Intellectual and Developmental Disabilities
Decision-Making Opportunities: a Key Aspect in Processes Aimed at Fostering Independent Living.
--Manuscript Draft--

Manuscript Number: IDD-D-23-00055R1

Article Type: Research

Keywords: Intellectual Disability; Extensive Support Needs; Community Living; Choice; Self-determination

Corresponding Author: Laura Esteban, PhD student
University of Salamanca: Universidad de Salamanca
Salamanca, SPAIN

First Author: Laura Esteban, PhD student

Order of Authors:
Laura Esteban, PhD student
Victor Arias
Patricia Navas
Miguel Ángel Verdugo

Manuscript Region of Origin: SPAIN

Abstract:
The aim of this study is to analyze the determining factors and processes associated with changes in self-determination of people with intellectual and developmental disabilities (IDD) and extensive support needs who moved to ordinary homes within the community. A repeated measures design was carried out, collecting data of 54 participants before the transition and six months after. Partial least square-structural equation modelling (PLS-SEM) was used to examine complex relationships between variables to estimate the models. After transition, participants’ levels of self-determination, received supports, and choice significantly increased. The effect that received supports had on self-determination was fully mediated by choice. If supports are not geared towards facilitating autonomy in daily decision-making, there will be no improvement in quality of life.
Decision-Making Opportunities and Independent Living

Decision-Making Opportunities: a Key Aspect in Processes Aimed at Fostering Independent Living.
Decision-Making Opportunities: A Key Aspect in Processes Aimed at Fostering Independent Living.

Abstract

The aim of this study is to analyze the determining factors and processes associated with changes in self-determination of people with intellectual and developmental disabilities (IDD) and extensive support needs who moved to ordinary homes within the community. A repeated measures design was carried out, collecting data of 54 participants before the transition and six months after. Partial least square-structural equation modelling (PLS-SEM) was used to examine complex relationships between variables to estimate the models. After transition, participants’ levels of self-determination, received supports, and choice significantly increased. The effect that received supports had on self-determination was fully mediated by choice. If supports are not geared towards facilitating autonomy in daily decision-making, there will be no improvement in quality of life.

Keywords

Intellectual Disability; Extensive Support Needs; Community Living; Choice; Self-determination
All people with intellectual and developmental disabilities (IDD), regardless of the intensity of their support needs, should have the opportunity to live according to their preferences and desires in the communities of their choice. This right to independent living, gathered in article 19 of the United Nations Convention on the Rights of Persons with Disabilities (2006), requires that the persons are at the center of the decision-making processes concerning their lives, being the causal agents of what happens in them.

Self-determined behaviors are known as those “volitional actions that enable the persons to act as the principal causal agents of their own life and to maintain or improve their quality of life” (Wehmeyer, 2005, p. 117). Being a causal agent implies that the person with IDD is responsible for certain things to occur during his or her life, which doesn’t necessarily mean being able to carry out the actions, but monitoring and controlling that these actions are set in motion (Shogren et al., 2017). The Causal Agency Theory integrates the volitional action (to decide), the agentic action (to act), and the action-control beliefs (to believe) as the key components associated with self-determination and establishes skills related to each one of them. For example, choosing and decision making, along with establishing goals, would be key elements of the volitional component. Self-managing, planning, problem solving, and goal achieving would be key skills for the agentic component, while self-awareness and self-knowledge are key for action-control beliefs (Shogren & Raley, 2022). Therefore, decision making, defined as the process of identifying several alternatives, choosing the preferred one and acting for that decision to be made, is a central aspect in self-determination (Wehmeyer et al., 2007). Self-determination is a broader concept than choice and decision-making, which aren’t more than the starting point or a good strategy to develop self-determination skills (Agran & Storey, 2010; Shogren & Raley, 2022).

According to the causal agency theory (Shogren et al., 2015), contextual changes can have an impact on how people may experience greater or lesser control over their lives. Thus,
several studies have associated less restrictive housing environments with improvements in personal control and self-determination (Bigby et al., 2012; Burke et al., 2021; Linehan et al., 2015; McConkey et al., 2016). Likewise, significant improvements in choices and control have also been noticed when people with IDD live in community settings (Bigby et al., 2012; Burke et al., 2021; Cvijetić et al., 2021; Dinora et al., 2020; Linehan et al., 2015; McConkey et al., 2016; Rogers et al., 2020; Shogren et al., 2017). Nevertheless, and despite evidence in favor of community living, there has been no significant change in the number of people with IDD who live in segregated institutions across Europe in the last ten years (Šiška & Beadle-Brown, 2020).

A segregated institution is characterized by rigidity in routines and activities, depersonalization, social distance, and block treatment. In such contexts, people have little or no control over their lives (European Commission, 2009; Mansell & Beadle-Brown, 2010). Likewise, families also might limit the control that people with IDD exercise over their life. The possibility of family members overriding the wishes of persons with IDD has been noted in other studies and appears to be motivated by a desire to protect them from potential harm and incorrect assumptions about their ability to choose (Casey et al., 2023a, 2023b). In addition, family members often believe that they are well positioned to guide the person’s decisions because they know the person very well (Hillman et al., 2012; Saal tink et al., 2012). This situation has a larger impact on individuals with extensive support needs, who are the target of this study. It is needed to ensure the right of living independently and emancipated from parents for all people with IDD, regardless of their support needs level. The target population of this study are also individuals with IDD that are getting older and likely to outlive their parents, who are their main support (McCausaland et al., 2019). This project is therefore aimed at promoting deinstitutionalization, but also preventing scenarios of future institutionalization of adult individuals who are still living with their families.

In the specific case of Spain, the country in which the present study was carried out, Verdugo and Jenaro (2019) noted that 36,000 people with disability, 91% of whom have an
intellectual disability, still live in institutions. Among those who remain institutionalized, virtually all require extensive or pervasive supports (Navas et al., 2017). People with extensive support needs are those ‘whose intellectual and adaptive functioning is significantly limited, and generally accompanied by other sensory deficits or other types of disability (mostly of a physical nature). This definition also encompasses people who, though they may not have any of the mentioned conditions, display severe behavioral problems or mental health issues that significantly limit their functioning’ (Navas et al., 2017, p. 13).

The greatest reasons for this group’s exclusion from processes aimed at fostering community living could be due to prejudices and beliefs about their ‘ability’ (Björnsdóttir et al., 2015; Burke et al., 2021) or reluctance to meet potential extra costs associated with intensive support requirements (Mansell, 2010). According to Cameranesi et al. (2022), these resistances are due to a lack of studies that provide conclusive results on how fostering community living could impact individuals with greater support needs.

The few studies available report improvements in adaptive behavior (Bigby et al., 2012; Heller et al., 1998), self-determination (Bigby et al., 2018; Young & Ashman, 2004), interpersonal relationships and participation (Bigby et al., 2012), and overall quality of life (Cameranesi et al., 2022; McCarron et al., 2019; Young & Ashman, 2004). Indeed, in their studies, McCarron et al. (2019) and Young and Ashman (2004) noticed that people with intellectual disabilities and greater support needs benefitted more from transitioning to the community than those whose support needs were less intense.

Cameranesi et al. (2022) suggest that the improvements noted could respond to the fact that living in smaller houses favors people’s decision-making as regards their everyday life, including the chance of participating in activities they find interesting, which, in turn, affords the opportunity to develop new skills. Nevertheless, living in smaller houses does not guarantee that people with IDD will have opportunities to decide over their lives (Laurin-Bowie, 2011). Indeed, when it comes to improving individuals’ emotional well-being, structural
and organizational aspects might not be variables as important as the type of support received (Beadle-Brown et al., 2015). It is, therefore, necessary to inquire into the external factors that might explain these improvements in quality of life and, more specifically, in self-determination, since research in this regard is still scarce (Vicente-Sánchez et al., 2018; Mumbardó-Adam et al., 2017).

For people with extensive support needs, having opportunities to become gradually familiar with the available options to make choices based on their own preferences is crucial (Shogren et al., 2015), as their ability to imagine themselves in different situations might be limited (Brown & Brown, 2009). It should also be noted that, even though capable of making a choice in their minds, a lack of communication skills could prevent them from expressing it to others (Antaki et al., 2006; Brown & Brown, 2009). Despite this, people with the most severe disabilities are capable of making choices (Cameron & Murphy, 2002), the issue being whether services provide adequate opportunities and supports for them to do so (Neely-Barnes et al., 2008).

This study aims to analyze the determining factors and processes associated with possible changes in self-determination of people with IDD and extensive support needs who moved to regular houses in the community, most of them with four places, in which people with IDD receive professional and individualized supports. In Spain, this type of service, allocated in the community, is only available for individuals with intermittent or limited support needs. To this end, the following research questions are raised:

1. To what extent do people’s status on the constructs of interest (i.e., self-determination, opportunities to make choices, and support received) vary following a change in their residential context?

2. Can the changes noticed be attributed to a change in residential context?

3. What type of relationship is there between the support received by the participants, the choices they make, and their level of self-determination?
4. Are the relationships between constructs stable after moving from one living context to another, or are there changes in the way they are related?

**Method**

**Participants**

The sample used in this study is composed of participants (N=54) of a pilot project implemented in different Spanish regions and aimed at promoting processes of deinstitutionalization and community living for people with IDD and extensive support needs. These people were either institutionalized (institutionalization history between 0.5 to 27 years -\(M = 11.3; SD = 7.5\)-) or had expressed, supported by their families, a desire to live in the community (29.6%). A total of 11 houses in the community were made available and the transition process was characterized by a common methodology that was aimed at generating learning about how to provide better support for people with more extensive support needs. To that end, support professionals were also trained in methodologies that favor inclusion, such as active support, positive behavioral support, or person-centered planning. As mentioned above, the sample includes 54 people with IDD, aged between 20 and 70 years old (\(M = 43.3; SD = 13.2\)). Other demographic characteristics can be consulted in Table 1. The a posteriori power estimate for this sample size and medium effect size (\(F > .2\)) is larger than .80 (alpha = .05).

<Insert Table 1>

Data about people with IDD were obtained through interviews with 51 informants, all of them professionals aged between 21 and 54 years old (\(M = 34.8; SD = 9.0\)), 84.3% of them being women. They were direct support professionals in 94.1% of the cases. The criteria for selecting informants were to be a professional who has known and observed the person in different contexts over long periods of time (for at least three months).
It was possible to interview the same informant at each data collection point in 23 cases. The main reason was that most of the staff who provided information of the person when she or he was at the residential facility did not provide support in the new living environment. Since possible sources of error might be associated with discrepancies between informants, we tried to minimize this effect by using directly observable behaviors as indicators and providing the interviewer who performed all the assessments with sufficient training to standardize data collection as much as possible.

**Instruments**

The data analyzed in this study were obtained using the following instruments:

- San Martín Scale (Verdugo et al., 2014). A questionnaire aimed at measuring the quality of life of people with significant disabilities. The scale is designed for proxy response and applied to a professional who has known and observed the person in different contexts. Its reliability coefficient is 0.97 and consists of 95 items organized around the eight domains of quality of life, with four answer options (1=never, 2=sometimes, 3=often and 4=always). The self-determination domain, which is of particular interest to this study, consists of 12 items. The main indicators of self-determination for people with IDD are goals and personal values, decisions and choices, and autonomy/personal control.

- Resident Choice Scale, RCS (Hatton et al., 2004). Applied as an interview with a key informant who knows the person well, the RCS measures environmental opportunities for self-determination in residential settings. This tool assesses the opportunities available for people with IDD to exercise choice on a total of 26 aspects related to everyday activities (e.g., what they eat or what they wear) or life-defining issues (e.g., who they live with or aspects regarding professionals providing supports) organized around eight domains. Informants are asked ‘In what ways is the person supported in making choices with regard to the following areas of their life?’ Responses to each item are rated by the interviewer on a 4-point scale ranging from
1 (no opportunities and no support to make decisions) to 4 (procedures in place for the person to make their own choices). The scale has a reliability coefficient of $\alpha = 0.95$.

- Active Support Participation Measure, ASPM (Jones & Lowe, 2018). This questionnaire assesses the person’s participation, as well as the type and amount of support needed for it, in a total of 99 daily life activities, organized around eight domains: food and drink preparation, self-care, household chores, use of household appliances, shopping, community activities, leisure and free time, and occupational activity. The frequency of performance of each activity in the last four weeks, as well as the amount and type of support required to engage in it (i.e., physical assistance, verbal support, or supervision), must be recorded.

**Procedure**

This prospective repeated-measures study involved the collection of data at two different points in time: before the person’s transition to the community and six months after. A member of the research team (always the same) moved to both residential contexts, where all the instruments were implemented by means of a structured interview with the reference professional of the person assessed. The interviews took place individually and lasted around an hour and a half. Informed consent was obtained from all the participants before beginning the interviews.

The research project and its design was approved by the Bioethics Committee of the University of (deleted for peer review).

Professionals gave their consent to participate and people with IDD also consented the collection and use of data about them. In the case of people who were legally incapacitated, their guardians gave consent but people with IDD were also consulted.

**Theoretical foundation and data analysis**

Figure 1 shows the evolution model (Roemer, 2016) used in this study. In the evolution model, the indicators obtained at different points in time are used to measure the endogenous and exogenous latent variables. The model in Figure 1 consists of two mediation models. In
these models, the support provided predicts self-determination both directly and indirectly through the possibility of making choices as a mediating variable. The mediation model estimated before the change in residential context (T1) is connected with the model estimated after the transition (T2) through the carryover effects (represented using a dotted line in Figure 1), understood as the effects of a construct on itself in later conditions. This self-regression effect can be interpreted as the stability of the construct over time (Duncan et al., 2013). A large carryover effect suggests that the construct is stable, so that people, regardless of any changes in their status on the construct over time, maintain a similar score pattern as a group. It also indicates that people’s status on the construct at a specific point in time could have a causal or predictive impact on their status on the same construct at a later time. By contrast, a small carryover effect indicates that “there has been a substantial reshuffling of the individuals’ standings on the construct over time” (Selig & Little, 2012, p. 266) so that the individuals’ current status on the construct does not depend on their previous one. If a significant change in people’s living context occurs (as is the case in this study), the carryover effects can also be partly interpreted as the extent to which a change in their living context entails changes in the construct.

Thus, for example, support needs could have a moderately large carryover effect since they not only depend on factors that can vary between assessments (e.g., residential context demands), but also on aspects that vary little or not at all over relatively short periods of time (e.g., degree of disability, or chronic health problems). However, as regards choice and self-determination, small carryover effects could be expected. If we assume the possibility that free choice over basic aspects of life does not depend on any unchangeable personal trait, but on the opportunities available in the context, a lack of correlation is to be expected in a scenario where there is a substantial change in residential dynamics.

The evolution model employed, shown in Figure 1, is useful to answer the research questions of this study. Hence, the first question (i.e., To what extent do people’s status on the
constructs of interest vary following a change in their residential context?) was addressed through the analysis of differences between latent scores obtained in T1 and T2 on each construct. To answer question 2 (i.e., Can the changes noticed be attributed to a change in residential context?), the significance and size of the carryover effects were analyzed. Question 3 (i.e., What type of relationship is there between the support received by the persons, the choices they make, and their level of self-determination?) was approached through the analysis of the significance and size of the paths for each of the cross-sectional models (T1 and T2). To answer question 4 (i.e., Are the relationships between constructs stable after moving from one living context to another or are there changes in the way they are related?), the significance and size of the difference between the regression paths obtained in T1 and T2 were analyzed, changes in how the variables relate to each other suggesting significant differences. Finally, we consider that the residence of origin (family home or institution) could influence the relationships between the variables. Therefore, we estimated the interaction effect between the type of residence at T1 and the regression paths.

<Insert Figure 1>

The models were estimated using partial least square-structural equation modeling (PLS-SEM). PLS-SEM is an alternative approach to covariance-based SEM (Chin et al., 2003; Tenenhaus, 2008). Unlike CB-SEM, PLS-SEM estimates latent variable scores in an iterative sequence of ordinary least-squares regressions (Wold, 1982). PLS-SEM is useful to examine complex relationships between variables, relaxing data distributional assumptions and specification requirements (Chin et al., 2008; Dijkstra, 2010). One of the main advantages offered by PLS-SEM is that it can estimate models with many indicators and latent variables in small sample sizes, generating robust estimations even when the number of observations is smaller than the number of parameters of the model (Dijkstra & Henseler, 2015).

Finally, the latent variables were specified as follows: support was measured using weight indicators that represent the score achieved by the participants on each of the
subscales of the ASPM (Jones & Lowe, 2018). Thus, the factor represents the general level of support needs for participation based on a weighted combination of the indicators of different support areas. The same procedure was followed for the RCS (Hatton et al., 2004), the factor representing a weighted summary of opportunities for choice and decision-making in relevant activities. Lastly, self-determination was directly measured using the answers to the items provided in the San Martín Scale (Verdugo et al., 2014). Materials and analysis code for this study are available by emailing the corresponding author.

Results

Step 1: Model fit and quality criteria

Assessment of the measurement models

First, the quality of the measurement models was examined as a prior step to interpreting the structural model. Table 2 shows the average of the factor loadings, the average variance extracted (AVE) values of each factor, and the composite reliability (CR) and Cronbach’s alpha estimators. Loadings above .708, AVE values above .50, and CR and alpha above .70. are considered acceptable (Hair et al., 2019). In all the cases the thresholds were exceeded, or very close values to them were achieved, with factor loading means between .67 and .72, AVE between .48 and .54, CR between .88 and .93, and alpha between .82 and .90. These results suggest acceptable reliability and convergence validity of the items at both measurement times.

Second, the discriminating validity of the constructs was assessed using the heterotrait-monotrait ratio (HTMT) of correlations (Henseler et al., 2015; Voorhees et al., 2016). Since the HTMT is the mean value of the item correlations across constructs relative to the geometric mean of the average correlations for the items measuring the same construct, high values (> .85) suggest discriminating validity problems. HTMT values ranged between .80 and .49, suggesting an adequate discriminant validity of the factors.
Assessment of the structural model

First, the variance inflation factor (VIF) of both the items (outer model) and the inner model, was used to detect multicollinearity. As a general rule, it is recommended that most of the VIF values be below 3 (Becker et al., 2015). As regards the inner model, VIF values were between 1 and 2.64. In the outer model (Figure 2), VIF values fell within the range of 1.23 to 6.18, with a mean of 3.08, a median of 2.77, and 69% of values falling below the recommended threshold. Since all the VIF values of the inner model were low, and most of the VIF (69%) of the outer model were below the recommended criterion, no reasonable evidence of excessive collinearity was found.

Secondly, the R² values of the endogenous constructs were examined as a measure of the model’s explanatory power (Shmueli & Koppius, 2011; Rigdon, 2012). Figure 2 shows the variance explained in each factor (R²) at each time (T1 and T2). At both moments, the predictor variables explained 24% of self-determination variance in T1, and 45% in T2. Although there are heuristics to interpret R² (e.g., values of 0.75, 0.50, and 0.25 can be considered high, moderate, and weak; Hair et al., 2011), in many cases R² must be interpreted in the actual research context, on the basis of the findings of previous studies that have analyzed relationships between similar constructs (Hair et al., 2019). Very few studies have addressed, using regression-based procedures, the relationship between variables similar to the ones used in this study. Nevertheless, previous results suggest moderate relationships (Bigby et al., 2012; Burke et al., 2021; Stancliffe et al., 2000), which is consistent with the findings of this study.
Step 2: Time-related differences in construct scores

Table 3 shows the result of the paired samples T-test, calculated using the construct scores yielded by the evolution model. A significant increase in the means of the three variables was observed, with medium-small effect sizes in support ($d = .43$) and self-determination ($d = .48$), and a large effect size in choice ($d = .79$). These results indicate that the residential and support change has been accompanied by substantial increases in the intensity of the support provided, in the opportunities of making choices, and in the level of self-determination.

<Insert Table 3>

Step 3: Estimation of regression paths

Figure 2 shows the standardized path coefficients and significance of the inner model, as determined by bootstrapping (10,000 sub-samples). No significant interaction effects were observed between residence at T1 (family home or institution) and the model parameters.

The carryover effect of support was moderately large (.677, $p < .05$), suggesting that, at least partially, the amount of support received by the individuals depends on factors that are stable over time. To a certain extent, this result was to be expected, since part of the support required can depend on conditions that are highly stable over time (e.g., chronic health conditions, or physical or sensory disability). The carryover effect of choice was significant but small (.30, $p < .05$), while the carryover effect of self-determination was non-significant, suggesting that current self-determination does not depend on the former level of self-determination, at least following an important change in residential context.

In model T1, support received did not have a significant impact on self-determination (.20, $p > .05$), but it did on choice (.65, $p < .05$). On the other hand, choice had a moderate and significant impact on self-determination (.49, $p < .05$). In addition, support showed a significant indirect effect on self-determination (.35, $p < .05$). These results suggest that the impact of the support received on the person’s current self-determination is not direct, but fully mediated by
other variables such as the possibility of choosing over everyday aspects that are important for the person.

In model T2, parameters followed very similar patterns: support did not have a direct effect on self-determination (−.02, \( p > .05 \)), but it did on choice (\( .62, \ p < .05 \)), and the indirect effect was significant (\( .42, \ p < .05 \)). Choice, once again, had a significant direct effect on self-determination, although it proved substantially larger than in T1 (\( .67, \ p < .01 \)).

We then tested whether the parameters obtained at T2 were significantly different from those obtained at T1, using the non-parametric Confidence Set Approach (Sarstedt et al., 2011). First, the bias-corrected and accelerated method was used to estimate the confidence interval of the paths (10,000 sub-samples). Subsequently, an analysis was conducted to check whether each path in T1 was within the confidence interval (CI) of its equivalent path in T2. If the value in T1 falls within the CI of T2, no significant differences between both paths can be proved. All the paths in T1 fell within the CI of the paths in T2, except for the path between choice and self-determination, which was substantially stronger at T2 (difference = \( .18, \ p < .05 \)). This result suggests that the same relationship dynamics are taking place in the residential facility and the community context. However, certain aspects of the relationship are substantially strengthened after moving into the community, since the impact of opportunities to choose on self-determination was significantly higher in the community context.

**Discussion**

The purpose of this study was to assess the extent to which people's choice-making opportunities and self-determination, as well as the support received, changed after moving into community houses where professionals provide more personalized supports. It also sought to study how the pattern of effects of the support received and choices made on self-determination is shaped. Likewise, another aim was to study the stability of the constructs as well as the relationships between them after the change in residential context.
After participants in this study moved to houses in the community, their levels of self-determination, choice, and support received significantly increased, the effect size also proving large in the case of choice. These results are consistent with studies that associate deinstitutionalization processes and less restrictive living settings with higher levels of choice, personal control, and self-determination (Bigby et al., 2012; Bigby et al., 2018; Burke et al., 2021; Linehan et al., 2015; McConkey et al., 2016; Neely-Barnes et al., 2008; Stainton et al., 2011). Moreover, the findings suggest that these changes take place relatively fast (six months after changing residence).

The reason for the increase in the amount and intensity of the support received could be the greater participation of the person in daily activities and decision-making processes in the community context, as opposed to the residential setting (Bigby et al., 2018; Cameranesi et al., 2021). Likewise, a significantly and moderately large carryover effect was found in supports received before and after the transition. This stability could be due to the fact that part of the support that a person needs depends on aspects that are relatively stable and have little potential to change, such as the existence of other disabilities or associated health issues, conditions that frequently affect people with extensive support needs (Mansell, 2010) and remain stable over time, influencing the support needs in other areas of their lives (Arias et al., 2020).

By contrast, small carryover effects were found in choice and self-determination. This suggests that participants’ former levels of self-determination and opportunities to choose did not define the levels observed after the transition, and the increase in these variables could be attributed to other context-related factors, such as changes in the support received or the new living environment. This result, which is consistent with previous studies (Jones et al., 2018; Shogren et al., 2015), is regarded as very relevant to promote independent living for people with extensive support needs, as it shows that environmental factors, which can be modified,
play an important role in the design of support strategies and interventions aimed at fostering self-determination in those who need more intensive supports.

According to the results obtained, the support received is not a direct predictor of individual self-determination, the latter being conditioned by the person’s opportunities to make choices. The increase in self-determination after the change in residential context suggests, therefore, an important impact of the support provided in the community setting on the person’s opportunities to make decisions on day-to-day aspects. The residential context change was accompanied by staff training processes in methodologies such as active support, positive behavioral support, and person-centered planning, which are known to provide people with greater control over their lives, improving their quality of life (Beadle-Brown et al., 2021; Lin et al., 2020). Hence, the findings suggest that, in the new housing context, where certain conditions that are typical of institutions (such as rigid routines) are no longer present, support is focused to a larger extent on promoting the person’s choice, and when the possibility of choice is available, a direct impact on self-determination is observed. In other words, the support received will only have a positive impact on self-determination in people with extensive support needs if such support effectively promotes their participation in decision-making processes.

The importance of choice and control for the improvement of other aspects such as social inclusion, interpersonal relationships, satisfaction, and self-esteem, has been noted in other studies (Frounfelker & Bartone, 2021; Mehling & Tassé, 2015) and can be generalized to the population without IDD (Deci & Ryan, 2012), whereas restrictions on the possibility of choosing are associated with depressive mood states (Gurland et al., 2010). For this reason, special attention should be placed on ensuring that the processes of deinstitutionalization and promotion of independent living are not limited to merely relocating the person. It is, therefore, necessary to adopt strategies for transforming how supports are provided (Verdugo
et al., 2021), respecting the people’s preferences and fostering their possibilities of making choices in daily life.

The findings of this study should be interpreted considering its limitations. First, only two measurement time points were included, which hinders research on relevant aspects such as how the relationship between constructs evolves in the medium and long term. Second, given the sample’s characteristics, all the instruments used in this study relied on proxy response which is considered valid for this population (Bertelli et al., 2019; Cameranesi et al., 2021). However, it is advisable to also gather the person’s subjective view when assessing individual quality of life and self-determination, because proxies might rate it lower (Mumbardó-Adam et al., 2023; Shogren et al., 2021). Future research should continue to delve into the possibilities of other methods that can gather the perspective of people with extensive or pervasive support needs using ethnographic or creative approaches (Cluley, 2017; Maes et al., 2021). Similarly, direct observation, despite its cost, allows researchers to improve the reliability and validity of information by being able to contrast the results of observation with information obtained from questionnaires and interviews.

Third, although the sample’s size met the requirements to ensure power, and the estimation algorithms used are practicable for small samples, a larger sample would have enabled more thorough analyses that could include other personal and contextual variables, as well as improve the generalizability of results. Lastly, due to ethics issues, an aleatory selection of the sample was not possible. It is important to note that the project is focused on the desires of people with IDD and their families. Future research could incorporate a comparison group who desire to remain living in residences. Having these two groups would allow us to analyze whether the typical characteristics of institutions (such as restrictions or segregation from the community) might hinder changes in support provision and individuals’ quality of life.

Despite its limitations, this study focuses on people with intellectual disabilities who require extensive support, a population group that is often underrepresented in the literature.
(Cameranesi et al., 2022; Maes et al., 2021). The results can likewise be considered for the design and improvement of services and supports aimed at this group, guiding them to a greater extent towards fostering the person’s opportunities to choose because if supports are not geared towards facilitating autonomy in daily decision-making, there will be no improvement in quality of life.

References


https://doi.org/10.3109/13668250.2017.1350835


Cameranesi, M., Chimney, K., & Shooshtari, S. (2022). Changes in the quality of life of persons with profound intellectual and multiple disabilities following community transition: A

https://doi.org/10.1016/j.ridd.2022.104360


https://doi.org/10.1046/j.1468-3156.2002.00165.x


https://doi.org/10.1177/17446295231189020


https://doi.org/10.2753/MTP1069-6679160402


http://oro.open.ac.uk/55664/1/FINAL%20MOVING%20AHEAD%20MAIN%20REPORT%20pdf.pdf


Stainton, T., Brown, J., Crawford, C., 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

https://doi.org/10.1111/j.1365-2788.2010.01378.x


Verdugo, M. A., Schalock, R. L., & Gómez, L. E. (2021). The quality of life supports model: twenty-five years of parallel paths have come together [el modelo de calidad de vida y
apoyos: la unión tras veinticinco años de caminos paralelos. Siglo Cero, 52(3), 9-28

http://dx.doi.org/10.14201/scero2021523928


Figure 1

Evolution Model
Figure 2

Estimated Model

Note. The values inside the circles are the R2 values
Table 1

*Characteristics of the sample*

<table>
<thead>
<tr>
<th>Variables</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous living arrangement</td>
<td></td>
</tr>
<tr>
<td>Residences for people with IDD</td>
<td>63.0</td>
</tr>
<tr>
<td>Family home</td>
<td>29.6</td>
</tr>
<tr>
<td>Non-specific residences for people with IDD</td>
<td>3.7</td>
</tr>
<tr>
<td>Other residential settings</td>
<td>3.7</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
</tr>
<tr>
<td>Unspecified intellectual disability</td>
<td>42.6</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>29.5</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>14.8</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>9.3</td>
</tr>
<tr>
<td>Other syndromes</td>
<td>3.8</td>
</tr>
<tr>
<td>Level of intellectual disability</td>
<td></td>
</tr>
<tr>
<td>Severe/profound</td>
<td>53.7</td>
</tr>
<tr>
<td>Moderate</td>
<td>24.1</td>
</tr>
<tr>
<td>Mild</td>
<td>7.4</td>
</tr>
<tr>
<td>Unknown</td>
<td>14.8</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>61.1</td>
</tr>
<tr>
<td>Physical disability</td>
<td>40.7</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>7.4</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>3.7</td>
</tr>
<tr>
<td>Mental health conditions</td>
<td>40.7</td>
</tr>
<tr>
<td>Acquired brain injury</td>
<td>5.6</td>
</tr>
<tr>
<td>Challenging behaviour</td>
<td>79.2</td>
</tr>
</tbody>
</table>
Table 2

*Measurement quality indicators*

<table>
<thead>
<tr>
<th>Construct</th>
<th>Mean of loads</th>
<th>AVE</th>
<th>CR</th>
<th>Cronbach alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supports (T1)</td>
<td>0.70</td>
<td>0.50</td>
<td>0.89</td>
<td>0.86</td>
</tr>
<tr>
<td>Supports (T2)</td>
<td>0.71</td>
<td>0.52</td>
<td>0.92</td>
<td>0.89</td>
</tr>
<tr>
<td>Choices (T1)</td>
<td>0.66</td>
<td>0.48</td>
<td>0.83</td>
<td>0.82</td>
</tr>
<tr>
<td>Choices (T2)</td>
<td>0.72</td>
<td>0.53</td>
<td>0.88</td>
<td>0.87</td>
</tr>
<tr>
<td>Self-det. (T1)</td>
<td>0.72</td>
<td>0.54</td>
<td>0.93</td>
<td>0.92</td>
</tr>
<tr>
<td>Self-det. (T2)</td>
<td>0.69</td>
<td>0.49</td>
<td>0.91</td>
<td>0.90</td>
</tr>
</tbody>
</table>

*Note.* AVE=Average variance extracted; CR=Composite reliability.
Table 3

*Paired Samples T-Test (rescaled latent scores)*

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Statistic</th>
<th>df</th>
<th>p-value</th>
<th>Mean difference</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support T1</td>
<td>Support T2</td>
<td>-2.74</td>
<td>38</td>
<td>0.009*</td>
<td>-6.57</td>
</tr>
<tr>
<td>Choice T1</td>
<td>Choice T2</td>
<td>-5.05</td>
<td>39</td>
<td>&lt;.001*</td>
<td>-12.1</td>
</tr>
<tr>
<td>Self-det T1</td>
<td>Self-det T2</td>
<td>-2.43</td>
<td>24</td>
<td>0.023*</td>
<td>-14.63</td>
</tr>
</tbody>
</table>