supported living. A study based on the narratives of people with intellectual disability and support staff.

Authors: Maria Pallisera (*), Montserrat Vilà (*), Judit Fullana (*), Maria-Josep Valls (**)

(*) University of Girona, Institute of Educational Research. C/Pl. St. Domènec 9, 17004 Girona, (Spain)

(**) University of Lleida (Spain)

Corresponding author details: Maria Pallisera, Institute of Educational Research, University of Girona, C/Pl. Sant Domenec, 9, 17004 Girona, Spain.

E-mail: maria.pallisera@udg.edu

Being in control: choice and control of support received in supported living. A study based on the narratives of people with intellectual disability and support staff.

Background. This research aims to study the role of people with intellectual disability in taking decisions regarding the support provided under the supported living model.

Method. Interviews were conducted with thirteen people with intellectual disability, and six support professionals with experience working in organizations offering personalized support. These covered the person's pathway, the support received, and their role in controlling this. Interviews were recorded and transcribed, and the data analysed through thematic content analysis in two consecutive phases, one descriptive and one interpretative.

Results. While supported living aims to provide personalized solutions to individual needs, support is conditioned to a greater or lesser extent by the assessment professionals make regarding the autonomy of the person with intellectual disability.

Conclusions. In order for individuals to make advances in their choice of, and control over, support received, people with intellectual disability must be empowered, and professional practices adapted through training.

Keywords: supported living; independent living; people with intellectual disabilities; choice and control; role of professionals

Introduction

Since the 1980s, progress towards the independent living of people with intellectual disability has necessarily focused its efforts on the opportunities and possibilities of choice and control that these people can exercise over their own lives (Bigby et al., 2017). And this has logically led to questioning the organizations that provide the support, how this support is planned, and the actions of the professionals who offer it.

The trend towards independent living aims to transform the institutional care model based initially on residences and, later, group homes, into more individualized support options, whereby people with intellectual disabilities receive support in their own homes (McConkey et al., 2016). Independent living is understood to be a question of human and civil rights: it refers to people having control over their lives, not the ability to perform activities by themselves (Morris, 1993, 2004), leaving behind the predominantly "functional" view that links independence with being able to realize certain activities without having to rely on others (Petner-Arrey & Copeland, 2014). This idea falls under the umbrella term supported living (SL) (Bigby et al, 2017). Conceptualized by Kinsella in 1993, this model establishes a different relationship between the support service and the individual; it is based, at the service level, on separating the provision of housing and support, thus facilitating personalized support (Bigby et al., 2017). Supported living seeks co-operation in developing the assistance people need to get on with their own lives, without exercising control over them but rather based on their choice of how, with whom, and where to live, and from where and how support is provided (Duffy 2012; O'Brien 1993). Such a focus is in the interests of people with ID, most of whom prefer to live in their own home, with the support needed for their independence (Deguara et al., 2012; Fisher & Purcal, 2010; Garcia Iriarte et al.,

2014; McConkey et al., 2016; Miller et al., 2008). SL is also aligned with the contents of the United Nation's Convention on the Rights of Persons with Disabilities (UN CRPD, United Nations 2006), which supports the rights and freedom of people with disability, promoting individual autonomy, independence, choice- and decision making, as well as the need for them to participate in making decisions regarding the policies and programmes that affect them (Curryer et al., 2015). Article 19 recognizes the right of all people with disability to decide where and with whom they wish to live, to have access to the support that gives them equal access to the community's services, and to have the same degree of choice and control over their lives as other members of the community. Furthermore, the support provided should be adaptable to individual preferences and requirements, as well as personal choice and self-management (United Nations, 2017).

Research into support models for independent living for people with intellectual disabiltiy has highlighted the better results that SL has in the areas of choice, frequency and range of recreational or community-based activities, while there are poorer health and money management (Bigby et al., 2017 and 2018). Other studies provide consistent evidence that greater choice and self-determination are available in smaller, less institutional settings (Siska, 2014; Walsh et al., 2010). In a study conducted in Canada, Stainton et al (2011) found that people who lived independently did report more choice and control in hiring and managing staff. More recently, in a study that compared outcomes for individuals across different accommodation options (group homes, personalized accommodation [SL], and support arrangements and congregated settings), McConkey et al (2016) also noted better results in choice and control in those people who live with personalized support.

Garcia Iriarte et al. (2016) specifically studied the role that support staff played in the transition processes of sixteen individuals from institutional spaces to group homes (nine people) and SL (seven people). The interviews carried out with those who received the support and the professionals who helped them highlighted how the support provided in supported living focused on the individual making decisions. The authors of this study noted the challenges that organizations face when attempting to change their support distribution model based on care/assistance, which has been prevalent in care provided by institutions. In a systematic review of research published on the impact of personalized support and the role support professionals play in relation to people with intellectual disability, Sims and Cabrita Gulyurtlu's study (2014) noted a lack of orientation as to how to implement personalized support, and the perception that the implementation of such support represents a threat to the traditional role of professionals, hindering its implementation.

Little research has been carried out that focuses specifically on SL, and particularly on those factors that may contribute to its success (Mansell & Beadle-Brown 2010; Bigby et al., 2018). In order to explore the experiences of people with supported living arrangements, Bigby et al. (2017) administered group and individual interviews to thirty-four people with intellectual disability who received support in three aspects of their lives (having choice and control; being supported; and being connected). Most of the participants positively valued the support provided, although they did also mention negative experiences regarding the controlling or excessively strict behaviour of some support professionals. They also noted that changes in support had sometimes been made without their agreement (for example, a reduction in the amount of support), showing that they had limited direct control over their own support. These results are in line with those found in Bond and Hurst's study (2010), which examined the

perspectives of nine people with intellectual disability who lived independently and received minimal professional support. While the majority were satisfied with the level of support received, some were concerned that they had not been able to choose the support professional, or the amount or intensity of support, and noted a lack of decision-making opportunities regarding issues they felt were important in their lives.

McConkey et al. (2016) insisted on the need to further examine the degree to which the support offered in SL promotes individual self-determination. Sims and Cabrita Gulyurtlu (2014) noted the need to research the experiences of people with intellectual disability in order to gain a deeper understanding of the impact of actions by support professionals, and assess how coherent these are with the personalized approach. An understanding of whether people receiving support under the SL model really can exercise self-determination on **how** and **when** they receive support, and **what** support they want to receive is important when determining whether this model offers personalized support in accordance with the right to an independent life (United Nations, 2006, and 2017), or whether it leads to one of the dissonances between services and users mentioned by O'Brien (1993), whereby professionals "practice the habits of control and call it support", and Duffy (2012), "people find themselves living in residential care by another name".

The aim of this research is to explore the role played by people with intellectual disability who receive supported living when taking decisions regarding the professional support they receive in order to achieve goals they consider to be relevant to their lives. Specifically, we wished to ascertain the extent to which these people exercise control and choice with regard to the support received in supported living, and examine, from their own viewpoint and that of their support professionals, the reasons why they have greater or lesser control over the support received in said living

arrangement. This information will help us formulate proposals to progress towards a model in which individuals exert control over their own lives.

This research forms part of a wider project aimed at identifying the problems and support that people with intellectual disability encounter when attempting to achieve their goal of independent living in Catalonia (Spain) and outlining ways in which these processes can be improved. The ethical aspects of the project were approved by MINECO (the Spanish Public Science Foundation.) In Spain, support for people with disability is managed through Act 1/2013 on the Rights of Persons with Disabilities and their Social Inclusion, and entails a combination of residential care and community-based services, with the group home model dominating in the latter case. As Verdugo and Jenaro (2019) state in their report on living independently and inclusion in the community, in Spain the emphasis has been placed on residential support rather than the community-based design that encourages independent living and social inclusion. Said report indicates that little progress has been made in implementing actions that move towards deinstitutionalization, and recommends investing sufficient resources to develop personalized support for all persons with disabilities, such as personal assistance. Some Spanish regions have developed supported living programmes, although these initiatives are still in the minority. In the case of Catalonia, since 2002 a yearly-renewable programme has provided financial aid (€500 per month) to adult people with disability living alone in their own home or homes with up to four people, to cover a maximum of 10 hours of individual support per person per week. Thus, this programme is only really an option for those with fewer support needs, coinciding with the dominant trend throughout most of Europe, with the exception of the UK (Siska, 2014[i]).

This financial aid is not given directly to the person, but to a previously-accredited organization that provides support services to people with disability. Around 1,300 people currently benefit from this service in Catalonia, and no recent studies have been conducted to analyse its impact on independent living for people with ID.

Methodology

A qualitative study was developed using interviews to obtain the narratives of people with intellectual disability who receive support in their own home under the SL model, and of professionals providing this support.

Participants

Participants with disability were selected using the following criteria: people over 18 with intellectual disability who benefit from the supported living programme, in a home that they either own or rent, who receive up to 10 hours of formal support per week, and who were generally satisfied with their participation on the supported living programme. A further criterion was that the person with disability and the professionals providing support had all been on their personal pathway within the SL programme for a minimum of two years, thus ensuring that they knew enough about the programme to evaluate it. Telephone contact was made with services offering SL in Catalonia, and they were asked to contact people who received SL and met the above-mentioned criteria. The professionals contacted were informed of the methodology to be used (two in-depth interviews with people receiving support in which personal information would be requested). Based on this information, the professionals made a preliminary selection of those people they thought would be willing to share this information with the researchers. The six service providers contacted 16 people, of whom 13 agreed to participate in the research. A letter outlining the aims of the research was then sent to

those people whose names had been provided by the services, and a first interview was arranged in collaboration with the service professionals. The first part of the meeting was spent explaining the research aims, before participants completed an accessible consent form guaranteeing their anonymity and the right to leave the study whenever they wished.

Eight women and five men agreed to participate in the study, aged between 31 and 64. Six of them had moved out of residential care, three had moved out of the family home, and four had lived alone without professional support before joining the supported living programme. Four lived in their own home, and the other nine lived in rental accommodation and had a tenancy agreement. One participant was retired, the others worked for a minimum of five hours a day, either in a sheltered workshop or in supported employment. Table 1 provides specific data on the situation of each of the participants with disabilities, indicating the following information for each: age, sex, organization that offers supported living arrangements, number of years they have been using the supported living programme and the people they live with, indicating whether this is their partner or other service users.

Six support professionals, all women aged between 35 and 54, took part in the study. They all held a degree in the socio-educational field, and had 8-15 years' experience in providing personalized support for people with ID. The programme establishes that people receiving support can choose the support organization they wish to use from among those operating in the area where they live. However, it is generally the organization that decides which professional will provide support. Table 1 shows the demographic characteristics of the people receiving support, and includes a reference to the organization providing support. The six organizations were based in five different towns in Catalonia. Organizations 1, 2, and 5 managed sheltered workshops, day

centres, homes/residences for people with disability, as well as the personalized living arrangement programme. Organizations 3, 4, and 6 managed professional training and supported employment programmes for people with intellectual disabilities. In the context in which the study was carried out, no norms were yet in place to incorporate the personalized approach in the actions of those organizations offering services to people with disabilities. At this time, it was the organizations that took decisions on the intensity, convenience, and subject of their professionals' on-the-job training. Over recent years, these organizations have invested in such training with the aim of incorporating person-centred approaches into their actions (AEES DINCAT, 2018)[ii].

(insert Table 1 around here)

Instruments

Two semi-structured interviews were used to gather information on the person with ID, while the professionals were interviewed once. The interviews helped to construct the narrative of the process that the interviewee followed from when they left the family home until the time of the interview. Visual strategies – a timeline drawing and photos taken by participants - were used to make it easier for them to express themselves in their own voice; complex questions were simplified to the same end, and an attempt was made to avoid the use of abstract and ambiguous terms (Hollomotz, 2018). Participants with disability were interviewed twice; the first interview focused on their pathway, the support they had received over the years, and their own assessment of their pathway. The second aimed to identify those things they would or would not change with regard to living independently, and explore their vision of the future. The aim of the interviews

with professionals was to gain an understanding of their point of view regarding the support the person had received, and the role they had played in the whole process.

Data collection

Seven of the interviews with people with intellectual disability took place on the premises of the support organization, while six interviewees chose the surroundings of their own home. In line with the approach adopted by Williams and Porter (2017), no direct questions were asked about "choice and control". Rather, this was explored through the analysis of experiences linked to the support they had received along their pathway. Care was also taken to use clear vocabulary, straightforward language, and images to aid understanding of the questions. The first interview began with a personal self-description in which the participant gave their personal data, current work situation and living arrangements. They were then asked to explain their pathway up to that point, which was reconstructed using a timeline, as mentioned above. Participants could choose whether to draw the timeline, or leave this to the interviewer. The line began at the moment they left the family home and ended at the time of the interviews. The participant was asked to provide data regarding where they had lived, support obtained at various times, the role played by professionals, family, and friends, and their own role on this pathway. In order to identify the moments participants considered to be most important, they added words, small drawings and dates to the line. The idea was to produce a sequence of events rather than specific dates. The interviewee helped place the occasions, places and people on the timeline. If they agreed, at the end of the first interview an appointment was made for a second. Participants were asked to bring three or four photographs of things they particularly valued in their current life to the second interview. The timeline was used as the starting point in the second interview to review the most important events linked to their personal process since they had left the family

home; the photos were then discussed and future plans explored. The first interview lasted an average of an hour, the second 45 minutes.

The support professionals were interviewed in their workplace once the two interviews with the person with intellectual disability had been completed. These interviews lasted an average of an hour. They were asked about the pathway of those participants they offered support to, the factors that they thought key in these pathways, the evolution of personal support received, and the reasons behind this evolution. All participants' interviews were audiotaped and transcribed in Catalan or Spanish, according to the interviewees' chosen language of communication.

Data analysis

The data analysis followed the qualitative directed content analysis approach, in which the codes are defined before and during data analysis, and derived from relevant pre-existing research findings (Hsieh & Shannon, 2005). There were two stages to the data analysis. The first was descriptive, reconstructing the participant's pathway; the second was interpretative, identifying the degree to which individuals chose and controlled support themselves. A more detailed description follows below.

First stage.

1. A researcher transcribed all the interviews. In line with the work done by Galletta (2013), thematic codes were used to perform a first encoding of each interview and obtain a description of the person's pathway, organized according to the following themes: description of the family context; occupational pathway; pathway to independent living; financial management; relationships; and future plans. One researcher then drafted an individual descriptive report of each case, organized according to the aforementioned themes. The report

included the timeline, photographs, and extracts of the narratives to illustrate each theme.

2. Two researchers then analysed the individual reports, producing an individual file that included more-detailed information on the process followed after leaving the family home, and specifying each different move that took place and why. The person/agent who had played a key role in taking the decision that led to each move was identified. Each move is taken to be a stage in their emancipation process, and details were noted of the length of time spent at the new accommodation, the type of accommodation (where and with whom), and the support received (when, how, and what). The short-term situation the person hoped for was also specified. Each file included excerpts from the interviews, reflecting the participant's experience and its importance on their pathway; the files also included the opinions expressed by the professionals in their interviews.

Second stage

In the second stage, an interpretative perspective was used to analyse the data. This involved an iterative process to identify any emerging thematic patterns (Galleta, 2013). When analysing the support received, the starting point was the individual reports. Two of the authors compiled a table and carried out a joint analysis of all reports. A brief interpretation of each pathway was listed in the table for each case. The extracts from the interviews were then re-analysed to detect the degree to which the interviewees had the opportunity to exercise choice of, and control over, the support received. The codes used were related to the following: who made decisions during the process; how this decision was made; what support was offered, when it was decided, and by whom. The four authors of the article jointly reviewed the information in the tables to ensure

consistency between the types of data recorded. Two patterns emerged from the overall analysis of the individual reports:

Pattern 1: Person in Control: support is designed based on the person's decisions.

Pattern 2: Person Controlled by professionals/Organization: support is a form of control by professionals.

Results

Table 2 shows the people who receive support in each of the two patterns identified, indicating their age. The acronym of the support person interviewed is in brackets.[1]

(insert Table 2 around here)

Pattern 1: Person in Control: Support is designed based on the person's decisions.

Seven of the participants who received SL made decisions regarding how to receive this support. Specifically, they chose the type of support they wanted to receive, and when to receive it. Depending on the reasons that have led to their controlling the support received, two groups were established with this pattern. The first was comprised of three people who are considered to have already had a very high level of autonomy prior to joining the SL programme. The second consists of four people who exercised a great degree of control over their lives and the support they received; this degree of control is the result of having undergone a lengthy learning process with the current support provider. Both the people who received support and the professionals who

---

[1] The names of participants receiving support are fictitous. The support professionals are referred to by letter S and the number corresponding to the service listed in Table 1. In the interviews with people receiving support, I1 refers to the first interview; I2, the second.

offered it agreed in attributing the greater control among the people in the two groups to their level of autonomy.

> *1.1. Person in control as a result of personal autonomy:* Ana, Marta and Santi comprise this group; their support professionals considered all three to be *highly autonomous people*. Ana and Marta had lived without support in their own home for over 10 years. In both cases, it was the organizations they were linked to for professional support (1 and 5) that had decided they could benefit from the personalized living arrangements programme; and this was what they were offered. Both Ana and Maria agreed to join the programme. At the time of the interview, Marta received two-and-a-half hours of support twice a week. She was initially reluctant to join the programme as she felt that, having lived alone for over 10 years, it meant a step backwards:

> "…for two or three years they were talking to me about joining the programme (SL). And at first, I didn't want to, I said no, and didn't want to. But right now, I do want to, and I really want to, and I love being with her because she understands me, helps me, gives me support, we go for walks together and talk." (I1)

The professionals acknowledged that Ana and Marta were the people who had been most involved in designing the support that met their own needs:

> "…all the support has been designed with Marta; she decided what she needed support for, and she's the person who's been most demanding regarding the quality of the service, and she still is. She's understood very well that she can make requests depending on her needs, and that the support is totally adapted to her demands." (S1)

Ana, who had lived on her own in her own flat for over 10 years before receiving support in the home, explained that she chose when and why to receive such support; namely, she called the support person whenever she needed to, whether to talk about things that were worrying her, or to ask for help with specific household tasks.

> "…they come to my place infrequently because there's little to do. There are other girls who get more, but not me. She only comes when I call her. Sometimes you just have to get things off your chest, talk stuff over, and that's how we spend the time. And if I need to clean the shutters, or do the kitchen cupboards, well, while we're talking, she holds the stepladder so I don't fall off…"

The professional who provided her support said that, from the beginning, Ana was very clear as to what she needed, and that she had lots of personal skills, and a high level of autonomy:

> "... right from the start the support has been really focused. Because sometimes they can't verbalize things very well, or the needs they have, and then, well, things happen. But with Ana, from the start, she told us really well and clearly what she needed. She's a perfect candidate to live alone; she has lots of resources and very few shortcomings." (S2)

Ana particularly valued her autonomy.

> "... tell me what you most value about your current situation. (Interviewer)
>
> "What do I value? Well, it's being relaxed, that nobody bothers me, and I'm very happy. Nobody tells me what I've got to do, that's peace and calm." (Ana, I2)

At the time of the interview, **Santi** had been living alone for three years after having spent three years living with two other users as part of the support programme. He was receiving support one afternoon per week. It was he who chose what support to receive, and when:

> -My educator who comes to the flat, more than anything it's because it's hard for me to cook. I can get by in everything else.
>
> -Everything else? (Interviewer)
>
> -Yes, cleaning and all that, I do myself. Sometimes, I ask her if I've got a question, but apart from the cooking, we don't do much more.
>
> -How often does she come? (Interviewer)
>
> -Once a week. It was hard for me to get her to come here just once a week.
>
> -Hard? (I)
>
> -Well, I had to insist, and in the end I got my way. And as Mondays were the best day for me, they gave in and I got her to come only once a week, on Monday afternoons (I1).
>
> In his second interview, Santi gave more details as to the help provided by the support professionals:
>
> -…we go out and buy the ingredients, I help her cut them up, I look at how she does it, and that's basically what we do. (I2)

1.2. Control as a "reward" for having gained specific knowledge after a lengthy training process: Maria, Juan, Sandra and Enric comprise this group. Maria, Sandra and Enric have been users of services that organize specific training for independent living, which gives people the chance to share a flat with people with no disability for a maximum of five years. Here they "have to learn to do everything, cook, absolutely everything (...) then support is taken away until, at the end of the pathway, what we do

is establish objectives with them" (S3). This was Maria's case. At the time of the interview, she lived in her own flat with two flatmates who rented a bedroom from her. Her support professional said that the support she received was very occasional: "It's, I don't know, maybe we're very idealistic, but *we've met so many goals with her* that I often wonder if the support she needs is only minimal". (S3)

Maria was very satisfied with her current life. She felt that she had the support of professionals ("we get the support we've asked for"). To this sense of well-being, she added the feeling of freedom that came with being able to decide to stay at home over the weekend:

> …before, we always had to ask the service [the organization that distributes support], because the flat wasn't mine, it belonged to the service, and you could stay, but you had to let them know. In theory, this flat is my home, and if I don't want to go out, well, I can stay at home. (I2)

Enric and **Sandra** were a couple, and had shared a flat with other flatmates for five years. Like Maria, they had taken part in training provided by another organization. They had been living together for two years at the time of the interviews. Enric's parents lived nearby, and they gave them informal support in a number of areas. They also received professional support when they requested it:

> …we took a new step, which is living alone without professionals, and we were lucky enough and had the chance to really live alone. This was our dream, to live alone, and we became independent.
>
> -You don't have any kind of support?
>
> -Well, when we need it.

-And when you do need it, what kind of support do you get?

-That of the organization when we need it or ask for it; and if we don't want it, we say no… (I1)

As in Maria's case, the professional confirmed that they needed little support because they had learnt a lot of skills.

The fourth person, **Juan,** had been receiving his personalized support for the past 12 years. Orphaned young, the fact that he could live in his family house facilitated his incorporation into the programme. He recognized that, had this not been the case, "I'd have gone to a group home and would have had to start from scratch".

-How does the support person help you? (Interviewer)

-Well, for example, shopping, things like clothes sometimes, and things that I see that I can't do or can't really manage, I also ask him. And emotional support. (Juan, I1)

Juan couldinvite whoever he wanted to his home, and he was the first person in his organization to travel alone, with a volunteer that he chose himself (his support professional). According to the professional, belonging to a group of self-advocates had made him more aware of his rights: "some time ago he talked a lot about support as being something external; but not anymore, he's clear that he chooses the help we give him". (S1)

Pattern 2: Person Controlled by professionals: support as a form of control

Six of the support-receiving participants (Moni, Gabi, Elena, Judit, Miguel and Paz) did not control this support; rather, it was the professionals who *took the basic decisions*

regarding support management. Two participants (Moni and Gabi) shared the same situation, namely, that their pathways had been determined by the decisions of the professionals and conditioned by their own personal achievements. At the time of the interview, **Moni** lived with a companion in a flat rented by the service provider, but had previously lived in a group home for 10 years.

> -Was it hard for you to go and live alone? (Interviewer)

> -Yes, I found it hard. [When she lived in a group home] I had a friend who was the first to leave, and when I saw this I told Rosa [the professional responsible for managing the SL service] that I wanted to leave too. *But she said no, that I wasn't ready*. And then *I thought that you can change*. And a couple of years later, more or less, *I changed what Rosa said needed changing*, and the change was made [meaning she was allowed to live independently and receive SL].

In the flat she lived in at the time of the interviews, "they don't let us have anyone over to sleep, they don't let us have dogs, but what if Marta (a friend) invites me over to her house to sleep? Maybe one day I'd like to invite her, but I can't. These things are a little strange".

> -And what if you had a partner? Could you then? (Interviewer)

> -No. That's the way it is, but I don't think it's right. (Moni I1)

Moni said she would like to have greater control over her life:

> ...now I'm living in this flat, but I'd like to have my own flat and have my own, totally independent life, to live alone in the long run. (I2)

The professional who organized Moni's support felt that some limitations had to be placed on her process towards independent living:

> Moni's evolution has been based on what she wanted. She has set herself goals, and has always found a way to achieve them. Having said that, there have always been steps backwards, right? She also planned how she could live, but did it at a time when it wasn't possible because there were many parts of her life that she still hadn't mastered (...). When we saw that her skills were more consolidated, then we asked for the support (SL) (S1)

Gabi lived with his partner. He had also undergone a lengthy process before reaching the position he was in at the time of the interviews. He had shared a flat for 13 years with three other service users, where, according to him and his support person, he learned "almost everything". When he met his partner, he insisted on living with her. The co-ordinator of the support programme set out a personalized plan to ensure that he was responsible enough and that his behaviour regarding personal and household care was correct.

> -What did this plan consist of? (Interviewer)
>
> -Well, saving, money stuff, knowing how to manage money, the housework, having a shower, cleaning, everything that having a flat involves.
>
> -And between asking to live in a flat with your partner, and going there, was it a long time? (Interviewer)
>
> -Well, it seemed like a long time to me. I had that idea, and said that I wanted do it right away, I wanted to live there right away, but, of course, there's

paperwork, the flat. That's what the co-ordinator told me, that *it was a long process and that it would take time*, you know what I mean? (Gabi, I1).

Gabi said he would like to have greater control over his life.

-To live with no support, or with less support, in my own flat, not depending on the association.

-Your own flat, you mean, but with support? The other day you said with less support. (Interviewer)

-If there's support, that would be different. I mean, I'd choose the person, I'd be the one to pay them. (Gabi, I2).

The support professional stated:

... we had to really slow him down, because his dream was to go and live in his own flat. But that's Gabi, isn't it? All this hurry. I'd say that he's a kid who's always pushing you, right? Because he has a fair few problems. But on the other hand, he always wants more, and that has to be watched, and from time to time we just have to slow it down, you know? (S4)

According to the professional, as with Moni, it was Gabi's desire and insistence that were driving him to meet the goals the professionals set him. This leads to the question: what would have happened had he been unable to meet them?

In three of the cases included in this pattern, families and professionals played an important role in decisions regarding the support offered. In the cases of **Elena** and **Paz**, the families wanted the support to focus on helping them follow a healthy diet. **Judit** agreed to receive SL as a condition imposed by her family for her to live in her own home, after a previous unsuccessful experience in which she had not received

professional support. She was quite reluctant to receive SL, and criticized the fact that she could not make certain decisions regarding how to organize her life, like her diet and other health-related issues.

Discussion

The aims of this research were twofold: to explore the role played by people with intellectual disability in making decisions regarding the professional support they received; and to examine the reasons why they controlled the support to a greater or lesser extent in such housing arrangements. This is necessary research if people with intellectual disability are to make progress in exerting control over their lives, as set out by the CRPD (United Nations 2006 & 2017).

It is noted that, while the participants were generally satisfied with the SL programme (this being one of the criteria for inclusion in the study), not all of them felt they controlled the support they received. This coincides with Bigby et al's (2017) finding that the general satisfaction of people with intellectual disability who receive SL is accompanied by a perception that the support they receive is too strict and controlling.

This research has highlighted how the degree of control that participants exercise over the support they receive is determined by the opinions that the professional support givers have of their capacity for autonomy. Those who receive support have internalized this opinion, as witnessed in their narrations. The above explains how the patterns detected in this research are based on arguments reflecting that the individuals with disability in this study view independent life from a dominant functional perspective, and not as a right that they have to control their own lives and the support they receive. Regardless of whether they were the ones receiving or offering support, the stories collected here revealed that individuals' control over the support they received was only

possible when the latter considered the former had attained sufficient mastery of the skills necessary to look after a home and themselves. This, in turn, may be the result of well-established personal autonomy or the consequence of a learning process in which the professionals feel they have a prominent role to play.

Through their professionals, the organizations tended to incorporate a reductionist view of independent living, managing the lives of the people to whom they offered support according to what they considered to be socially acceptable (Callus, 2013), and establishing the conditions that have to be met in order to enjoy greater autonomy (Yates, 2005). This view was often legitimized in the discourses of the people with disabilities themselves, who accepted the dominant role organizations and professionals play in making decisions regarding their lives, barely criticizing either, with said organizations and professionals tending to act as agents who decide rather than encouraging people to exercise choice and control (Fullana et al., 2019).

This study revealed that one aspect making it difficult for people with intellectual disability to acquire control over their life was linked to professional practices and, by extension, to the excessively protective vision organizations had of their role. Professionals' beliefs and expectations regarding the nature and frequency of supervision form part of the organizational dimension; and despite its relevance to the distribution of correct personalized support practices (Bigby et al., 2019a), this is an area that has been little studied. This research illustrated the problems organizations face in moving from an institutional culture towards the personalized support model posited by a number of authors (Clement & Bigby, 2012; Duggan & Linehan, 2013), corroborating the need to further explore staff teams' 'organizational culture' in order to learn more about the conditions that influence staff practices in terms of social climate, management practices and their own support practices (Walsh et al., 2010). Taking

decisions on independent living is not merely limited to the place where one lives, but also includes all facets of a person's life, routines, and lifestyle (NU 2017, Com. 24), and it must be guaranteed that people with disability are responsible for those decisions that affect their lifestyle without others setting pre-established conditions. This perspective should be implicitly included in the training of not just front-line staff, but also professionals in charge of organizations providing support, as noted in previous studies (Beadle-Brown et al., 2015; Clement & Bigby, 2012; Pallisera et al., 2018). Staff training and strong practice leadership are two issues that need to be addressed if progress is to be made in developing personalized support that respects people's rights, as recent studies have shown (Bigby et al., 2019b).

Undoubtedly, one necessary way of improving the control that people with ID have over the support they receive is to contribute to their empowerment, thereby making them aware that they can take decisions and limiting interference by others. As Yates (2005) noted, it is necessary to empower people with intellectual disability to ensure that they control the support they receive. This means working hand-in-hand with them to help them comprehend their situation by highlighting and addressing the problem, and ensuring they receive training that is based on the rights' model of the CRPD and respects their right to take decisions, including those regarding the support they wish to receive.

Neither should it be forgotten that social policy is a dimension that conditions the quality of support. In this sense, one challenge that has still to be fully addressed in Spain is that of organizations offering support that incorporates personalized solutions, respecting the decision-taking rights of people with intellectual disability.

Limitations

One limitation of this research is that it was carried out with people participating in the SL programme in Catalonia (Spain), access to which is only possible if the person with intellectual disability has a high level of autonomy. Therefore, it does not include those people who need a greater degree of support. That said, the results obtained here regarding the options people with greater autonomy have in choice and control over support also allow for reflection on the situation of those people who need more support. Another limitation is the small number of participants in the study. It should be highlighted, however, that the participants received support from six different organizations managing the support programme in five different counties in Catalonia; this provides a certain degree of representativeness with regard to how people with intellectual disability see how the programme works across a range of organizations.

References

Act 1/2013 on the Rights and Social Inclusion of people with disabilities (Madrid, BOE –Official State Bulletin, 3rd of December 2013).

AEES DINCAT (2018). Memòria 2018. http://www.aeesdincat.cat/wp-content/uploads/2019/06/4.-MemoriaDINCAT_2018_vs3_ONLINE.pdf (Retrieved 7/05/2020)

Beadle-Brown, J., Bigby, C., & Bould, E. (2015). Observing practice leadership in intellectual and developmental disability services. Journal of Intellectual Disability Research, 59(part12), 1081–1093. https://doi.org/10.1111/jir.12208

Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *42* (4), 309-319. doi: 10.3109/13668250.2016.1253051

Bigby, C., Bould, E., & Beadle-Brown, J. (2018). Comparing costs and outcomes of supported living with group homes in Australia. *Journal of Intellectual & Developmental Disability*, *43* (3), 295-30., doi: 10.3109/13668250.2017.1299117

Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2019a). Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level. Journal of Intellectual and Developmental Disability, 0(0), 1–13. https://doi.org/10.3109/13668250.2019.1671965

Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2019b). Predicting good Active Support for people with intellectual disabilities in supported accommodation services: Key messages for providers, consumers and regulators. Journal of Intellectual and Developmental Disability, 0(0), 1–11. https://doi.org/10.3109/13668250.2019.1685479

Bond, R. J., & Hurst, J. (2010). How adults with learning disabilities view living independently. *British Journal of Learning Disabilities*, *38*(4), 286–292. Doi:10.1111/j.1468-3156.2009.00604.x

Callus, A-M. 2013. *Becoming Self-Advocates. People with Intellectual Disability seeking a Voice*. Bern, Switzerland: Peter Lang.

Clement, T., & Bigby, C. (2012). Competencies of front-line managers in supported accommodation: issues for practice and future research. Journal of Intellectual & Developmental Disability, 37(2), 131–40. https://doi.org/10.3109/13668250.2012.681772

Curryer, B., Stancliffe, R. J., & Dew, A. (2015). Self-determination: Adults with intellectual disability and their family. *Journal of Intellectual and Developmental Disability*, *40*, 394–399. doi: 10.3109/13668250.2015.1029883

Deguara, M., Jelassi, O., Micallef, B., & Callus, A.-M. (2012). How we like to live when we have the chance. *British Journal of Learning Disabilities*, *40*(2), 123–127. doi:10.1111/j.1468-3156.2012.00743.x

Duffy, S. (2012). The limits of personalisation. *Tizard Learning Disability Review*, *17*(3), 111–123. doi: 10.1108/13595471211240951

Duggan, C., & Linehan, C. (2013). The role of "natural supports" in promoting independent living for people with disabilities; a review of existing literature. British Journal of Learning Disabilities, 41(3), 199–207. https://doi.org/10.1111/bld.12040

Fisher, K. R., & Purcal, C. (2010). Effective personalised housing support for people with disabilities – case study analysis. *Australian Journal of Social Issues*, *45*(4), 527–543. doi: 10.1002/j.1839-4655.2010.tb00196.x

Fullana, J., Pallisera, M. & Diaz-Garolera, G. (2019). How do people with learning disabilities talk about professionals and organizations? Discourse on support practices forindependent living. Disability & Society. doi: 10.1080/09687599.2019.1594701

Galletta, A. (2013). *Mastering the semi-structured Interview and Beyond*. New York, USA: New York University Press

Garcia Iriarte, E., O'Brien, P., McConkey, R., Wolfe, M., & O'Doherty, S. (2014). Identifying the key concerns of Irish persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *27*(6), 564–575. doi:/10.1111/jar.12099

Garcia Iriarte, E., Stockdale, J., McConkey, R., & Keogh, F. (2016). The role of support staff as people move from congregated settings to group homes and personalized arrangements in Ireland. *Journal of Intellectual Disabilities*, *20*(2), 152–164. doi:10.1177/1744629516633966

Hollomotz, A. (2018). Successful interviews with people with intellectual disability. *Qualitative Research*, 18 (2), 153-170. doi: /10.1177/1468794117713810

Hsieh, H-F. & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. Qualitative Health Reserch, 15 (9), 1277-1288. doi: 10.1177/1049732305276687

Mansell, J., & Beadle-Brown, J. (2010). Deinstitutionalisation and community living: Position statement of the comparative policy and practice special interest research group of the international association for the scientific study of intellectual disabilities1. *Journal of Intellectual Disability Research*, *54*(2), 104–112. doi: /10.1111/j.1365-2788.2009.01239.x

McConkey, R., Keogh, F., Bunting, B., Garcia Iriarte, E., & Watson, S. F. (2016). Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalized arrangements and group home placements. *Journal of Intellectual Disabilities*, *20*(2), 109–120. doi:10.1177/1744629515624639

Miller, E., Cooper, S.-A., Cook, A., & Petch, A. (2008). Outcomes Important to People With Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *5*(3), 150–158. doi10.1111/j.1741-1130.2008.00167.x

Morris, J. 1993. Independent lives? Community Care and Disabled People. Basingstoke, England: The McMillan Press LTD.

Morris, J. 2004. "Independent living and community care: A disempowering framework". Disability and Society, 19(5): 427–442. Doi: https://doi.org/10.1080/0968759042000235280

O'Brien, O. (1993). Supported Living: What's the Difference? Center on Human Policy. Syracyse University. https://mn.gov/mnddc/parallels2/pdf/90s/93/93-SLD-RSA.pdf (accessed the 28th April 2018).

Pallisera, Maria, Vilà, M., Fullana, J., Díaz-Garolera, G., Puyalto, C., Valls, M.-J. (2018). The role of professionals in promoting independent living : Perspectives of self- - advocates and front- - line managers. Journal of Applied Research in Intellectual Disabilities, (April), 1–10. https://doi.org/10.1111/jar.12470

Petner-Arrey, J. & Copeland, S. R. (2014.) 'You have to care.' Perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities*, *43* (1), 38–48. doi: 10.1111/bld.12084

Sims, D., & Cabrita Gulyurtlu, S. S. (2014). A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities. *Health & Social Care in the Community*, *22*(1), 13–21. doi: 10.1111/hsc.12048

Siska, J. (2014). Comparative analysis of the current state of affairs in community living. DISCIT Project. FP7-SSH2012-2SSH.2012.3.2-2. https://blogg.hioa.no/discit/files/2016/02/DISCIT-D-6-1-final.pdf (accessed the 28th May 2019)

Stainton, T.; Brown, C.; Crawford, R.; Hole, R. & Charles, G. (2011) Comparison of community residential supports on measures of information & planning; access to & delivery of supports; choice & control; community connections; satisfaction; and,

overall perception of outcomes. *Journal of Intellectual Disability Research, 55*(8), 732-745. doi: 10.1111/j.1365-2788.2010.01378.x

United Nations (2006) Convention on the Rights of Persons with Disabilities. Available at: http://www. un.org/disabilities/default.asp?id=17. (Accessed 30th September 2018)

United Nations (Committee on the Rights of Persons with Disabilities) (2017) General comment on article 19: Living independently and being included in the community. 29th August 2017 (CRPD/C/18/1)

Verdugo, M.A., & Jenaro, C. (2019). ANED country report living independently and being included in the community. Spain. Academic Network of European Disability experts. Retrieved from (https://www.disability-europe.net/theme/independent-living) (accessed the 30th May 2019)

Walsh, P. N., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R. L., & Moseley, C. (2010). Supported Accommodation for People With Intellectual Disabilities and Quality of Life: An Overview. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(2), 137–142. doi: 10.1111/j.1741-1130.2010.00256.x

Williams, V., & Porter, S. (2017). The Meaning of 'choice and control' for People with Intellectual Disabilities who are Planning their Social Care and Support. *Journal of Applied Research in Intellectual Disabilities*, *30*, 97–108. doi: 10.1111/jar.12222

Yates, S. (2005). Truth, Power, and Ethics in Care Services for People with Learning Difficulties. In S. Tremain (Ed.), *Foucault and the government of disability* (pp. 65-77). Ann Arbor, USA: University of Michigan Press.

Participants (people receiving support)	Age	Sex	Organization	Years in supported living programme	Living arrangements at time of interviews
Marta	42	F	1	2	Living alone in own flat
Moni	31	F	1	3	Sharing rented flat with another service user.
Juan	40	M	1	12	Sharing own home with another service user
Santi	47	M	2	7	Living alone in own flat
Gabi	42	M	2	6	Living with partner in rented flat
Elena	46	F	3	2	Living alone in own flat
Judit	42	F	4	6	Living with partner in rented flat
Paz	31	F	4	3	Living with partner in rented flat
Miguel	63	M	5	5	Living with partner in rented flat
Ana	57	F	5	3	Living alone in own flat
Sandra	30	F	6	2	Living with partner in rented flat
Enric	31	M	6	2	Living with partner in rented flat
Maria	31	F	6	3	Sharing own flat with two more service users

Table 1. Participants receiving support

Pattern 1: Person in control			Pattern 2: Person controlled	
1.1.Person in control as a result of personal autonomy	1.2.Person in control as a "reward" for having gained knowledge following period of training		Moni, 31 (S1)	Gabi, 42 (S4)
Ana, 57 (S2)	Maria, 31 (S3)			
Marta, 42 (S1)	Juan, 40 (S2)		Elena, 46 (S5)	Judit, 42 (S6)
Santi, 47 (S4)	Sandra, 30 (S3)		Miguel, 63 (S2)	Paz, 31 (S6)
	Enric, 31 (S3)			

Table 2. Distribution of participants in identified patterns