

# Quality of Life of Young People with Intellectual Disabilities in Argentina, Chile and Spain

## Calidad de Vida de Jóvenes con Discapacidad Intelectual en Argentina, Chile y España

María Lucía Morán Suárez<sup>1</sup> and Laura Elisabet Gómez Sánchez<sup>2</sup>

<sup>1</sup>Department of Education, Universidad de Cantabria, Spain

<sup>2</sup>Department of Psychology, Universidad de Oviedo, Spain

The construct of quality of life (QoL) has moved from a philosophical perspective to the development of a paradigm of supports to people with intellectual disability (ID). However, these advances have been focused mostly on the adult stage. Therefore, the goals of this study were: (1) to assess the association between personal and environmental factors and the QoL of children and adolescents with ID and (2) to describe QoL-related personal outcomes in the childhood and adolescence stages. The sample was composed of 546 participants from 49 organizations located in Argentina, Chile and Spain. Ages ranged from 4 to 21 years old ( $M = 13.3$ ;  $SD = 4.6$ ) and assessments were conducted by 154 professionals and relatives. The KidsLife Scale was used. The scale comprises 96 items divided into the eight QoL domains. Significant differences were found in QoL-related personal outcomes depending on the age, level of ID, level of support needs, type of schooling and country. Furthermore, the lowest scores were obtained in the social inclusion and self-determination domains. This study contributes to enhance the knowledge of the construct of QoL in children and youth with ID. Also, it serves as a guide for the development of supports, programs, and social policies aimed at promoting their QoL.

*Keywords:* quality of life, intellectual disability, infancy, adolescence, assessment

El constructo de calidad de vida (CV) ha pasado de ser una noción filosófica a convertirse en un marco de referencia en la prestación de apoyos a las personas con discapacidad intelectual (DI). No obstante, tales avances se han limitado mayoritariamente a la etapa adulta. Por ello, los objetivos de este estudio fueron: (a) evaluar las asociaciones entre factores individuales y ambientales y la CV de población infantojuvenil con DI y (b) describir los resultados personales relacionados con su CV en la infancia y la adolescencia. La muestra no probabilística por conveniencia estuvo compuesta por 546 participantes provenientes de 49 organizaciones de Argentina, Chile y España. El rango de edad osciló entre los 4 y los 21 años ( $M = 13,3$ ;  $DE = 4,6$ ) y las evaluaciones fueron realizadas por 154 profesionales y familiares. Se utilizó la Escala KidsLife, que cuenta con 96 ítems organizados en torno a las ocho dimensiones de CV. Se calcularon los estadísticos descriptivos de las puntuaciones y se utilizó la prueba t de Student para muestras independientes y el análisis de varianza. Se encontraron diferencias significativas en CV en función de la edad, el nivel de DI, el nivel de necesidades de apoyos, el tipo de escolarización y el país, así como puntuaciones más bajas en inclusión social y autodeterminación. Este estudio contribuye a mejorar el entendimiento del constructo de CV en población infantojuvenil con DI y sirve de guía para orientar los apoyos, los programas y las políticas dirigidas a promover su CV.

*Palabras clave:* calidad de vida, discapacidad intelectual, infancia, adolescencia, evaluación

In recent decades the construct of quality of life (QOL) has evolved from a philosophical and merely sensitizing notion to become a social construct, an area of applied research and a frame of reference in the provision of supports and services, the evaluation of outcomes and the development of social policies (Gómez et al., 2021; Verdugo et al., 2021).

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María Lucía Morán  <https://orcid.org/0000-0001-5650-6711>

Laura Elisabet Gómez  <https://orcid.org/0000-0002-0776-1836>

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Correspondence concerning this article should be addressed to Laura E. Gómez, Facultad de Psicología, Universidad de Oviedo, Plaza Feijoo s/n, 33003, Oviedo, Asturias, Spain. Email: [gomezlaura@uniovi.es](mailto:gomezlaura@uniovi.es)

Although there are several models that attempt to operationalize QOL (e.g., Cummins, 2005; Felce & Perry, 1995; Petry et al., 2005; Schalock & Verdugo, 2002; The WHOQOL Group, 1995), in this paper we started from the QOL model of Schalock and Verdugo (2002) because it is the most widespread in the field of intellectual disability (ID) and because of the large amount of empirical evidence that it accumulates (Arias et al., 2018; Claes et al., 2012; Fernández et al., 2018; Gómez et al., 2020a; Mora et al., 2020; Morán et al., 2019a). According to this conceptual framework (Schalock et al., 2011), QoL is understood as a desired state of personal well-being that (a) is multidimensional, (b) has universal (*etic*) and culture-bound (*emic*) properties, (c) possesses objective and subjective components, and (d) is influenced by personal characteristics and environmental factors. The model includes eight core dimensions (i.e., emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights) that are common to all people, although they may vary in the importance and value that each person attributes to them (Schalock et al., 2007). The measurement of each of these dimensions is done through QOL indicators, defined as "perceptions, behaviors or specific conditions of the dimensions of quality of life that reflect a person's well-being" (Schalock & Verdugo, 2002, p. 14). Table 1 presents a definition of each of the QOL dimensions, as well as the most commonly used indicators for their assessment.

**Table 1**  
*QOL Dimensions and Indicators (Gómez et al., 2016a).*

Dimension	Definition	Indicators
SI	Going to places in the city or neighborhood where other people go to and participating in their activities like everybody else, feeling integrated, having the support of other people.	"Integration", "Participation" and "Supports".
SD	Deciding for oneself and having the opportunity to choose the things one wants, how one wants their life to be, their work, their free time, the place where they live, the people they are with.	"Autonomy", "Goals", "Opinions" and "Personal Preferences".
EW	Feeling calm, safe, relaxed, not nervous.	"Satisfied with life", "Self-Image", "Affection and emotion", "Stability" and "Mental Health".
PW	Good health, feeling in good shape, having healthy eating habits.	"Rest, sleep", "Hygiene", "Food", "Healthcare" and "Physical Health".
MW	Having enough money to buy what one needs or desires, having a home and adequate services.	"Housing", "New Technologies and Assistive Technology", "Material Goods" and "Services".
RI	Being considered as equal to others, being treated equally, having one's personality respected, one's opinions, desires, intimacy, rights.	"Exercising Rights", "Intimacy", "Confidentiality", "Respect" and "Knowing Your Rights".
PD	The possibility to learn different things, having knowledge and achieving personal fulfilment.	"Problem Solving", "Daily Life Activities" and "Teaching/Learning".
IR	Relating to other people, having friends and getting on well with people (neighbors, colleagues and others).	"Communication", "Family Relations", "Friends", "Colleagues" and "Society".

*Note:* SI = social inclusion; SD = self-determination; EW = emotional well-being; PW = physical well-being; MW = material well-being, RI = rights; PD = personal development; IR = interpersonal relationships.

The QOL construct has important applications and implications, as it facilitates the development and evaluation of individualized supports, fosters evidence-based practice design, promotes personal outcome assessment, provides strategies for continuous quality improvement, and facilitates organizational transformation (de Geus-Neelen et al., 2019; Gómez et al., 2010a; Schalock et al., 2018, 2019). However, despite the remarkable progress made in the application of the concept of QoL in the field of disability (Nieuwenhuijse et al., 2019), the child and adolescent population with ID has had less access to these changes (Gómez et al., 2016b; Townsend-White et al., 2012). Thus, the few studies on QoL in childhood and adolescence coincide in pointing to lower QoL scores compared to their non-disabled peers (Coudronnière et al., 2017; Ncube et al., 2018; Papadopoulou et al., 2017) and tend to focus on family rather than individual QoL (e.g., Hassanein et al., 2021; Staunton et al., 2020).

At this point, it is necessary to distinguish the concept of *individual QoL* from others currently widely used, such as *family QoL* (e.g., Balcells et al., 2019), *health-related QoL* (e.g., Schoemaker & Houwen, 2021), *subjective well-being* (e.g., Ng & Diener, 2022), *psychological well-being* (e.g., Ryff, 2013) or *self-determination* (e.g., Shogren et al., 2021). Thus, while these constructs are more focused on specific aspects, in this study it is a concept (i.e., individual QoL) that goes beyond and approaches QoL from a broader perspective by integrating all relevant areas of a person's life and assessing them through subjective and objective elements.

In the Ibero-American context there are several instruments that allow the assessment of individual QoL based on the model of Schalock and Verdugo (2002), such as the GENCAT Scale (Verdugo et al., 2010) for users of social services; the INICO-FEAPS Scale (Gómez et al., 2015; Verdugo et al., 2017) and the Personal Outcomes Scale (Carbó-Carreté et al., 2015) for adults with ID; the San Martín Scale (Verdugo et al., 2014), aimed at adults with significant support needs; the Quality of Life Scale (Alcedo et al., 2008) and the FUMAT Scale (Gómez et al., 2008; Verdugo et al., 2009) for aging people with disabilities; or the CAVIDACE Scale (Fernández et al., 2019), aimed at adult population with brain damage. In the case of younger people, there are the CVI-CVIP (Sabeh et al., 2009; Urzúa et al., 2013) and the CCVA (Dejo et al., 2018; Gómez-Vela & Verdugo, 2009) scales, aimed, respectively, at the child and adolescent population in general, being also suitable for people with ID and high levels of functioning.

More recently, overcoming the psychometric limitations of the latter two, and in response to the growing demand from family members, professionals and organizations for instruments that respond to the need to assess QOL in the adolescent and child population with ID and significant support needs, the KidsLife Scale (Gómez et al., 2016a) and its versions for people with Down syndrome (Gómez et al., 2017) and autism spectrum disorder (ASD; Gómez et al., 2018) were developed. Although this scale addresses the assessment of the central dimensions and indicators that are relevant for this population, its recent creation entails that yet there are no studies that, applying it to a large sample, allow us to come closer to understanding of which are the QOL dimensions in which the child and adolescent population with ID presents greater strengths and which are susceptible to improvement. Likewise, it is still a pending task in this population to know which variables are associated with their QOL.

Although research has been carried out in Spain on individual QOL in children and adolescents, the literature focuses on specific groups, such as the population with rare diseases (González et al., 2016), ASD (Morán et al., 2019a) or Down syndrome (Morán et al., 2022). In general, these studies find better scores in the dimensions of material and physical well-being and worse scores in the dimensions of social inclusion and self-determination. Significant differences in QOL or its dimensions were also observed as a function of age, level of DI, level of support needs, gender, type of schooling and size of the organization (González et al., 2016; Morán et al., 2019b, 2022). However, to date, none have presented personal outcomes in individual QOL for the set of young people with ID. In Chile, although there are some studies on individual QoL (e.g., Castro et al., 2016; Vega et al., 2023), the scarce research on the infant and juvenile population with ID focused on a sample of 28 children receiving pediatric care (Santander et al., 2022). Castro et al. (2016) and Vega et al. (2023) found lower scores in the dimensions of personal development, interpersonal relationships and social inclusion and a significant negative correlation between the level of ID (adaptive behavior and cognition) and QOL. In contrast to Spain and Chile, as far as the authors of this article are aware, Argentina lacks specific research on individual QOL in the child and adolescent population with ID. Regarding the adult population, it is worth mentioning the existence of a study that compared the individual QOL of 681 people with ID in Argentina, Brazil and Colombia, using the Integral Scale (Gómez et al., 2010b). This study found significant differences in objective QOL depending on the country, but not in subjective QOL.

Given the scarcity of data on the QOL of children and adolescents with ID and related variables, the present study had two objectives. First, to assess possible associations between individual and environmental factors and the QOL of children and youth with DI identified as relevant in the literature, such as sex, age, level of DI, level of support needs, size of organization, type of schooling and country of residence (Córdoba-Andrade et al., 2019; Gómez et al., 2010b, 2016, 2020b; Morales et al., 2021; Morán et al., 2019b; Ncube et al., 2018; Santander et al., 2022; Williams et al., 2021). Second, to evaluate and describe the personal QOL-related outcomes of the infant and juvenile population with ID in Argentina, Chile, and Spain. The ultimate goal of this study was to identify the limitations and strengths of this population in the different dimensions of this construct, so as to allow the design and evaluation of supports and programs aimed at improving their QOL.

## Method

### Type of Study

A cross-sectional study was carried out with a non-probabilistic convenience sampling, through the participation of centers that served people with ID and showed interest in participating in the study

### Participants

The criteria for sample selection were: (a) having ID, (b) being between 4 and 21 years of age, and (c) receiving educational, social or health services in an organization providing support for people with ID. The only exclusion criterion was being outside the educational system, since the instrument includes items related to this area. As for the informants, they had to have known the person being evaluated for at least six months and have the opportunity to observe him/her in different settings for extended periods of time (e.g., family members, teachers, support providers, among others).

The sample consisted of 546 participants receiving support in a total of 49 organizations and centers for people with ID located in Argentina, Chile and Spain. Information about the study and the invitation to participate in it were disseminated at various international congresses and scientific conferences, as well as in social networks (e.g., Facebook, X) and on the web page of the Institute for Integration in the Community (INICO, University of Salamanca, Spain; <https://inico.usal.es>), Plena Inclusión and Down España. Similarly, many centers interested in collaborating offered to do so after reading the various publications produced by the research team (articles, books and book chapters). At the same time, an exhaustive Internet search was carried out for centers that serve people with ID and a mass mailing was made requesting their participation.

The procedure was the same in all three countries. Those centers that showed interest in participating received a link requesting information about the center, the person in charge of coordinating the evaluation and the number of people to be evaluated.

The 49 organizations that participated offered subsidized (41.8%), private (35.2%) or public (23.1%) services and were mainly educational (69.6%), followed by health services (26.4%) or social services (4%). Most (80.1%) served more than 50 users. The centers were located mostly in urban settings (78.2%) in Argentina (Buenos Aires, Santa Fe), Chile (Concepción, Santa Bárbara, Los Angeles) and Spain (Andalucía, Asturias, Castilla y León, Castilla-La Mancha, Cataluña, Comunidad Valenciana, Extremadura, Galicia and País Vasco).

Participants ranged in age from 4 to 21 years ( $M = 13.3$ ,  $SD = 4.6$ ). More than half of the participants (61.9%) were male. 35.8% had mild, 41.6% moderate, 21.2% severe, and 6.4% profound levels of ID, according to official reports from service provider centers (where having an official diagnosis of ID is a mandatory requirement for receiving supports). The majority had an extensive (32.1%) or intermittent (28.6%) level of support needs. The conditions associated with ID most frequently presented by participants were ASD (19%), mental health problems (15.6%), behavioral problems (15%), physical disability (14.5%), and Down syndrome (10.1%). A large majority of participants had a family (96%) and almost three quarters of the sample resided in or attended the family home (53.7%). The majority (64%) attended special education schools, 33.1% attended regular education centers (i.e., regular schooling) and 2.9% were enrolled in the combined modality. Table 2 shows the characteristics of the group of participants by country.

**Table**  
*Sociodemographic Data of the Participants by Country*

		Argentina (n = 176)	Chile (n = 183)	Spain (n = 187)
Age	Mean	11.2	14.2	14.4
	SD	4.3	4.1	4.8
	Minimum	5	4	4
	Maximum	21	21	21
Sex	Female	61 (34.7)	81 (44.3)	66 (35.3)
	Male	115 (65.3)	102 (55.7)	121 (64.7)
ID level	Mild	63 (35.8)	82 (44.8)	23 (12.3)
	Moderate	65 (36.9)	88 (48.1)	74 (39.6)
	Severe	31 (17.6)	9 (4.9)	76 (40.6)
	Profound	17 (9.7)	4 (2.2)	14 (7.5)
Level of support needs	Limited	52 (29.5)	49 (26.8)	12 (6.4)
	Intermittent	69 (39.2)	34 (18.6)	53 (28.3)
	Extensive	36 (20.5)	78 (42.6)	61 (32.6)
	Generalized	19 (10.8)	22 (12.0)	61 (32.6)
He/she has a family	167 (94.9)	173 (94.5)	184 (98.4)	
Resides or attends family home	73 (41.5)	67 (36.6)	153 (81.8)	
Type of schooling	Special	77 (50.3)	92 (52.0)	162 (86.6)
	Combined	9 (5.9)	-	6 (3.2)
	Ordinary (regular)	67 (43.8)	85 (48.0)	19 (10.2)

*Note:* ID = intellectual disability. The value in parentheses represents the percentage. There are missing data on type of schooling in Argentina (n = 23) and Chile (n = 6) since informants did not indicate any option.

## Instrument

The KidsLife Scale (Gómez et al., 2016a, 2016b) was used, which assesses the QOL of young people with ID aged 4-21 years who are users of social, educational or health services. The scale is completed by external observers who have known the person being assessed for at least six months and have the opportunity to observe him/her in different contexts for extended periods of time (e.g., parents, teachers, support providers, among others).

It has 96 items formulated in the third person and organized around the eight dimensions of QOL (Schalock & Verdugo, 2002): Social Inclusion, Self-Determination, Emotional Well-Being, Physical Well-Being, Material Well-Being, Rights, Personal Development and Interpersonal Relationships. Each dimension is made up of 12 items. Some examples of items per dimension are: *He/she is integrated with his/her peers in class* (Social Inclusion); *He/she chooses how to spend his/her free time* (Self-determination); *Specific measures are taken so that his/her environment is recognizable and predictable* (Emotional Well-Being); *He/she receives support from all necessary health professionals* (Physical Well-Being); *He/she has the material goods he/she needs* (Material Well-Being); *The confidentiality of his/her assessments is adequately protected* (Rights); *He/she learns things that make him/her more independent* (Personal Development); *Specific measures are taken to maintain and extend his/her social networks* (Interpersonal Relationships). Its response format consists of a Likert-type scale with four options: 1: *never*, 2: *sometimes*, 3: *frequently* and 4: *always*. Therefore, the theoretical range of scores can oscillate between 96 and 384 points in the total scale and from 12 to 48 in each of the dimensions, with higher scores indicating better results in QOL. The average administration time of the scale is 25 minutes. The instrument also includes a section of sociodemographic data on the person being assessed (i.e., sex, age, level of ID, level of support needs, level of dependency, percentage of disability, other conditions of the person being assessed, type of residence and centers attended, type of schooling, locality and province of residence), the main informant and the organization where the person receives supports and services.

It also contains standardized scores and percentiles for each of the eight QOL dimensions and allows obtaining a QOL profile. The Kidslife Scale is available for free download (<https://sid-inico.usal.es/documentacion/escala-kidslife/>).

This scale has numerous evidences of reliability. Thus, for example, in the validation study, adequate evidence of internal consistency was obtained: the total scale obtained a Cronbach's alpha coefficient of .96, while the dimensions ranged from .78 for rights to .90 for personal development. Validity was also evidenced, based on the internal structure of the scale: RMSEA<.060; CFI>.98; TLI>.98; SRMR<.50 (Arias et al., 2018; Gómez et al., 2016b). Table 3 presents evidence of the internal consistency of the scale in the sample of the present study, broken down by country and dimension.

**Table 3**

*Internal Consistency Coefficients (Cronbach's Alpha) by Country and Dimension*

Country	<i>n</i>	SI	SD	EW	PW	MW	RI	PD	IR
Argentina	176	.87	.81	.86	0,84	.89	.83	.91	.88
Chile	183	.90	.91	.94	.89	.92	.90	.95	.93
Spain	187	.86	.88	.82	.79	.82	.76	.86	.82

*Note:* SI = social inclusion; SD = self-determination; EW = emotional well-being; PW = physical well-being; MW = material well-being; RI= rights; PD = personal development; IR = interpersonal relationships.

## Procedure

Once the liaison with the organizations had been completed, they were sent all the material necessary to carry out the assessments (i.e., more detailed information about the study, the instruction manual, informed consent, and the scale). In order to ensure that the informants had a good knowledge of the person's living conditions, the informants were proposed by the staff in charge of coordinating the application of scales in each center.

The evaluations were carried out by 154 informants, mostly women (87.7%), with a mean age of 38.2 years ( $SD = 9.3$ ). A large proportion (93.2%) were direct care professionals, mainly teachers and psychologists, while 6.8% were parents, mainly mothers (78.4%). The average length of relationship with the person being evaluated was three years; the majority maintained a frequency of contact with the person being evaluated daily or several times a week (72.5%). A total of 58.8% of the informants needed to consult other people in order to complete the scale, mainly family members (32.1%) and educators (24.2%). The questionnaires could be filled out electronically or on paper

The research team was available at all times to answer questions, comments and suggestions through e-mails, telephone calls and in some cases, face-to-face meetings.

The study was approved by the Ethics Committee of the University of Oviedo and complied with the principles of the Declaration of Helsinki. Informed consent signed by parents or legal guardians was obtained in all cases. No personal data were collected, but the participants were identified by means of anonymized alphanumeric codes to guarantee the confidentiality of the evaluations. These codes also made it possible to send organizations a report with the assessments and results obtained (i.e., aggregated data) in each center so that the scores could be used to guide their individualized support plans and organizational strategies aimed at improving the QOL of the people they support.

## Data Analysis

First, the existence of significant differences was analyzed as a function of various individual and environmental variables with the aim of guiding professional and organizational practices to improve QOL.

The variable age (4-21 years) was divided into three categories: 4-10 years, 11-15 years and 16-21 years.

Student's *t-test* for independent samples was used to contrast the relationship between the two-level variable (i.e., sex) and the total score in QOL and the dimensions. In the case of variables with more than two levels (i.e., age, level of DI, level of support needs, school size, type of schooling and country), analysis of variance (ANOVA) and the corresponding post hoc tests were used (i.e., Scheffe if the homoscedasticity condition was met, or Dunnett's T3 if equal variances were not assumed).

In all cases a significance level of 99% was established ( $p < .01$ ) and effect sizes were calculated (Cohen's *d* for the *t-test* and partial eta squared for the ANOVAs). Effect sizes were interpreted according to Cohen's (1988) criteria: 0.01 = small; 0.06 = medium; 0.14 = large.

Second, descriptive statistics were calculated for the scores (i.e., mean, standard deviation, mode, median, minimum, maximum, skewness, kurtosis and valid response percentages) by country.

Analyses were performed using the SPSS 24 statistical package.

## Results

### Factors Associated with QOL and its Dimensions

The association between individual (i.e., sex, age, level of ID and level of support needs) and environmental factors (i.e., size of the organization receiving services, type of schooling and country of residence) with QOL and its dimensions was assessed. Tables 4 and 5 show the factors that resulted in significant differences in the total score and in the eight dimensions at a 99% confidence level.

Looking at the individual variables, *sex* did not lead to significant differences in the total score ( $t_{(544)} = -.859$ ;  $p = .391$ ) or in the scores per dimension: Social Inclusion ( $t_{(544)} = .688$ ;  $p = .492$ ); Self-Determination ( $t_{(544)} = -1.517$ ;  $p = .130$ ); Emotional Well-Being ( $t_{(544)} = -.608$ ;  $p = .543$ ); Physical Well-Being ( $t_{(544)} = -.296$ ;  $p = .767$ ); Material Well-Being ( $t_{(544)} = .765$ ;  $p = .444$ ); Rights ( $t_{(544)} = -.870$ ;  $p = .385$ ); Personal Development ( $t_{(544)} = -1.871$ ;  $p = .062$ ) and Interpersonal Relationships ( $t_{(544)} = -2.029$ ;  $p = .043$ ). As for *age*, there were significant differences in the scores obtained in the Self-Determination ( $F_{(2)} = 10.123$ ;  $p < .001$ ;  $\eta^2 = .036$ ) and Rights ( $F_{(2)} = 6.251$ ;  $p = .002$ ;  $\eta^2 = .023$ ) dimensions, but with small effect sizes. The results of the *post hoc* tests showed that the group of participants aged 16 to 21 years achieved significantly higher scores on Self-Determination than the participants aged 4 to 10 years ( $p < .001$ ) and 11 to 15 years ( $p = .005$ ) and on Rights, compared to the group aged 4 to 10 years ( $p = .002$ ).

In turn, the *level of ID* resulted in significant differences in the total score with a moderate effect size ( $F_{(3)} = 16.104$ ;  $p < .001$ ;  $\eta^2 = .082$ ) in favor of participants with mild and moderate ID, compared to those with severe and profound ID ( $p < .001$ ). Significant differences were also found in most dimensions, with large effect sizes, in Self-Determination ( $F_{(3)} = 47.475$ ;  $p < .001$ ;  $\eta^2 = .208$ ) and Interpersonal Relationships ( $F_{(3)} = 41.740$ ;  $p < .001$ ;  $\eta^2 = .188$ ), medium effect sizes in Social Inclusion ( $F_{(3)} = 17.221$ ;  $p < .001$ ;  $\eta^2 = .087$ ) and Personal Development ( $F_{(3)} = 13.202$ ;  $p < .001$ ;  $\eta^2 = .068$ ) and small effect sizes on Rights ( $F_{(3)} = 10.208$ ;  $p < .001$ ;  $\eta^2 = .053$ ) and Material Welfare ( $F_{(3)} = 4.410$ ;  $p = .004$ ;  $\eta^2 = .024$ ).

**Table 4**  
*Individual Factors that Led to Significant Differences (F-Statistic) in QoL and its Dimensions (n = 546)*

Individual factor	SI	<i>p</i>	SD	<i>p</i>	EW	<i>p</i>	PW	<i>p</i>	MW	<i>p</i>	RI	<i>p</i>	PD	<i>p</i>	IR	<i>p</i>	QOL	<i>p</i>
Age	.590	.555	10.123	<.001	.026	.975	.857	.425	1.076	.342	6.251	.002	1.627	.197	2.288	.102	2.889	.056
ID level	17.221	<.001	47.475	<.001	1.236	.296	.432	.730	4.410	.004	10.208	<.001	13.202	<.001	41.740	<.001	16.104	<.001
Level of support needs	18.582	<.001	30.676	<.001	2.504	.058	7.580	<.001	6.116	<.001	7.648	<.001	9.868	<.001	28.985	<.001	16.419	<.001

Note. *SI* = social inclusion; *SD* = self-determination; *EW* = emotional well-being; *PW* = physical well-being; *MW* = material well-being; *RI* = rights; *PD* = personal development; *IR* = interpersonal relationships; *QOL* = quality of life.

**Table 5**  
*Environmental Factors that Led to Significant Differences (F-Statistic) in QoL and its Dimensions (n = 546)*

Environmental factor	SI	<i>p</i>	SD	<i>p</i>	EW	<i>p</i>	PW	<i>p</i>	MW	<i>p</i>	RI	<i>p</i>	PD	<i>p</i>	IR	<i>p</i>	QOL	<i>p</i>
Size of the organization	8.641	<.001	8.334	<.001	19.538	<.001	27.316	<.001	20.948	<.001	21.313	<.001	14.188	<.001	12.636	<.001	22.694	<.001
Type of schooling	6.506	.002	5.952	.003	1.699	.184	1.221	.296	.826	.438	.880	.415	.858	.425	5.827	.003	1.676	.188
Country of residence	3.364	.035	18.176	<.001	2.610	.074	25.820	<.001	13.656	<.001	4.747	.009	2.304	.101	7.679	<.001	.051	.951

Note: *SI* = social inclusion; *SD* = self-determination; *EW* = emotional well-being; *PW* = physical well-being; *MW* = material well-being; *RI* = rights; *PD* = personal development; *IR* = interpersonal relationships; *QOL* = quality of life.



Regarding the *level of support needs*, there were significant differences in the total score ( $F_{(3)} = 16.419$ ;  $p < .001$ ;  $\eta^2 = .083$ ) with a medium effect size (and in the *post hoc* tests), so that participants with an extensive and generalized level of support needs achieved significantly lower scores, compared to those with a limited and intermittent level of support ( $p < .001$ ). Along the same lines, significant differences were found in all dimensions, with the exception of the emotional well-being dimension, with large effect sizes in Self-determination ( $F_{(3)} = 30.676$ ;  $p < .001$ ;  $\eta^2 = .145$ ) and Interpersonal Relationships ( $F_{(3)} = 28.985$ ;  $p < .001$ ;  $\eta^2 = .138$ ), with a medium effect size in Social Inclusion ( $F_{(3)} = 18.582$ ;  $p < .001$ ;  $\eta^2 = .093$ ) and with small effect sizes in Personal Development ( $F_{(3)} = 9.868$ ;  $p < .001$ ;  $\eta^2 = .052$ ), Physical Well-Being ( $F_{(3)} = 7.580$ ;  $p < .001$ ;  $\eta^2 = .040$ ), Rights ( $F_{(3)} = 7.684$ ;  $p < .001$ ;  $\eta^2 = .041$ ) and Material Wellbeing ( $F_{(3)} = 6.116$ ;  $p < .001$ ;  $\eta^2 = .033$ ).

When considering environmental factors, the *size of the organization* resulted in significant differences in the total score with a large effect size ( $F_{(4)} = 22.694$ ;  $p < .001$ ;  $\eta^2 = .144$ ). *Post hoc* tests revealed that the group of participants receiving services in centers between 101 and 200 users obtained worse QOL scores than those from centers with 21 to 50 users, 51 to 100 users, or with more than 200 users ( $p < .001$ ). In addition, participants in centers with less than 20 users obtained worse scores than those in centers with more than 200 users ( $p = .005$ ). Regarding the dimensions, significant differences were observed in all of them, with a large effect size in Physical Well-being ( $F_{(4)} = 27.316$ ;  $p < .001$ ;  $\eta^2 = .168$ ), with medium effect sizes in Rights ( $F_{(4)} = 21.313$ ;  $p < .001$ ;  $\eta^2 = .136$ ), Material Well-Being ( $F_{(4)} = 20.948$ ;  $p < .001$ ;  $\eta^2 = .134$ ), Emotional Well-Being ( $F_{(4)} = 19.538$ ;  $p < .001$ ;  $\eta^2 = .126$ ), Personal Development ( $F_{(4)} = 14.188$ ;  $p < .001$ ;  $\eta^2 = .095$ ) and Interpersonal Relationships ( $F_{(4)} = 12.636$ ;  $p < .001$ ;  $\eta^2 = .085$ ) and small effect sizes in Social Inclusion ( $F_{(4)} = 8.641$ ;  $p < .001$ ;  $\eta^2 = .060$ ) and Self-Determination ( $F_{(4)} = 8.334$ ;  $p < .001$ ;  $\eta^2 = .058$ ).

Regarding *the type of schooling*, there were significant differences in the scores obtained in the dimensions Social Inclusion ( $F_{(2)} = 1.676$ ;  $p = .088$ ;  $\eta^2 = .025$ ), Self-Determination ( $F_{(2)} = 5.952$ ;  $p = .003$ ;  $\eta^2 = .023$ ) and Interpersonal Relationships ( $F_{(2)} = 5.827$ ;  $p = .003$ ;  $\eta^2 = .022$ ) with small effect sizes. The results of the *post hoc* tests showed that the group of participants in regular education achieved significantly scores than those in special education on Social Inclusion ( $p = .002$ ) and Interpersonal Relationships ( $p = .004$ ).

Finally, *country of residence* resulted in significant differences with medium effect sizes in Physical Well-Being ( $F_{(2)} = 25.820$ ;  $p < .001$ ;  $\eta^2 = .087$ ) and Self-Determination ( $F_{(2)} = 18.176$ ;  $p < .001$ ;  $\eta^2 = .063$ ) and with small effect sizes in Material Well-Being ( $F_{(2)} = 13.656$ ;  $p < .001$ ;  $\eta^2 = .048$ ), Interpersonal Relationships ( $F_{(2)} = 7.679$ ;  $p = .001$ ;  $\eta^2 = .028$ ), and Rights ( $F_{(2)} = 4.747$ ;  $p = .009$ ;  $\eta^2 = .017$ ). More specifically, the group of participants residing in Chile presented better scores in Self-determination than those coming from Argentina and Spain ( $p < .001$ ) and better scores in Interpersonal Relations than those residing in Spain ( $p = .001$ ). In contrast, the group of participants from Chile scored worse on Physical Well-Being ( $p < .001$ ) and Material Well-Being ( $p < .001$ ), compared to those from Argentina and Spain.

### Distribution of Scores in Argentina

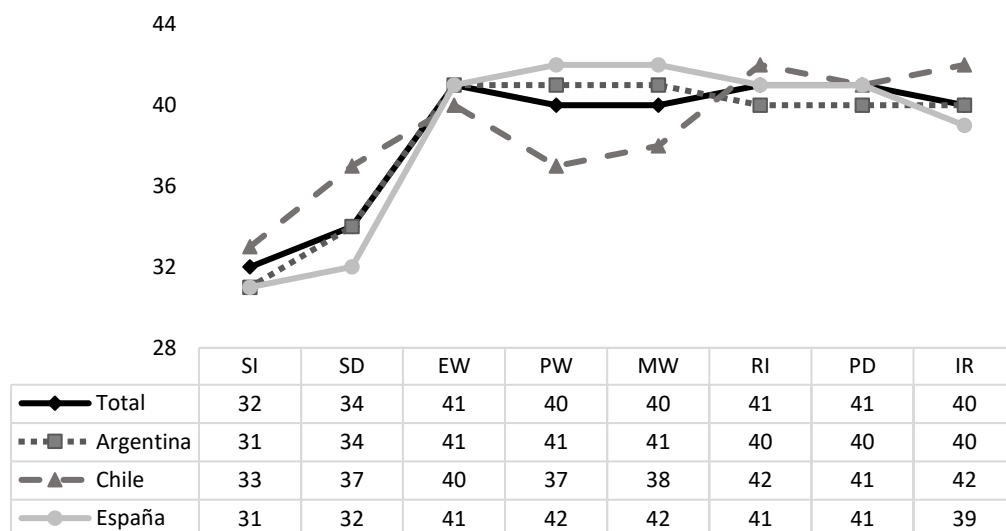
In the Argentine sample, the distribution of the scores obtained on the scale showed negative skewness and positive kurtosis (skewness =  $-0.90$ , kurtosis =  $.40$ ). The scores ranged from 174 to 376. Scores ranged from 174 to 376. Looking at the dimensions, the highest scores were obtained in Emotional Well-Being and Physical Well-Being, while the lowest scores were in the dimensions Social Inclusion and Self-Determination. Table 6 and Figure 1 show these results.

**Table 6**  
*Descriptive Statistics of the Scores in the Argentine Sample (n = 176)*

Statistics	SI	SD	EW	PW	MW	RI	PD	IR	Total
n items	12	12	12	12	12	12	12	12	96
Media	31.54	33.61	41.52	41.36	40.80	39.84	39.97	40.00	308.65
Median	30	34	43	44	43	40	42	41	319
Fashion	27	29	48	47	48	42	48	46	325
DE	8.15	6.38	5.64	6.28	6.77	5.81	7.10	6.68	43.85
Min.	15	18	25	22	22	21	19	21	174
Max.	48	48	48	48	48	48	48	48	376
Asymmetry	0.21	-.07	-1.02	-1.08	-1.00	-.85	-.95	-.89	-.90
Kurtosis	-.78	-.48	.55	.32	.12	.54	.16	.11	.40

Note: SI = social inclusion; SD = self-determination; EW = emotional well-being; PW = physical well-being; MW = material well-being, RI = rights; PD = personal development; IR = interpersonal relationships.

**Figure 1**  
*Distribution of Dimension Scores for the Total Sample and by Country*



When analyzing the valid percentages of the most positive responses (*always*) given by informants to each of the items in the Emotional Well-being and Physical Well-being dimensions, it is observed that the majority of participants receive praise and compliments when they do something well (88.1%), affection and appropriate physical contact when they need it (85.8%), measures to prevent or treat problems derived from physical disabilities (81.8%), supports that guarantee them adequate postural comfort (80.7%), supports they need from professionals (79.5%), immediate attention when they are unwell (77.8%), attention to the diagnosis and treatment of possible sensory disabilities (77.3%), as well as to their facial expressions, looks and direction of sight, voice, muscle tension, posture, movement and physiological reactions (76.1%). In addition, the people who provide them with supports know their individual expressions of emotional well-being (75.6%) and discomfort (72.7%).

In contrast, in the Social Inclusion and Self-Determination dimensions, it is observed in the most negative responses (*never*) that a large proportion of the persons with ID evaluated do not participate in the development of their individual support plan (54%), in natural groups in their community (46.6%) or in activities outside the center with people outside their support context (34.7%). A third did not decorate the room to their tastes (34.7%).

The opinion of a quarter is not taken into account when changes are made in the center (26.7%), and a similar percentage (25%) does not engage in leisure activities with people of their own age. Almost one in five do not participate in inclusive activities that interest them (19.3%) nor do they have opportunities to get to know other environments different from the place where they live (18.2%); nor do they participate in inclusive activities suitable for their physical and mental conditions (17.6%) or enjoy vacations in inclusive environments (17%).

**Distribution of Scores in Chile**

A negative skewness was observed in the distribution of the scores obtained on the scale (skewness = -.80, kurtosis = -.11) by the group of Chilean participants. The observed scores ranged from 381 to 142. The highest values were obtained in Interpersonal Relations and Rights. The lowest scores, on the other hand, were seen in the dimensions Social Inclusion and Self-Determination. This information is presented in Table 7 and Figure 1.

**Table 7**  
*Descriptive Statistics of the Scores in the Chilean Sample (n = 183)*

Statistician	SI	SD	EW	PW	MW	RI	PD	IR	Total
n items	12	12	12	12	12	12	12	12	96
Media	33.05	36.62	40.14	37.15	38.21	41.63	41.47	41.74	310.02
Median	32	38	42	38	39	43	44	45	320
Fashion	29	36	48	48	48	48	48	48	318
DE	7.81	7.99	7.43	8.24	8.20	6.29	7.31	7.05	52.11
Min.	15	16	16	18	15	17	18	20	142
Max.	48	48	48	48	48	48	48	48	381
Asymmetry	.15	-.65	-.92	-.44	-.65	-1.10	-1.12	-1.25	-.80
Kurtosis	-.72	-.51	.23	.86	-.38	.82	.37	.84	-.11

Note: SI = social inclusion; SD = self-determination; EW = emotional well-being; PW = physical well-being; MW = material well-being, RI = rights; PD = personal development; IR = interpersonal relationships.

If we examine the most positive responses (*always*), in the Interpersonal Relations and Rights dimensions, we see that in most cases the confidentiality of their individual assessments is protected (87.4%), the person and his/her legal guardian are informed about the application of physical restraint measures (80.9%), he/she is treated with respect (76%), adequate time is provided for him/her to respond when interacting with him/her (75.4%), activities are designed to facilitate peer interactions in the center (75.4%), his/her rights are respected and defended (74.9%), he/she has relationships with peers of his/her age in the educational center (74.3%), the best way to communicate information to him/her has been identified (73.2%), the people who provide support understand the communication system he/she uses (68.9%), and he/she uses a communication system that is understandable in different contexts (65.6%).

On the other hand, among the most negative responses (*never*) of informants in the Social Inclusion and Self-Determination dimensions, we find that more than half of the people evaluated do not participate in the development of their individual support plan (53.6%). One third do not enjoy vacations in inclusive settings (33.9%). Almost a quarter do not participate in natural groups in their community (23%) and around a fifth of the sample do not decorate their room to their tastes (20.8%) or have opportunities to get to know environments other than where they live (20.2%). A considerable number of the participants do not use community environments, such as schools, cafeterias, libraries, swimming pools, cinemas, parks or beaches (12%), do not choose the food they eat (10.4%), do not enjoy measures that enhance their participation in the community (8.7%), do not participate in inclusive activities appropriate to their physical and mental conditions (7.7%) or have opportunities to refuse to do activities irrelevant to their health (7.1%).

## Distribution of Scores in Spain

The distribution of scores (Table 8 and Figure 1) showed a slight negative skewness and a negative kurtosis (skewness =  $-.24$ ; kurtosis =  $-.59$ ). The range of scores ranged from 230 to 372. The highest mean scores were obtained in Material Well-Being and Physical Well-Being, while the lowest scores were in the dimensions Social Inclusion and Self-Determination.

**Table 8**  
*Descriptive Statistics of the Scores in the Spanish Sample (n = 187)*

Statistician	SI	SD	EW	PW	MW	RI	PD	IR	Total
n items	12	12	12	12	12	12	12	12	96
Media	31,12	32,18	41,24	41,67	41,79	41,06	40,72	39,16	308,93
Median	30	32	42	43	43	42	42	40	314
Fashion	30	34	44	44	46	42	43	35	288
DE	6,47	7,17	4,81	5,29	5,09	4,59	5,28	5,56	31,28
Min.	17	15	26	18	26	29	24	24	230
Max.	48	47	48	48	48	48	48	48	372
Asymmetry	0,33	-0,01	-0,70	-1,30	-0,88	-0,44	-0,60	-0,37	-0,24
Kurtosis	-0,47	-0,67	0,04	2,16	0,28	-0,40	-0,38	-0,55	-0,59

Note: SI = social inclusion; AU = self-determination; BE = emotional well-being; BF = physical well-being; BM = material well-being, DE = rights; PD = personal development; IR = interpersonal relationships.

Regarding the most positive responses (*always*), in the Material and Physical Well-being dimensions, the majority of participants residing in Spain receive immediate attention when they feel unwell (85.6%), have access to adapted technical aids (82.4%), receive care from health professionals (81.3%), have free access to the places where they go about their daily routines (72.7%), enjoy measures to prevent or treat pain (72.2%), receive periodic supervision of their medication (71.7%), maintain adequate postural comfort (71.1%), have their personal belongings within reach (70.1%), have prevention or treatment of problems derived from physical disabilities (69.5%), as well as diagnosis and treatment of sensory disabilities (66.3%).

On the other hand, if we consider the most negative responses (*never*), in the Social Inclusion and Self-Determination dimensions, more than a third do not decorate the room to their tastes (39.6%), do not participate in natural groups in their community (39%) or in the development of their individual support plan (38%). Approximately one in four people do not participate in activities outside the center with people outside their context of supports (29.9%) nor do they choose with whom to spend their free time (24.6%). Some do not choose how to spend their free time (17.1%) or the food they eat (17.1%), do not participate in inclusive activities that interest them (15%) or enjoy vacations in inclusive settings (13.4%), and their opinion is not taken into account when changes are made in the center (12.8%).

## Discussion

Given the paucity of literature examining the construct of QoL in the child and adolescent population with ID and its determinants (Enciso et al., 2021; Gómez et al., 2016b; Townsend-White et al., 2012; Williams et al., 2021), the main objectives of this study consisted of describing the association of different individual and environmental factors with QOL and its dimensions, as well as analyzing the personal outcomes related to QOL achieved by young people with ID in Argentina, Chile and Spain, according to the professionals and family members who provide them with supports and know them well.

Although the sample of participants consisted mostly of males (61.9%) -adjusting to the gender distribution of the DI (McGuire et al., 2019)-, no significant differences were observed in QOL as a function of gender, as in previous studies with adults (Balboni et al., 2020; Simões & Santos, 2017). However, the group of participants between 16 and 21 years of age obtained better results in Self-Determination and Rights than the younger participants.

As has been observed in other works, as young people with ID get older, their scores in Rights and Autonomy improve (Morán et al., 2022; Pérez, 2010; Vivas, 2011). The level of ID was also significantly related to the total QOL score and to all dimensions, with the exception of Emotional and Physical Well-Being, as was the level of support needs, with the sole exception of the Physical Well-Being dimension. This influence of the level of ID and support needs is consistent with previous studies (e.g., González et al., 2016; Morán et al., 2022; Santander et al., 2022; Vega et al., 2023) and it is not surprising if one takes into account that the outcomes of people with ID as measured by the KidsLife Scale are highly dependent on the support systems they have, supports that are often not offered to them, because they are considered unable to participate in making decisions about their lives (Esteban et al., 2021).

Regarding environmental factors, the group of participants receiving services in centers with a greater number of users obtained higher scores in both QOL and its dimensions. These results are consistent with those obtained in the infant and juvenile population with Down syndrome (Morán et al., 2022), but a priori clash with those obtained in studies with adult population with ID, in which it is usually found that the most recommendable residential solutions in terms of QOL are usually small centers and apartments distributed in the community (Bertelli et al., 2013; Young, 2006), as better outcomes, more privacy and greater opportunities to make choices are observed in these (Cocks & Boaden, 2011). It is also true that other authors, such as Shaw et al. (2011), note that small community living arrangements may also present limitations related to community participation, observing that some people with ID preferred the opportunity to live in larger groups and near other residences where people with ID lived. In addition, larger centers probably have better infrastructure, a greater availability of material and human resources, and a wider range of activities, supports, and services. Therefore, in future studies it would be important to consider not only the size of the center, but also other factors that could be relevant to the quality of life of people with ID.

In addition, the group of participants in regular education scored significantly higher on Social Inclusion and Interpersonal Relationships compared to their peers in special education. This is related to what has been found in previous studies, which gather that inclusive education fosters opportunities to establish interactions and friendships with non-disabled students and reduces stigmatization of students with special needs, by promoting a greater understanding of disability and more positive attitudes towards diversity (González et al., 2016; Papadopoulou et al., 2017; Tryfon et al., 2021). However, there are still barriers that make it difficult for inclusive education to be truly effective and of quality. In the face of this, it is essential to increase material and personal resources in educational centers, improve teacher training on attention to diversity and the use of universal design in the classroom (Lanterman & Applequist, 2018), integrate the paradigm of individualized supports and the VC model in the school context (Gómez et al., 2021; Morán et al., 2023; Sánchez-Gómez et al., 2020) and foster the active involvement and coordination of all educational agents (Coudronnière et al., 2017; Simón et al., 2016).

Focusing on the differences observed between the three countries, in both Spain and Argentina the highest scores were found in Physical, Material and Emotional Well-being, a result in line with previous work which shows that the rehabilitative model still prevails in these countries in the provision of services, very focused on meeting basic needs (e.g., Gómez et al., 2010b; Morán et al., 2019a, 2022; Santamaría et al., 2012). In Chile, on the other hand, the highest scores are obtained in Interpersonal Relationships and Rights. These high scores in Interpersonal Relationships are consistent with those of the study conducted by Santander et al. (2022), but the higher scores obtained in Rights are surprising. Although there is an enormous variety of factors associated with the idiosyncrasies of each country that interact with each other and could explain these differences, a plausible interpretation of this phenomenon could be related to the results noted above on the size of the centers in which people with ID receive services, since it is in Chile where the lowest percentage of people residing with their families is observed. Perhaps it is precisely the larger size of the centers that facilitates interpersonal relationships among residents and perhaps residing in a professional rather than a family environment is what favors respect for their rights (Gómez et al., 2020c; Morales et al., 2021).

On the other hand, in the three countries the lowest scores are observed, as in previous studies conducted with children (Arias et al., 2018; Morán et al., 2018, 2019a, 2019b, 2022; Williams et al., 2021) and adults (Castro et al., 2016; Gómez et al., 2016c), in the dimensions Social Inclusion and Self-Determination. Thus, as advocated by Morán et al. (2019a), the areas in which the greatest limitations were observed were those in which the person with ID is the protagonist in terms of participation in community life and decision-making. It is noteworthy that, as the case of Chile highlights, having a high score in Interpersonal Relations does not necessarily mean being included in the community.

Therefore, it is essential, on the one hand, to promote the participation of people with ID in social and recreational activities in the community, appropriate to their interests and with the necessary active supports, so that they have a social role. On the other hand, it is essential to provide them with the necessary supports so that they can have control over their own lives, exert influence in the contexts in which they develop, make choices and take meaningful decisions. In this sense, training of professionals and family members in measuring personal QOL-related outcomes and support needs, provision of individualized supports, person-centered planning, rights fulfillment, supported decision making, social inclusion and community participation should be encouraged (Beadle-Brown et al., 2016; Esteban et al., 2021; Mumbardó-Adam et al., 2017; Shogren et al., 2017; Verdugo & Navas, 2017) since such training enables the development of data-driven interventions aligned with individual preferences and goals.

However, the results of this study should be taken with some caution because, despite the large number of participants, the sample size per country could be improved. In addition, it is a convenience sample, so it is not representative of the population with ID in each country. Thus, for example, the participation of people with ID schooled in regular education centers was higher in Argentina and Chile than in Spain, where the participation of people with ID schooled in special education centers was higher. It should also be noted as a limitation that, although the KidsLife Scale has been validated in the Spanish context, it is still in the process of adaptation and validation in Argentina and Chile.

On the other hand, it should be taken into account that this is an evaluation carried out by third parties and that, therefore, it reflects their perspective or vision of people with ID. Their perceptions will most likely differ from the perceptions of people with ID themselves about their QOL. However, considering the views of family members and other close contacts when assessing the QOL of people with ID is an important practice (Schalock et al., 2021), especially when dealing with young people. In this sense, the heteroinformed perspective is especially useful when the aim of the evaluation is focused on assessing the appropriateness or effectiveness of supports and interventions, as they tend to show more sensitivity to change than self-reports (Morán et al., 2019a). To address this limitation, it would be desirable not only to have these assessments, but also to include self-reports, as both views are necessary and complementary (Balboni et al., 2013; Berástegui et al., 2021; Nieuwenhuijse et al., 2020). Thus, a fundamental line of future research should focus on the self-reported version of the KidsLife Scale.

Another possible limitation lies in having different types of informants, such as professionals and family members. Therefore, it would also be necessary to evaluate the inter-rater agreement of the scale in future studies. Finally, the design of this study and the analyses carried out only allow us to suggest associations between variables and outcomes, never causality. In addition, there are numerous variables that could account for some of the differences observed and that should be included in future studies, such as socioeconomic level, ethnicity or sociodemographic factors of the informants. With respect to the latter, we initially considered including data on the type of informant, sex, age, frequency of contact and duration of the relationship. However, these variables were finally excluded from the data analysis, due to the existence of multiple informants for the majority (58.8%) of the questionnaires.

Despite this, this study is an important contribution to the field of DI, in that it uses a large sample and an instrument with ample evidence of validity and reliability, and takes into account a wide range of variables (personal and contextual), it focuses on the QOL of a group that is often excluded in research and goes beyond strictly health-related QOL to include personal outcomes linked to all the dimensions important to a person, most of which are highly context-dependent and therefore modifiable through the appropriate provision of support in social, educational and health services. Thus, the results of the scale are of great use in guiding evidence-based practices aimed at improving the QoL of this vulnerable population, as it is essential to detect the circumstances associated with QoL limitations and, based on these, to undertake the necessary changes. The information from this study may be essential for improving personal outcomes related to QOL, as well as for guiding the development of person-centered planning and the provision of individualized supports for the individual.

This study allows a better understanding of the current understanding of the QOL construct in the population of children and adolescents with ID, serving as a guide for families, professionals and organizations to estimate the support and programs aimed at promoting their QOL and social policies to ensure human rights, empowerment and effective inclusion of people with ID in society, with full guarantee of their rights.

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