

Quality of Life and the International Convention on the Rights of Persons With Disabilities: Consensus Indicators for Assessment

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Abstract

Background: The quality of life construct provides an ideal conceptual framework for translating such abstract concepts as self-determination, equity, accessibility, and inclusion. Through consultation with expert raters, we sought to develop and validate a bank of indicators and items, based on the quality of life conceptual framework, to be used as a means of evaluating and implementing the Articles of the Convention on the Rights of Persons with Disabilities (CRPD). **Method:** Thirty-two experts in the field of intellectual and developmental disabilities participated, rating the suitability, importance, and clarity of a bank of 296 items, as well as the relevance of controlling for 70 sociodemographic variables. **Results:** After qualitative and quantitative analysis of the data, the final selection comprised 60 sociodemographic variables and 153 items that scored highly on all criteria and produced an excellent level of agreement between the experts. **Conclusions:** This bank of items and set of sociodemographic variables constitute the pilot version of a CRPD assessment and monitoring instrument with sufficient evidence of content validity, which may be useful in developing evidence-based practices and in detecting rights violations.

Palabras clave: Quality of life, rights, Convention on the Rights of Persons with Disabilities, intellectual disability, developmental disabilities, assessment.

Resumen

Calidad de Vida y la Convención Internacional Sobre los Derechos de las Personas con Discapacidad: Indicadores Consensuados Para la Evaluación. Antecedentes: el constructo de calidad de vida proporciona un marco conceptual ideal para traducir conceptos abstractos como autodeterminación, equidad, accesibilidad o inclusión. Mediante una consulta a expertos se pretende desarrollar y validar un banco de indicadores e ítems basados en el marco conceptual de la calidad de vida que pueda ser utilizado para evaluar e implementar los derechos recogidos en la Convención sobre los Derechos de las Personas con Discapacidad (CDPD). **Método:** participaron 32 expertos en el campo de las discapacidades intelectuales y del desarrollo calificando la idoneidad, importancia y claridad de un banco de 296 ítems, así como la relevancia de controlar 70 variables sociodemográficas. **Resultados:** tras el análisis cualitativo y cuantitativo de los datos, se llegó a una solución consensuada de 60 variables sociodemográficas y 153 ítems que puntuaron alto en todos los criterios y obtuvieron un excelente grado de acuerdo entre los expertos. **Conclusiones:** este banco de ítems y conjunto de variables sociodemográficas constituye la versión piloto de un instrumento de evaluación y seguimiento de la CDPD con suficientes evidencias de validez basadas en el contenido, que puede ser útil para desarrollar prácticas basadas en la evidencia y para detectar violaciones de derechos.

Keywords: calidad de vida, derechos, Convención sobre los Derechos de las Personas con Discapacidad, discapacidad intelectual, discapacidades del desarrollo, evaluación.

Society's perspectives and beliefs about the rights of people with disabilities have changed dramatically in recent decades. These changes have come to be reflected not only in national laws but also in specific international conventions that serve as a guide for the development of social policies and professional practices for this population. Since its adoption (United Nations, 2006) and its entry into force for States Parties—including Spain—in 2008, the Convention on the Rights of Persons with Disabilities

(CRPD) has been ratified by 185 countries (United Nations, 2022), demonstrating the global commitment to equality, dignity, and freedom for persons with disabilities.

The CRPD contains 50 Articles, 26 of which (Arts. 5 to 30) set out specific obligations for States, such as the right of people with disabilities to enjoy legal capacity in all aspects of life and on an equal basis with others (Art. 12); to choose where and with whom they live (Art. 19); to access, on an equal basis with others, the physical environment, transportation, information, and communications (Arts. 9 and 21); to marry and found a family (Art. 23); to be included in the general education system with reasonable accommodation according to individual needs and the provision of the necessary individualized supports (Art. 24); to have access to habilitation and rehabilitation services, available from the earliest possible stage, and provided by suitably trained professionals

(Art. 26); or to earn a living through work freely chosen in a work environment that is open, inclusive, and accessible (Art. 27).

Although the CRPD emphasizes rights already recognized in previous human rights declarations, people with intellectual and developmental disabilities (IDD) continue to experience double, triple, or even multiple levels of discrimination (Gómez et al., 2011; Morales et al., 2021; Morán et al., 2019; Navas et al., 2012). For this reason, many scholars have stressed the need to define specific objectives and indicators to evaluate and implement the CRPD, and have suggested the quality of life (QOL) construct as a conceptual framework to facilitate this task (Claes et al., 2016; De Maeyer, 2017; Faragher & Van Ommen, 2017; Gómez, Monsalve et al., 2020; Gómez et al., 2021a; Karr, 2011; Lombardi et al., 2019; Mittler, 2015; Navas et al., 2012; Schalock et al., 2019; Shogren & Turnbull, 2014; Verdugo et al., 2012, 2021). The QOL construct provides an ideal conceptual framework for translating such abstract political concepts as self-determination, equity, accessibility, or inclusion into evidence-based practices (Gómez, Verdugo et al., 2020; Schalock et al., 2017). Of the different QOL conceptual frameworks in the field of disability, the most widely used for this purpose in the scientific literature is the model proposed by Schalock and Verdugo in 2002 (Gómez, Monsalve et al., 2020). It understands QOL as a state of personal wellbeing made up of eight core domains that interact with each other: rights, self-determination, social inclusion, interpersonal relationships, personal development, emotional wellbeing, material wellbeing, and physical wellbeing (Schalock et al., 2011).

Almost a decade ago, Verdugo et al. (2012) laid the groundwork for the present study by arguing in their theoretical paper that the 26 Articles of the Convention were closely linked to the eight QOL domains, and, consequently, that the fulfillment or violation of these Articles could be evaluated through QOL-related personal outcomes. They suggested evaluating the specific rights by aligning them to the QOL domains, thereby operationalizing the CRPD. In this way, the implementation of the Convention could be monitored and evaluated by organizations providing supports to people with IDD, with the ultimate aim of improving the rights and freedoms contained therein. More recently, Lombardi et al. (2019) went a step further by conducting a Delphi study in which international experts reached a consensus on the relationship between the CRPD Articles and a substantial number of core QOL indicators. A total of 153 experts (comprising people with IDD, family members, professionals, researchers, and law experts) from 10 countries (Brazil, Canada, the Czech Republic, Germany, Israel, Italy, Portugal, Spain, Taiwan, and the United States) took part in the study. The outcome of this Delphi study was a set of 83 cross-culturally validated QOL indicators, which were mapped to the eight QOL domains and the 26 CRPD Articles. Next, Gómez, Monsalve et al. (2020) carried out a systematic review of the scientific literature published between 2008 and 2020. Among their findings, they identified instruments that had been used to date to (partially) monitor the CRPD, and a multitude of indicators and personal outcomes associated with the 26 Articles mapped to the eight QOL domains. These three studies were the starting point for the present research, serving as a guide to propose, for people with IDD, measurable personal outcomes (i.e., items) associated with each Article of the Convention.

The overall aim of the present study is to take the next logical step in the process of constructing an assessment instrument to evaluate the implementation of the CRPD for people with IDD. Specifically,

we consulted with expert raters to develop and validate a bank of items, based on Schalock and Verdugo's (2002) QOL conceptual framework, to be used as a means of evaluating and implementing the Articles of the CRPD. The purpose of the instrument is not to provide precise statistics on rights violations nor to inform the country reports submitted to the United Nations Committee; its aim is rather (a) to give a voice to people with IDD regarding everyday situations in their daily lives that do not necessarily end up being reported; (b) to act as a tool that professionals and relatives can use to detect any breach, abuse, or denial of rights, thereby helping them enhance the supports and services they provide to this group; and (c) to serve as a guide for organizations to identify the strengths and greatest needs of this population in relation to rights. In this way, the evaluation presented in this study focuses more on the microsystem (i.e., improving the lives of people with IDD) and on the mesosystem (i.e., improving the provision of natural and professional supports offered by organizations) than on the macrosystem (i.e., lawmaking or producing country reports).

Methods

Participants

We invited 33 experts in the field of rights and the QOL of people with IDD to participate. All agreed to take part, although in the end 32 returned their item ratings (i.e., one expert did not complete the task due to lack of time). The majority of participants were women ($n=26$; 81.3%). They came from a range of geographical locations within Spain. In total, eight of the country's 17 autonomous communities were represented in the consultation: Andalusia, Aragon, Cantabria, Castile and Leon, Madrid, Murcia, Navarra, and the Principality of Asturias. To be considered experts, participants were required to have contact or experience with IDD: almost three-quarters (71.9%) had over 10 years' experience or contact; six experts (18.8%) had between six and ten years; and the three remaining experts (9.4%) had between two and five years' experience.

The experts' contact or experience with IDD was extremely varied, since the aim was to involve a diverse range of stakeholders, including professionals, academics, and family members. It was possible for the same individual to have different expert profiles (for example, being both the mother of a person with IDD and a professional working with people with IDD). In fact, the convergence of several profiles in the same expert was extremely common (68.7%; $n=22$). The most frequent mix was academic knowledge combined with professional contact (25%; $n=8$), followed by experts who, in addition to these credentials had altruistic experience (21.8%; $n=7$). With the exception of one person, all family members ($n=6$) had not only a personal relationship to someone with IDD, but also had academic training, professional experience, and altruistic contact with them.

Academic knowledge was the most common expert credential: the vast majority of participants (87.5%; $n=28$) had specific formal training in IDD. Similarly, there was a high representation of professionals: three-quarters (75%; $n=24$) were working or had worked with people with IDD. Just over one-third of the experts (40.6%; $n=13$) had altruistic contact, that is, they were volunteering or had volunteered with people with IDD. Almost one-quarter (21.9%; $n=7$) had personal or family contact, meaning they had close others with IDD.

Of those who reported relevant academic credentials, the majority (72%) had postgraduate qualifications (master's or doctorate) and worked in this area as teachers and researchers. Professional profiles were extremely diverse, ranging from direct-care staff to managers in third-sector disability organizations (e.g., *Plena inclusión*, *Down España*) and educational establishments (i.e., special schools and ordinary schools). Volunteer activities mentioned by experts were most commonly performed in those third-sector disability organizations. Experts who reported family contact were primarily the mothers of people with IDD, although a sister and a niece were also included.

As regards IDD subfields, participants identified themselves as experts in social inclusion (62.5%; $n=20$); education (62.5%; $n=20$); mental health (37.5%; $n=12$); social services (31.3%; $n=10$); attitudes (28.1%; $n=9$); rights (25%; $n=8$); assessment or psychometrics (18.8%; $n=6$); gender (18.8%; $n=6$); situations of risk, vulnerability or humanitarian emergencies (18.8%; $n=6$); accessibility (15.6%; $n=5$); information and communication technologies (15.6%; $n=5$); and employment (9.4%; $n=3$). Their experience and expertise extended to IDD at all life stages: 31.3% ($n=10$) designated themselves as experts in childhood, 34.4% ($n=11$) in adolescence, 25% ($n=10$) in adulthood, and 21.9% ($n=7$) in older adults.

Instrument

The initial item bank to be rated by the experts was based on the three earlier studies (Gómez, Monsalve et al., 2020; Lombardi et al., 2019; Verdugo et al., 2012). Informed by the combined results of these three studies, we proposed 52 indicators to evaluate the 26 CRPD Articles, which were structured around the eight QOL domains. Each CRPD Article was operationalized in central indicators, which refer to specific conditions, behaviors and perceptions and which are observable and measurable. Each indicator was operationalized in items, which refer to specific QOL-related personal outcomes. The proposal essentially corresponded to that put forward by Lombardi et al. (2019), but it was simplified to allow the effective evaluation of rights with sufficient evidence of content validity. For example, we removed some redundant indicators that were repeated in more than one domain, we merged some specific indicators into a more general one, we changed some indicators to another, or we assessed them using sociodemographic data (as recommended by Gómez, Monsalve et al., 2020). Since it is recommended that the initial number of items should be at least double the number in the final version of the instrument (Muñiz & Fonseca-Pedrero, 2019), the next step was to draft at least one item to evaluate each indicator, on the assumption that each CRPD Article and each QOL domain would have at least 20 items (i.e., at least 80 items, 10 in each domain, in the final version).

To draft the items, the research team considered the QOL domain the Article was aligned to, the content of the Article itself as stated in the CRPD, and the 52 evaluation indicators proposed. In addition, the team examined the scales used to assess some of the Articles, as identified in the review by Gómez, Monsalve et al. (2020), and the most recent gray literature on the CRPD published by disability organizations in Spain (e.g., reports by *Plena inclusión* and CERMI). Most of the items included (71.9%; $n=213$) were new items proposed by the research team or were based on the literature review by Gómez, Monsalve et al. (2020). Nine items were taken directly from the description of the Convention Articles

(United Nations, 2006). Further, a considerable number of items (12.8%) were drawn from existing instruments: the National Core Indicators-Adult Consumer Survey (NCI-ACS; Houseworth et al., 2019; Tichá et al., 2018; $n=15$), the ITINERIS Scale (Aznar et al., 2012; $n=21$), the KidsLife Scale (Gómez et al., 2016; $n=1$), and the European Child Environment Questionnaire (ECEQ; Colver et al., 2011; $n=1$). Similarly, after reading the gray literature, we included items drawn from the Asturian Women's Institute's guide on gender violence, *Guía sobre Violencia de Género* (Instituto Asturiano de la Mujer, 2018; $n=1$); and from the Spanish report on human rights and disability (CERMI, 2018; $n=28$).

As it is shown in Table 4 (first column), the proposed instrument initially comprised a total of 296 items structured around the eight QOL domains (between 25 and 45 items per domain), the 26 CRPD Articles (between 2 and 38 items per Article), and indicators (between 1 and 19 items per indicator). All items were expressed in the first person so that they could be answered by people with IDD using a Likert-type scale. Moreover, each was accompanied by a clarification with examples and explanations of the item content. For example, for the item "*My home is physically accessible*" (Material Wellbeing domain; Article 28 "Adequate standard of living and social protection"; "Adequate housing" indicator), we included the following clarification: "*In the place where I live, I can move around without any problems (for example, there are no obstacles that prevent me from entering, leaving, or moving around inside it)*".

Likewise, we suggested including sociodemographic data that would be relevant to evaluate and control in the measurement of rights. Although the instrument was designed to be answered primarily by people with IDD, variables related to other possible informants (i.e., professionals, family members, and close others) were also introduced. Thus, if a third party was to complete the scale about a person with IDD, they would respond to the same items (with the same clarifications), but these would be written in the third person (e.g., "*Their home is physically accessible*").

The research team proposed a total of 70 variables that could be collected as sociodemographic data, each with its corresponding set of response options or answer format. Of these 70 variables, 82.8% were associated with one of the specific CRPD Articles (i.e., Articles 6, 7, 8, 11, 12, 19, 21, 23, 24, 25, 26, 27, 28, and 30), and were of interest because of their potential cross-cutting impact on the other Articles and on all the QOL domains. For example, controlling for gender was a way to evaluate Article 6 (women with disabilities); age was a way to evaluate Article 7 (children with disabilities); country of birth to evaluate Articles 11 (immigration: situations of risk and humanitarian emergencies) and 18 (liberty of movement and nationality); and capturing an individual's chronic conditions and associated disabilities was a way to evaluate Article 25 (health). This way of evaluating the CRPD Articles circumvents the limitation of not being able to establish causal relationships in the evaluation of rights that do not directly depend on actions that can be carried out for the benefit of this population. For instance, poor health status may be the consequence of a rights violation due to the person not receiving appropriate treatment, but a person may have poor health status for other reasons, despite receiving appropriate care.

Procedure

We used a convenience sample of experts. To begin with, we contacted academic and professional experts who had gained

recognition in Spain for their publications and contributions on the subject. These in turn were able to suggest other experts and relatives of people with IDD. At this first contact, experts were informed of the general aim of the study, the basic characteristics of the instrument being developed, and the tasks they would be asked to undertake. If they wished to collaborate, the experts clicked on a URL to a short survey in which they supplied contact information and details of their experience in IDD.

Experts who expressed an interest in taking part were then recontacted by the research team, this time with specific instructions for carrying out the task. They were emailed detailed instructions along with an Excel workbook made up of nine worksheets (or tabs) corresponding to the nine sections of the instrument: a sociodemographic data section and eight QOL domains. Confidentiality was ensured by keeping the responses anonymous.

For the “sociodemographic data” section, experts were reminded that there could be three types of respondents (i.e., people with IDD, family members, or professionals). Some data were therefore conditioned by (i.e., they would only appear depending on) the type of respondent. In this first worksheet, there was a column specifying the variable to be collected and then another indicating how it was to be measured (the response options). The experts’ task was to rate the suitability or relevance of the variable and its operationalization (i.e., the suitability of collecting a particular piece of data and how it was to be collected). They were given a scale with four options (1=*not at all suitable*, 2=*somewhat suitable*, 3=*quite suitable*; 4=*highly suitable*). In addition, if they felt that the variable or the way it was collected was not suitable or could be improved, they were asked to give a brief explanation in the next column (i.e., “Comments/suggestions”). They were also able to use these cells to suggest other personal data they considered relevant but that were not already collected.

The next eight sheets in the Excel workbook presented the items structured around the eight QOL domains (one QOL domain on each worksheet/tab). The first column of each worksheet (i.e., QOL domain) showed the number of the Convention Article being evaluated. The second column gave the title of the Article in question; the third provided a summary of the Article content. The fourth column listed the indicators proposed for evaluating each CRPD Article. Thus, each QOL domain could be evaluated by one or more Convention Articles, and each Convention Article could be evaluated by one or more indicators. The fifth column presented the proposed items; the sixth, the accompanying clarifications to facilitate understanding of the item content.

Across the eight worksheets, experts were asked to (a) rate the *suitability*, *importance*, and *clarity* of the items on a 4-point scale, where 1=*not at all*, if they felt the item was not at all suitable for evaluating that particular indicator or Convention Article (suitability), was not important for evaluating that particular indicator or Convention Article (importance), or was unclear or not understood (clarity); 2=*not very*, if they felt the item was not very suitable, not very important, or not very clear; 3=*very* if they considered the item to be very suitable, very important, or very clear; and 4=*absolutely*, if they considered the item to be totally suitable, absolutely important, or perfectly understood; and (b) to rate the *usefulness of the clarifications* included to facilitate understanding of the items. In this case, a 5-point scale was used: 1=*not at all*, if the clarification did nothing to facilitate understanding of the item; 2=*not very*, if the clarification helped somewhat but not

enough to better understand the item; 3=*very*, if the clarification helped enough to better understand the item; 4=*absolutely*, if the clarification provided all the necessary help to understand the item; and 5=*no clarification needed*, if they felt the item was so clear that no additional comments were required. Finally, each sheet included a column where the experts could leave comments and suggestions to improve the content and wording of the items and their corresponding clarifications. In this last column, the experts could also indicate if they thought that items assessed different Articles, indicators, or QOL domains.

The experts returned the completed task within 1 to 5 weeks of receipt. The average time to complete the task was first estimated at around 5 hours, but subsequently was placed at approximately 10 hours of work.

Data Analysis

To provide evidence of the instrument’s content validity based on the judgment of the experts, both qualitative and quantitative analysis methods were used.

The qualitative element involved a depth analysis of the comments and suggestions put forward by the 32 experts for each of the items and sociodemographic variables, with a view to improving the wording of the items, making the clarifications more useful, and checking whether the items would be better placed in indicators, Articles, or QOL domains other than those they were initially assigned to by the research team. In this sense, it was taken into account if several experts coincided in their suggestions.

Quantitative analyses were based on the following: (a) *descriptive analysis* (i.e., mean, standard deviation); (b) *percentage agreement* (i.e., the number of experts who gave scores of 3, 4, or 5 to the items, divided by the total number of experts, and multiplied by 100); and, for the “importance” criterion, (c) the research team calculated the *Content Validity Ratio* (CVR) of the items (i.e., the number of experts who gave scores of 3, 4, or 5 to the items, minus half the total number of participating experts, then divided by half the total number of participating experts) and the *Content Validity Index* (CVI=the mean of the CVR values of the retained items) of the eight domains and the instrument as a whole.

The CVI proposed by Lawshe (1975) assumes that any item considered essential by more than half of the panelists has some degree of content validity; the higher the number of panelists who perceive the item as essential, the greater the degree of content validity. Thus, the CVI is usually interpreted directly as having a value that can range from -1 to +1, but it must exceed .80 for the set of items to be defined as relevant. Adopting a less stringent perspective, Lawshe himself produced a table showing the values obtained in this index and the number of experts used; the minimum recommended values (at a confidence level of 95%) were between .33 and .31 for a panel of 30 to 35 experts.

Finally, the research team computed the Fleiss (1981) kappa (κ), which measures the level of agreement among two or more raters for data on a nominal or ordinal scale while controlling for the effect of chance. This κ coefficient can also range from -1 to +1. The closer the statistic is to +1, the greater the degree of inter-rater agreement; the closer to -1, the greater the degree of disagreement. A value of $\kappa=0$ means that the agreement observed is no better than what would be obtained by chance. According to Fleiss, values below .40 are considered “poor”, values from .40 to .75 are interpreted as “good”, and values above .75 are rated as “excellent”.

To perform this computation, we used Randolph's (2008) software, collapsing the response options "3=very" and "4=absolutely" to signify agreement on the high level of suitability, importance, and clarity of the item, as well as on the usefulness of the clarification (in this case, the response "5=no clarification needed" was also added). Conversely, we collapsed response options "1=not at all" and "2=not very" to denote agreement among raters on the lack of suitability, importance, and clarity of the item, or on the limited usefulness of the clarification.

Results

Descriptive Analysis of the Proposed Variables and Items

First, we analyzed the suitability of the 70 variables collected as sociodemographic data and their response options. While the scores given by the experts were taken into account, the selection of these variables was not based on a quantitative criterion (i.e., cut-off point for percentage agreement, mean, or standard deviation), but on the qualitative analysis of their comments. The descriptive analysis was essentially used to highlight items that required changes in how the variable was collected (particularly in the response options), although it also served to eliminate 10 variables that the majority of raters agreed were irrelevant or unsuitable for collection (e.g., sexual orientation, gender identity, or ethnic origin of the person with disability; legal or illegal immigration status; language spoken at home). A total of 60 variables were thus retained for the pilot instrument. They referred to the three types

of informants: professionals (e.g., gender, frequency of contact with the person, position, employer), family members (e.g., gender, frequency of contact with the person, relationship to the person), and the person with disability (e.g., identification code). Table 1 presents the sociodemographic data that were judged valid, organized according to their relationship to the Convention Articles (all refer to the person with disability).

Next, we carried out descriptive analysis on the items proposed by QOL domain. Table 2 shows that the mean ratings of the items by domain were generally high: means for suitability, importance, clarity, and usefulness were above 3 (*very*); and there was limited dispersion across the scores (standard deviations were below 1 in most cases). The highest mean scores were observed for the importance of the items ($M=3.58$) and for the Rights domain ($M=3.62$), while the lowest were recorded for the clarity of the items ($M=3.38$) and for the Personal Development domain ($M=3.43$). Similarly, there was a high level of agreement among the experts on the importance and suitability of the items (with average agreement percentages above 91%). The CVR ranged from .75 to 1 and the CVI ranged from .85 (Personal Development, Self-Determination, and Social Inclusion) to .88 (Interpersonal Relationships, Rights, and Material Wellbeing).

Item Selection

The next step was to set the criteria for items to be eliminated from the bank. Items that obtained the following results for suitability and importance were deemed not relevant and were

Table 1
Organization of valid sociodemographic variables by relationship to CRPD Articles

Art.	Article title	Valid variables
6	Women with disabilities	Gender
7	Children with disabilities	Date of birth
11 & 18	Situations of risk and humanitarian emergencies; Liberty of movement and nationality	Country of birth and autonomous community (or city) of residence
19	Living independently and being included in the community	Type of residence, home ownership, cohabitants, and area of residence
12	Supported decision-making / legal guardian	Legal capacity
8	Awareness-raising	Family involvement
21	Freedom of expression and opinion, and access to information	Communication and literacy
23	Respect for home and the family	Marital status of the person with disabilities
24	Education	Education level, type of schooling, and type of educational establishment
25	Health	Chronic health conditions, disabilities, IDD diagnosis, level of functioning, degree of mobility, psychological disorders and taking medication, type of medication
26	Habilitation and rehabilitation	Centers where receiving supports and services
27	Work and employment	Employment status and work environment
28	Adequate standard of living and social protection	Disability benefits, individual's income level, family unit income level
28	Adequate standard of living and social protection	Certificate of disability, recognized degree of disability, recognized level of dependency
26	Habilitation and rehabilitation	Recent application of the Supports Intensity Scale, type of support needed, Support Needs Index score, recent QOL assessment, specify Quality of Life Scale, Quality of Life Index, emotional wellbeing score, physical wellbeing score, material wellbeing score, personal development score, interpersonal relationships score, self-determination score, social inclusion score, and rights score

Table 2
Descriptive statistics and inter-rater agreement for proposed items by domains

	Suitability of item			CVI	Importance of item			Clarity of item			Usefulness of clarification			
	% Agree.	M	SD		% Agree.	M	SD	% Agree.	M	SD	% Agree.	M	SD	M
PD	90.71	3.55	0.69	.85	92.52	3.57	0.64	81.58	3.29	0.80	77.55	3.32	0.96	3.43
SD	92.36	3.53	0.65	.85	92.71	3.52	0.63	90.14	3.41	0.69	87.29	3.66	0.93	3.53
IR	93.75	3.62	0.61	.88	94.13	3.63	0.58	89.13	3.39	0.68	85.63	3.55	0.84	3.54
SI	90.79	3.57	0.67	.85	92.55	3.59	0.63	91.99	3.41	0.66	83.89	3.43	0.89	3.50
RI	90.78	3.60	0.68	.88	94.05	3.65	0.62	89.02	3.42	0.71	86.81	3.82	1.06	3.62
EW	87.03	3.49	0.72	.83	91.29	3.57	0.64	87.41	3.33	0.72	89.68	3.55	0.76	3.49
PW	90.71	3.53	0.71	.87	93.40	3.56	0.66	87.76	3.34	0.74	86.81	3.49	0.87	3.48
MW	92.31	3.55	0.65	.88	93.83	3.55	0.63	92.23	3.43	0.67	91.19	3.57	0.80	3.52
<i>M_{crit}</i>	91.05	3.55	0.67	.86	93.06	3.58	0.63	88.66	3.38	0.71	86.11	3.55	0.89	

Note: PD=Personal Development; SD=Self-Determination; IR=Interpersonal Relationships; SI=Social Inclusion; RI=Rights; EW=Emotional Wellbeing; PW=Physical Wellbeing; MW=Material Wellbeing; CVI=Content Validity Index

removed: (a) a mean of less than 3; (b) a standard deviation greater than or equal to 1; (c) a percentage agreement below 80%; or (d) a CVI less than or equal to .58. Analysis of both the clarity of the item and the usefulness of the accompanying clarification was for information purposes only (i.e., results were not used to eliminate items, since the wording could be improved in later phases of the research, using the qualitative comments of the experts and through the adaptation and validation of the items in easy-read format). As shown in Table 3, 29 items were eliminated, most of them as a result of the percentage agreement criterion. The Rights domain had the greatest number of items removed, while all items in the Interpersonal Relationships domain were deemed relevant.

The next step involved a thorough review of the items rated as valid (*N*=267) to select those that, in the opinion of the experts, best reflected the QOL domains, the Convention Articles, and the proposed indicators. The research team took into account the scores given by the experts, their qualitative comments, and the content of the items (rejecting the least clear, most ambiguous, or redundant items). At this stage, the team sought to select items with (a) high means; (b) low standard deviations; (c) high percentage agreements; and (d) high CVI scores. It was also decided that (a)

each indicator should be evaluated by at least one item; (b) each Convention Article should be evaluated by a minimum of two items; and (c) each QOL domain should have between 10 and 25 items.

At the end of this process, 153 items were retained and there were some changes to the initial proposed organization of the instrument. Changes worthy of note include the following: (a) refining the wording of 76 items (thereby improving their clarity) and clarifications (thereby enhancing their usefulness) by incorporating the experts' suggestions (e.g., changing the word "community" to "neighborhood", and in the clarification explaining that we mean the place where the person lives); (b) eliminating items (and consequently Convention Articles) because their content was not directly related to actions that can be implemented to improve rights, but rather they reflect conditions that can have a cross-cutting influence on all rights, are taken as given, and cannot be manipulated or changed from the microsystem or mesosystem level: Articles 6 (women with disabilities), 7 (children with disabilities), 11 (situations of risk and humanitarian emergencies), 18 (liberty of movement and nationality), and 25 (health); (c) reassigning six items to different Articles within the Social Inclusion domain

Table 3
Nonvalid items by criteria and domain

	Suitability of item			CVR	Importance of item			Clarity of item			Usefulness of clarification			N Nonvalid
	% Agree.	M	SD		% Agree.	M	SD	% Agree.	M	SD	% Agree.	M	SD	
PD	3	-	-	2	2	1	-	10	2	2	17	6	14	3
SD	3	-	-	4	4	-	-	7	-	-	6	1	13	4
IR	-	-	-	-	-	-	-	3	1	-	7	-	5	0
SI	4	1	-	2	2	1	-	1	1	-	12	1	11	4
RI	7	-	4	1	1	-	-	6	1	-	5	-	22	7
EW	5	3	1	3	3	2	1	6	2	1	2	1	3	5
PW	3	1	1	1	1	-	-	6	1	-	5	1	5	4
MW	2	-	-	-	-	-	-	1	-	-	1	-	-	2
<i>N</i>	27	5	6	13	13	4	1	40	8	3	55	10	73	29

Note: PD=Personal Development; SD=Self-Determination; IR=Interpersonal Relationships; SI=Social Inclusion; RI=Rights; EW=Emotional Wellbeing; PW=Physical Wellbeing; MW=Material Wellbeing; CVR=Content Validity Ratio

(i.e., items initially assigned to Article 18 “liberty of movement and nationality” under “physical access to streets, transportation, and community” were moved to Article 9 “accessibility”); and (d) reassigning two valid items from the Physical Wellbeing domain to the Rights domain because, although they referred to medical interventions (e.g., “I have undergone medical interventions without having given my consent. For example: operations, forced sterilization, abortions...”), the experts’ comments suggested that they fitted better with Article 15 (i.e., freedom from torture or cruel, inhuman or degrading treatment or punishment).

The 153 items were distributed across the eight QOL domains, 21 Articles, and 41 indicators (Table 4). The QOL domains comprised an average of 19 items: Physical Wellbeing was the domain with the least number of items ($n=14$); Self-Determination had the most ($n=25$). Most of the items considered valid (73.8%; $n=113$) were new items proposed by the research team based on the literature review by Gómez, Monsalve et al. (2020). The other items deemed valid were as follows: 15 items inspired by the Spanish report on human rights and disability (CERMI, 2018); 11 items drawn from the ITINERIS Scale (Aznar et al., 2012); six items taken from the wording of the CRPD Articles (United Nations, 2006); six items from the NCI-ACS (Houseworth et al., 2019; Tichá et al., 2018); one item from the KidsLife Scale (Gómez et al., 2016); and one item from the ECEQ (Colver et al., 2011).

Descriptive Analysis and Inter-Rater Agreement Analysis for Selected Items

The experts’ ratings were highest for the selected items in the Rights domain ($M=3.71$), while they were lowest for the items in the Personal Development domain ($M=3.51$). The mean inter-rater percentage agreement was above 95% and the mean κ coefficient was over .40 in all cases (Table 5). In fact, agreement based on this coefficient was excellent in all QOL domains for the criteria of item suitability and importance, with the exception of the suitability of the Emotional Wellbeing items, whose mean κ value ($\kappa=.73$) was just below the threshold for this classification ($\kappa=.75$). The lowest agreement, but adequate, was that observed in the criterion of usefulness of clarifications ($k=.60$), as well as that observed in the clarity of the items in personal development ($k=.47$).

Discussion

Monitoring the effective implementation of the CRPD for people with IDD is a clear and critical priority in many countries. This study proposed a specific pool of items as the starting point for the construction of an instrument that demonstrates sufficient levels of validity and reliability.

The set of sociodemographic variables and the item bank validated in this study could constitute the pilot version of a CRPD assessment instrument with the following essential characteristics: (a) it is based on a sound conceptual framework, namely QOL; (b) it contains an adequate number of items related to the 26 CRPD Articles and the eight QOL domains; (c) it demonstrates sufficient evidence of content validity; (d) it is aimed at people with IDD of any age, although respondents may also be family members or close others and professionals; and (e) it is administered through a web application that adjusts the wording of the items to the type of informant (e.g., first person if the person with IDD is responding and third person if a professional or close other is responding) and

adapts the presentation of the items according to the responses of the participants (e.g., children under 18 will not see items related to employment).

This study proposes the indicators and items that would serve to operationalize the CRPD Articles, and in addition it provides sufficient and relevant content-based evidence. In particular, it demonstrates the relevance of the controlling demographic variables as well as the suitability and importance of the retained items. While there is also evidence pointing to the clarity of the items and the usefulness of the accompanying clarifications (suggesting they could be applied in their current form), given the emphasis of the CRPD and the growing interest in inclusive research (Gómez et al., 2021a), the next step in our investigation would be to adapt the instrument to easy-read format and to have it validated by people with IDD. In other words, the population directly concerned by the instrument would validate the wording of the items, the clarifications, and the instructions for administration. This step would provide further evidence of the instrument’s content validity. More importantly, people with IDD would be contributing to the process of developing and validating the instrument by collaborating in research tasks, thus allowing us to evaluate the usefulness of the tool by its intended users. In this way, as recommended by Gómez et al. (2021a, 2021b), the tool will enable not only an outcome-focused and principle-focused evaluation, but also a utilization-focused one.

It is important to highlight the four key strengths of this study. First, the initial proposal of items and sociodemographic variables was based on three earlier publications, which means that there was already evidence of content validity. The second strength relates to the size of the expert group, which was double or triple the size used in studies with similar characteristics (Fernández et al., 2018; Gómez et al., 2015; Swerts et al., 2021; Vicente et al., 2019); moreover, our experts showed a high degree of heterogeneity and level of expertise. Their participation, in conjunction with the close collaboration of people with IDD, confirms that the pilot version of the tool proposed in this research is suitable and useful for the main stakeholders to whom it is addressed. Third, the tool offers a triple view on how the same person’s rights are realized—the view of the person with IDD, that of a relative or close other (natural support), and that of a professional (professional support)—allowing the agreements and disagreements among the three perspectives to be analyzed (e.g., Balboni et al., 2013). Finally, it also includes variables that may influence the exercise or violation of specific CRPD Articles and the QOL of people with IDD (e.g., gender, age, level of support needs).

Our study is not without limitations. Among these, we should point out that we used a convenience sample of experts, although we tried to correct this issue to some extent by employing a snowball strategy (i.e., once an initial group of experts was identified, they had the opportunity to suggest other participants). In addition, there may be a risk of bias due to the fact that the items were already assigned to the indicators, Articles and QOL domains. Given the existing previous studies and the large number of items and variables to be assessed, we did not use a “matching task”, but a “rating scale approach” (Sireci & Faulkner-Bond, 2014). Lastly, the final number of items and sociodemographic variables may appear quite high, especially given that they will be completed by people with IDD. However, it should be remembered that this is a pilot version and that a large number of items will likely be eliminated in subsequent validation studies. In an attempt

Table 4
Organization of instrument items following expert consultation

Domain (n items in initial instrument)	CRPD Articles (Verdugo et al., 2012)	Indicators based on Lombardi et al. (2019)	Proposed changes to indicators	Final instrument		
				n items by indicator	N items by CRPD Article	N items by domain
Personal Development (n=38)	24 (education)	1. Educational setting		3		
		2. Involvement in an educational program		4		
		3. Lifelong learning	"Education level" indicator assessed through sociodemographic data	4	17	17
		4. Personal skills		4		
		5. Supports for personal growth and development		3		
Self-Determination (n=45)	14 (liberty and security of person)	6. Freedom of movement		3		
		7. Freedom of choice		3		
		8. Personal autonomy	"Safe and secure environment" indicator moved to Art. 16 (EW)	4	14	
		9. Personal control		3		
		10. Realizing personal goals		1		25
Interpersonal Relationships (n=25)	21 (freedom of expression and opinion)	11. Access to information		2		
		12. Level of understanding the information		5		
		13. Using information		2	11	
		14. Opportunities to express opinion		2		
		15. Right to set up their own family	Art. 30 of this domain eliminated because already included in SI	4	16	16
16. Right to be a parent	4					
17. Dating people of own choice	7					
Social Inclusion (n=39)	8 (awareness-raising)	18. Acts of awareness to increase social inclusion		2	2	
		19. Accessibility in streets, transportation, and community buildings	Art. 18 indicators (physical access to streets, transportation, and community) moved to Art. 9 "Presence in cultural, recreational, and leisure events" eliminated	7	7	
		20. Living in a home with minimum intrusion from others	"Home ownership" and "rental contract" indicators assessed through sociodemographic data	2	2	
		21. Ways to be mobile		2		23
		22. Opportunity to travel	"Way to transport across environments" and "way to be personally mobile" merged "Opportunity to travel" indicator included (previously in Art. 30)	1	3	
Rights (n=41)	20 (personal mobility)	23. Voting		2		
		24. Participation in groups, boards/committees, and public office	Two indicators merged "Voting" indicator added	2	4	
		25. Participation in cultural events (e.g., concerts, theaters, movies, museums), and in recreational or leisure events (e.g., hobbies, sports)	Various indicators previously in Art. 30 in IR merged	5	5	
		26. Non-discrimination	Four indicators already assessed in other Articles eliminated: "presence in the community" and "participation in community activities" (Art. 30; SI), "competitive employment" (Art. 27; MW), "dating and intimacy with people of own choice" (Art. 23; IR) "Non-discrimination" indicator added	3	3	
		27. Making choices about end-of-life decisions	"Making choices about contraception" indicator eliminated	3	3	
Emotional Wellbeing (n=33)	10 (right to life)	28. Legal competence (supported decision-making)	"Access to legal services" and "receives due process" eliminated because already covered in Art. 13 (RI) Legal competence supplemented with "supported decision-making" Also assessed through sociodemographic data	4	4	21
		29. Accommodations in the defense of rights, the judicial and penitentiary system	Indicators ("defense attorney"; "participation in one's defense"; "adjudication by a magistrate, judge or jury"; "fair sentence"; "understanding the charges") merged into one indicator	3	3	
		30. Personal injuries caused by others	"If guilty, the punishment received is commensurate to that received by others" indicator eliminated	4	4	
		31. Control over personal areas		2	2	
		32. Confidentiality of information	"Personal access to communication" changed to confidentiality	2	2	
Physical Wellbeing (n=36)	16 (freedom from exploitation, violence and abuse)	33. Living in a safe environment (i.e., not being abused by others)	Three indicators merged	8	8	
		34. Experiencing respect and dignity	Two "experiencing equality" indicators merged and included in Art. 5 (RI)	10	10	18
		35. Medical and emotional interventions if needed		7		
Material Wellbeing (n=39)	26 (habilitation and rehabilitation)	36. Appropriate therapies	Also assessed through sociodemographic data	7	14	14
		37. Paid employment		6		
		38. Job training programs	Also assessed through sociodemographic data	3	9	
Material Wellbeing (n=39)	27 (work and employment)	39. Annual income covers basic expenses and allows for discretionary spending		4		19
		40. Adequate housing	"Unemployment insurance" indicator eliminated (assessed through sociodemographic data)	3	10	
		41. Public assistance		3		

Table 5
Descriptive analysis and inter-rater agreement analysis for selected items

Dom	Suitability of item					Importance of item					Clarity of item					Usefulness of clarification					N	
	% Ag.	M	SD	α	95% CI	CVI	% Ag.	M	SD	α	95% CI	% Ag.	M	SD	α	95% CI	% Ag.	M	SD	α		95% CI
PD	95.40	3.68	0.58	.83	[.75, .90]	.92	96.14	3.66	0.57	.85	[.80, .91]	84.19	3.34	0.77	.47	[0.38, 0.57]	80.33	3.35	0.92	.41	[.29, .54]	17
SD	96.38	3.65	0.57	.86	[.81, .91]	.94	97.13	3.65	0.55	.89	[.84, .94]	91.38	3.43	0.66	.70	[0.60, 0.79]	89.38	3.67	0.86	.63	[.55, .71]	25
IR	95.70	3.66	0.55	.84	[.77, .91]	.91	96.09	3.66	0.53	.85	[.77, .93]	92.58	3.45	0.64	.72	[0.65, 0.80]	86.72	3.60	0.85	.54	[.44, .64]	16
SI	95.65	3.70	0.55	.84	[.77, .90]	.93	96.47	3.70	0.53	.86	[.81, .92]	94.16	3.46	0.61	.78	[0.72, 0.85]	83.42	3.42	0.88	.47	[.36, .58]	25
RI	95.24	3.71	0.58	.82	[.76, .88]	.95	97.62	3.74	0.51	.91	[.87, .94]	92.41	3.49	0.65	.73	[0.63, 0.83]	89.73	3.90	0.98	.64	[.54, .73]	21
EW	92.71	3.63	0.63	.73	[.66, .80]	.91	95.66	3.71	0.56	.83	[.77, .89]	91.67	3.41	0.67	.70	[0.61, 0.78]	92.36	3.61	0.74	.72	[.64, .79]	18
PW	96.43	3.69	0.55	.86	[.79, .94]	.95	97.54	3.72	0.52	.90	[.84, .97]	93.75	3.47	0.64	.77	[0.67, 0.87]	90.18	3.57	0.82	.65	[.55, .74]	14
MW	96.71	3.67	0.53	.87	[.81, .93]	.95	97.53	3.67	0.50	.90	[.85, .96]	93.91	3.49	0.61	.77	[0.69, 0.86]	93.09	3.63	0.74	.74	[.67, .82]	19
M	95.53	3.67	0.57	.83		.93	96.77	3.69	0.53	.87		91.76	3.44	0.66	.71	[0.38, 0.57]	88.15	3.59	0.85	.60		19.13

Note: PD=Personal Development; SD=Self-Determination; IR=Interpersonal Relationships; SI=Social Inclusion; RI=Rights; EW=Emotional Wellbeing; PW=Physical Wellbeing; MW=Material Wellbeing; CVI=Content Validity Index

to overcome this limitation, the electronic tool to be used to administer the instrument will allow the data to be saved, meaning that the assessment can be completed over several sessions.

Despite these limitations, we believe that this proposal is an interesting starting point to develop and validate an instrument for assessing the rights set out in the CRPD for people with IDD. In this respect, the instrument will be pioneering in the international arena and relevant for both the scientific and applied fields. The value of this assessment tool lies in its potential to raise awareness about the rights enshrined in the CRPD; to design, implement, and evaluate the effectiveness of interventions and programs aimed at raising awareness about rights, exercising rights and upholding rights; and ultimately to improve the QOL of people with IDD. Future research

should focus on adapting and validating it in easy-read format; applying it to a broad sample of people with IDD, family members, and professionals; and providing evidence to validate the response process, the internal structure of the scale, and the relationship to other variables (Muñiz & Fonseca-Pedrero, 2019).

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