Operationalisation of quality of life for students with intellectual and developmental disabilities to improve their inclusion

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A B S T R A C T

Background: Quality of life (QoL) is regarded as a framework to enhance inclusive education outcomes in different domains for all students, especially for those with intellectual and developmental disabilities (IDD). Assessment tools are needed to implement this framework. Although there is a long trajectory of QoL assessment in people with IDD, we identify a lack of instruments for students with IDD who attend to general education contexts.
Aims: The goal of this study is to produce a pool of items in order to develop a field-test version of a QoL instrument for this target group.
Methods: 14 educational professionals participated in a four-round Delphi study, assessing the content of the items proposed according to four criteria (suitability, importance, observability and sensitivity).
Results: The results of this study provided evidence of content validity regarding the pool of items that will be included in a field-test version.
Conclusions: The results obtained are important for the development of a QoL assessment tool to improve the inclusion of students with IDD in general education settings.

What this paper adds?

1 It lays the foundations for developing a QoL assessment tool for students with IDD in general education settings, that could be also used to evaluate whether education is producing relevant outcomes linked to student's inclusion.

2 It is an example of a systematic process of identification and refinement of items for the assessment of QoL in students with IDD enrolled in general education settings, based on a consentaneous and participative approach that gathers the perspectives of educational professionals.

3 It provides the items of the different QoL domains with evidence of content validity regarding the four criteria evaluated (suitability, importance, observability and sensitivity). Thus, it constitutes an important milestone in the development of a new assessment instrument.

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1. Introduction

Inclusive Education (IE) is associated with positive personal outcomes for all students, since it involves a methodology adapted to the requirements of each student and, among other positive benefits, it allows the acquisition of social skills such as learning to value diversity (Llabrés, Muntaner, & de la Iglesia, 2019). In relation to students with disabilities, the available evidence supports that IE promotes positive personal outcomes in different areas of their lives, such as cognitive and social spheres (Hehir et al., 2016), the acquisition of knowledge and academic skills (Kurth & Mastergeorge, 2010a, 2010b; Lee, Soukup, Little, & Wehmeyer, 2009), communication and social interactions (Carter & Hughes, 2005; Fisher & Meyer, 2002), self-determination (Hughes, Cosgriff, Agran, & Washington, 2013), the sense of belonging and learning expectations (Shogren et al., 2015), and in post-school outcomes (Jackson, Ryndak, & Wehmeyer, 2008; Ryndak, Morrison, & Sommerstein, 1999; Ryndak, Jackson, & White, 2013), being the latter essential for social inclusion beyond the educational stage (Amor, Fernández, Verdugo, Aza, & Schalock, 2020), a pending challenge for young people with intellectual and developmental disabilities (IDD) (Morán, Gómez, & Alcedo, 2019).

One of the countries that has taken on the commitment to develop an inclusive education system is Spain, based on the adaptation of its educational legislation to supra-national frameworks that recognize the right to education without exclusions (UNESCO, 2015; United Nations, 2006). However, the educational reality in Spain is far from being inclusive for certain groups, especially people with IDD (Alcaraz-García & Arnaiz-Sánchez, 2020; Huete, 2017; Ramos & Huete, 2016). The existence of a special education system, parallel to general education, and the use of psychopedagogical approaches that focus on only educational and intrinsic needs (i.e., without considering environmental barriers) create the conditions for a "systematic segregation" based on poor decision making (United Nations, 2018; Verdugo, Amor, Fernández, Navas, & Calvo, 2018).

Thus, it arises the need to adopt models that offer more guarantees to students with IDD and favor their access, participation, learning and maximum development in general education contexts, as stated in Article 24 on education of the United Nations International Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). Two complementary approaches that have been considered key to this are the supports paradigm (Schalock et al., 2010; Thompson et al., 2009) and the quality of life (QoL) model (Schalock & Verdugo, 2002). These approaches have converged at Quality of Life Supports Paradigm (Gómez, Schalock, & Verdugo, 2021; Schalock, Verdugo, Gomez, & Reinders, 2016; Verdugo, Schalock, & Gómez, 2021). This paradigm gathers the implications of both approaches, offering a conceptual and applied framework that allows –based on the IE objectives set out in the CRPD– to understand the needs of students with IDD, to plan supports and to evaluate the impact that this planning has on vital domains important for the student (Schalock, Van Loon, & Mostert, 2018).

The supports paradigm offers an alternative in the way of conceiving the needs and strengths of the students, as well as in the provision of support (Amor, Verdugo, Calvo, Navas, & Aguayo, 2018; Verdugo et al., 2018). From this perspective, IDD is understood as a state of functioning characterized by an intense and persistent mismatch derived from the interaction between the student's competences and environmental demands, defined by educational activities and contexts (Thompson, Walker, Shogren, & Wehmeyer, 2018). Thus, the extraordinary support needs of students with IDD are global and not only for learning (Amor et al., 2018), and they may appear in response to the demands of the classroom, in the educational institution or in the community. According to Thompson et al. (2018), based on the assessment of the multifaceted, extraordinary support needs of students with IDD, the supports planning and implementation should have an impact on the participation and personal outcomes of these students by bridging the gap between competencies and demands, and thus favoring their inclusion.

Having a multidimensional evaluation framework of personal outcomes is essential to understand the extent to which the implementation of supports is contributing to the development of the students in each area. It is necessary to adopt approaches that allow directing the educational focus towards the overall development of the student as a criterion for defining programs and evaluating results, going beyond the vision of education as curricular learning and focusing on the student's personal outcomes in the classroom, educational institution and community (Amor et al., 2020; Llabrés et al., 2019; Sánchez-Gómez, López, Amor, & Verdugo, 2020). This is precisely what complements the QoL perspective. The Quality of Life Supports Paradigm takes a multidimensional QoL approach, given the conceptual and practical implications it offers (Amor et al., 2020). From the perspective of this model, QoL is conceptualized as a desired state of personal well-being that incorporates objective and subjective elements, which is influenced by personal and environmental factors, and considers eight domains of the student's life (Schalock & Verdugo, 2002): material wellbeing (MW), physical wellbeing (PW), emotional wellbeing (EW), personal development (PD), self-determination (SD), interpersonal relations (IR), social inclusion (SI) and rights (RI). Thus, talking about QoL in education implies assuming a comprehensive approach to the students focused on the globality of the domains that make up their life, from which we understand their aspirations and needs to define programs and offer supports aimed at improving their results in these areas (Muntaner, Forteza, Rosselló, Verger, & De la Iglesia, 2010; Muntaner, 2013; Sánchez-Gómez et al., 2020; Verdugo, 2009). Consistent with this multidimensional view of the student, QoL offers a widely validated framework for measuring personal outcomes (Amor et al., 2020; Pazey, Schalock, Schaller, & Burkett, 2016; Sánchez-Gómez et al., 2020). Each domain of QoL is operationalized in central indicators, which refer to specific conditions, behaviors and perceptions and which are observable and measurable. Indicators are sensitive to the goals set out in the articles of the CRPD (Gómez et al., 2020; Navas, Gómez, Verdugo, & Schalock, 2012; Verdugo, Navas, Gómez, & Schalock, 2012). Efforts have been made in order to align the domains of the model with the goals set forth in article 24 (Amor et al., 2020; Turnbull, Turnbull, Wehmeyer, & Park, 2003): (a) access would be related to RI; (b) participation with SI and IR; (c) learning with SD and PD; and (d) development of students to their fullest potential with EW, PW, MW, PD and SD. The sensitivity of the QoL indicators to the goals of IE is critical to support the educational transformation towards IE by underpinning the reflection of schools and high schools on the own educational processes that carry out to include diverse learners on the base of personal outcomes in areas crucial to access, participation, learning and development of students to their fullest potential (European Association of Service providers for Persons

with Disabilities, 2021). Moreover, it is important to emphasize that indicators are developed through items that allow the evaluation of personal outcomes, which refer to the aspirations and situations in different areas (Amor et al., 2020; Fernández, Verdugo, Gómez, Aguayo, & Arias, 2018). Considering that the involvement of the different social agents (within and outside the educational community) is fundamental in the path towards IE, then the point of view of families, students and professionals should be included in the development of QoL items. The involvement of professionals is central to the educational system change, but it is also important to take into account relatives and students, as suggested by Simón and Barrios (2019) and Messiou (2019), respectively.

The aforementioned alignment between the QoL model (Schalock & Verdugo, 2002) and the CRPD, allows the former to constitute as a framework that contributes to operationalize goals of action to enhance the participation of students with IDD in key areas linked to their inclusion. The assessment of personal outcomes through QoL-related instruments may serve as a starting point in the definition of such goals. Once the goals have been established, to achieve them, students with IDD face activities in specific contexts that constitute environmental demands which interact with the students' competencies, thus generating support needs when the demands exceed their competencies (Amor, Fernández, Verdugo, Aza, & Calvo, 2021). The pattern and intensity of the extraordinary support needs of students with IDD can be addressed using instruments like the Supports Intensity Scale—Children's version (Thompson et al., 2016; Verdugo et al., 2019; Verdugo, Aguayo, Arias, & García-Domínguez, 2020), thus allowing multidisciplinary teams to gather relevant information on the type of support, frequency of support, and daily support time required by the student to successfully participate in such activities and contexts. According to Amor et al. (2021), once all the information is gathered, the development of thoughtful personalized educational plans systematically addresses the goals defined by aligning them with the support needs, personalized supports, the available resources, and adequate temporalization. And last, the assessment of personal outcomes using QoL-related instruments is a strategy to shed lights on the extent to which supports implemented have produced an improvement in the personal outcomes of the student and thus mirroring not only advances in QoL but also an enhanced participation in areas linked to the goals of the CRPD.

With the aim of approaching the conceptual and measurement implications of QoL, instruments have been designed for the evaluation of personal outcomes in the Spanish educational context based on the QoL model by Schalock and Verdugo (2002). In the Spanish general education contexts, there are two available tools: the Childhood Quality of Life Assessment (Spanish abbreviation: CVI-CVIP) (Sabeh, Verdugo, Prieto, & Contini, 2009), focused on pre-school and primary education, and the Adolescent Students Quality of Life Assessment Questionnaire (Spanish abbreviation: CCVA) (Gómez-Vela & Verdugo, 2009), for students with and without special educational needs in secondary education. There are also tools in the context of special education, such as the KidsLife scales (Gómez et al., 2016, 2017, 2018), aimed at children and young people with IDD. Despite the availability of these instruments, there is still an important obstacle to the practical application of the QoL model to favor the inclusion of students with IDD. This difficulty is given by the characteristics of the model. Thus, while the domains are universal, the indicators are culturally and contextually sensitive, which translates into the need to validate them (through items that define personal outcomes) in interest groups and in the contexts in which they participate (Fernández, 2019; Gómez, 2009). It is the validation of the indicators in specific contexts and groups that makes it possible to evaluate personal outcomes and make decisions based on the information provided by them (Amor et al., 2020). In this sense, the above tools do not offer guarantees to gather evidence of personal outcomes that support processes of educational transformation towards the inclusion of the students with IDD. Thus, instruments such as the CVI-CVIP (Sabeh et al., 2009) and the CCVA (Gómez-Vela & Verdugo, 2009) lack a multidimensional vision by not encompassing the eight QoL domains. On the

Table 1
Participant's Sociodemographic characteristics.

	N	%
Academic formation		
PhD	5	35.7
Degree	6	429
Master's degree	2	14.3
Professional formation ("FP")	1	7.1
Autonomous community		
Andalusia	4	28.6
Aragon	4	28.6
Valencian Community	3	21.4
Community of Madrid	1	7.1
Cantabria	1	7.1
Balearic Islands	1	7.1
Work's type		
Educational Practice	11	78.6
Research in education	3	21.4
Work center		
Regular school	5	35.7
Disability organization	3	21.4
University	3	21.4
Resource center	2	14.3
Special school	1	7.1
Previous experience in Delphi studies		
With experience	8	57.1
Without experience	6	42.9

other hand, the KidsLife scales (Gómez et al., 2016, 2017, 2018) have been mostly validated in segregated contexts.

There is, therefore, a lack of instruments for evaluating personal outcomes that are aimed at students with IDD schooling in general education contexts from which to support decision-making focused on the globality of the students to promote their inclusion. The development of instruments of this nature must obey a planned process that starts from the identification of the central indicators to the domains that are relevant to students with IDD schooling in general contexts, as well as significant items that correspond to the indicators for measuring personal outcomes as a basis for the construction of a pilot test and its validation (Fernández et al., 2018; Gómez et al., 2014; Gómez, Arias, Verdugo, Tassé, & Brown, 2015). Thus, the objective of this work is to obtain a sufficient and adequate set of items for the implementation of the QoL construct in students with IDD enrolled in the primary education stage in the regular modality. The primary education stage has been selected as it is the first and most extensive stage of compulsory schooling and given its importance for the educational trajectory of the students (Amor et al., 2020). To address this objective, we have developed a Delphi study through which the consensus perspective of experts has been gathered.

2. Methods

2.1. Participants

This work involved 14 professionals (11 women) from the Spanish educational field who were selected through an incidental sampling strategy. To participate, professionals were required to have at least three years' experience in education with students with IDD. The participants ($M = 38.71$ years; $SD = 7.43$; age range 30–55 years) had a mean professional experience of 12.79 years ($SD = 6.04$, range 3–27 years) and formed a group with heterogeneous characteristics (see Table 1).

Professionals were invited to be part of the Delphi group through specialized forums, such as the State Meeting on Inclusive Education held in Toledo (Spain), in November 2019, the University of Salamanca's Institute for Community Inclusion (INICO) website and social media, and through the dissemination of the project's goal and participants' requisites by a group of professionals dedicated to promote Inclusive Education in Spain. Plena inclusión (i.e., the main provider of supports and services related to the social, school and community inclusion of people with IDD in Spain, which comprises more than 900 organizations) also contributed to this recruiting process. Thus, the sampling method involved dialogue with professionals from different organizations to select the most suitable participants, always considering the characteristics of the study and the requirements to participate. Finally, 15 professionals were selected to participate, but one of them withdrew from the study in the first round due to personal reasons.

Table 2

Quality of life domains and examples of specific indicators to students with IDD [adapted from Schalock and Verdugo (2002); and, Fernández et al. (2018)].

Quality of Life domain (No. of items included)	Domain's description	Exemplary core indicators identified
Material wellbeing (18)	To have resources to cover their needs.	- Belongings - Educational institution and community resources - Socioeconomic status
Physical wellbeing (16)	To keep healthy, be in a good shape and have healthy habits	- Health status - Healthy habits (e.g., eating, sleeping, resting, physical exercise) - Health care
Emotional wellbeing (24)	To be calm and safe; not to be overwhelmed and nervous	- Satisfaction - Self-concept - Self-esteem - Positive feelings - Absence of negative feelings
Personal development (17)	To have opportunities to learn, develop skills, acquire knowledge and self-fulfillment	- Skills, knowledge and competences - Daily living activities - Learning opportunities
Self-determination (18)	To decide for yourself and have the opportunity to choose the things you want	- Personal goals and objectives - Elections - Self-direction
Interpersonal relations (20)	To have friends, get along well and related to different people	- Interactions - Rewarding social contacts - Meaningful relations
Social Inclusion (21)	To participate in community activities under equal conditions; to go to places in the city or neighborhood where other people go; to feel part of society and have the support of others	- Accessibility - Participation - Recognition
Rights (20)	To be considered and treated in the same way as the rest of the people, which implies respect for one's way of being, one's opinions, desires and intimacy	- Human and legal guarantees (e.g., dignity, respect, equality)

2.2. Instrument

The process used to create the initial pool of items, which the Delphi study experts were later asked to assess, comprised two stages: (a) two parallel reviews, of which one was a literature review on QoL, IE and students with IDD; and the other, a review of assessment tools; and (b) discussion between direct care professionals and expert researchers in Delphi methodology, IE and QoL.

At first, through the literature search, the central indicators were identified for the domains of the QoL model that were most relevant for the population and context under study. Thus, the most relevant indicators were selected based on personal (i.e., related to IDD) and contextual factors (e.g., idiosyncrasy of the primary educational stage, characteristics of the general education system). Once these indicators were identified, a set of items was designed that collected personal needs, experiences and aspirations with which to evaluate personal outcomes based on the indicators that operationalize the domains. Some of these items emerged from the literature; others, from the analysis of existing QoL tools in general educational contexts (Gómez-Vela & Verdugo, 2009; Sabeh et al., 2009) and special education (Gómez et al., 2016, 2017, 2018), as well as tools oriented to education reflection (Booth & Ainscow, 2018; Echeita, Fernández-Blázquez, Simón, & Martos, 2019; Muntaner, 2013). As a result of this phase, 240 items were obtained (30 for each QoL domain).

At a later stage, a discussion forum was held between the study authors and direct care and research professionals (n = 36). We discussed the relevance of the items elaborated according to the objective pursued by the tool. Once the items were discussed, the starting pool was reduced, from 240 to 154 items.

Through this previous study, an initial pool of 154 items was built based on those indicators identified as most relevant for the target. Table 2 shows the indicators identified for each QoL domain, the description of the domains and the number of items in each one of them.
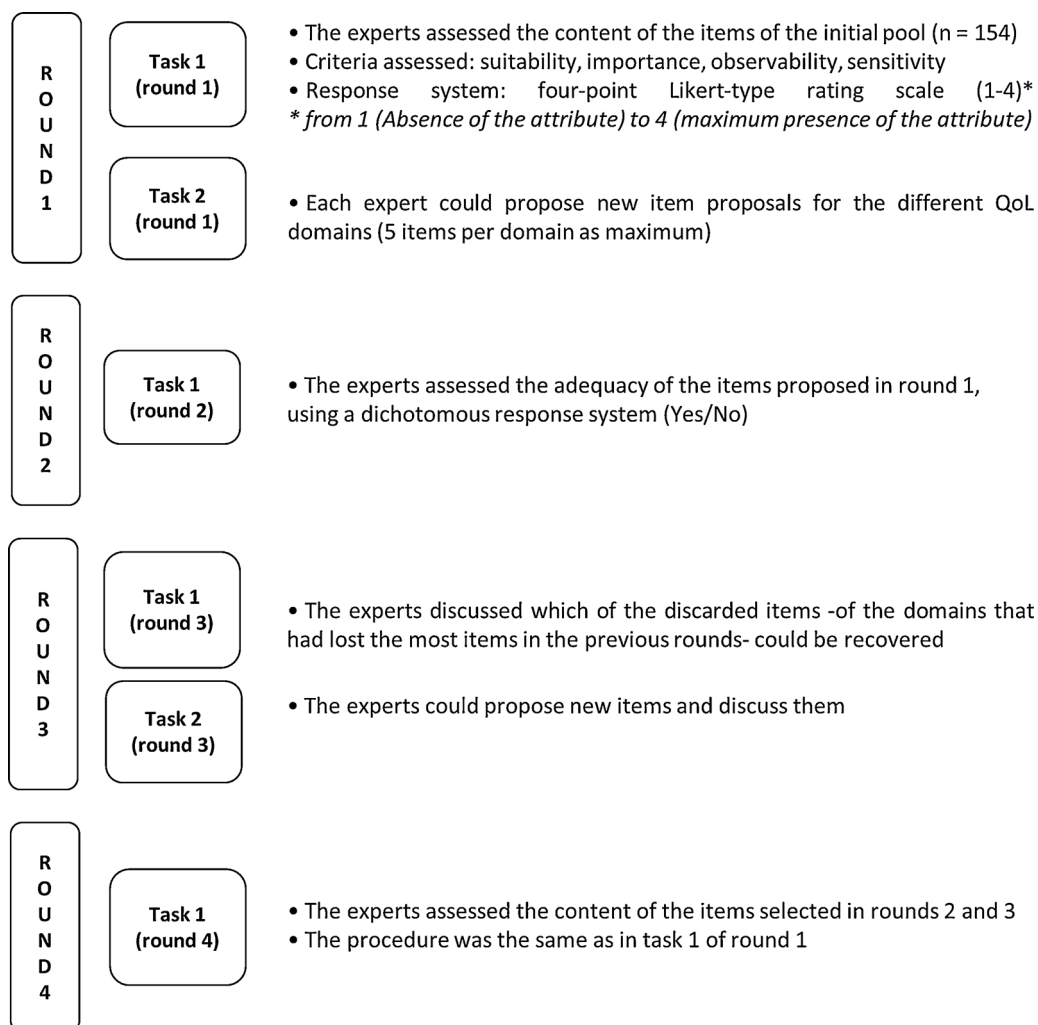

Fig. 1. Structure of the Delphi study.

2.3. Procedure

The present work has been developed using the Delphi method, an information gathering technique that allows consensus on the opinion of a group of experts through repeated consultations (Reguant-Álvarez & Torrado-Fonseca, 2016). In the framework of development of QoL evaluation tools, the Delphi method is used as a starting point as it is used to provide the items with evidence of content validity.

Firstly, an information letter, about the Delphi study, was shared with the experts. The collaboration was voluntary and led to the signing of the informed consent form. It was reported the existence of a withdrawal clause in case they wished to abandon the research at any time without consequence. An email address was available to consult any questions during the course of the investigation. This work has complied with the Organic Law 3/2018, of December 5, on Protection of Personal Data and guarantee of digital rights and with Regulation (EU) 2016/679 (General Data Protection Regulation).

The current study had four rounds (see Fig. 1), consistent with other studies that have used the same methodology to design instruments oriented to the evaluation of personal outcomes from the perspective of the QoL model (Fernández et al., 2018; Gómez et al., 2015). The experts evaluated the content of the items from the initial pool, and they also evaluated new proposals made by themselves. Four criteria were assessed for each item: (a) suitability (i.e., adequacy of the item to the QoL domains proposed in the document); (b) importance (i.e., relevance of the item to assess the QoL domain in the students and the target context); (c) observability (i.e., possibility that the content of the item is assessed by an external person); and (d) sensitivity (i.e., ability to modify the content encompassed in the item through educational practices, policies and cultures).

Moreover, during the study, the research team reviewed and discussed the items proposals generated by the professionals in the second task of the first and third rounds, in order to select the items that were most representative of the QoL construct, and also to control overlap between items, eliminating duplicates and merging proposals (see data analysis for further information). And finally, once the four rounds were finished, the research team carried out a review of the items considered suitable, important, observable and sensitive, with the objective of reducing the number of items to 96 (12 per domain).

2.4. Data analysis

Quantitative analyses have been used in the first task of round 1, in rounds 2 and 4, and in the final item reduction phase. Thus, in task 1 of round 1 and in round 4, to determine the selection of items according to the four criteria analyzed (i.e., suitability, importance, observability and sensitivity), the M and SD of the given scores were calculated by the experts for each item, considering as valid an item only if it exceeded $M \geq 3.5$ and $SD < 1$ in each criterion. These cut-off points are based on those used in previous research on the development of QoL assessment tools (Fernández et al., 2018; Gómez et al., 2014, 2015), although they are more restrictive with respect to the value of M –which was decided to go up because of the extensive work prior to starting Delphi–. For round 2, the percentage of professionals who agreed with the incorporation of the items judged in that round was calculated, placing as a cut-off point that 12 experts out of 14 agreed with their incorporation, a criterion also used in Fernández et al. (2018). Finally, once the resulting pool of items was reduced to 96, the degree of agreement of the judges for each criterion and each domain was calculated using the Bangdiwala's weighted concordance coefficient ($B^{W}N$) for ordinal data, a measure that ranges from 0 to 1, where 0 indicates no agreement and 1 maximum possible agreement (Bangdiwala, 1987). All data were analyzed using IBM SPSS Statistics software (v. 26) and R v.3.6.1.

Qualitative analyses have been used to select the item proposals generated by professionals in the second task of round 1 and in round 3, as well as to choose the most representative items from the pool validated in the Delphi study according to the indicators of the domains when reducing to the final set of 96 items. The qualitative criteria used in this work, based on previous references on educational evaluation (Popham, 2003) and QoL scale development (Fernández et al., 2018; Gómez et al., 2014, 2015), were significance (i.e., the alignment with the area to be evaluated), sensitivity (i.e., the ability to be modified by educational policies, cultures and practices), clarity (i.e., the language accessibility), and uniqueness (i.e., the distinction of its content with respect to the other items).

3. Results

3.1. Round 1

The content of 113 items (73.4 % of the initial pool) has been considered valid in relation to their suitability, importance,

Table 3
Descriptive analyses for round 1 (task 1) by criteria.

	M	SD	Valid ítems	% Valid	Non-valid items	% Non-valid
Suitability	3.87	0.33	150	97.4	4	2.6
Importance	3.87	0.31	150	97.4	4	2.6
Observability	3.77	0.41	141	91.6	13	8.4
Sensitivity	3.66	0.52	125	81.2	29	18.8

Note. M = Mean; SD = Standard deviation.

observability and sensitivity, while there were 41 items (26.6 %) that did not meet all the criteria based on the cut-off points ($M \geq 3.5$; $SD < 1$). Table 3 shows M and SD of the total count of items for each criterion, as well as the number and percentage of valid items (to be kept) and rejected (to be eliminated). Suitability and importance were the criteria best evaluated by the participants, with a lower number of discarded items (n = 4, 2.6 %); sensitivity was the criterion that led to the highest number of discards (n = 29, 81.2 %). Table 4 indicates the distribution of valid and invalid items by QoL domains. In this case, the domains with the highest number of discards were MW (n = 10, 55.6 %), EW (n = 12, 50.0 %) and PW (n = 5, 31.25 %). On the contrary, SI (n = 1, 4.8 %) and RI (n = 1, 5.0 %) hardly contributed discards.

Regarding the items proposed by the Delphi group of experts (i.e., task 2), the research team selected 61 items [MW (n = 9), PW (n = 4), EW (n = 6), PD (n = 8), SD (n = 8), IR (n = 12), SI (n = 8), RI (n = 6)] out of a total of 111 proposals.

3.2. Round 2

36 of the 61 proposals (59.0 %) were evaluated as adequate, since 12 or more professionals considered them appropriate. The selection rate was similar in all domains (see Fig. 2), the highest in EW and RI (66.7 %) and the lowest (50.0 %) in PW and SD.

3.3. Round 3

The results of the first two rounds justify that the third round focused on the domains of MW and PW, since they had fewer retained items [MW (n = 13), PW (n = 13), EW (n = 16), PD (n = 20), SD (n = 18), IR (n = 21), SI (n = 25), RI (n = 23)]. The experts discussed the relevance of including the discarded items in MW and PW from round 1 and 2, and they proposed new ones. This work allowed to collect 24 items among those recovered and the new ones: 12 from MW, 11 from PW and one from SI. Although the core domains of the round were MW and PW, the professionals proposed an item ("The people of the educational team exchange information with the people of student's circle of support in order to promote the participation of the student in the community") whose indicator (participation) corresponded to the SI domain, so that item was placed in the SI domain, for its assessment in the subsequent round.

3.4. Round 4

44 of the 60 items (73.3 %) were rated as sufficiently suitable, important, observable and sensitive. Table 5 shows the statistics obtained by criteria, and Table 6 shows the distribution of items by domains. As in the first round, compliance with the criteria was greater in suitability and importance, and lower in sensitivity. With regard to domains, MW and PW continued to maintain high percentages of items that did not reached the cut-off points in any of the criteria; IR and RI had high rates of discarded items in this fourth round (MW: 35.3 %, PW: 30.8 %, IR: 42.9 %, RI: 50.0 %), while EW, PD and SD did not have any discarded items.

Combining these results with those of the first round, a pool of 157 suitable, important, observable and sensitive items was obtained [MW (n = 19), PW (n = 20), EW (n = 16), PD (n = 20); SD (n = 18), IR (n = 18), SI (n = 25), RI (n = 21)]. It was necessary to reduce the number of items to develop a manageable field-test version of the assessment tool. Thus, the research team conducted an exhaustive review of the resulting item pool in order to select the best ones for each domain based on their descriptive statistics (*M, SD*), and paying attention to the indicators covered and overlaps between the items. As a result of this step, the final pool was made up of 96 items distributed among the eight domains (i.e., 12 per domain).

3.5. Agreement between experts regarding the final item pool

For these 96 items, the agreement between the experts was calculated. Table 7 summarizes the data for the $B^W N$ for the criteria (i.e., sensitivity, importance, suitability, and observability) by domains. Scores ranged between 0.83 (sensitivity in MW domain) and 0.96 (importance in EW, SI, and RI domains; and suitability in IR and RI domains), and all the statistics calculated indicated a very good agreement between the experts. The criterion on which the average agreement size among experts was the highest was importance ($B^W N = 0.94$). Conversely, sensitivity had the lowest agreement ($B^W N = 0.88$). Looking at the average scores received by domains, the highest agreement was reached for RI ($B^W N = 0.94$), PW and IR ($B^W N = 0.93$), while the lowest agreement was found in MW ($B^W N = 0.88$) and PD ($B^W N = 0.90$). Nevertheless, the average level of agreement regarding the domains was very high ($B^W N = 0.92$).

Table 4
Descriptive analyses for round 1 (task 1) by domain.

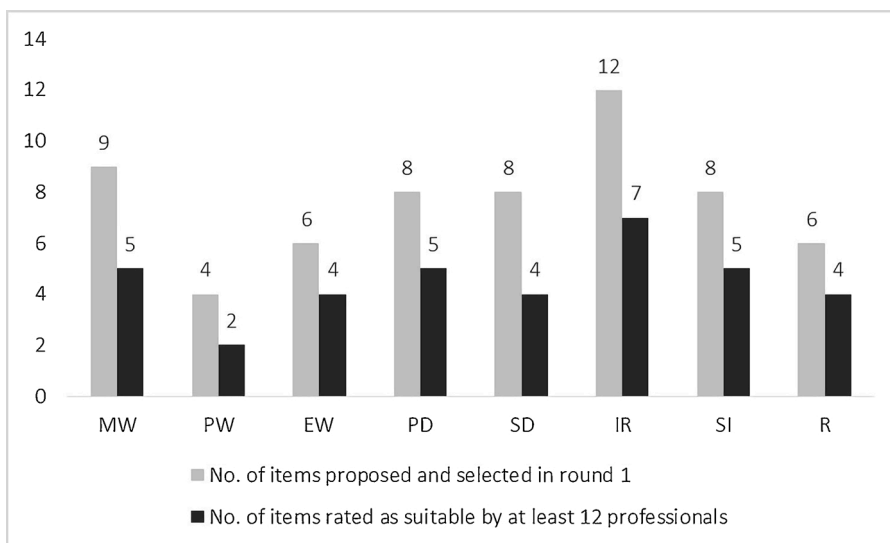|	Valid items	% Valid	Non-valid items	% Non-valid
Material wellbeing	8	44.4	10	55.6
Physical wellbeing	11	68.75	5	31.25
Emotional wellbeing	12	50.0	12	50.0
Personal development	15	88.2	2	11.8
Self-determination	14	77.8	4	22.2
Interpersonal relations	14	70.0	6	30.0
Social inclusion	20	95.2	1	4.8
Rights	19	95.0	1	5.0
Total	113	73.4	41	26.6

Fig. 2. Analyses for round 2 by domain.
Note. MW = Material wellbeing; PW = Physical wellbeing; EW = Emotional wellbeing; PD = Personal development; SD = Self-determination; IR = Interpersonal relations; SI = Social inclusion; RI = Rights.

Table 5
Descriptive analyses for round 4 by criteria.

	M	SD	Valid items	% Valid	Non-valid items	% Non-valid
Suitability	3.83	0.38	60	100.0	0	0.0
Importance	3.88	0.28	60	100.0	0	0.0
Observability	3.76	0.45	57	95.0	3	5.0
Sensitivity	3.66	0.52	44	73.3	16	26.7

Note. M = Mean; *SD* = Standard deviation.

Table 6
Descriptive analyses for round 4 by domain.

	Valid items	% Valid	Non-valid items	% Non-valid
Material wellbeing	11	64.7	6	35.3
Physical wellbeing	9	69.2	4	30.8
Emotional wellbeing	4	100.0	0	0.0
Personal development	5	100.0	0	0.0
Self-determination	4	100.0	0	0.0
Interpersonal relations	4	57.1	3	42.9
Social inclusion	5	83.7	1	16.7
Rights	2	50.0	2	50.0
Total	44	73.3	16	26.7

Table 7
Weighted statistics of agreement among experts.

QoL Domain	$B^W N$ Sensitivity	$B^W N$ Importance	$B^W N$ Suitability	$B^W N$ Observability	M
Material wellbeing	.83	.92	.88	.91	.88
Physical wellbeing	.90	.94	.95	.91	.93
Emotional wellbeing	.88	.96	.95	.89	.92
Personal development	.91	.94	.89	.88	.90
Self-determination	.89	.93	.95	.92	.92
Interpersonal relations	.88	.95	.96	.94	.93
Social inclusion	.84	.96	.93	.95	.92
Rights	.94	.96	.96	.90	.94
M	.88	.94	.93	.91	.92

Note. QoL = Quality of Life; $B^W N$ = Bangdiwala's weighted statistic; *M* = Mean; *SD* = Standard deviation.

4. Discussion

The aim of this study has been to define a set of items with evidence of content validity to evaluate QoL in students with IDD enrolled in primary education stage in the Spanish context of general education. As a result of this study, a final set of 96 suitable, important, sensitive and observable items has been obtained (i.e., 12 for each domain of QoL).

The four criteria used in this study have been used successfully in other studies focused on the design of QoL tools from the perspective of the Shalock and Verdugo's model used in other population groups, such as adults with significant disabilities (Gómez et al., 2015) or adults with acquired brain injury (Fernández et al., 2018). With respect to each criterion, the sensitivity criterion was the one that discarded the largest number of items throughout the study, while that importance and suitability were the two criteria that generated fewer discards. The results for these criteria correspond to those found in the above-mentioned works (Fernández et al., 2018; Gómez et al., 2015).

Considering the distribution of the items discarded after applying the previous criteria by domains, MW and PW were the two which were more consistently during the study. Thus, for MW, there were 10 (55.6 %) discards in the first round and six (35.3 %) in the fourth, while, for PW, there were, respectively, five (31.3 %) and four (30.8 %) discards. In the case of the EW domain, there were a high number of items eliminated in round 1 (n = 12, 50.0 %), but none were discarded in round four.

Monitoring what happened with EW domain throughout the study allows us to understand this finding: although half of the items were eliminated, 12 items remained for EW after the first task; to these must be added that the participants generated 6 appropriate additional items: four (66.7 %) of these items were valued as adequate by 12 of 14 professionals, and finally this consensus was confirmed in round 4.

Regardless of procedural aspects, the findings regarding the domains of MW and PW can be understood by considering two complementary points of view. On the one hand, taking into account the composition of the Delphi group and, on the other hand, keeping in mind the literature on QoL and students with IDD. Firstly, it is likely that the lack of representation of health professionals, beyond psychologists, and those responsible for educational policies (e.g., lawmakers or political representatives) among the participants is related to the difficulty of validating items of these domains. Indicators such as health care could gain greater relevance by including, for example, school nurses (professionals that have little recognition in the Spanish context), while the inclusion of those responsible for educational policies could be related to higher scores on items related to purchasing power and financial support. Secondly, the literature on QoL and students with IDD shows that these two domains are not usually taken into account in the promotion of personal outcomes from educational settings. In a recent study, Sánchez-Gómez et al. (2020) analyzed different educational intervention works with students with different disabilities in general and special educational contexts: for none of the studies analyzed, the domains of MW and PW were defined as the goal in which to generate positive personal outcomes. Thus, the relative lack of consensus found in our work, would seem to suggest that these two domains are not fully understood in the educational context. Therefore, an exhaustive pedagogical work is necessary regarding a holistic conception of the students with IDD to offer opportunities for inclusion, as pointed out by different authors (Amor et al., 2020; Sánchez-Gómez et al., 2020; Schalock et al., 2018).

Like most studies, this one is not without its limitations. First, the sampling strategy was incidental, selecting the participants based on predefined characteristics. In this sense, although a varied set of participants was selected and an optimal size was ensured to balance and manage contributions, the definition of other inclusion criteria could have generated a different pool of items to obtained here. However, the identification indicators and the definition of the initial pool of items was not only based on the literature: it also involved discussion with a wide range of direct care and research professionals (n = 36). The other major limitation is that, for reasons beyond the study design, it has not been possible to include relatives and students with IDD in the process of refining the items. In this sense, although initially it was proposed to hold parallel focus groups with families and students with IDD, the situation experienced in Spain due to the high incidence of COVID-19 and its impacts in people with IDD and their families (Navas, Amor, Crespo, Wolowiec, & Verdugo, 2021), made the research team decide to postpone holding such groups at a later stage.

The limitations found may be the starting point for further research to complete this and complement it. A pressing line of research is to build on the findings of this study through the development of focus groups with students with IDD and their relatives to address the extent to which, under their point of view, the items provided are regarded as appropriate to measure personal outcomes in the targeted population or if, on the contrary, new proposals are necessary. Once accomplished, conducting a pilot study to test for evidence of validity and reliability of the resulting instrument is the priority to develop the standardized measure. In this sense, it will be necessary to collect information on a minimum number of students enrolled in primary education with IDD in general education contexts, stratifying, appropriately, the distribution of the participants considering, among other variables, gender, age, educational stage or ownership from the educational institution.

Students with IDD are frequently forgotten despite being key in the development of IE (Messiou, 2019); likewise, the active participation of people with IDD becomes a differential factor in the study of QoL (González, Ducca, & García, 2020). Through this, it is possible to identify subjective indicators about what constitutes QoL for them in each of the domains. Knowing the vision of students with IDD and their families will allow the design of a QoL evaluation instrument based on the students and their relatives own perspective, which, added to the one built from this work, enables a double approach to the evaluation of personal outcomes. This issue has been identified by research on QoL as a key to, in addition to supporting contextual transformation processes (e.g., at the educational institution level), to develop personalized support plans incorporating desired vital goals based on indicators identified by their own people with IDD (Aza, Verdugo, Orgaz, Fernández, & Amor, 2020).

Finally, once the psychometric properties of the items selected in this current study have been tested, the resulting QoL index could be applied in general education contexts, together with the Supports Intensity Scale—Children's version (Thompson et al., 2016; Verdugo et al., 2019, 2020), for the purpose of putting into practice the Quality of Life Supports Paradigm to improve the inclusion of

students with IDD.

5. Conclusions

As a conclusion, this study has involved a systematic process of identification and refinement of items for the evaluation of QoL in students with IDD enrolled in general primary school contexts. Complementing this study by including all relevant stakeholders and testing the pilot version of the instrument in the targeted population are the next steps in this research.

Last, providing educational administrations with an instrument of this nature will make it possible to support processes of reflection and educational transformation, based on the evidence of personal outcomes of students with IDD in a set of domains sensitive to the objectives included in the CRPD (United Nations, 2006), whose goal is to offer greater guarantees of personal outcomes and inclusion.

CRediT authorship contribution statement

Inés Heras: Conceptualization, Writing - original draft, Methodology, Data curation, Formal analysis, Writing - review & editing. **Antonio M. Amor:** Project administration, Conceptualization, Supervision, Writing - review & editing, Methodology, Data curation, Formal analysis. **Miguel Ángel Verdugo:** Project administration, Conceptualization, Supervision, Investigation, Writing - review & editing. **M. Isabel Calvo:** Conceptualization, Writing - review & editing.

Declaration of Competing Interest

None.

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