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Improving Quality of Life and Reducing Behavioral Problems of People With Intellectual and Developmental Disabilities Through Deinstitutionalization

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ABSTRACT

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Keywords: Intellectual and developmental disabilities Extensive support needs Community living Choice Participation Antecedents: People with intellectual and developmental disability (IDD) with extensive support needs are more likely to live in segregated and highly institutionalized environments. The aim of this study was to analyze changes in functioning and quality of life for people with IDD and extensive support needs after transitioning to ordinary homes in the community. Method: The sample included 54 adults with IDD and extensive support needs, who were assessed at three time points: before transition, six months later, and one year after transition. The Resident Choice Scale, San Martin Quality of Life Scale, Active Support Participation Measure, and the Behavior Problem section of the Inventory for Client and Agency Planning were administered. Partial least squares-structural equation modeling (PLS-SEM) and t-tests for repeated measures were carried out. **Results:** There were significant improvements in decision-making, participation and independence in daily activities and quality of life, as well as a reduction in the presence and intensity of behavioral problems. **Conclusions:** The benefits found in this study support transformation processes towards more inclusive services and professional practices that foster people's rights and feeling of belonging to the community.

Mejoras en Calidad de Vida y Reducción de Problemas de Conducta en Personas con Discapacidad Intelectual y del Desarrollo tras un Proceso de Desinstitucionalización

RESUMEN

Antecedentes: Las personas con discapacidades intelectuales y del desarrollo (DID) con grandes necesidades de apoyo tienen más probabilidades de vivir en entornos segregados y altamente institucionalizados. Este estudio pretende analizar los cambios en el funcionamiento y calidad de vida de este colectivo tras la transición a viviendas ubicadas en la comunidad. Método: La muestra incluyó 54 adultos con DID con grandes necesidades de apoyo que fueron evaluados en tres momentos temporales: antes de la transición, seis meses y un año después de la misma. Se aplicaron los instrumentos Resident Choice Scale, la Escala de Calidad de Vida San Martín, Active Support Participation Measure y la sección de Problemas de Conducta del Inventory for Client and Agency Planning. Los datos fueron analizados a partir de modelos de ecuaciones estructurales de mínimos cuadrados parciales (PLS-SEM) y pruebas t para medidas repetidas. Resultados: Se observaron mejoras significativas en toma de decisiones, participación e independencia en actividades ententrados apoyan la necesidad de llevar a cabo procesos de transformación hacia servicios y prácticas profesionales más inclusivas que fomenten los derechos y la pertenencia comunitaria.

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Palabras clave:

Discapacidades intelectuales y del desarrollo Grandes necesidades de apoyo Vida en comunidad Elección; Participación Under the auspices of traditional medical models, people with disability in general, and with intellectual and developmental disability (IDD) in particular, have lived as 'captives' in institutions until well into the twentieth century. According to the definition provided by the European Commission (2009), institutions or segregated environments are places where people have no right to exercise control over their lives.

Comprehensive individual development, including psychological development, can only take place under conditions that protect human rights (American Psychological Association [APA], 2014). Psychology has played an important role in the promotion of and advocacy of some of these rights for people with IDD (Navas et al., 2017), such as the right to self-determination (Wehmeyer, 2006, 2020), quality of life (Gómez et al., 2021; Verdugo et al., 2021), and inclusive education (Amor et al., 2018), among others. However, it has yet to be involved in achieving systemic change that promotes the right to live in the community for all individuals, including those with IDD. The deinstitutionalization movement started to take shape more than 50 years ago and later received a major boost with the adoption of the Convention on the Rights of Persons with Disabilities [CRPD] (UN, 2006). However, there have been no substantial changes in the number of institutionalized people in Europe over the last decade (Šiška & Beadle-Brown, 2020). Deinstitutionalization and independent living are still a challenge for people with IDD, their families, and the professionals that provide them with support, a challenge that is even greater for those with extensive support needs (Jones & Gallus, 2016).

People with extensive support needs, frequently referred to as people with 'profound and multiple intellectual disabilities' (Maes et al., 2021), 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 aforementioned conditions, display severe behavioral problems or mental health issues that significantly limit their functioning' (Navas et al., 2017, p.13).

The transformation that is occurring in the field of IDD towards community-based services and personalized support aimed at improving quality of life and self-determination (Mumbardó-Adam et al., 2023; Verdugo et al., 2021) is having a significant impact on psychologists and other professionals and their involvement in planning support for people with IDD (Schalock et al., 2019). Nevertheless, people with extensive support needs are still more likely to live in highly institutionalized environments (Mansell, 2010; Navas et al., 2017). The professional practices in such environments offer fewer opportunities for selfdetermination and participation, under the perception that the goal of inclusion is very difficult to achieve for this group (Baker, 2007; Beadle-Brown et al., 2015; Bigby et al., 2009; Netten et al., 2010) or that there will be an increase in the cost of services (Mansell, 2010). In Spain, where this study took place, 31,482 people with IDD are still living in institutions, and more than half of them have extensive support needs (Verdugo & Navas, 2017). The development of community-based services remains poor and insufficient (Verdugo & Jenaro, 2019).

Because of this segregation, almost 60% of individuals with IDD and extensive support needs have few or no opportunities to forge friendships, 75% find it difficult to keep in touch with

their relatives, and 70% engage in passive activities outside the community (Verdugo & Navas, 2017).

Inclusion in the community of those who require more support leads to improvements in their adaptive behavior and selfdetermination (Bigby et al., 2018; Young & Ashman, 2004), as well as their quality of life (Cameranesi et al., 2022). Indeed, the studies by McCarron et al. (2019) and Young & Ashman (2004) reported that people with IDD and extensive support needs benefited more from the transition to community living than their peers with disability but less intensive needs. Other studies report that these benefits translated into an improvement in interpersonal relationships (Bigby et al., 2018; Hemmings, 2008), and an increase in participation (Bigby et al., 2018).

Given the improvements that living in the community can entail for this population group, who is frequently excluded from community models, Plena inclusión España (an associative movement that brings together 950 organizations that provide support for people with IDD in Spain) launched a pilot project to promote the transformation of current residential services towards a support and service model aimed at achieving inclusion in the community of those with more significant support needs, helping them to build a life project in 'normal homes, in normal environments'. This project is aimed at promoting deinstitutionalization, but also preventing the future institutionalization of individuals with IDD that are getting older and still live with their families, being likely to outlive their parents or relatives who are their main support (McCausland et al., 2019). Therefore, the project is aimed at promoting the right to live independently for individuals who have been institutionalized or never had the opportunity to emancipate themselves from their parents. With the support of the Administration, the organizations taking part in this pilot project facilitate the transition of individuals with IDD into a new community living context, encouraging that the decision be made by the person with any support that may be required, and focusing each transition on the needs of the person and his or her family. As well as making 11 housing units in the community available (most of them with four places), the project is characterized by intensive training for support professionals in methodologies such as active support, positive behavior support, or person-centered planning (Navas et al., 2022a) that are proven to foster participation, control over one's life, and inclusion in the community (Bowring et al., 2020; Lin et al., 2020; McCausland et al., 2022).

Evaluation of the effectiveness of interventions and programs aimed at raising awareness about rights, exercising and upholding rights, and ultimately improving the quality of life of people with IDD, is desirable and necessary (Gómez et al., 2022, 2023; Morán et al., 2023). So, another of the project's goals is to longitudinally analyze the impact that different living environments might have on the life of people with IDD and extensive support needs, collecting data at three points in time: before the move, six months and one year after transition. Hence, the purpose of this study is to analyze the extent to which people's choices, participation in daily activities, behavioral problems, and quality of life vary after a change in residential setting that was also accompanied by professional training. Drawing from previous literature, which states that community living settings are less restrictive and offer more participation opportunities (Bigby et al., 2012; Burke et al., 2021; Linehan et al., 2015; McConkey et al., 2016), it is hypothesized that six months and one year after the move the participants will score higher on measurement instruments that assess choice, quality of life, and participation in daily activities. On the other hand, it is also expected that the frequency and severity of the participants' challenging behaviors will have decreased.

Method

Participants

The sample was made of 54 people with IDD and extensive support needs (57.4% men) between the ages of 20 and 70 (M = 43.3; SD = 13.2). Before transition, 70.4% of the sample were institutionalized, while the remaining 29.6% were living with their families. The rest of the characteristics of the sample can be consulted in Table 1.

Participants were selected from seven organizations involved in the project. Random sampling was not possible because the project is focused on the desires of people with IDD to move into houses within community settings, desires previously identified by service providers through person-centered planning. The only selection criteria were that all participants had to be people with extensive support needs living in institutions or with their parents and wishing to change their living environment. All participants met these two criteria.

The data regarding people with IDD were obtained through 51 informants, all of them professionals between the ages of 21 and 54 (M = 34.8; SD = 9.0; 84.3% women). Of these professionals 94.1% were direct support professionals, 2% were occupational therapists and 3.9% psychologists.

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). Although it was intended to interview the same informant at each data collection point, this was not possible in all cases (23 of 51 informants participated in all data collection points). 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.

Most professionals (64.7%) were trained by the same agency in person-centered planning, active support and positive behavior support, and 27.5% had been trained in at least one of these methodologies.

Instruments

The level at which the person makes choices in spheres of his or her life was assessed using the Resident Choice Scale, RCS (Hatton et al., 2004). This measure consists of 26 items organized around eight domains that refer to decision-making in different aspects of daily life (Table 2). Designed for proxy respondents, the RCS uses a four-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 choices). The original scale has a Cronbach α of .95, and good interrater reliability (Hatton et al., 2004). There is no Spanish validation of this measure, so a composite reliability analysis for this study was performed (Table 2).

Sample Characteristics

Variable	(%)
Living arrangement before transition	
Residence for people with IDD	63.0
Family home	29.6
Non-specific residences for people with IDD	3.7
Other	3.7
Diagnosis	
Unspecified intellectual disability	42.6
Autism spectrum disorder	29.5
Cerebral palsy	14.8
Down syndrome	9.3
Other	3.8
Level of ID	
Severe/profound	53.7
Moderate	24.1
Mild	7.4
Unknown	14.8
Comorbidities	61.1
Physical disability	40.7
Hearing impairment	7.4
Visual impairment	3.7
Mental health conditions	40.7
Acquired brain injury	5.6
Challenging behavior	79.2

The person's level of participation and the support required to get involved in different daily living activities was assessed using the Active Support Participation Measure, ASPM (Jones & Lowe, 2018). This instrument consists of 108 items that are organized around eight activity domains (specified in Table 3) and must be completed by somebody who is well acquainted with the person with IDD. The frequency of participation of the person in the activity over the last four weeks is to be indicated for each item, as well as the degree of support required and received (i.e., physical assistance, verbal cues, or supervision). As for the RCS, this tool has not yet been validated with the Spanish population, so a composite reliability analysis was carried out for this study (Table 3).

San Martín Scale (Verdugo et al., 2014a), created to assess the quality of life of people with significant disabilities (using proxies who know the person to be assessed very well), was used. The scale has confirmed reliability and validity. The Cronbach's alpha coefficient for the total scale was .97 (Verdugo et al., 2014a, 2014b). It consists of 95 items that are organized around eight quality of life domains (Table 4) proposed by Schalock & Verdugo (2002).

Finally, information on the frequency and severity of behaviors of concern was gathered using the problem behavior section of the Inventory for Client and Agency Planning (ICAP; Bruininks et al., 1986), validated and adapted to Spanish by Montero (1993). This instrument has adequate internal consistency ($\alpha = .80$) and satisfactory test-retest reliability ($\alpha = .88 - .98$) and inter-rater reliability ($\alpha = .92$) (Montero, 1993). The behavioral problems section used in this study gathers the frequency (on a 6-point Likert-type scale from 0 '*never*' to 5 '*once or more in the last hour*') and severity (on a 5-point Likert-type scale from 0 '*it is not a problem*' to 4 '*extremely severe*') of eight types of problem behaviors (Table 5).

Procedure

This study involved the gathering of longitudinal data at three different points in time: before the transition to the community housing units, six months later, and twelve months after the move. The research team moved to both living environments (i.e., institutional –or before transition- and community), where the instruments were implemented by the same person through a structured individual interview with the reference professional of the person assessed, except for the San Martín Scale, which, since it is designed as a self-report by proxies, was completed by the professionals themselves.

Informed consent was obtained from all the participants before starting the interviews. The research project and its design were approved by the Bioethics Committee of the University of Salamanca.

Data Analysis

Given the study's exploratory and predictive nature and the small sample size, the chosen approach was based on partial least square-structural equation modeling (PLS-SEM; Hair et al., 2019). PLS-SEM is a nonparametric technique that makes no assumptions about the distribution of the data and does not require independence of observations (Hair et al., 2019; Rigdon, 2016). Therefore, it can be used with small samples with no major accuracy problems or convergency issues in estimates (Reinartz et al., 2009; Wold, 1982).

The aim of the analysis was to estimate the significance and size of the mean differences between successive assessments (before the move T1, six months after the move T2, and one year later T3) for each latent variable. To obtain the factor scores, we first estimated a PLS-SEM model on the raw data, where the time of the assessment acts as an observable binary predictor variable. Because the PLS algorithm standardizes all variables, when the predictor is a binary variable, the regression path does not have a straightforward interpretation in terms of differences between scores obtained at different time points. To facilitate interpretation of the results, the regression paths were used to estimate the direction and statistical significance of change, and the standardized factor scores were employed to estimate the size of latent mean differences using a repeated-measures t-test. Effect sizes were interpreted according to Cohen (1988): small (from .20 to .50), medium (.50 to .80), and large (greater than .80). Models were estimated using Smart-PLS software (Ringle et al., 2015).

Table 2				
Latent Variable Analysis	and Mean	Comparison	on the	RCS

Results

The results are presented separately in the sections "Choice", "Participation in Activities and Received Support", "Quality of Life" and "Behavioral Problems".

Choice

Table 2 shows the results for the Resident Choice Scale factors: the standardized regression parameter of each model (Beta), the probability associated with the null hypothesis of equality of scores between evaluation moments, the effect size (Cohen's d), and the composite reliability analysis. After six months in the new residential setting, there was a statistically significant increase in people's opportunities to make choices in their everyday lives, except for decisions related to "meals" and "staffing issues". Effect sizes were small for "employment/daytime activities", moderate for "personal appearance" and "leisure/relationships", and large for "major home decisions", "household appearance/possessions" and "household routines".

The analysis of the participants' scores at six months and one year after transition into the community yielded no statistically significant differences, except in the "meals" and "household routines" variables. This result implies that the improvements in the opportunities for decision-making that were observed at six months from the move were still present one year after the transition. In the case of "meals" and "household routines" there were significant and positive differences of a moderate size, which suggests improvements in these two areas that had not been previously observed (in the case of "meals") or that continued to increase people's opportunities to choose (in the case of "household routines"). Opportunities to make decisions concerning aspects related to support professionals remained unchanged over time.

Participation in Activities and Received Support

An index based on the amount and type of support received by the person to carry out an activity over the last month was calculated for each of the ASPM domains (Table 3). Since item scores range from 0 (highest level of support) to 3 (lowest level of support), the higher the score on each factor, the lower the support required (i.e., greater autonomy in performing the activity).

Variable	Beta	Prob.T1=T2	d	CR	Beta	Prob T2=T3	d	CR			
Personal appearance	.31	.03*	.62	.81	18	.19	21	.71			
Major home decisions	.41	<.001**	.88	.85	15	.87	02	.83			
Meals	.16	.26	.32	.85	.34	<.001**	.57	.87			
Staffing issues	.20	.10	.40	.78	07	.07	29	.79			
Employment/ daytime activity	.24	.02*	.49	.74	.20	.40	.13	.72			
Leisure/ relationships	.35	<.001**	.73	.74	.16	.53	.10	.75			
Household appearance/possessions	.38	<.001**	.82	.84	.21	.77	.04	.82			
Household routines	.42	<.001**	.89	.84	.31	<.001**	.47	.81			

Note. CR = composite reliability; *= significant difference (p < .05); ** = significant difference (p < .01); d = Cohen effect size; Beta = standardized regression between the time of assessment and the latent scores on the factor (positive values other than zero suggest systematic differences in favor of the second time of assessment).

As shown in Table 3, six months from the transition there was a statistically significant increase in scores for most of the domains, which means fewer support needs and therefore greater autonomy, in activities related to meal preparation, use of household appliances, occupational activities, and household chores, with large effect sizes except in the occupational domain, where the effect size was medium. Such increases remained at one year, except in the occupational domain, where significant changes in the negative direction were reported. Regarding community and self-care dimensions, a significant decrease in autonomy was reported at six months, but one year after the move there were significant improvements with a medium effect size. No significant differences were registered for the shopping and leisure dimensions at any of the assessment times.

Quality of Life

Table 4 shows the results of the quality of life analysis at group level. All the variables (i.e., quality of life domains) achieved sufficient reliability to be analyzed except for self-determination and physical wellbeing at times T2-T3 because of the low composite reliability indexes obtained in T3 (CR < .70), which precluded analysis. In all cases, there was a significant increase in quality of life scores six months after the move, with generally large effect sizes (between .58 and 1.1). No changes in T3 were registered in personal development, social inclusion, and interpersonal relationships, which indicates that the improvements observed at six months were maintained one year later. By contrast, positive and significant differences were reported in emotional well-

Table 3						
Results of Latent	Variable Analysis	and Differences	Between	Means or	the A	SPM

being, material well-being, and rights, which suggests that these dimensions continued to grow over time.

Behavioral Problems

We observed a high variability in the prevalence of behavioral problems at T1, ranging from 15 cases of destruction of property (29%) to 35 cases of stereotypies (64%). Given the large reduction in sample size and the consequent loss of statistical power, we decided to limit the analysis to the description of the frequency and severity of problem behaviors at different time points. Table 5 shows the group-level descriptive statistics at each moment of assessment, and for each of the challenging behaviors assessed. Six months after the move, a reduction in average frequency at group level was reported for all the behavioral problems assessed: from 13% in self-injury to 54% in non-collaborative behavior. One year later there was a high level of continuity of the improvements observed at six months. In certain cases, the frequency observed dropped even more one year after (hetero-aggression, destruction of property, stereotypies, and withdrawn behavior).

Regarding the severity of the problem behaviors, Table 6 shows that the results keep pace with those observed for frequency, although with more noticeable improvements six months after the move, with reductions in severity between 19% (self-harm) and 58% (uncooperative behavior). Once again, there was continuity of the improvements observed one year after transition, and the severity even improve for self-injury (38%), hetero-aggression (72%), destruction of property (68%), and stereotypies (49%).

5	55							
Variable	Beta	Prob.T1=T2	d	CR	Beta	Prob.T2=T3	d	CR
Meals	.45	<.001**	1.00	.91	10	.37	20	.91
Shopping	.15	.17	.30	.93	.11	.05	14	.93
Community	26	.01*	54	.94	.40	.01*	.56	.94
Self-care	33	<.001**	69	.91	.56	<.001**	1.36	.91
Household appliances	.49	<.001**	1.17	.94	22	.32	.21	.94
Leisure	.16	.15	.31	.83	.18	.14	.33	.83
Occupational	.27	.01*	.55	.74	27	<.001**	87	.74
Household chores	.44	<.001**	.96	.88	.17	.10	34	.88

Note. CR = composite reliability. d = Cohen effect size. Beta = standardized regression between the time of assessment and the latent scores on the factor (positive values other than zero suggest systematic differences in favor of the second time of assessment). * p < .05. ** p < .01

Table 4

Resul	ts oj	the	Quality	oj	^c Life	Anal	ysis	at	Group	Level	
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Variable	Beta	Prob.T1=T2	d	CR	Beta	Prob.T2=T3	d	CR
Self-determination	.42	<.001**	.92	.92	na	na	na	<.70
Emotional well-being	.51	<.001**	1.16	.93	.60	<.001**	1.24	.85
Physical well-being	.36	<.001**	.77	.90	na	na	na	<.70
Material well-being	.41	<.001**	.90	.90	.55	<.001**	1.01	.89
Rights	.54	<.001**	1.19	.91	.64	<.001**	1.19	.77
Personal development	.33	<.001**	.71	.95	.12	.54	.21	.87
Social inclusion	.29	.02*	.59	.94	35	.31	.14	.91
Interpersonal relationships	.44	<.001**	.94	.91	.56	.10	.34	.92

Note. CR = composite reliability. d = Cohen effect size. Beta = standardized regression between the time of assessment and the latent scores on the factor (positive values other than zero suggest systematic differences in favor of the second time of assessment), na = not applicable.

* *p* < .05. ** *p* < .01

Table 5					
Average Group Scores R	egarding the Frequency	of Behavioral Problem	s at Different	Points in Ti	me

	-					
Category	n	Average frequency T1	Average frequency T2	Average frequency T3	Difference T1-T2	Difference T1-T3
Self-injury	16	2.30	2.00	2.00	-13%	-13%
Hetero-aggression	22	2.70	1.59	1.45	-41%	-46%
Destruction of property	15	2.64	1.92	1.64	-27%	-38%
Disruptive behavior	30	3.36	2.06	2.05	-39%	-39%
Stereotypies	35	3.94	2.62	2.20	-34%	-44%
Socially offensive	26	3.03	1.73	2.11	-43%	-30%
Withdrawn	28	3.85	2.25	1.92	-42%	-50%
Non-collaborative	31	2.96	1.37	1.55	-54%	-48%

Note. T1 = before transition. T2 = six months after transition. T3 = one year after transition.

Table 6

Average Group Scores Regarding the Severity of Behavioral Problems at Different Points in Time

Category	Cases	Average severity T1	Average severity T2	Average severity T3	Difference T1-T2	Difference T1-T3
Self-injury	16	1.60	1.30	1.00	-19%	-38%
Hetero-aggression	22	1.81	.81	.50	-55%	-72%
Destruction of property	15	2.00	1.00	0.64	-50%	-68%
Disruptive behavior	30	1.43	.86	1.00	-40%	-30%
Stereotypies	35	1.71	1.05	.88	-39%	-49%
Socially offensive	26	1.34	.96	.96	-28%	-28%
Withdrawn	28	1.71	.96	1.03	-44%	-40%
Non-collaborative	31	1.66	.70	.81	-58%	-51%

Note. T1 = before transition. T2 = six months after transition. T3 = one year after transition.

Discussion

The purpose of the study was to analyze the changes in living conditions of 54 people with IDD and extensive support needs that moved into regular houses in the community as part of a project aimed at favoring this group's deinstitutionalization and independent living. Overall, the results show a clearly positive trend towards the improvement in participants' functioning and quality of life.

First, the process aimed at fostering independent living is promoting greater participation of the people in decision-making regarding aspects of daily living that concern them. The results obtained using the RCS (Hatton et al., 2004), reveal greater choicemaking in matters concerning the environment in which they live, their appearance and personal care, daily living-environment routines, and property they own in their new home, aspects that tend to be much more structured in institutional settings. Hence, the data obtained show that community living environments allow the fostering of people's opportunities for control in such areas. The results obtained are consistent with studies that have associated deinstitutionalization processes and less restrictive living environments 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). According to Chowdhury & Benson (2011) and Talman et al. (2019), shared responsibility between professionals and people with IDD in decision-making concerning aspects of daily living increases after this type of process of moving to community settings. As an area for improvement in future processes, it is worth mentioning that people with IDD seem to still have little room for making decisions

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regarding who will provide support and how. To change this scenario, psychologists should focus their work on strengthening and positively supervising frontline support teams, accompanying them in natural contexts and ensuring the empowerment of the people with IDD they support (Tamarit, 2018).

The results on the ASPM (Jones & Lowe, 2018) also reveal significant progress towards greater skill's development and independence (lower need for support from the professional or provision of less targeted support) one year after the change in residence, with size effects that range from medium (e.g., activities in the community) to large (e.g., household chores). Such positive changes remain present, or even improve, over time. An exception is the occupational area, which could be due to the closure of many non-residential support services in the context of the pandemic (Navas et al., 2022b). A significant decrease in autonomy was reported at six months for community and self-care activities. After the move people were confronted for the first time with activities in which they had no opportunity to participate in, therefore having to learn how to perform them (hence the greater need for support at the beginning, which over time was reduced). The improvements registered in the participation of the people with IDD are consistent with the results of other studies (Beadle-Brown et al., 2012; Beadle-Brown al., 2015; Bigby et al., 2012), in which participants required less support to carry out activities and experienced an increase in their participation.

The results obtained using the San Martin Scale for the assessment of quality of life (Verdugo et al., 2014a) reveal that all the people, despite a certain degree of variability, experience benefits in some of the assessed domains. These findings are similar to the ones recently obtained by Cameranesi et al. (2022), according to whom people with extensive support needs

experienced improvement in all quality of life domains after the deinstitutionalization process. The results of the present study are striking because they have been obtained within a limited time frame, whereas most of the changes can only be noticed after longer periods (Schalock et al., 2018). Nevertheless, it must be emphasized that the participants have undergone very important changes in their immediate environment, which plays a very relevant role in the improvement of personal results (Schalock et al., 2018; Shogren et al., 2020).

Likewise, after the transition to the new housing units, there was an overall decrease in the frequency and severity of the behavioral problems that some of the people displayed in the institutional setting. Although challenging behavior is one of the most widely addressed topics in the field of IDD, few studies have examined the changes in these types of behaviors during deinstitutionalization processes, and those that have approached the issue yield conflicting results (Martin et al., 2012). Certain studies report a reduction in problem behaviors in some people, while there might be an increase in others as a response to the greater demands of the environment (Bigby et al., 2012; Emerson & Hatton, 1996). Other studies have either found no significant differences (Heller et al., 1998) or claim that the improvements found are not maintained long-term (Cooper & Picton, 2000). Some of these differences could be attributed to methodological aspects, such as diversity in the definition of challenging behavior, or the size and characteristics of the sample and the measurement instruments used (Emerson & Hatton, 1996; Kozma et al., 2009). The results of this study should encourage psychologists to adopt a proactive behavioral intervention in natural contexts (Tamarit, 2018) instead of traditional behavior modification techniques. For example, Bowring et al. (2020) reported that interventions based on positive behavior support in community settings improved quality of life and social outcomes for people with IDD.

In short, according to the data, the process has been positive for all the people involved. Moreover, it should be noted that these positive data have been obtained in a context of a pandemic whose repercussions have been significant not only for organizations and their professional staff but also for the people with IDD (Navas et al., 2020).

The findings of this study must be interpreted considering its limitations. First, the lack of a control group prevents us from making causal inferences about the relationship between the changes in supports and the observed improvements. There are, however, several issues related to the inclusion of a control group in these types of studies. The first one refers to the nature of the study itself since it is guided by the desires of individuals with IDD and their families. On the other hand, as Maes et al. (2021) highlight, finding an appropriate control group is quite challenging due to the complexity of the characteristics of the target group.

Second, the data were gathered during the pandemic (2020-2022), which might have had an impact on the participants' personal results due to the already-mentioned restrictions.

Third, due to the small sample size, it was not possible to analyze possible sources of error associated with discrepancies between informants. In this study we have tried to minimize this effect by: (a) using directly observable behaviors as indicators, and (b) providing the interviewer with sufficient training to standardize data collection as much as possible. Nevertheless, it is desirable that in future research statistical controls be implemented to correct standard errors and adjust estimators for possible non-independence of observations (e.g., by multilevel analysis).

Fourth, it was not possible to engage participants with IDD in a traditional interview procedure. Although the use of proxies is considered valid for this population (Bertelli et al., 2019; Cameranesi et al., 2021) future research should include methods that can also gather the perspective of people with extensive support needs using ethnographic or creative approaches (Esteban et al., 2023; Maes et al., 2021).

Lastly, a larger sample would have allowed analysis according to different personal and environmental variables. It would be interesting to analyze the results considering the person's previous institutionalization history since a recent study reported worse results in certain aspects for people who have spent long periods of time in institutions (Stancliffe et al., 2023). Likewise, other service or staff related factors (i.e., ratios or organizational culture) could lead to different results (Beadle-Brown et al., 2021; Friedman, 2022).

Despite its limitations, this study is an important step towards the development of public policies and services that are more focused on the needs of people with IDD and extensive support needs, a group that is frequently underrepresented in the literature (Cameranesi et al., 2022; Maes et al., 2021). This research provides answers to other shortcomings detected in the studies on independent living available to date since a broad and solid range of indicators has been assessed (Bigby & Beadle- Brown, 2018; Chowdhury & Benson, 2011). Furthermore, using longitudinal data provides more reliable inferences on the changes and their dynamic (Cooper & Pincton, 2000). We hope this study contributes to the dissemination and application of psychological research to strengthen and inform implementation efforts of the CRPD. It is necessary to advocate for public policies that support global change towards the elimination of oppressive practices and conditions to persons with disabilities (APA, 2014), and psychology should play a key role in promoting change in social and normative changes (Tamarit, 2018). The results of this study support the processes aimed at fostering community living and transforming organizations' services and professional practices towards approaches that are more inclusive and respectful of people's rights and community membership. To this end, Schalock and Verdugo (2012) set out strategies for change, including the development of highperformance teams, overcoming resistance to change and changing thinking styles, establishing support systems aimed at improving personal outcomes and evidence-based practices, being the role of psychologists fundamental in this regard.

Author Contributions

Patricia Navas: Conceptualization, Funding Adquisition, Investigation, Methodology, Project Administration, Writing -Original Draft, Writing - Reviewing and Editing. Laura Esteban: Data Curation, Investigation, Writing - Original Draft, Writing - Reviewing and Editing. Víctor Arias: Data Curation, Formal Analysis, Methodology, Writing - Reviewing and Editing. Miguel Ángel Verdugo: Conceptualization, Funding Adquisition, Writing - Reviewing and Editing.

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Declaration of Interests

The authors declare no conflict of interest.

Data Availability Statement

Analysis code is available by emailing the corresponding author.

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