



Empowering lives: How deinstitutionalization and community living improve the quality of life of individuals with intellectual and developmental disabilities

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ABSTRACT

Background: The number of people with intellectual and developmental disabilities (IDD) living in residential settings has not changed substantially in recent years in Spain. To change this situation the project “My House: A Life in the Community” aims to promote the transition of individuals with IDD and high support needs into community settings.

Aims: This paper deepens the understanding of the underlying mechanisms responsible for the changes observed in the process of deinstitutionalization.

Methods: A longitudinal study was designed to evaluate the quality of life of individuals with IDD ($n = 90$) across different environments at two distinct time points: when they were living in an institution and nine months after transitioning to a community-based setting. A comparison group ($n = 72$) consisting of individuals who remained institutionalized was included to carry out intergroup comparisons. *T*-tests were used to estimate mean differences both between and within groups. Longitudinal path models were used to investigate the processes underlying the relationships between variables.

Results: After transition, movers obtained significantly higher mean scores on all variables with large or very large effect sizes. However, simply moving to a different place was not the factor responsible for the observed improvements: positive changes in quality of life require the constant availability of opportunities to support decision making.

Implications: deinstitutionalization will only lead to improvements in quality of life if it favors people's control over their lives. Community living should therefore be understood not as an autonomous life but as a chosen one.

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What this paper adds?

Previous studies have shown that community settings enhance the quality of life of people with intellectual and developmental disabilities (IDD). However, studies to date have mostly been limited to cross-sectional comparisons of relatively small groups, failing to explore the underlying mechanisms of change and improvement after deinstitutionalization. This work contributes to expanding existing knowledge on this matter by focusing on variables other than quality of care, which has been the main focus of past research (Bigby & Beadle-Brown, 2018). It does so by prioritizing the inclusion of individuals with extensive support needs and through a longitudinal design that includes a group of individuals who remained institutionalized. The results showed that people with IDD, including those with higher support needs, saw their quality of life improved in community settings. However, for these improvements to take place, supports are needed to promote personal choice and decision making.

1. Introduction

Individuals with intellectual and developmental disabilities (IDD) have the right to live and participate in the community with the supports they may need. However, in the specific case of Spain, the country in which this paper is framed, there is still insufficient development of community-based services (United Nations, 2019; Verdugo & Jenaro, 2019).

For people with IDD, living in what is known as an “institution” means experiencing little or no control over their lives due to professional practices strongly associated with institutional culture, such as depersonalization (European Commission, 2009; Mansell & Beadle-Brown, 2010), among other factors. For this group, deinstitutionalization processes translate into improvements in self-determination and decision making (Bigby et al., 2017; Bredewold et al., 2020; Conder & Mirfin-Veitch, 2020; McCarron et al., 2019; McConkey et al., 2016) and participation (Verdonschot et al., 2009; Walsh et al., 2010), as well as greater satisfaction with their own lives (Bredewold et al., 2020; Chowdhury & Benson, 2011; Kozma et al., 2009; McCarron et al., 2019).

However, transitioning to community living settings poses singular difficulties for those with extensive or pervasive support needs. This heterogeneous group, in addition to presenting significant limitations in their intellectual functioning and adaptive behavior, may present other medical, physical, and mental health conditions (Mansell, 2010; Nakken & Vlaskamp, 2007; Navas et al., 2017) that require more frequent and intense supports. Perhaps for this reason, people with IDD and high support needs have not traditionally been considered in deinstitutionalization processes (Björnsdóttir et al., 2015; Burke et al., 2021) and have very few opportunities to choose where or with whom to live (Esteban et al., 2023; Salmon et al., 2018).

This situation is accompanied by a paucity of studies on community living in this group, as pointed out by several authors (McCarron et al., 2019; Salmon et al., 2018; Stoeckel et al., 2022)—perhaps due to the difficulties involved in accessing this population (Maes et al., 2021). With some exceptions (e.g., Bredewold et al., 2020), the few studies that have been conducted suggest positive results in their general quality of life and in specific quality-of-life domains such as self-determination (Bigby et al., 2018; Cameranesi et al., 2022; Kilroy et al., 2015; Leaning & Adderley, 2015; McCarron et al., 2019; Navas et al., 2024). However, most of the studies lack a comparison group to analyze the extent to which positive changes—if any—can be attributed to the deinstitutionalization process, and when this group does exist, it is either small in size or longitudinal data on their quality of life is not collected (Cameranesi et al., 2022; Jones & Gallus, 2016; Karban et al., 2013; Kilroy et al., 2015; McCarron et al., 2019; Owen et al., 2015).

A recent study involving people with profound intellectual and multiple disabilities and complex care needs shows that transition to the community is associated with improvements in all dimensions of quality of life (Cameranesi et al., 2022); it hypothesizes that these results could respond to the fact that living in smaller houses favors people's decision making regarding their everyday life. Therefore, it seems that self-determination plays a key role in these processes. The concept of self-determination has its historical roots in the independent living movement (Nirje, 1969) and is now defined as “a dispositional characteristic manifested as acting as the causal agent in one's life” (Shogren et al., 2015, p. 258). The concept of self-determination goes far beyond autonomy and can therefore be exercised by those with greater support needs (Wehmeyer, 2005).

Self-determination, as a strategy to improve quality of life, should be promoted in two complementary ways: by supporting the development of personal talents and skills related to self-determination (e.g., decision making) and by building personal growth opportunities that enhance the ability to act as a causal agent (Mumbardó-Adam et al., 2024). Although deinstitutionalization can contribute to setting in motion processes that increase control over one's life, such as decision making, we know of no research that has shown that a better quality of life will be achieved if this occurs. Research to date has mostly focused on analyzing the role of contextual factors such as housing size or location, professional training, or person-centered practices to increase decision-making opportunities for those moving into community settings (e.g., Kilroy et al., 2015; Humphreys et al., 2020; Owen et al., 2015). However, it has not demonstrated whether such opportunities are responsible for the observed improvements in quality of life, even though personal choice has been identified as a main element of the supports system within the Quality of Life and Supports Model (Gómez et al., 2021).

As noted by Stancliffe et al. (2023), there is still a need to further explore factors that are key to improvements in overall quality of life. To do so, this paper attempts to deepen the understanding of the underlying mechanisms responsible for the changes observed in a process of deinstitutionalization initiated in Spain in 2022. The Spanish Government's Recovery, Transformation, and Resilience Plan, supported by NextGenerationEU funds, aims to achieve full inclusion of people at risk of exclusion by testing elements of innovation in social services that enhance community participation. To do so, the Ministry of Social Rights and 2030 Agenda has financed 20 pilot projects focused on deinstitutionalization, prevention of institutionalization, and the promotion of community participation.

This paper analyzes one of these projects, “Mi Casa: Una Vida en Comunidad” (“My House: A Life in the Community,” hereinafter, Mi Casa Project), run by the main disability service provider in Spain, Plena inclusión. This project aims to implement housing models in the community for people with IDD, especially for those with extensive or pervasive support needs, who were living in institutions

prior its implementation. Throughout this project, individuals with IDD move into a new living context within their communities, while support professionals seek to allow each person to decide how they want to live, focusing each relocation on individual needs and desires. These processes are combined with intensive training for direct support professionals in methodologies such as active support, positive behavioral support, and person-centered planning, which are known to provide people with IDD with greater opportunities to participate in and make decisions over their own lives (Beadle-Brown et al., 2021).

A longitudinal study was designed to compare the quality of life of people with IDD in different contexts and at two time points: when still living in the institution and in a community setting nine months later. We incorporated a comparison group made up of individuals who remained institutionalized (see Section 2) with the aim of performing intergroup comparisons as well. The groups are referred to as movers and stayers, respectively.

It is hypothesized that the deinstitutionalization process will yield positive outcomes among movers, such as increased access to and participation in daily activities that may improve some aspects of their quality of life (i.e., direct effect). These improvements will not be observed among stayers. It is further hypothesized that experiencing control over one's life ("control" being represented by the degree to which the person makes choices in their daily life) is a necessary means for deinstitutionalization to have a positive effect on people's overall quality of life (mediation effect). Other variables, such as age, sex, or the intensity of the support needs, will not be as important as decision making in improving individuals' quality of life.

2. Methods

2.1. Participants

The participants in this study were 162 people living in institutions (i.e., nursing homes and residential settings) located in different regions across the country and managed by 20 service providers. These individuals with IDD had a history of institutionalization ranging between six and 50 years ($M = 14$; $SD = 10.3$).

The group of movers consisted of 90 participants (55.6 %). Their selection was conditioned by the short-term desire of each person to move out of the institution in accordance with their life project. They moved into 25 houses in the community, most of them with three or four places. Stayers ($n = 72$; 44.4 %) were then selected within each service provider and institution. Following the procedure described in Cullen et al. (1995), as each person moved, a person with IDD who was not due to move was identified. Movers and stayers were matched on the criteria of age ($t = 1.53$, $p = 0.127$), sex ($\chi^2 = 0.564$, $p = 0.453$), length of institutionalization ($t = -1.02$, $p = 0.306$), and support needs ($t = -0.112$, $p = 0.456$). This selection was made within each of the participating service providers and institutions because organizational culture constitutes an important factor that could influence the process of deinstitutionalization and its results (Humphreys et al., 2020; Owen et al., 2015). For this reason, there were fewer stayers than movers, since it was not possible to perform the described matching procedure in all cases.

The sample of movers was made up of 90 people with IDD, 75.66 % of whom had extensive or pervasive support needs. All of them were adults between the ages of 18 and 76 ($M = 46.1$; $SD = 15.3$), and 56.7 % were males. Of the sample, 26 people (29 %) were described as having a severe or profound intellectual disability. Among the group of stayers, 66 % had extensive or pervasive support needs. Their ages ranged between 22 and 78 ($M = 47.6$; $SD = 13.2$), and 62 % were males. Of the sample, 21 people (29.4 %) were described as having a severe or profound intellectual disability.

The data for people with IDD at different time points were obtained through interviews conducted by six interviewers, all of them women and psychologists, with ages ranging from 26 to 35 years old. All interviewers received specific training prior to data collection. They interviewed participants' direct support professionals, who were mostly women and knew the person with IDD for at least three months and saw them on a daily basis. The professionals who were to provide supports to movers in the new community settings were all trained (if they did not already have this background) in person-centered planning, active support, and positive behavior support.

2.2. Instruments

The following measures were used:

- Active Support Participation Measure, ASPM (Jones & Lowe, 2018): This questionnaire assesses frequency of participation in the last four weeks and registers the amount of support needed (i.e., help for most of the steps of the task, help for a few steps of the task, or no help needed) and the type of assistance given to the person (i.e., physical assistance, verbal support, or supervision) for actively participating in a total of 99 daily life activities related to food and drink preparation, self-care, household chores, use of household appliances, shopping, community activities, leisure and free time, and occupational activity. Psychometric analysis indicated adequate internal consistency of the scale (Navas et al., 2024).
- Resident Choice Scale, RCS (Hatton et al., 2004): This instrument assesses the opportunities available for the person with IDD to exercise choice in a total of 26 aspects related to everyday life (personal appearance, major home decisions, meals, staffing issues, employment/daytime activity, leisure/relationships, household appearance/possessions, and household routines). Designed for proxy respondents, the RCS uses a 4-point Likert scale format, ranging from 1 (*no opportunities and no support to make decisions*) to 4 (*procedures in place for the person to make his or her own choices*). The scale has high internal consistency ($\alpha = .95$).
- San Martín scale (Verdugo et al., 2014): This questionnaire aims at measuring the quality of life of people with IDD and the lowest levels of functioning. Proxies who know the person assessed very well answer 95 items organized around the eight domains of

quality of life proposed by [Schalock and Verdugo \(2002\)](#), using a 4-point Likert scale (1 = *never*, 2 = *sometimes*, 3 = *often*, and 4 = *always*). The Cronbach's alpha coefficient for the total scale is .97 ([Verdugo et al., 2014](#)).

2.3. Procedure

Data collection was carried out at two different points in time: before transition to the community and nine months after the move. The research team moved to both living environments (i.e., institutional and community) and implemented the instruments through a structured interview with the reference professional of the person with IDD being assessed. The interviews were conducted individually and lasted around 1.5 hours. Informed consent was obtained from both professionals and individuals with IDD (or their legal representatives, if necessary) before starting the interviews.

The study data were collected and managed using REDCap (Research Electronic Data Capture), a secure web-based software platform designed to support data capture for research studies ([Harris et al., 2019](#)) hosted at (deleted for peer review). The research project and its design were approved by the Bioethics Committee of the same university.

2.4. Data analysis

Data analysis was conducted in three stages. First, since quality of life and supports for participation (measured by the San Martín scale and ASPM, respectively) are complex constructs consisting of a large number of dimensions, we used confirmatory factor analysis to investigate whether it was possible to reduce the information to a unidimensional level that would allow for the use of a general single indicator for each construct, as has been suggested in other studies using this type of general index (e.g., [Verdugo et al., 2010](#)). To this end, we analyzed the fit of each data set to the unidimensional confirmatory model, as well as the convergent validity (average variance extracted, AVE) and internal consistency of the scores (Cronbach's alpha and McDonald's omega).

In the second phase, we used *t*-tests to estimate mean differences in quality of life, choices (as measured by the RCS), and supports for participation both between groups (i.e., differences between movers and stayers before and after the deinstitutionalization process began) and within groups (i.e., changes observed between the first and second measures in each group).

In the third phase, we used a "change model" ([Roemer, 2016](#)) to investigate the processes underlying the relationships between variables through a path model. The purpose of a change model is to examine how change over time in a particular construct affects change in other constructs assessed during the same period. To do this, we created a new set of variables, where each new construct was the result of the difference between the factor scores obtained before (T1) and after (T2) deinstitutionalization. For example, the new variable "change in quality of life" could take positive, negative, or null values (0), representing an increase, decrease, or no change between T1 and T2, respectively. We developed two models (M1 and M2), shown in [Figs. 1 and 2](#).

In M1, the variable "change in residential service" or cRes (coded as 0 = *person remains in the residential facility* and 1 = *person moves to community living*) directly predicts changes in quality of life, supports for participation, and choices. We include three control variables—gender, age, and the presence of extensive or pervasive support needs—so that the model paths can be interpreted as the effect of deinstitutionalization once the effect of the control variables is partialized.

The second model (M2) is a multiple parallel mediation model ([Hayes, 2018](#)) in which deinstitutionalization (cRes in [Fig. 2](#)) acts as the independent variable, change in quality of life (cQoL) acts as the dependent variable, and change in supports for participation (cSP) and choices (cChoice) act as the mediator variables. The model hypothesizes that deinstitutionalization from traditional institutions to community housing will predict positive changes in quality of life, both directly (parameter *a*) and indirectly through changes in supports for participation (parameters *b* and *d*) and choices (parameters *c* and *e*). Thus, the mediation process hypothesizes that

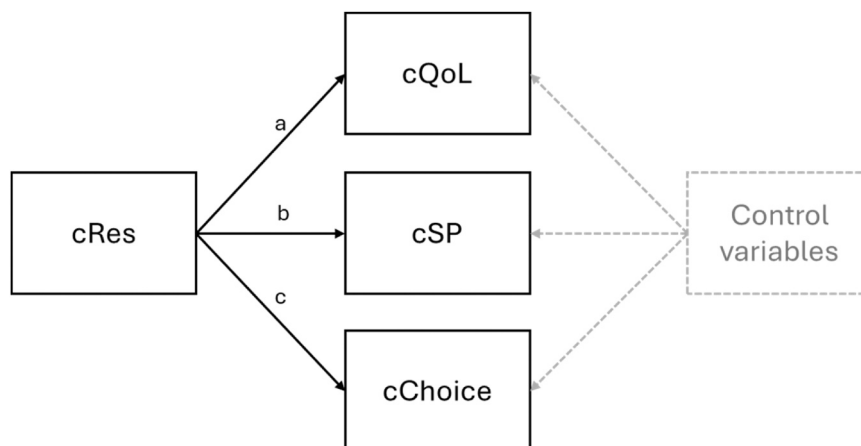


Fig. 1. Conceptual Representation of Model 1. Note: cRes = change in residential setting; cQoL = change in quality of life; cChoice = change in choices; cSP = change in supports for participation. Control variables (age, sex, and presence of extensive or pervasive support needs) are represented together to facilitate the visualization of the figure.

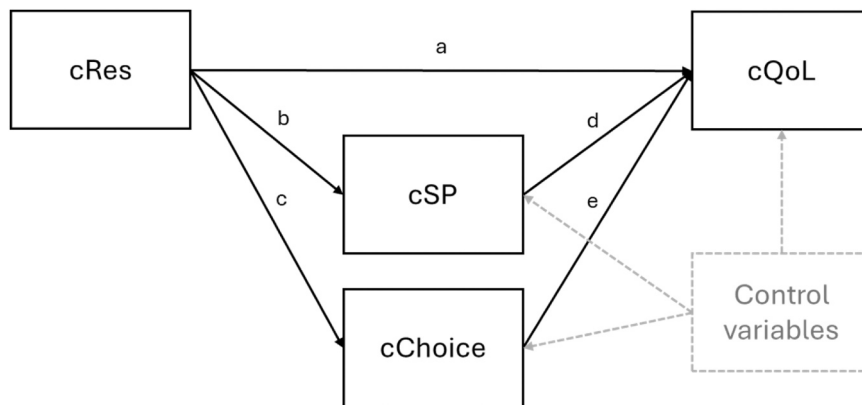


Fig. 2. *Conceptual Representation of Model 2.* Note: cRes = change in residential setting; cQoL = change in quality of life; cChoice = change in choices; cSP = change in supports and participation. Control variables (age, sex, and presence of extraordinary support needs) are represented together to facilitate the visualization of the figure.

improvements in quality of life after deinstitutionalization are at least in part conditional on the new living environment being accompanied by positive changes in participation and autonomy in daily activities.

While it is reasonable to assume that improving supports for participation would lead to increased opportunities for decision making, the opposite phenomenon could also occur, so we did not specify a directional relationship between choice and supports for participation in M2. To determine whether this relationship is recursive or directional, data from three or more time points would be needed to allow for the estimation of models appropriate for causal effects research (e.g., random intercept cross-lagged models; Hamaker et al., 2015). Therefore, we decided to model the relationship between choices and supports for participation by estimating their partial correlation without specifying a causal relationship.

Data analysis was performed using MPlus v.8.1 (Muthén & Muthén, 2023), and JASP v. 0.19 (JASP Team, 2024). For parameter estimation, the possible non-independence of observations from the same institution was taken into account by including a multilevel component in all models (i.e., TYPE= COMPLEX within MPlus).

3. Results

3.1. Phase 1: estimation of the measurement models

Given the low proportion of missing data (mean data coverage > 95 %), all available data were used in the item factor models using full information maximum likelihood (Enders & Bandalos, 2001). Table 1 shows the results of the factor analysis for the final unidimensional models of the San Martín (quality of life), ASPM (supports for participation), and RCS (choices) scales.

In the case of the San Martín scale (QoL), we first created eight parcels from the factor scores obtained after estimating eight unidimensional models from the responses to the items, corresponding to the theoretical dimensions of the instrument. Second, we estimated a unidimensional model using the parcels as continuous indicators (robust maximum likelihood). The fit allowed us to retain the unidimensional model (RMSEA = .05, CFI = .96, TLI = .94), and the scores acquired sufficient convergent validity and internal consistency (AVE = .65, Cronbach's alpha = .91, McDonald's omega = .92).

In the case of the ASPM, each individual indicator receives three scores (frequency, type, and amount of support). Thus, each indicator can be considered as scored by three methods, which theoretically measure partially different facets of the same phenomenon. For this reason, we first estimated a monotrait-multimethod model for each factor to assess the contribution of each of the methods (frequency, quantity, and type) to support measurement, following the recommendations of Verdugo et al. (2019). We found that quantity and type measures shared, on average, 93 % of the common variance, while frequency measures contained, on average, 47 % of method-specific variance. This finding may be because frequency scores are highly dependent on the specific activity being assessed; for example, frequency scores for daily activities such as personal care will be systematically higher than for community leisure activities that are not performed daily. This difference may introduce systematic variance not related to support needs but

Table 1
Results of Confirmatory Factor Analysis.

Instrument	fp (df)	RMSEA (CI)	CFI	TLI	AVE	Cronbach's α	McDonald's ω
QoL	24 (28)	.05 (.00–.08)	.96	.94	.65	.91	.92
ASPM	21 (14)	.06 (.04–.08)	.94	.91	.57	.85	.87
RCS	113 (351)	.08 (.08–.09)	.92	.91	.48	.81	.83

Note: QoL = quality of life; fp = free parameters; df = degrees of freedom; RMSEA = root mean square error of approximation; CFI = comparative fit index; TLI = Tucker–Lewis index; AVE = average variance extracted.

rather to whether the activity being assessed is inherently frequent or sporadic. Consequently, we decided not to use the frequency scores and, given the high convergence of the other two methods, we constructed new scores from a linear combination of amount and type of support. The transformed scores can be interpreted as a general estimate of the support needs associated with participation in home and community activities: an increase in scores indicates an increase in participation and related supports. We then performed the same parceling and factor analysis procedure described for the San Martín scale, obtaining acceptable results (RMSEA = .06, CFI = .94, TLI = .91, AVE = .57, Cronbach's alpha = .85, McDonald's omega = .87).

In the case of the RCS, we estimated the unidimensional model using item responses as ordinal indicators (weighted least squares with mean and variance adjusted). In addition, after analyzing sources of local misfit (Saris et al., 2009), we released five correlations between the residual variances of items that (a) had a modification index greater than 10, (b) had a standardized expected parameter of change greater than 0.3, and (c) had obvious conceptual, syntactic, or semantic similarities. The final unidimensional model showed a reasonably good fit, though with an AVE value slightly below the recommended minimum of .50 (RMSEA = .08, CFI = .92, TLI = .91, AVE = .48, Cronbach's alpha = .81, McDonald's omega = .83).

Once the unidimensional models were fitted, we estimated three sets of factor scores to be used in subsequent analyses (quality of life, supports for participation, and choices).

3.2. Phase 2: mean comparisons

Table 2 shows the descriptive statistics derived from the factor scores. Table 3 shows the results of the mean comparisons between groups at each of the assessment points: before deinstitutionalization (T1) and nine months later (T2). Table 4 shows the results of the within-group contrasts (repeated measures *t*-tests). In five of the 12 contrasts, the normality assumption was not met (Shapiro–Wilk test < .05). However, the magnitude of the skewness and kurtosis indices and the shapes of the Q-Q distributions and density functions suggested that the deviations from normality were small. We also found no evidence of violation of the assumption of homoscedasticity in any of the independent means contrasts (Welch test > .05). Therefore, we decided to use Student's *t*-test in all contrasts.

As expected, movers and stayers did not differ significantly on any of the variables assessed at T1, although power was low in all cases given the sample size and the magnitude of the empirical effect sizes (for $N = 162$, an effect size greater than 0.45 is required to achieve power of .80). In contrast, at T2, movers obtained significantly higher mean scores ($p < .001$) on all variables with large or very large effect sizes (quality of life $d = 1.52$; supports for participation $d = 1.34$; choices $d = 0.91$).

In the repeated measures contrast, movers showed significant improvements on all three variables assessed nine months after deinstitutionalization, with large effect sizes (quality of life $d = 1.00$; supports for participation $d = 0.94$; choices $d = 1.27$). Stayers showed significant improvements of small size in supports for participation ($p = .008$, $d = 0.32$) and choices ($p = .022$, $d = 0.28$) but not in quality of life ($p = .062$, $d = 0.26$).

3.3. Phase 3: path models

Once we verified the existence of relevant effects associated with the deinstitutionalization process, we estimated the path models and the confidence intervals of the estimators (bootstrapping with 10,000 iterations). Fig. 3 shows the results of Model 1.

All three paths were significant ($p < .01$). Since the paths starting from the variable cRes are presented in a partially standardized format, they represent the average between-group difference expressed in standard units, which can be interpreted similarly to a Cohen's *d*. Thus, leaving the institution was associated with strong, positive changes in quality of life ($b = 0.80$), supports for participation ($b = 0.76$), and choices ($b = 1.12$). Control variables had no significant effects ($p > .05$), except for the intensity of the support needs, showing that individuals with greater support needs had moderately more positive changes in choices ($b = 0.31$, $p = .02$) and supports for participation ($b = 0.37$, $p = .003$).

Fig. 4 and Table 5 show the results of M2 (mediation model). The model was able to explain 30 % of the observed changes in QoL. The direct effects suggest a significant and positive association between deinstitutionalization and change in choices ($b = 1.12$, $p < .001$) and supports for participation ($b = 0.77$, $p < .001$). Similarly, we observed significant direct effects suggesting a positive

Table 2
Descriptive statistics (factor scores).

Variable	Measure	Group	Mean	Median	std. dev.
QoL	T1	Stayers	−0.31	−0.37	0.90
		Movers	−0.33	−0.40	1.03
	T2	Stayers	−0.20	−0.12	0.47
		Movers	0.18	0.17	0.38
S/P	T1	Stayers	−0.50	−0.49	0.76
		Movers	−0.25	−0.26	0.93
	T2	Stayers	−0.26	−0.39	0.85
		Movers	0.85	0.70	0.82
Choices	T1	Stayers	−0.51	−0.41	0.61
		Movers	−0.39	−0.36	0.70
	T2	Stayers	−0.40	−0.34	0.67
		Movers	0.59	0.58	0.63

Note: QoL = quality of life scores; S/P = support for participation scores; T1 = first time measure; T2 = second time measure.

Table 3
Results of Independent Samples t-Tests.

Variable	<i>t</i>	<i>p</i>	VS-MPR	Cohen's <i>d</i> (s.e.)	Power ($\alpha = .05$)
QoL (T1)	−1.13	.258	1.05	0.18 (0.15)	.21
S/P (T1)	−1.85	.066	2.05	0.29 (0.16)	.45
Choices (T1)	0.09	.924	1	0.10 (0.18)	.10
QoL (T2)	−5.09	< .001	> 1.000	0.91 (0.19)	1
S/P (T2)	−8.48	< .001	> 1.000	1.34 (0.19)	1
Choices (T2)	−9.62	< .001	> 1.000	1.52 (0.20)	1

Note: QoL = quality of life scores; S/P = support for participation scores; T1 = first time measure; T2 = second time measure; VS-MPR = Vovk-Sellke maximum *p*-ratio; s.e. = standard error.

Table 4
Results of Repeated Measures t-Tests.

Group	Variable	<i>t</i>	<i>p</i>	VS-MPR	Cohen's <i>d</i> (s.e.)	Power ($\alpha = .05$)
Stayers	QoL	−1.91	.062	2.14	0.26 (0.10)	.59
	S/P	−2.73	.008	9.67	0.32 (0.11)	.76
	Choices	−2.38	.020	4.73	0.28 (0.07)	.65
Movers	QoL	−8.69	< .001	> 1.000	1.00 (0.14)	1
	S/P	−8.91	< .001	> 1.000	0.94 (0.16)	1
	Choices	−12.07	< .001	> 1.000	1.27 (0.16)	1

Note: QoL = quality of life; S/P = support for participation; VS-MPR = Vovk-Sellke maximum *p*-ratio; s.e. = standard error.

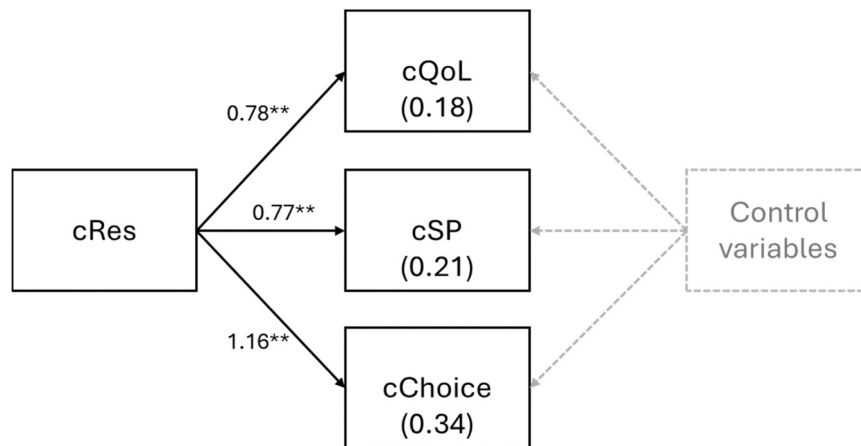


Fig. 3. Results of Model 1. Note: * = $p < .01$; cRes = change in residential setting; cQoL = change in quality of life; cChoice = change in choices; cSP = change in supports for participation. Paths from cRes are partially standardized. Control variables (age, sex, and presence of extraordinary support needs) are represented together to facilitate the visualization of the figure. In parentheses: proportion of variance explained by all exogenous variables.

impact of change in both mediators (i.e., choices and supports for participation) on the observed changes in quality of life ($b = 0.24$, $p = 0.012$ in the case of choice; $b = 0.30$, $p = .001$ in the case of supports for participation). The indirect effects of deinstitutionalization on the observed change in quality of life scores were positive and significant for both mediators ($b = 0.27$, $p = .015$ for choice; $b = 0.24$, $p = .010$ for supports for participation). However, after controlling for the effect of mediators, deinstitutionalization had no significant direct effect on change in quality of life ($b = 0.33$, $p = .176$). In other words, holding constant the level of change in choice and supports for participation, individuals did not differ in their quality of life regardless of whether they participated in the deinstitutionalization process or not. This result suggests that the relationship between change of living environment and improvement in quality of life is fully mediated by changes in the opportunities to make choices and the received supports for participation. Thus, according to our results, the deinstitutionalization process will have little or no effect on quality of life unless it is accompanied by improvements in people's opportunities to make daily choices and to participate in daily activities at home and in the community, as well as in the supports needed to facilitate such participation. Finally, the control variables of age and sex showed no significant effects ($p > .05$), suggesting that the observed changes occur for both men and women of different ages. The presence of high support needs showed significant and positive effects on the change in choices ($b = 0.33$, $p = .03$) and in supports for participation ($b = 0.37$, $p = .003$), indicating that the deinstitutionalization process had a significantly greater positive effect on people with higher support needs.

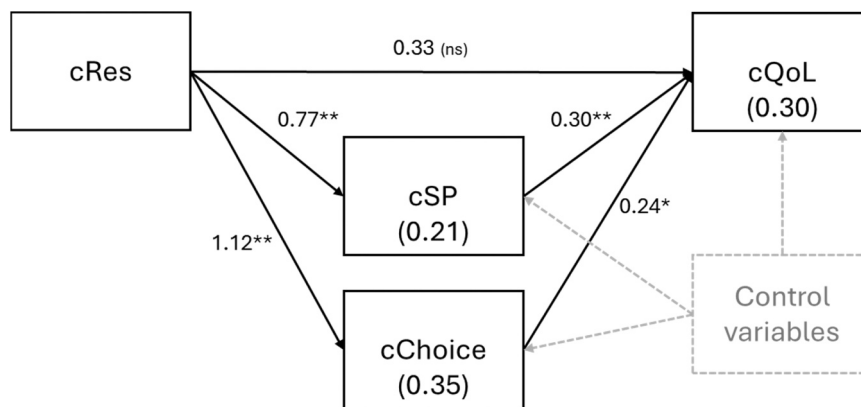


Fig. 4. Results of Model 2. Note: ** = $p < .01$; * = $p < .05$; ns = $p > .05$; cRes = change in residential setting; cQoL = change in quality of life; cChoice = change in choices; cSP = change in supports for participation. Paths from cRes are partially standardized. Control variables (age, sex, and presence of extraordinary support needs) are represented together to facilitate the visualization of the figure. In parentheses: proportion of variance explained by all exogenous variables.

Table 5
Results of Path Model 2.

Effect type	Path	Estimate	s.e.	p
Direct	cRes -> cSP	0.77	0.19	< .001
Direct	cRes -> cChoice	1.12	0.17	< .001
Direct	cRes -> cQoL	0.33	0.24	.176
Direct	cSP -> cQoL	0.30	0.09	.001
Direct	cChoice -> cQoL	0.24	0.05	.012
Specific indirect	cRes -> cChoice -> cQoL	0.27	0.12	.015
Specific indirect	cRes -> cSP -> cQoL	0.24	0.09	.010
Total indirect	cRes -> cQoL	0.48	0.24	< .001
Total	cRes -> cQoL	0.80	0.25	< .001

Note: cRes = change of residential service; cQoL = change in quality of life; cChoice = change in choices; cSP = change in supports for participation.

4. Discussion

In this study, people with IDD significantly improved their quality of life after a process of deinstitutionalization, but the sole fact of moving to a different physical place was not the factor responsible for the observed improvements; rather, underlying causal dynamics explained the positive results achieved. Improvements in quality of life appeared to be completely mediated by two other variables: the supports that the person receives to participate in daily activities and the degree to which the person makes decisions and choices about aspects of their daily life. Both variables have been necessary for the deinstitutionalization process described here to translate effectively into improvements in quality of life. These findings support the idea that community living is not necessarily an autonomous life but as a chosen one. Understanding this is key for appropriate implementation of deinstitutionalization processes. Thus, it is essential to ensure that the processes of deinstitutionalization go beyond simply relocating individuals. It is crucial to implement strategies and professional practices that transform the way support is provided, considering people's preferences, and enhancing their ability to make choices in everyday life.

Changes in the residential environment resulting from deinstitutionalization do not directly affect the participants' quality of life, but they have indirect effects through both improvements in the level of participation in daily activities and people's ability to make choices. This implies that promoting people's participation, autonomy, and control over relevant aspects of their lives may be key to ensuring the effectiveness of deinstitutionalization programs. These findings may also help to explain why the positive outcomes associated with deinstitutionalization processes appear to stabilize or even reverse over time (Chowdhury & Benson, 2011): improvements in quality of life and their long-term maintenance require the constant availability of opportunities that promote choice and decision making. Although decision making is only one of the key aspects of self-determined behavior, this result suggests—as Mumbardó-Adam et al. (2024) hypothesize—that self-determination is not only a quality of life domain but also an important ally when it comes to achieving valued personal outcomes.

This work also provides evidence on the positive effects that deinstitutionalization processes have on people with high support needs—a group for which research, especially of a longitudinal nature, has been scarce to date (McCarron et al., 2019; Salmon et al., 2018; Stoeckel et al., 2022). Thus, nine months after the move, individuals with IDD and higher support needs experienced even greater changes than their housemates. These results are quite relevant for Spain at a time when the government has just approved the “Strategy for a New Model of Care in the Community: A Process of Deinstitutionalization (2024–2030),” as they will help ensure that

changes in the provision of supports or services under this strategy do not leave behind the individuals with the most significant disabilities.

Other variables referring to the person, such as age or gender, had no effect on the observed results. With regard to age, being older could mean a longer history of institutionalization that may hinder the achievement of positive outcomes (Stancliffe et al., 2023), though Ireland (2014, p. 54) suggests that “if a person had spent many years in an institutional setting but is now being offered many opportunities for change, there is no relationship to their score on quality of life.” Regarding gender, although some authors suggest that being male does seem to predict a higher probability of remaining institutionalized or being institutionalized again (Martin & Ashworth, 2010; McConkey et al., 2013), this study—similar to others (Bhaumik et al., 2011; Martin et al., 2018)—found no gender effect once both men and women transitioned to community settings.

Finally, it should be noted that improvements did not occur among stayers (or when changes were observed, they were of a small nature), which allows us to suggest that the deinstitutionalization process and the changes associated with it are responsible for the positive outcomes achieved, since movers and stayers did not show statistically significant differences in the measured variables prior to the move. Furthermore, intragroup differences among movers observed between the two time points also suggests changes can be attributed to the deinstitutionalization process, whereas they were not observed within the group of stayers.

Despite the strengths of this study, some limitations should be noted. First, it was not possible to form both groups (movers and stayers) randomly for several reasons. First, transition to a community setting was determined by the short-term desire of each person to move out of the institution, in accordance with their life project. We selected participants within each organization to constitute the group of stayers that resembled those who were going to move, considering characteristics such as age, length of institutionalization, gender, and the intensity of the support needs. We made this selection within each of the nursing homes or residential settings from which participants came, because organizational culture constitutes an important factor that could influence the process and its results (Humphreys et al., 2020; Owen et al., 2015). For this reason, there are fewer stayers than movers, since not everyone could be matched on the decided criteria.

Second, only two measurement time points were included, which limits research on how the relationship between quality of life, supports, and self-determination evolves in the medium and long term. Future research will also need to include more comprehensive measures of self-determination that assess not only skills related to self-determination, such as decision making, but also agentic actions and action-control beliefs (Shogren & Raley, 2022).

Third, all the instruments used in this study relied on proxy response due to the characteristics of the sample. Future studies should also gather the participants' subjective views, because proxies might provide lower ratings for quality of life (Mumbardó-Adam et al., 2023; Shogren et al., 2021).

Finally, studying the role that the community played in the changes observed was beyond the scope of this paper. Future research should explore, as McCarron et al. (2019) pointed out, community readiness to support people to live in the new settings. There is also no research exploring the extent to which people with IDD who transition to community achieve a quality of life like that of their fellow citizens without any type of disability—an essential aspect of the normalization principle that originally inspired the deinstitutionalization processes. Indeed, it seems that those who move from institutions to community settings are at greater risk of re-institutionalization (Stancliffe et al., 2023). This risk may reflect the fact that necessary changes for inclusion have not occurred in the meso- and macro-system so that people can exercise their right to live in the community as stated in Article 19 of the Convention on the Rights of Persons with Disabilities (United Nations, 2006). Recent developments in the field of intellectual disability such as the Shared Citizenship Paradigm (Schalock et al., 2022) can help achieve these changes while ensuring that the processes of deinstitutionalization are not limited to merely relocating individuals and that they are at the center of every decision-making process concerning their lives.

5. Conclusion

This study provides evidence that people with IDD achieve better quality of life in community settings. It further demonstrates that these positive outcomes are also achieved by people with high support needs, a group that remains in institutions on the wrong belief that community living is an unattainable goal for them. These results are not observed among a group of individuals who remained institutionalized, which indicates that the deinstitutionalization process might be responsible for the improvements observed. Finally, the present study highlights that deinstitutionalization will only lead to improvements in quality of life if supports favor people's autonomy and control over their lives. While contextual changes may impact the degree to which the person with IDD experiences control over their life (Shogren et al., 2015), they cannot be limited to physical aspects of the living environment; they must involve deep transformations in the way that disability organizations deliver supports.

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CRedit authorship contribution statement

Eva Vicente: Writing – review & editing, Writing – original draft. **Laura Esteban:** Investigation, Data curation. **Víctor B. Arias:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Formal analysis, Data

curation. **Patricia Navas:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Laura García-Domínguez:** Investigation, Data curation. **Miguel Ángel Verdugo:** Writing – review & editing, Supervision. **Inés Heras:** Investigation, Data curation. **Paula Rumoroso:** Investigation, Data curation. **Verónica M. Guillén:** Writing – review & editing, Writing – original draft. **Natalia Alvarado:** Investigation, Data curation.

Declaration of Competing Interest

The authors declare no conflict of interest.

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Data availability

Analysis code is available by emailing the corresponding author

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