# ORIGINAL ARTICLE



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# The influence of meaningful activities in the quality of life and functional autonomy of adults with intellectual disability: A prospective study during the COVID-19 pandemic

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# Abstract

**Background:** The COVID-19 pandemic might negatively impact the quality of life and functional autonomy of Spanish adults with intellectual disability, and meaningful activities could prevent this negative progression.

**Methods:** This is a prospective cohort study in Spanish adults with intellectual disability during the COVID-19 pandemic. Quality of life, functional autonomy and functional independence were measured. The meaningful activities studied were structured-leisure, community

self-management, and occupational and physical activities.

**Results:** Seventy-three participants were included in the study. Quality of life and functional autonomy significantly deteriorated during the COVID-19 pandemic (all p > .001). Greater participation in community self-management activities before COVID-19 was associated with less detriment to quality of life ( $\beta = -.312$ ; p = .008), while greater participation in occupational and physical activities was associated with less detriment to the performance of instrumental activities ( $\beta = -.317$ ; p = .016; and  $\beta = -.285$ ; p = .030, respectively).

**Conclusion:** People with intellectual disability living in residential homes experienced a decrease in their quality of life and functional autonomy during the COVID-19 pandemic. Their involvement in community self-management activities and physical and occupational activities before the pandemic had preventive effects on the detriment to the quality of life and functional autonomy.

## KEYWORDS

exercise, occupational therapy, physical activity, SARS-CoV

# 1 | INTRODUCTION

Intellectual disability is characterised by significant limitations in intellectual functioning and adaptive behaviours (American Association on Intellectual and Developmental Disabilities, 2011). It negatively influences the quality of life (Balboni et al., 2020), functional autonomy (i.e., the ability to independently perform tasks of daily living, including basic and instrumental activities) and social inclusion (Alonso-Sardón et al., 2019; Louw et al., 2020). The intellectual disability prevalence in adults living in high-income countries varies worldwide, ranging from 0.5 to 8 cases per 1000 inhabitants in Australia and Canada, respectively (McKenzie et al., 2016). The variety of methodologies, case definitions and data sources to define and registry the disability could explain the differences between countries around the world. In the

case of Spain, the prevalence rate was 5% in the year 2020, considering the data from the National Registry of Social Services (Base estatal de datos de personas con discapacidad, 2020). People with intellectual disabilities have increased their life expectancy (Patja et al., 2000), and it is essential to identify efficient interventions that allow them to live those years with a better quality of life, functional autonomy and social participation (Di Maggio et al., 2020).

The Model of Human Occupation explains that meaningful activities (e.g., physical activities, leisure activities or occupational activities) help organise patterns of daily life within a person's environment, which is essential to achieve functional autonomy and social participation (Eakman, 2013; Kielhofner & Burke, 1980). For instance, physical activity interventions in people with intellectual disability have positive effects on their physical and psychosocial health (Kapsal et al., 2019). Furthermore, engagement in leisure activities positively influences their functional autonomy and social relationships (Merrells et al., 2018), which increases their opportunities to develop meaningful friendships and reduces the feeling of loneliness (Duvdevany, 2008). Lastly, the promotion of occupational activities (e.g., community participation and interpersonal relationships) has shown to enhance the quality of life and functional autonomy of this population (Alonso-Sardón et al., 2019; Merrells et al., 2018; Simões & Santos, 2017).

The COVID-19 pandemic disrupted most of the mentioned meaningful activities for people with intellectual disability living in Spain (Navas et al., 2021). Consequently, their routines changed drastically with no options for performing physical, leisure and occupational activities, as happened in other countries (Murray et al., 2021). It is logical to assume that these limitations derived from COVID-19 had a negative impact on their quality of life and functional autonomy to perform activities of daily living (ADL), although there is a lack of evidence in this regard (Alonso-Sardón et al., 2019; Simões & Santos, 2017; Theis et al., 2021). Therefore, it would be interesting to know whether the involvement in meaningful activities before COVID-19 could somehow protect this population against significant detriments to quality of life and functional autonomy. These results could help to guide interventions for people with intellectual disability after COVID-19 and would provide valuable information to be considered in potential new waves of this pandemic.

The aims of this study were: (1) to determine the progression of quality of life and functional autonomy to perform basic and instrumental ADL in Spanish people with intellectual disability living in residential homes during the COVID-19 pandemic, and (2) to study whether several activities offered in the residential homes before COVID-19 influenced the progression of quality of life and functional autonomy to perform basic and instrumental ADL.

# 2 | METHODS

# 2.1 | Study design and population

A prospective cohort study was conducted at two residential homes for adults with intellectual disability, located in the city of Granada (Southern Spain), between November 2019 and September 2020. Initially, this project aimed to follow up on the quality of life and functional autonomy of these adults while they received occupational therapy interventions. However, the COVID-19 pandemic affected the development of the project and we decided to also report on the two aims mentioned in the introduction.

As a background, in Andalusia (south of Spain) the Public Social and Health Service supports people with an intellectual disability through two main options: (1) support in their own home or family home, and (2) residential homes for those people without family support or socio-economic difficulties and a disability percentage higher than 33%. The disability percentage is the outcome used in Spain to assess the degree of disability, considering physical, mental and sensory disability along with complementary social factors (family environment and employment, educational and cultural situation) that may hinder their social integration. The equivalence between the disability percentage and the level of intellectual disability is mild (0%-24%), moderate (25%-49%), severe (50%-75%), and profound (76%-100%). Each of the residential homes included in the study has a capacity for 45 people with intellectual disability. The participants in the present study were living in one of the two residential homes belonging to the Public Social and Health Service of Andalusia where they received comprehensive health and occupational therapy, but they did not participate in community employment programs. The inclusion criteria to participate in the study were (1) being between 18 and 65 years old, (2) diagnosis of intellectual disability (according to the WHO International Classification of Diseases). (3) having a disability percentage higher than 33% (based on the disability percentage accepted by the Ministry of Health and Social Policies-Spain), (4) living in the residential homes before and after the lockdown. (5) surviving the COVID-19 pandemic by the end of the study, and (6) accepting to participate in the study. All participants who met the inclusion criteria were offered to participate in the study after signing the informed consent form filled out by the participants and their relatives or legal guardians. The aims and characteristics of the study were comprehensively explained to the participants, asking them to ensure their correct understanding, and we emphasised their right to withdraw from the study at any time. They had the opportunity to ask and clarify any doubts. The study was carried out according to the guidelines established by the Helsinki Declaration and Law 14/2007 on Biomedical Research. The ethics committee of the University of Granada approved the study.

# 2.2 | Meaningful activities offered

The care/support provided by professionals from both residential homes used the person-centred planning (Claes et al., 2010) and the individual support plans (Herps et al., 2016). The purpose was to determine each person's priorities and create a support system that allowed them to plan and achieve the desired lifestyle. Each person with intellectual disability had a "key worker" at the residential home, who was the person in charge of supervising the progression of the individual

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support plan and of communicating any request of the person with intellectual disability to the other professionals during the daily staff meetings. The people with intellectual disability included in the study did not participate in community programs of employment (which are very limited in our region) prior to COVID-19. They had the opportunity to choose and participate in other different meaningful activities carried out inside and outside the residential homes: structured-leisure activities (outside), community self-management activities (outside), occupational activities (inside), and physical-sport activities (inside and outside). A detailed description of these activities is provided in Table 1. The activity choice was supported by the care/support professionals considering the interest and motivation of each person with intellectual disability and was added to the individual support plan. In addition, people with intellectual disability who live in residential homes usually receive visits from their family and friends. However, the country was locked down between March 2020 and July 2020 due to the pandemic, and all people living in residential homes were homebound with no chances to receive visits and no opportunities to participate in any of the abovementioned meaningful activities.

# 2.3 | Data collection

Data were collected through personal interviews at the residential homes with the "key worker" of each person with intellectual

disability. The interviews were conducted by an occupational therapist with long experience in supporting people with intellectual disability and were carried out at four-time points: November 2019 and January 2020 (before the COVID-19 pandemic), and April 2020 and September 2020 (after the COVID-19 pandemic). The sociodemographic data of the patients were collected during interviews with the caregivers and included the following data: age, gender, weight, height, body mass index, legal capacity (yes/no), family support (the family visits the person or calls her/his at least once a week = yes/no) and illiteracy. Data related to disability percentage, and the participation in the different types of activities described in Table 1 (number of activities in which each person participates) were collected by the medical staff.

# 2.4 | Outcomes

# 2.4.1 | Quality of life

The quality of life, i.e. the primary outcome, was assessed using the GENCAT scale, which was designed to assess the quality of life of social services users (Verdugo et al., 2010). The scale was based on a multidimensional model considering eight areas: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

ΓAΒ	LE	E 1	L	Descripti	on of t	the meaningfu	l activities	offered t	to Spanisl	n peopl	e with	intellectua	l disabilit	y who	live i	in resic	lential	homes
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Activities	Description	Examples	Place	Duration	Periodicity	Supported by
Structured leisure activities	Non-mandatory activity that is intrinsically motivated and in which one participates during free time. They can be group or individual activities. The group activities are decided in a consensus meeting by health professionals.	Cinema, bowling, cultural exhibitions, concerts, theatre, gastronomic outings, amusement parks, beaches or pubs	Outside	3 h	Five per week	Occupational therapists and assistant professionals
Community self- management activities	Activities mainly focused on solving daily requirements. They are mainly individual activities.	Medical appointments, shopping, bank appointments, meetings to solve bureaucratic issues, post office visits	Outside	2 h (mean)	It depends on the person's needs	Occupational therapists and assistant professionals
Physical activities	Physical sports activities aimed at promoting physical well-being. They can be group or individual activities. They choose the activities and they can	Yoga, basket, multisport, dancing, football, gym, petanque Gym, Latin dancing, swimming, running, football	Outside Inside	1-2 h 1 h	2 per week 1 per week	Sport coaches Psycho-motility therapists and physical therapists
	change their choice twice a year.	rootbair				physical inclupious
Occupational activities	Activities oriented to learning skills needed to perform a future job or a future meaningful occupation.	Workshops on gardening, crafts, Wood, taking care of animals	Inside	3 h	5 per week	Occupational therapist assistants

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The scale includes 69 items which are scored on a 4-point Likert-like scale (1: "Never or almost never", 2: "Sometimes", 3: "Frequently", and 4: "Always or almost always"). Higher values indicate a higher quality of life. The internal consistency of the scale is high, with Crombach's  $\alpha = .92$  (Verdugo et al., 2010). The GENCAT scale was designed to be filled out by caregivers who have been working with people with intellectual disability for more than 3 months. The "key professionals" of each person with intellectual disability included in the present study completed the questionnaire.

# 2.4.2 | Functional autonomy in basic ADL

The functional autonomy to perform the ADL was assessed using two scales: (1) The Functional Independence Measure (FIM) for the basic ADL (Hobart et al., 2001), and (2) the Lawton Instrumental ADL Scale (Lawton & Brody, 1969). The FIM consists of 13 items related to physical domains and five items concerning cognitive and social functioning aspects. The 18 items are grouped into six activity categories including self-management, sphincter control, mobility, locomotion, communication and social cognition. Each item scores between 1 (lower level of function) and 7 points (higher level of function). The total score ranges between 18 and 126 points; the higher the score, the greater the functional autonomy. The internal consistency of the FIM has been reported as very good, with a Cronbach's  $\alpha = .95$  (Hobart et al., 2001). The FIM was previously used to assess the functional autonomy of people with intellectual disability (Andersson & Alberto, 2013).

# 2.4.3 | Functional autonomy in instrumental ADL

The Lawton IASL Scale was previously used to assess the autonomy of people with intellectual disability in eight areas (Hilgenkamp et al., 2011; Lawton & Brody, 1969): the ability to use the telephone, shopping, food preparation, housekeeping, laundry, modes of transportation, responsibility for own medications, and ability to handle finances. The total score ranges from 0 (lower function = dependent) to 8 (higher function = independent) points. The internal consistency of the Lawton IADL scale is very good (i.e., Crombach's  $\alpha$  = .94) (Vergara et al., 2012), and it presents good test-retest reliability r = 0.93 (Edwards, 1990).

# 2.5 | Statistical analysis

The descriptive data of quantitative variables are presented as mean and standard deviations. The categorical variables are described by frequencies and percentages (n, %). Before performing the analyses, the data were examined to detect extreme values to limit their influence on the analyses, but no extreme values were identified. Kolmogorov–Smirnov tests and inspection of histograms were performed, and all outcomes showed normal distributions.

To answer how COVID-19 affected the outcomes of the study, we used Repeated Measures ANOVA analyses and the Bonferroni post hoc test in the four-time points (i.e., November 2019, January 2020, April 2020 and September 2020). To determine the influence of the different activities on the outcome changes, we used linear regression analyses with the study outcomes (i.e., Gencat scale, Functional Independence Measure and Lawton IADL scale) as the dependent variables and the different activities as independent variables. Several potential confounders (i.e., age, sex, BMI, legal capacity, family support, illiteracy, disability degree and disability percentage) were considered in stepwise linear regressions, and we finally included age and disability percentage since they demonstrated a significant prediction in the model. No multicollinearity among the independent variables was found in any of the analyses (VIF < 10). All analyses were performed using SPSS software (version 24.0, IBM Corporation), and the level of significance was set at p < .050.

# 3 | RESULTS

A total of 73 participants were included in the study. The sociodemographic and clinical characteristics at baseline and the values of quality of life and functional autonomy to perform basic and instrumental ADL are presented in Table 2. Overall, there were 29 women and 44 men aged  $45.18 \pm 13.89$  years with a mean disability percentage of  $72.4\% \pm 9.22$ .

The results from the Repeated Measures ANOVA are shown in Figure 1. Overall, quality of life and functional autonomy to perform basic and instrumental ADL significantly deteriorated over time (all p < .001), being the period from January to April 2020 (i.e., the beginning of the COVID-19 pandemic in Spain) the turning point. Table 3 presents the same Repeated Measures ANOVA analysis but on the subscales of quality of life and functional autonomy in basic ADL.

Table 4 shows the prospective associations between the different meaningful activities conducted before COVID-19 with changes in quality of life and functional autonomy to perform basic and instrumental ADL. A higher number of community self-management activities before COVID-19 were associated with less detriment to quality of life ( $\beta = -.312$ ;  $R^2 = 0.222$ ; p = .008). A higher number of occupational and physical activities before COVID-19 were associated with less detriment to the functional autonomy to perform instrumental ADL ( $\beta = -.317$ ;  $R^2 = 0.145$ ; p = .016; and  $\beta = -.285$ ;  $R^2 = 0.130$ ; p = .030, respectively). These findings occurred independently of the age and the disability percentage since they were adjusted for these confounders. None of the other meaningful activities (i.e., structured leisure and community self-management activities) demonstrated any prospective association with the remainder outcomes (all p > .05).

# 4 | DISCUSSION

This study provides relevant information on the negative impact of the COVID-19 pandemic on the quality of life and functional FIM score (18-126 pts)

Dependence in ADLs (0-8 pts)

Variables included	November 2019	January 2020	April 2020	September 20
Sociodemographic or clinical				
Age (years)	45.18 ± 13.89	-	-	-
Women ( <i>n</i> /%)	29/40%	-	-	-
Men (n/%)	44/60%	-	-	-
BMI (kg/m²)	29.06 ± 5.71	-	-	-
Legal capacity (n/%)	59/81%	-	-	-
Family support (n/%)	57/78%	-	-	-
Illiteracy (n/%)	26/36%	-	-	-
Level of ID (n/%)				
Moderate	43/59%	-	-	-
Severe	30/41%	-	-	-
Activities (n/month)				
Structured leisure	2.64 ± 2.1	2.71 ± 2.01	-	-
Community self-management	2.08 ± 2.63	1.79 ± 2.42	-	2.30 ± 2.90
Occupational	7.73 ± 2.73	7.47 ± 2.92	-	2.05 ± 2.48
Physical	2.41 ± 2.57	2.45 ± 2.61	-	-
Self-advocates (n/%)	19/26%	19/26%	-	16/22%
Outcomes				
GENCAT index (52–138 pts)	102.07 ± 11.10	102.18 ± 11.07	70.33 ± 10.48	71.19 ± 12.22

#### **TABLE 2** Descriptive characteristics of the participants.

Abbreviations: ADLs, activities of daily living; BMI, body mass index; FIM, functional independence measure; ID, intellectual disability.

 $108.74 \pm 13.94$ 

 $3.01 \pm 1.35$ 

 $110.42 \pm 15.74$ 

 $3.88 \pm 1.47$ 

autonomy of Spanish people with intellectual disability, and on how participation in several meaningful activities can affect the detriment of these outcomes. We found a significant reduction in guality of life and functional autonomy in the performance of instrumental and basic ADL of people with intellectual disability living in residential homes during the COVID-19 pandemic. However, involvement in more community self-management activities before the pandemic had a protective effect on the detriments to quality of life. Similarly, participation in more physical and occupational activities had a protective effect on the detriments to functional autonomy in the performance of instrumental ADL.

Enhancing the quality of life of people with intellectual disability should be a major concern of institutions and governments, and one of the main aims of the individual support plans (Herps et al., 2016). The individual support plans guide the process of developing personal goals, selecting resources and developing support strategies (Herps et al., 2016). However, the limitation imposed during the COVID 19 pandemic hindered the normal development of these individual support plans. People with intellectual disability living in residential homes experienced a total restriction of visits. They were deprived of participation in meaningful activities (i.e., physical, leisure or occupational activities), and this fact could explain the detriment to quality of life during the pandemic (Murray et al., 2021). Nevertheless, our results show that those people involved in more community selfmanagement activities before COVID-19 demonstrated less detriment to their guality of life. It is essential to know that these activities were self-selected by the residents with intellectual disability. Furthermore, community self-management activities are framed within the personcentred planning, a methodology that leaves freedom of decision to patients to reach greater individualisation, personalisation and selfdetermination (Claes et al., 2010). For instance, they can decide to go shopping or attend medical appointments by themselves, activities promote the social inclusion and self-determination that (McCormack & McCance, 2016). These activities are feasible for any person with intellectual disability regardless of their skills and limitations since they are guided by care/support professionals who provide specific support according to their individual needs (Rasheed & Miller, 2006). All these factors together could explain why participation in community self-management activities prevents a greater decrease in the quality of life of people with intellectual disability in situations similar to the one experienced with the COVID-19 pandemic.

 $101.27 \pm 17.0$ 

1.56 ± 0.97

On the other hand, structured leisure, occupational and sports activities did not influence the detriments to the guality of life of residents with intellectual disability. The influence of leisure activities on quality of life is controversial in the literature, with some studies suggesting positive effects (Duvdevany, 2008), while others demonstrate no effects (Badia et al., 2013). This discrepancy could lie in the characteristics of these leisure activities, in whether the leisure activity is really meaningful for them, and in the type of support provided by the

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96.37 ± 20.15

 $2.21 \pm 1.83$ 



**FIGURE 1** Changes in the quality of life, and functional autonomy in basic and instrumental activities of daily living before and after the COVID-19 pandemic. A figure with three plots (quality of life, functional independence measure and dependence in activities of daily living) presenting the mean and standard deviation progression in four-time frames: November 2019 and January 2020 (before the COVID-19 pandemic), and April 2020 and September 2020 (after the COVID-19 pandemic). We see how the three variables get worse after the COVID-19 pandemic in our sample of adults with intellectual disability.

care/support professionals in charge. For instance, the leisure activities conducted in this study were decided and somehow "imposed" by the professionals. This fact could explain the lack of effect on the JARID

quality of life of our participants. Similarly, occupational and physical activities were guided and structured by the care/support professionals, which limited the decision-making capacity and self-determination. Physical activity interventions in people with intellectual disability have demonstrated a larger effect on physical health (e.g., cardiorespiratory fitness, muscular strength or flexibility), while benefits on psychological factors are less accentuated (Kapsal et al., 2019). Among the eight dimensions of quality of life, physical exercise seems to enhance physical well-being. However, there are still seven dimensions in which it might not be having the expected results. Future interventions should elucidate what types of occupational and physical activities are more favourable for the quality of life of this population.

The achievement of functional autonomy is a major goal in interventions for people with intellectual disability (Herps et al., 2016). Functional autonomy is strongly influenced by the environment in which they live (Christiansen & Baum, 1997), such as the opportunities that the person has to perform basic and instrumental ADL (Townsend, 2007). The restrictions experienced during the COVID-19 pandemic limited people with intellectual disability in performing some of these basic and instrumental ADL and this could have negatively affected their functional autonomy (Murray et al., 2021; Theis et al., 2021). Interestingly, our results demonstrated that those residents who participated in physical and occupational activities before the pandemic showed less detriment to their functional autonomy; more specifically, when performing instrumental ADL such as shopping, doing the laundry or housekeeping. A possible explanation is that the physical and occupational activities performed by the residents could have enhanced the development of several skills needed to perform instrumental ADL properly. For instance, physical and occupational activities were conducted following structured schedules and conditions that, overall, required organisational skills, teamwork and commitment. A recent systematic review with meta-analysis demonstrated that physical activity positively affects several psychosocial variables involved in the optimal development of instrumental ADL, such as self-efficacy, self-concept and mental health (Kapsal et al., 2019). These factors are linked to the ability to exert control over their motivations and environment, self-acceptance, and their mental and social well-being (Bailey, 2003; Kapsal et al., 2019; Salles, 2017). It is reasonable to assume that those residents who performed more physical and occupational activities before the COVID-19 pandemic enhanced these skills, which could help prevent a more significant deterioration of the functional autonomy by performing instrumental ADL (Bondár et al., 2020).

The deterioration of the functional autonomy in the performance of basic ADL, such as bathing, sphincter control or climbing stairs, was not prevented by the involvement in any of the meaningful activities studied. One possible explanation is that these activities lack direct transfer to basic ADL, which are conducted independently at home and do not require the same level of skills that we mentioned above for the instrumental ADL (Carmona-Torres et al., 2019). In January 2020, before the COVID-19 pandemic, the average response on the questionnaire measuring functional autonomy in basic ADL

Changes in the subscales of quality of life and functional autonomy in activities of daily living before and after the COVID-19 TABLE 3 pandemic.

Outcomes	November 2019	January 2020	April 2020	September 2020	ANOVA F	Partial $\eta^2$	p Value
GENCAT quality of life							
Emotional wellbeing (1-16 pts)	11.46 ± 2.59	11.46 ± 2.59	6.94 ± 2.94	6.47 ± 2.62	251.17	0.780	<.001
Interpersonal relationship (1–17 pts)	9.78 ± 2.88	9.89 ± 2.65	6.07 ± 2.64	5.86 ± 2.63	163.21	0.697	<.001
Material wellbeing (1–13 pts)	10.26 ± 1.84	10.26 ± 1.84	7.32 ± 2.34	7.89 ± 2.18	96.77	0.577	<.001
Personal development (1–16 pts)	11.96 ± 2.39	11.96 ± 2.39	5.41 ± 2.44	5.32 ± 2.47	571.74	0.888	<.001
Physical wellbeing (1–14 pts)	11.44 ± 1.78	11.44 ± 1.78	9.01 ± 2.38	11.13 ± 2.43	42.59	0.375	<.001
Self-determination (1–16 pts)	22.78 ± 4.88	22.78 ± 4.88	17.03 ± 3.38	15.21 ± 5.17	200.32	0.736	<.001
Social inclusion (1–17 pts)	10.92 ± 1.99	10.92 ± 1.99	2.57 ± 1.81	3.08 ± 2.57	577.40	0.890	<.001
Rights (1–13 pts)	7.08 ± 3.06	7.08 ± 3.06	3.78 ± 2.18	3.32 ± 2.31	109.52	0.607	<.001
FIM functional autonomy in basic ADL	_S						
Self-care (6–36 pts)	35.74 ± 5.85	37.03 ± 9.35	33.15 ± 7.77	30.97 ± 9.67	25.45	0.261	<.001
Sphincter control (2-14 pts)	13.45 ± 1.8	13.42 ± 1.8	13.27 ± 1.94	13.21 ± 2.21	3.11	0.041	.027
Transfers (3–21 pts)	20.59 ± 1.56	20.59 ± 1.56	20.41 ± 2.24	20.23 ± 2.86	2.53	0.034	.058
Locomotion (2-14 pts)	13.47 ± 1.73	13.47 ± 1.73	13.25 ± 2.14	13. ± 2.57	5.87	0.075	.001
Communication (2–14 pts)	11.1 ± 3.08	11.16 ± 3.09	9.67 ± 3.44	8.73 ± 3.97	57.75	0.445	<.001
Social cognition (3–21 pts)	14.4 ± 4.51	14.75 ± 4.38	11.52 ± 4.48	10.23 ± 4.82	116.89	0.619	<.001

Note: Values with lower than 0.050 are bold.

TABLE 4	ifluence of activities before COVID-19 on the changes in the quality of life, and functional autonomy in basic and instrumental
activities of d	ly living.

	$\Delta$ Quality	of life		$\Delta$ FIM			$\Delta$ Lawton and Brody		
Activities pre-COVID-19	ß	R <sup>2</sup>	р	ß	R <sup>2</sup>	р	ß	R <sup>2</sup>	р
CSM	312	0.222	.008	150	-	.241	154	-	.214
Structured leisure	142	-	.196	.153	-	.192	083	-	.467
Occupational	106	-	.418	084	-	.543	317	0.145	.016
Physical	143	-	.272	093	-	.500	285	0.130	.030

Note: Values with lower than 0.050 are bold.

Abbreviations: CSM, community self-management activities; FIM, functional independence measure.

(i.e., Functional Independence Measure) was 6.1 points out of 7 possible. This indicates a high level of independence and, therefore, the meaningful activities had a low chance of improving this functional autonomy. Furthermore, Figure 1 shows that functional autonomy in basic ADL experienced less detriment than instrumental ADL. This seems reasonable, since during the home isolation due to COVID-19 the participants in this study continued to perform most of the basic ADL (e.g., self-care, sphincter control, transfer and locomotion activities), while the practice of instrumental activities was significantly limited or even cancelled (Villani et al., 2020).

The COVID-19 pandemic has most severely affected residents with intellectual disability since they have experienced higher rates of infection, hospitalisation and mortality (Landes et al., 2020). Furthermore, sudden changes in their routines and usual activities, as occurred during the quarantine, negatively affect the overall quality of life (Hou et al., 2020; Vetri et al., 2021). This study demonstrates for the first

time in a Spanish population of people with intellectual disability that the COVID-19 quarantine is significantly detrimental to the quality of life and functional autonomy in the performance of basic and instrumental ADL. In addition, we identified that several meaningful activities had a protective effect against this deterioration. Based on these results, further efforts are needed to restore their level before the pandemic, and we encourage the inclusion of community selfmanagement, and physical and occupational activities to optimise the benefits of these outcomes. Findings from the present study would be of interest to (1) social and health care systems that need to implement strategies to avoid detriment to quality of life and functional autonomy in possible outbreaks of the pandemic; and (2) care/support professionals working with this population who should emphasise community self-management and physical and occupational activities in the individual support plans of residents with intellectual disability.

To our knowledge, this is the first longitudinal study focused on the quality of life and functional autonomy of the people with intellectual disability living in residential homes during the COVID 19 pandemic. However, several limitations should be addressed. First, the observational design of the study, even longitudinal, prevents the establishment of causality. Second, our prospective analysis only includes baseline predictor values, and we cannot know how participation in meaningful activities after the COVID-19 pandemic influences changes in quality of life and functional autonomy. Third, the study was conducted with a convenience sample of people with intellectual disability living in residential homes and is limited to a specific Spanish region (i.e., Granada). Therefore, an a priori sample size calculation to obtain enough statistical power was not performed. However, we performed a post hoc analysis based on the power achieved and considering our sample size, and we found that our results have enough statistical power with a low likelihood of making a type II error. Anyhow, our results cannot be extrapolated to the general Spanish population of people with intellectual disability. Lastly, we considered in our analysis several potential confounders that could be partially explaining the results (i.e., age, sex, BMI, legal capacity, family support, illiteracy, disability degree and disability percentage). Nevertheless, there are further variables that have been demonstrated to be relevant in this population that should be considered in future studies, such as social support, adaptive behaviour or medication (Balboni et al., 2020; MacLeod & MacLure, 2020; Merrells et al., 2018).

# 5 | CONCLUSION

People with intellectual disability living in residential homes experienced a decrease in their quality of life and functional autonomy during the COVID-19 pandemic. Their involvement in community self-management activities and physical and occupational activities before the pandemic had preventive effects on the detriment to quality of life and functional autonomy. The community participation restrictions faced by people with intellectual disability should be reconsidered, and new strategies for support should be provided in future waves of the pandemic.

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## CONFLICT OF INTEREST STATEMENT

No potential conflict of interest was reported by the authors.

#### DATA AVAILABILITY STATEMENT

The data supporting the results of this study is available upon request to the corresponding author. We decided to do not publish this data in open source due to privacy restrictions.

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#### REFERENCES

- Alonso-Sardón, M., Iglesias-De-Sena, H., Fernández-Martín, L. C., & Mirón-Canelo, J. A. (2019). Do health and social support and personal autonomy have an influence on the health-related quality of life of individuals with intellectual disability? *BMC Health Services Research*, 19, 63. https://doi.org/10.1186/s12913-018-3856-5
- American Association on Intellectual and Developmental Disabilities. (2011). Discapacidad intelectual: Definición, clasificación y sistemas de apoyo. Alianza Editorial. https://www.amazon.es/Discapacidad-intelectual-Definici%C3%B3n-clasificaci%C3%B3n-sistemas/dp/8420652628
- Andersson, L. R., & Alberto, J. J. (2013). Medida De La Independencia Funcional Con Escala Fim En Los Pacientes Con Evento Cerebro Vascular Del Hospital Militar Central De Bogotá En El Periodo Octubre 2010 -Mayo 2011. Revista Med, 21(2), 34–42.
- Badia, M., Orgaz, M. B., Verdugo, M. Á., Ullán, A. M., & Martínez, M. (2013). Relationships between leisure participation and quality of life of people with developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 26, 533–545. https://doi.org/10.1111/jar. 12052
- Bailey, J. A. (2003). Self-image, self-concept, and self-identity revisited. Journal of the National Medical Association, 95, 489–490.
- Balboni, G., Mumbardó-Adam, C., & Coscarelli, A. (2020). Influence of adaptive behaviour on the quality of life of adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33, 584–594. https://doi.org/10.1111/jar.12702
- Base estatal de datos de personas con discapacidad. (2020). https:// imserso.es/el-imserso/documentacion/estadisticas/base-estatal-datospersonas-con-discapacidad
- Bondár, R. Z., di Fronso, S., Bortoli, L., Robazza, C., Metsios, G. S., & Bertollo, M. (2020). The effects of physical activity or sport-based interventions on psychological factors in adults with intellectual disabilities: A systematic review. *Journal of Intellectual Disability Research*, 64, 69–92. https://doi.org/10.1111/jir.12699
- Carmona-Torres, J. M., Rodríguez-Borrego, M. A., Laredo-Aguilera, J. A., López-Soto, P. J., Santacruz-Salas, E., & Cobo-Cuenca, A. I. (2019). Disability for basic and instrumental activities of daily living in older individuals. *PLoS One*, 14, e0220157. https://doi.org/10.1371/journal. pone.0220157
- Christiansen, C., & Baum, M. (1997). Occupational therapy: Enabling function and wellbeing. https://www.amazon.com/Occupational-Therapy-Enabling-Function-Well-Being/dp/1556422482
- Claes, C., van Hove, G., Vandevelde, S., van Loon, J., & Schalock, R. L. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and Developmental Disabilities*, 48, 432–453. https:// doi.org/10.1352/1934-9556-48.6.432
- Di Maggio, I., Shogren, K. A., Wehmeyer, M. L., & Nota, L. (2020). Selfdetermination and future goals in a sample of adults with intellectual disability. *Journal of Intellectual Disability Research*, 64, 27–37. https:// doi.org/10.1111/jir.12696
- Duvdevany, I. (2008). Do persons with intellectual disability have a social life? The Israeli reality. Salud Publica de Mexico. https://doi.org/10.1590/ s0036-36342008000800016
- Eakman, A. M. (2013). Relationships between meaningful activity, basic psychological needs, and meaning in life: Test of the meaningful activity and life meaning model. OTJR Occupation, Participation and Health, 33, 100-109. https://doi.org/10.3928/ 15394492-20130222-02
- Edwards, M. M. (1990). The reliability and validity of self-report activities of daily living scales. *Canadian Journal of Occupational Therapy*, *57*, 273–278. https://doi.org/10.1177/000841749005700507

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- Herps, M. A., Buntinx, W. H. E., Schalock, R. L., Van Breukelen, G. J. P., & Curfs, L. M. G. (2016). Individual support plans of people with intellectual disabilities in residential services: Content analysis of goals and resources in relation to client characteristics. *Journal of Intellectual Disability Research*, 60, 254–262. https://doi.org/10.1111/jir.12245
- Hilgenkamp, T. I. M., van Wijck, R., & Evenhuis, H. M. (2011). (instrumental) Activities of daily living in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 32, 1977–1987. https://doi.org/ 10.1016/j.ridd.2011.04.003
- Hobart, J. C., Lamping, D. L., Freeman, J. A., Langdon, D. W., McLellan, D. L., Greenwood, R. J., & Thompson, A. J. (2001). Evidencebased measurement: Which disability scale for neurologic rehabilitation? *Neurology*, *57*, 639–644. https://doi.org/10.1212/WNL.57. 4.639
- Hou, W. K., Lai, F. T., Ben-Ezra, M., & Goodwin, R. (2020). Regularizing daily routines for mental health during and after the COVID-19 pandemic. *Journal of Global Health*, 10, 020315. https://doi.org/10.7189/ jogh.10.020315
- Kapsal, N. J., Dicke, T., Morin, A. J. S., Vasconcellos, D., Maïano, C., Lee, J., & Lonsdale, C. (2019). Effects of physical activity on the physical and psychosocial health of youth with intellectual disabilities: A systematic review and meta-analysis. *Journal of Physical Activity and Health*, 16, 1187–1195. https://doi.org/10.1123/jpah.2018-0675
- Kielhofner, G., & Burke, J. (1980). A model of human occupation, part 1. Conceptual framework and content. American Journal of Occupational Therapy, 34, 777–788.
- Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York state. *Disability and Health Journal*, 13, 100969. https://doi.org/10. 1016/j.dhjo.2020.100969
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Selfmaintaining and instrumental activities of daily living. *The Gerontolo*gist, 9, 179–186. https://doi.org/10.1093/geront/9.3\_Part\_1.179
- Louw, J. S., Kirkpatrick, B., & Leader, G. (2020). Enhancing social inclusion of young adults with intellectual disabilities: A systematic review of original empirical studies. *Journal of Applied Research in Intellectual Disabilities*, 33, 793–807. https://doi.org/10.1111/jar.12678
- MacLeod, J., & MacLure, K. (2020). People with intellectual disabilities and their experience of medication: A narrative literature review. *Journal of Applied Research in Intellectual Disabilities*, 33, 976–991. https://doi. org/10.1111/jar.12719
- McCormack, B., & McCance, T. (2016). Person-centred practice in nursing and health care: Theory and practice. https://www.wiley.com/en-us/ Person+Centred+Practice+in+Nursing+and+Health+Care%3A+Theory +and+Practice%2C+2nd+Edition-p-9781118990568
- McKenzie, K., Milton, M., Smith, G., & Ouellette-Kuntz, H. (2016). Systematic review of the prevalence and incidence of intellectual disabilities: Current trends and issues. *Current Developmental Disorders Reports*, 3, 104–115. https://doi.org/10.1007/s40474-016-0085-7
- Merrells, J., Buchanan, A., & Waters, R. (2018). The experience of social inclusion for people with intellectual disability within community recreational programs: A systematic review. *Journal of Intellectual and Developmental Disability*, 43, 381–391. https://doi.org/10.3109/ 13668250.2017.1283684
- Murray, G. C., McKenzie, K., Martin, R., & Murray, A. (2021). The impact of COVID-19 restrictions in the United Kingdom on the positive behavioural support of people with an intellectual disability. *British Journal* of Learning Disabilities, 49, 138–144. https://doi.org/10.1111/bld. 12379

- Navas, P., Amor, A. M., Crespo, M., Wolowiec, Z., & Verdugo, M. (2021). Supports for people with intellectual and developmental disabilities during the COVID-19 pandemic from their own perspective. *Research in Developmental Disabilities*, 108, 103813. https://doi.org/10.1016/j. ridd.2020.103813
- Patja, K., livanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: A 35-year follow-up study. *Journal of Intellectual Disability Research*, 44, 591–599. https:// doi.org/10.1046/j.1365-2788.2000.00280.x
- Rasheed, B. S., & Miller, S. (2006). Person-centered planning: Practices, promises, and provisos. The Journal for Vocational Special Needs Education, 28, 47–59.
- Salles, A. (2017). Self-efficacy as a measure of confidence. JAMA Surgery, 152, 506. https://doi.org/10.1001/jamasurg.2017.0035
- Simões, C., & Santos, S. (2017). The impact of personal and environmental characteristics on quality of life of people with intellectual disability. *Applied Research in Quality of Life*, 12, 389–408. https://doi.org/10. 1007/s11482-016-9466-7
- Theis, N., Campbell, N., De Leeuw, J., Owen, M., & Schenke, K. C. (2021). The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. *Disability and Health Journal*, 14, 101064. https://doi.org/ 10.1016/j.dhjo.2021.101064
- Townsend, E. (2007). Enabling occupation II: Advancing an occupational therapy vision for health, well being & justice through occupation. https:// www.amazon.com/Enabling-Occupation-II-Advancing-Occupational/dp/ B0097SAGHS
- Verdugo, M. Á., Arias, B., Gómez, L. E., & Schalock, R. L. (2010). Development of an objective instrument to assess quality of life in social services: Reliability and validity in Spain. *International Journal of Clinical* and Health Psychology, 10(1), 105–123.
- Vergara, I., Bilbao, A., Orive, M., Garcia-Gutierrez, S., Navarro, G., & Quintana, J. M. (2012). Validation of the Spanish version of the Lawton IADL scale for its application in elderly people. *Health and Quality* of Life Outcomes, 10, 130. https://doi.org/10.1186/1477-7525-10-130
- Vetri, L., Elia, M., Vitello, G. A., Greco, D., Gagliano, C., Costanzo, M. C., ... Musumeci, S. A. (2021). Impact of daytime routine modifications on people with severe intellectual disability amid COVID-19 pandemic. *Perspectives in Psychiatric Care*, 57, 1536–1537. https://doi.org/10. 1111/ppc.12696
- Villani, E. R., Vetrano, D. L., Damiano, C., Di Paola, A., Ulgiati, A. M., Martin, L., ... Carfi, A. (2020). Impact of COVID-19-related lockdown on psychosocial, cognitive, and functional well-being in adults with down syndrome. *Frontiers in Psychiatry*, 11, 578686. https://doi.org/ 10.3389/fpsyt.2020.578686

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