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THE #RIGHTS4METOO SCALE: A TOOL TO MONITOR COMPLIANCE WITH THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

La escala #YoTambién Tengo Derechos: una herramienta para monitorizar la Convención sobre los Derechos de las Personas con Discapacidad

Laura E. Gómez Sánchez
Universidad de Oviedo. España
gomezlaura@uniovi.es
https://orcid.org/0000-0002-0776-1836

M. Lucía Morán Suárez
Universidad de Oviedo. España
https://orcid.org/0000-0001-5650-6711

Patricia Solís García
Universidad de Oviedo. España
https://orcid.org/0000-0002-2962-5819

Marta Sierra Maroto
Universidad de Oviedo. España

Patricia Pérez Curiel
Universidad de Zaragoza. España
https://orcid.org/0009-0005-8409-161X

Miguel Ángel Verdugo Alonso
Universidad de Salamanca, INICO. España
https://orcid.org/0000-0002-5802-8220

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Abstract: There is a lack of psychometrically validated tools to evaluate the extent to which people with intellectual disability (ID) truly exercise their rights in all areas of their lives. The aim of this article is to provide evidence about the usefulness and reliability of the pilot version of the #Rights4MeToo Scale, an instrument based on the Quality of Life Supports Model. The scale can be self-reported by people with ID or hetero-reported by family members or professionals. First, through a qualitative study with self-advocates with ID, we provide evidence about the need and usefulness of this tool to understand and monitor compliance with the Convention on Rights of Persons with Disabilities (CRPD). Next, we present preliminary data on the internal consistency of the items that make up the pilot version, analyzing the responses of 1,200 people with ID, family members, and professionals. The #Rights4MeToo Scale will make it possible to conduct national studies on compliance with the CRPD, not to mention international comparative studies when the scale is adapted to the legal and cultural context of other countries.

Keywords: Convention on the Rights of Persons with Disabilities; CRPD; quality of life; sustainable development goals; intellectual developmental disorder; intellectual disability.

Resumen: Resulta urgente e ineludible contar con herramientas, con adecuadas evidencias de validez y fiabilidad, que permitan evaluar hasta qué punto las personas con discapacidad intelectual (DI) verdaderamente ejercen sus derechos en todos los ámbitos de su vida. El objetivo de este artículo consiste en proporcionar evidencias acerca de la utilidad y la fiabilidad de la versión preliminar de la escala #YoTambién Tengo Derechos, un instrumento diseñado a partir del Modelo de Calidad de Vida y Apoyos. La escala puede ser autoinformada por personas con DI o heteroinformada por familiares o profesionales. Por un lado, mediante un estudio cualitativo con autogestores con DI se proporcionan evidencias acerca de la necesidad y la utilidad de esta herramienta para conocer y monitorizar el cumplimiento de la Convención. Por otro lado, presentamos datos preliminares de la consistencia interna de los ítems, analizando las respuestas de 1.200 personas con DI, familiares y profesionales. La escala #YoTambién Tengo Derechos permitirá llevar a cabo estudios nacionales sobre el cumplimiento de la Convención sobre los Derechos de las Personas con Discapacidad y, con su adaptación al contexto legal y cultural de otros países, estudios comparativos internacionales.

Palabras clave: Convención sobre los Derechos de las Personas con Discapacidad; CDPD; calidad de vida; objetivos de desarrollo sostenible; trastorno del desarrollo intelectual; discapacidad intelectual.

1. Introduction

Can people with intellectual disability (ID) enjoy the same rights as other people? The answer to this question today would be a resounding “yes”, at least in terms of rhetoric. Since the entry into force of the Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) in 2008, people with disability in signatory countries —including Spain— should enjoy the same rights and freedoms as other citizens without discrimination. Unfortunately, what happens in practice is very different, as people with ID especially face frequent attitudinal and contextual barriers that hinder their true inclusion and participation in society (McConkey *et al.*, 2021; Slater *et al.*, 2020). We continue to witness flagrant violations of rights, especially against people with greater support needs (Buchner *et al.*, 2021; Chalachanová *et al.*, 2021; Esteban *et al.*, 2021; Gómez and Navas, 2022; Morales *et al.*, 2021; Morán *et al.*, 2019; Navas *et al.*, 2018; Pérez-Curiel *et al.*, 2023). Worse still, there is an alarming lack of documentation about the nature and extent of such violations and situations of discrimination, as well as insufficient —or non-existent— participation of people with ID in the preparation of human rights reports (Mitler, 2015; Petri, 2022).

The recognition of the rights of people with disability is undoubtedly a fundamental and necessary step toward full inclusion. However, there is currently an urgent need for tools with adequate evidence of validity and reliability that allow for an objective and quantitative evaluation of the extent to which people with ID truly exercise their rights in all areas of their lives (Didi *et al.*, 2018; Gómez *et al.*, 2020; Houseworth *et al.*, 2019; Luckasson *et al.*, 2023; Tichá *et al.*, 2018). In fact, Articles 31 and 33 of the Convention obligate the States Parties to issue reports on the fulfillment of the ratified rights in their respective territories, and also to ensure that people with ID and the organizations that represent them participate fully at all levels of the monitoring process.

The CRPD serves as a suitable framework for promoting, protecting, and monitoring the fulfillment of the rights of people with ID, and therefore for recognizing, quantifying, and making visible the serious and complex situations of disadvantage and discrimination faced by this sector of the population. At the same time, the quality of life construct has for more than a decade been presented as the best vehicle for monitoring the fulfillment and violation of rights, actively involving people with ID in the evaluation process (Gómez *et al.*, 2020; Karr, 2011; Lombardi *et al.*, 2019; Navas *et al.*, 2012; Verdugo *et al.*, 2012). Numerous studies have pointed to the perfect alignment between the domains of quality of life and the rights promulgated in the CRPD (Gómez *et al.*, 2020; Gómez *et al.*, 2022) and also the Sustainable Development Goals (SDGs; Gómez *et al.*, 2023), which urge countries to reduce inequality and ensure that "no one is left behind" (United Nations, 2015). The evaluation of central indicators and personal outcomes related to quality of life allows for the operationalization —and therefore the measurement— of aspects as abstract as those defended in the CRPD and the SDGs.

To date, only partial attempts have been made to monitor the compliance of the CRPD for people with ID, using six assessment tools with some psychometric guarantees, although none of them was originally designed for nor fully serves this purpose (Gómez *et al.*, 2020): the ITINERIS scale (ISRPID; Aznar *et al.*, 2012), the European Child Environment Questionnaire (ECEQ; Colver *et al.*, 2011), the National Core Indicators-Adult Consumer Survey (NCI-ACS; Houseworth *et al.*, 2019; Tichá *et al.*, 2018), the KidsLife Scale (Morales *et al.*, 2021), the GENCAT Scale, and the INTEGRAL Scale (Gómez *et al.*, 2011). The NCI-ACS evaluates service quality, and the ECEQ evaluates environmental factors. The KidsLife Scale, the GENCAT Scale, and the INTEGRAL Scale are quality of life measures that include some items to evaluate the rights domain, but the items are too few and too generic to monitor the CRPD. The ISRPID is inspired by the Montreal Declaration and does not evaluate all the rights included in the CRPD. Additionally, the scientific literature contains evidence only about the internal consistency of participants' responses in Chile, but it says nothing of the scale's validity. As for the Rights of Persons with Disabilities scale (Karr, 2011), it only has 17 items —insufficient to evaluate all the rights in the CRPD— and its psychometric properties have only been explored in very small non-Spanish samples.

Thanks to the work carried out by INICO in particular (University of Salamanca), Spain is a pioneer in the development of quality of life assessment tools (e. g., Fernández *et al.*, 2019; Gómez *et al.*, 2015, 2016; Verdugo *et al.*, 2014), but also of instruments specifically designed to monitor the rights defended in the CRPD. In the last decade, since Verdugo *et al.* (2012) first made the proposal to align the Articles of the CRPD with the eight quality of life domains, we have advanced toward an internationally agreed proposal not only of the domains but also of the core quality of life indicators related to each of the rights promulgated in the CRPD (Gómez *et al.*, 2020; Lombardi *et al.*, 2019), which have subsequently been specified, adapted, and nationally validated for application throughout the Spanish territory (Gómez *et al.*, 2022).

The aim of this article is to provide evidence on the usefulness and reliability of the pilot version of the #Rights4MeToo Scale (Gómez *et al.*, in press), an instrument based on the Quality of Life Supports Model (Gómez *et al.*, 2021a, 2021b; Morán *et al.*, 2023; Verdugo *et al.*, 2021) and more specifically on the eight-domain quality of life conceptual framework proposed by Schalock and Verdugo (2002). The #Rights4MeToo Scale is designed and currently being validated to (1) give voice to people with ID, so that they can not only know what their rights are but also quickly and easily communicate situations in their daily lives that involve discrimination or noncompliance with the CRPD (i. e., microsystem); (2) be useful for professionals, family members, and other support providers to detect strengths and weaknesses in terms of rights (i. e., microsystem); and (3) evaluate and monitor the effectiveness of programs and supports implemented by organizations (i. e., mesosystem), as well as guide the development or improvement of public policies (i. e., macrosystem).

In this article, we begin by briefly presenting the development process and the available evidence on the content-based validity of the scale. Next, we demonstrate the need and usefulness (i. e., face validity) of this tool to understand and monitor compliance with the CRPD through a qualitative study with people with ID. Finally, we provide data on the internal consistency of the items that make up the pilot version through its application to a large sample of people.

2. Method

2.1. *Instrument*

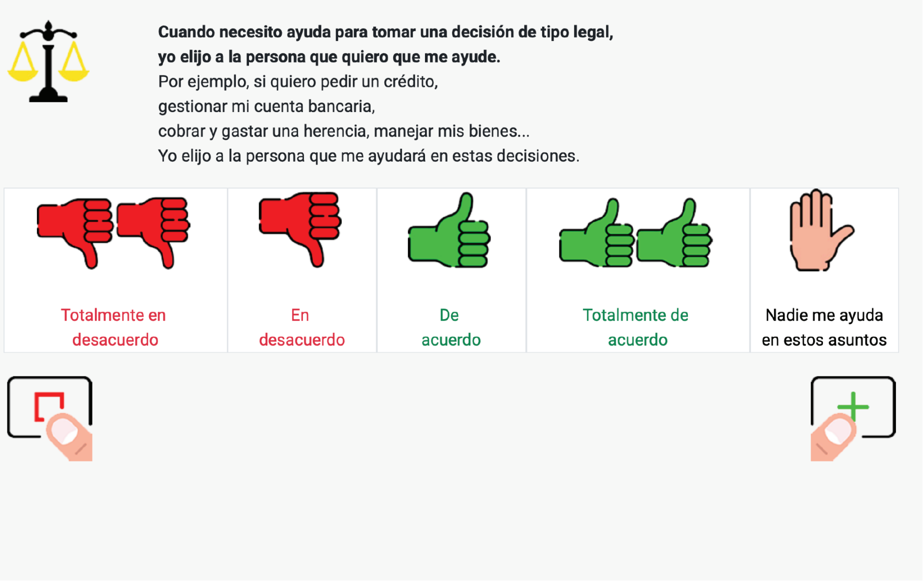
We used the pilot version of the #Rights4MeToo Scale (*#YoTambién Tengo Derechos* in Spanish; Gómez *et al.*, in press), which derives its title from the popularized hashtag from the #MeToo movement. Its purpose is to evaluate compliance with the rights ratified in the CRPD. The scale consists of 153 items, organized around the eight quality of life domains proposed in Schalock and Verdugo's (2002) model and around the CRPD Articles that contain specific rights. The content and organization of the scale have been validated in several studies as summarized below.

First, using Verdugo *et al.*'s (2012) proposed alignment between the CRPD and the eight quality of life domains, a Delphi study involving 153 experts from 10 countries (including people with ID, family members, professionals, researchers, and legal experts) facilitated an international consensus on several dozen quality of life indicators that enable the operationalization of the CRPD in people with ID (Lombardi *et al.*, 2019). Second, the Delphi study was subsequently complemented by a systematic review, which extracted more than a hundred indicators that were found to be useful for measuring the implementation of the CRPD and that related to the eight quality of life domains (Gómez *et al.*, 2020). Third, we conducted a consultation with 32 Spanish experts (including academics, professionals, and family members of people with ID), achieving consensus on the suitability, importance, and clarity of 153 items to monitor compliance with the rights of people with ID in Spain. These items make up the pilot version of the #Rights4MeToo Scale. As described in detail in Gómez *et al.* (2022), the 153 items are distributed around the eight quality of life domains and 41 core indicators (each indicator is evaluated by between 1 and 10 items). Each quality of life domain includes between 14 items (i. e., physical well-being) and 25 items (i. e., self-determination), and evaluates between one and seven specific rights of the CRPD.

Subsequently, the 153 items were adapted to easy-to-read language and validated by people with ID. As shown in Figure 1, the items are short statements, written in the first person when the person with ID is responding about themselves and in the third person when someone close to the person with ID is responding. The content of each item is presented in bold, followed by a brief explanation to facilitate understanding. All items are answered using a four-option Likert response format (ranging from *totally disagree* to *totally agree*). Response options are always presented in text (with red font if referring to disagreement or negation, and green font if referring to agreement or affirmation). The options are accompanied by icons (thumbs up or thumbs down) in these same colors, depending on whether they indicate agreement or disagreement. Items about issues that may not be applicable to all people or for which a negative response would not necessarily imply situations of disadvantage or discrimination include a fifth option (represented by a hand icon in a different color), accompanied by a statement relevant to the situation being described. For example, in the item *When I need help making a legal decision, I choose the person I want to help me* (Figure 1), the respondent could choose *completely disagree* or *disagree* if they could not choose a person when they needed help, but they would also have the option to select *nobody helps me with these matters* (fifth response option) if they did not need this type of support.

As shown in Figure 1, the items are presented one at a time on the screen and are always accompanied by an icon representing the quality of life domain to which they belong. To answer the *next* item, the person clicks on the icon with a finger on

Figure 1. Example item and response format in the #Rights4MeToo Scale (self-report version)



Cuando necesito ayuda para tomar una decisión de tipo legal,
yo elijo a la persona que quiero que me ayude.
Por ejemplo, si quiero pedir un crédito,
gestionar mi cuenta bancaria,
cobrar y gastar una herencia, manejar mis bienes...
Yo elijo a la persona que me ayudará en estas decisiones.

the + symbol. If the person tries to access the next item without selecting a response, the system returns an error message reminding them that they must choose an option to continue. If the person wants to take a break and continue the assessment later, they can click on the icon with a finger on a square symbol *(exit and save)*.

The presentation of the items differs depending on the preferences and characteristics of the person responding or being evaluated. The software application allows for customization and individualization of the evaluation experience, so that the user can choose which quality of life domain to start with and the order in which to complete the other domains. Similarly, the items are written with she/her pronouns if the person being assessed indicates that she identifies with this gender, and the work-related items are not presented if the person is not of working age.

When people with ID respond (i. e., self-reported version), due to the length of the questionnaire, the recommendation is to complete it in two or three sessions of approximately 45 minutes each. When professionals, family members, and legal representatives respond (i. e., hetero-reported version), the scale is usually completed in a single session of approximately 20 minutes.

The online version of this tool includes a feature to download a report that automatically calculates the total scores in the eight quality of life domains and provides the specific responses to each of the items aligned to the relevant CRPD Articles.

Since we are still conducting fieldwork to provide evidence of the scale's validity, the download feature is currently available only for the responses of professionals but not for the responses of people with ID or their families. This is to safeguard the confidentiality of their responses.

2.2. *Participants*

To provide evidence regarding the face validity of the scale, we conducted a qualitative study with four participants: three self-advocates with ID and a psychologist who was working with them and who had 23 years of experience in the field of ID. The participants with ID were two women aged 46 and 57, and a 41-year-old man. One of the women lived with her husband; the other lived with her parents and son. The man lived alone. All three had basic education and none were employed. None of the participants with ID had previously participated in research, while the psychologist had done so on five occasions.

Next, once the pilot version of the #Rights4MeToo Scale was adapted to easy-to-read format, it was administered to a large sample as part of an exploratory quantitative study. The aim was to provide evidence of reliability. The scale could be completed by people with ID who were 12 years of age or older. It could also be completed by someone who was close to the person with ID (e. g., family members and professionals), provided that they were 4 years old or older and had known the person with ID for at least 6 months. In total, 1,200 people responded, of whom 515 were people with ID (43 %), 91 were family members or legal representatives (8 %), and 594 were professionals (49 %).

Of the people with ID who completed the self-reported version, 54 % identified as male and two identified as nonbinary. Their ages ranged from 12 to 66 years old ($M = 35$, $SD = 12$). The vast majority did not have children (nine people had children) or partners (18 people reported having a partner). Nearly one-third (30 %) were in the education system, and only one in five (20 %) had a job at the time of evaluation. As for the family members who completed the scale for a relative with ID (hetero-reported version), the majority were parents (67 %) and siblings (21 %), with four out of five identifying as female and having contact with the person with ID at least four times a week. As for the professionals, all were support providers for people with ID in a Spanish third-sector organization. They included caregivers (20 %), psychologists (20 %), support technicians or monitors (14 %), educators (12 %), and teachers (11 %). Also, the vast majority (74 %) of the professionals identified as female.

2.3. *Procedure*

First, the pilot version of the scale was adapted into easy-to-read language and validated by the *Servicio Adapta* of *Plena inclusión* Asturias (Sierra, 2022).

This process involved three self-advocates with ID, a psychologist who acted as a facilitator in the validation sessions, and a professional. The professional was responsible for the initial adaptation of the items, instructions, and response format, and then for any subsequent modifications and formatting of the instrument. The process was completed in a total of five sessions, each approximately 2 hours long.

Before and after this process of adaptation and validation in easy-to-read language, we conducted an interview (with 10 questions) with the three people with ID (Table 1). The first interview, called the *initial interview*, included six questions that were asked before providing the self-advocates with any information, and four questions that were asked after explaining the research objectives and defining inclusive research. In other words, after asking the first six questions, the interviewer informed the self-advocates with ID that they were going to review the suitability of the items on the #Rights4MeToo Scale and participate as experts in an inclusive study. She explained that they would validate the text in easy-to-read language. More importantly, she emphasized that they would also act as experts: They could modify the items, instructions, and response format to improve understanding; they could include new items that they deemed important and that had not initially been considered; they could eliminate items they considered inappropriate; and they could make any comments or suggestions they wished to provide about the study because their opinions would be taken into account. The second interview, called the *final interview*, contained the same 10 questions as the initial interview and aimed to collect information about the self-advocates' experience and check if they had improved their knowledge and changed their initial opinions. Approximately 2 weeks elapsed between the initial and final interviews. The professional answered 10 similar questions, but only in the final interview, to collect her opinions about respect for the rights of people with ID, their inclusion in research, and her experience in the validation process.

Second, once the content and format of the pilot version of the #Rights4MeToo Scale had been adapted and validated, we developed an electronic version, an instruction manual, and an explanatory video on how to use it. Next, we promoted the study at various courses and conferences, on the INICO website, and on social media. Additionally, we conducted an exhaustive web search for organizations that provide services to people with ID in Spain and contacted them by email. For those entities that expressed an interest in participating, the research team provided them with the necessary information to conduct the evaluations and was available to answer questions via email, phone, video calls, and face-to-face meetings.

The project to develop and validate the scale was authorized and supported by the Ministry of Social Rights and Welfare of the Principality of Asturias, and by the Research Ethics Committee of the University of Oviedo (17_RRI_2021). All participants provided their informed consent to participate in the study. Confidentiality and anonymity of the responses were guaranteed by not collecting personal data that could identify the participants.

TABLE 1. Structure and content of the initial and final interview

	Initial Interview	Final Interview
Self-advocates with ID	1. What is research for you? 2. Do you think that people with ID are taken into account in research? 3. Do you know about the CRPD? What do you know about it? 4. Do you think that the rights of people with ID are respected? 5. Which rights do you think are respected? 6. Which rights do you think are not respected? After providing them with information: 7. What good things do you think will come from participating in this validation process? 8. What bad things do you think will come from participating in this validation process? 9. How do you think your relationship with your colleagues will be during the validation process? 10. How do you think your participation in this validation process can benefit all people with ID?	1. What is research for you? 2. Do you think that people with ID are taken into account in research? 3. What do you know now about the CRPD? 4. Do you think that the rights of people with ID are respected? 5. Which rights do you think are respected? 6. Which rights do you think are not respected? 7. What good things have come from participating in this research? 8. What bad things have come from participating in this research? 9. How has your relationship been with your colleagues during the validation process? 10. How do you think your participation in this validation process can benefit all people with ID?
Professional		1. Do you think people with ID should be included as researchers? 2. Do you think people with ID are taken into account in research? 3. What do you know about the CRPD? 4. Do you think the rights of people with ID are respected?

TABLE 1. Structure and content of the initial and final interview

	Initial Interview	Final Interview
		5. Which rights do you think are respected? 6. Which rights do you think are not respected? 7. What good things have come out of participating in this research? 8. What bad things have come out of participating in this research? 9. How has the relationship been between the people involved in the validation process? 10. How do you think your participation in this validation process can benefit all people with ID?

2.4. *Data Analysis*

First, to provide evidence of the utility or face validity of the scale, we used a qualitative methodology to analyze the responses of the self-advocates with ID who had been interviewed during the easy-to-read validation process. The qualitative analysis followed several stages to organize and process the information (Creswell, 2014): (a) definition of themes, subthemes, and interview questions; (b) definition of categories and subcategories; (c) information coding; (d) information analysis; (e) codes; and (f) validation of information prediction. The construction of categories was based on the structure of the interview questions, although we simultaneously worked with the possibility of emergent categories. Each text segment was identified with a code or subcode assigned to each category using the MAXQDA program. Initially, we established two large blocks: initial interview and final interview. As summarized in Table 2, the categorization of each theme was performed based on four content categories that formed the basis of the code system. Subsequently, discourse analysis allowed us to distinguish 19 subcategories in the responses, which constituted the codes and subcodes for qualitative analysis.

Next, to provide evidence of the reliability of the subscales that make up the #Rights4MeToo Scale, we analyzed their internal consistency by calculating

TABLE 2. Subcategories in the qualitative analysis

Category	Subcategory	Description
Participation of people with ID in research	*First-person perspective*	Opinions about adopting a first-person perspective in research
Knowledge of rights	*CRPD*	Knowledge about CRPD
	List of rights	Rights they know
Respect for rights of people with ID	*They are respected*	Fulfillment of the rights of the CRPD
	They are not respected	Noncompliance with the rights of the CRPD
	What rights? Accessibility	Statements related to this right
	What rights? Health	Statements related to this right
	What rights? Privacy	Statements related to this right
	What rights? Equality and nondiscrimination	Statements related to this right
	What rights? Education	Statements related to this right
	What rights? Employment	Statements related to this right
	What rights? Independent living	Statements related to this right
	What rights? Respect for home and family	Statements related to this right
	What rights? Participation in cultural life	Statements related to this right
	What rights? Participation in political life	Statements related to this right
Fulfillment of expectations about participation in the research	*Positive opinions: Offering help*	Positive opinions about participation in research related to offering help
	Positive opinions: Collaboration	Positive opinions about participation in research related to collaborating
	Positive opinions: Learning	Positive opinions about participation in research related to learning
	Negative Opinions	Negative opinions about participation in research

Cronbach's alpha (α) after administration to a large sample (1,200 participants). We analyzed the internal consistency of the total scale and of the eight quality of life domains, broken down by type of informant (i. e., people with ID, professionals, and family members).

3. Results

3.1. *Face Validity*

The results from the initial and final interviews, presented below, provide evidence about the usefulness, appropriateness, and apparent validity of the scale (i. e., that the test measures what it was designed to measure and that its content is acceptable and appropriate for people with ID). Interview excerpts are included (in italics) to illustrate the results: Comments made by the three self-advocates with ID are preceded by the letters "SA", and those made by the professional are preceded by the letters "PR".

3.1.1. Evidence From the Initial Interview

In the initial interview with the people with ID, when asked *What is research for you?* we found that their knowledge of the characteristics and objectives of research was vague and superficial. Their idea of research was exclusively associated with the health sciences and the context of the laboratory, excluding other scientific fields and other forms of conducting science.

- *SA1: It's about verifying the health systems, the environment, science… Studying it.*
- *SA2: Well, to be honest, I don't really know… I don't think I've ever done it.*
- *SA3: For example, someone who researches a rare disease, or the coronavirus, studying something in a laboratory.*

All three self-advocates complained that people with ID were not included in research, despite the importance of knowing their point of view firsthand. Their *level of knowledge about the CRPD* varied: One person did not know about it, another had some generic knowledge, while the third referred to specific rights.

- *SA1: Talks about the rights of people with ID, that they must be protected and not suffer discrimination.*
- *SA3: Talks about the rights of people with disability, health, independent living, work, which is also a right, and the importance of respecting the rights of people with any disability.*

When asked *Do you think the rights of people with ID are respected?* the self-advocates stated that there had been some advances and society seemed to be more aware of the negative consequences of discrimination, but their rights were still violated. They believed that the right to participate in political life was respected, but there were more specific rights that they considered were not respected. The most frequently mentioned was the right to equality and nondiscrimination: They felt that their opinions were not taken into account, that they were infantilized, and that they were treated differently because of their ID. Regarding the right to education, they stated that they were not taken into consideration in school, and they denounced a lack of disability training in teachers. The participants also highlighted the noncompliance with the right to health, stating that they were not well informed in consultations, that they did not understand the discourse of professionals (right to accessibility), and that their data was not adequately protected, as it was provided to others without their consent (right to privacy). They also highlighted the right to independent living: They wanted to choose how, with whom, and where they lived, without anyone deciding for them. One person pointed out the difficulties they experienced when they wanted to go out and participate in cultural life.

- *SA1: Before, no [they were not respected], but now yes [they are respected]. Before, people with disability were not respected at all, they were laughed at, insulted, in school they were not taken into account, and teachers did not know how to treat them. The treatment... People in general don't know how to treat people with disability, for example, in doctors' appointments, they don't explain things well, they use complicated words, and if you go with someone without a disability, they talk to them instead of you.*
- *SA2: It depends, sometimes yes and sometimes no. Because people, for example, treat you like a child, and don't let you do anything. And they don't take into account what you think or what you like... They don't treat me like a normal and adult person, for example, with money, they don't trust me to spend it.*
- *SA3: They don't take into account the opinions of people with disability. Things are being achieved, such as the right to vote, but there is still a lot to do, for example, the equal rights of people with disability and those without disability.*

In relation to their *expectations* regarding their participation in this research, they expressed great satisfaction in knowing that they were going to collaborate with the university and contribute to an important task. They emphasized that their opinion would be taken into account, that they would learn new things, and that they would help others learn about their rights. They did not express any negative expectations about their participation but anticipated a good and respectful relationship with each other. They highlighted collaborative work, having worked together on other occasions, and even having a friendship as strong points. All stated that their participation would have a positive impact for people with ID and society in general.

- *SA1: If I conduct research, the validation work will serve for all people with ID to understand it. So that others understand what we are validating. If we work together and contribute, I myself investigate what people with ID do not understand. We help each other so that we can all understand.*
- *SA2: By participating in this validation, I will not only learn, but we will do something good for the world, so that everyone can better understand things. Because it will be better explained, more clearly, simply and easily. And it is very important that we can understand things, because if we don't understand, we miss out on doing things, or if we don't understand well, we can make mistakes and mess up…*
- *SA3: Because thanks to the work we do, we can help other people, we have the opportunity to work on behalf of the rest of the people with ID.*

3.1.2. Evidence From the Final Interview

After participating in the validation process, our participants with ID gained a more precise idea of what research is. They still highlighted that research serves to learn about a topic, but now included the idea of research as a process that requires reading, informing oneself, and working. They no longer saw research only in the context of a laboratory, but ideas related to fieldwork and data collection techniques also emerged. They maintained their complaint that people with ID are not included in research, and one participant expressed gratitude for the opportunity to participate in this study. The professional reaffirmed the convenience and necessity of having people with ID participate in research, especially when it comes to topics that directly affect them.

- *SA1: It's when you investigate something to learn more and gain knowledge. When you don't know something about a topic and study it. It's what scientists do in laboratories, or when you're asked questions in surveys or interviews.*
- *SA2: It's studying about a topic, like the Convention on the Rights of Persons with Disabilities, which is what we did. We read about it, discussed what we thought… our monitor explained things to us… We studied it and learned new things.*
- *SA3: It's studying and working on something, searching for information about a topic.*

Further, their knowledge about the CRPD became more complete. As well as indicating that its mission was to protect the rights of persons with *disability*, they added that it was an international agreement and listed some of its principles: equal opportunities, nondiscrimination, and the freedom to make decisions.

- *SA1: It is an agreement made between many countries to recognize the rights of people with disability to participate in society on equal terms as others, without discrimination.*

- *SA2: It serves to protect the rights of people with disability, like me. It recognizes the rights of people with disability and ensures that there is no discrimination, and that we all have equal opportunities.*
- *SA3: It aims to recognize the rights of people with disability on equal terms with people without disability. Because people with disability also have the right to make their own decisions, have a partner, children...*
- *PR: It recognizes the rights of people with disability and establishes that States must guarantee them. It talks about inclusive education, independent living, social participation... It defends equal opportunities, nondiscrimination, social inclusion...*

The self-advocates upheld their position about the violation of their rights in some instances, although they now showed greater knowledge about specific rights: They mentioned rights that did not appear in the initial interview, provided more complete explanations, and gave more personal examples. They maintained that one of the most respected rights was the right to participate in political life, adding that the right to education and health was respected (despite indicating limitations in these areas in the initial interview). They reiterated that their right to live independently was violated (explaining that families made it difficult to fulfill this right) and that they experienced discrimination (complaining of being treated differently and not having the same opportunities to participate in society). They added the violation of their right to family (complaining that families often made it difficult for them to have partners and children) and to work (stating that they should work alongside people without disability and earn the same as them). Similarly, the professional recognized that progress had been made in terms of rights, but that there was still much work to be done, especially in education and social awareness. Among the rights she considered most violated were access to information, leisure, culture, justice, and the labor market.

- *SA1: In most cases, yes [they are respected]. But in others, there is still a lot to do. Because what politicians say is one thing and what actually happens is another thing... But supposedly, after the Convention, things should improve because it was made for that, countries committed to respecting and not excluding people with disability and recognizing their rights. The right to live alone, independently [is respected]. But not all people can choose who they want to live with, sometimes their families don't let them become independent because they think they can't live alone. But if they wanted to, they could. The right to education [is respected]. Children with disability can study in schools with others who don't have disabilities. And now there are many aids to help them study. I had to stop studying because the teachers ignored me and I didn't understand anything. But now they have teachers to help children with disability. The right to work [is respected]. You can't be discriminated against for having a disability, nor can you be paid less. People with disability can work just like everyone else. I can't work now, but when I worked, I worked with people who didn't have disabilities.*

It depends on the type of job. Not everyone is suited for every job. The right to choose who to vote for is now recognized. People with disability have the right to vote in elections recognized.

- *SA2: We are increasingly taken into account, but there is still a lot of work to be done. And with families, because they overprotect us and do not allow us to make our own decisions. Although I was helped a lot and they did take me into account. The right to education, yes [it is respected]. The right to live independently, in my case yes [it is respected]. I was very lucky with my family. But I know many cases of classmates who don't, they don't respect that right, they don't let them have a boyfriend or girlfriend, or live with them, or in a flat on their own... The right to work... it's very difficult to find work when you have a disability. It happens to me, that I am epileptic and I cannot work. The right to health, yes [it is respected]. The right to have a family, no [it is not respected], in most cases, no. Although I have friends who became mothers. But it's not the norm. The right to participate on equal terms, no [it is not respected]. People with disability are not taken into account.*
- *SA3: There is still a lot of discrimination. Just because you have a disability doesn't mean you can't have a partner or children. And often it's the parents themselves who don't allow it. The right to independent living, in some cases, to work, to health is respected... There is still a lot of discrimination, people with disability are still seen as different.*

The participants' expectations of a positive experience, as expressed in the initial interview, were confirmed in the final interview. Additionally, their expectations of acquiring knowledge about the CRPD were met. They did not mention any negative aspects, although they reported some comprehension difficulties that they were able to resolve with the support of the professional. All three participants highlighted that mutual help, their experience of working together, and their friendship facilitated the process. They expressed pleasure at having collaborated in this research and emphasized that they could help other people. In particular, they highlighted the positive social impact that their participation in this research would have, by facilitating cognitive accessibility and respecting the rights of people with ID.

- *SA1: I really enjoyed it; I love participating in projects. I also love validating easy-to-read materials, changing words I don't understand, and looking them up in the dictionary... We're a group that normally works together, we've known each other for a long time and we're friends as well as colleagues, so it was easy to work together.*
- *SA2: Well, it will help a lot of people with disability because when things are made easier, they are easier for everyone to understand. Otherwise, we miss out on a lot of things because we don't understand them.*
- *PR: Everyone was very motivated, enthusiastic, and interested in the work, actively participating. I hope this work will be positive for all people with ID, as access to reading and information is a right and a social need.*

3.2. *Reliability*

Table 3 presents the Cronbach's alpha for each of the eight quality of life domains, which comprise the items aligned to the different Articles of the CRPD. Overall, the internal consistency of the total scale was excellent in the three groups of participants (i. e., people with ID, family members, and professionals), although it was slightly higher in the scale completed by professionals. Regarding the internal consistency of the individual quality of life domains, the highest coefficients were observed in self-determination, and the lowest —albeit adequate— coefficients were observed in interpersonal relationships and material well-being.

TABLE 3. Internal consistency (Cronbach's alpha) for the domains and the total scale

	PD	SD	IR	SI	RI	EW	PW	MW	Total	*N* people
People with ID	,822	,870	,788	,831	,794	,832	,828	,732	,948	515
Professionals	,839	,912	,699	,869	,825	,866	,823	,674	,958	594
Relatives	,829	,918	,745	,865	,810	,866	,795	,614	,950	91
N items	17	25	16	23	21	18	14	19	153	

Note. PD = Personal Development; SD = Self-Determination; IR = Interpersonal Relationships; SI = Social Inclusion; RI = Rights; EW = Emotional Well-Being; PW = Physical Well-Being; MW = Material Well-Being.

4. Discussion

The CRPD is facilitating the gradual evolution from highly institutionalized services to much more flexible, individualized, and community-based services in many countries (Bueschi *et al*., 2022). Additionally, the mandatory compliance reports produced by States Parties have become important sources of information about the lives of people with disability. These reports often highlight the significant barriers that people with disability —and people with ID in particular— encounter in their full participation in society (Chalachanová *et al*., 2021). The reports are therefore considered of great relevance and are used by academics, researchers, organizations, professionals, governments, legislators, and citizens. However, the way in which most of them are developed and presented is further proof of the deficient representation of people with ID, who are often left out: They rarely have a voice in the development of the reports, and the content of the documents is often cognitively inaccessible to them (Petri, 2022). Likewise, when research is conducted on their rights, it is unusual for people with ID to be included as co-researchers. On the rare occasions when they are involved, their role is often limited to being questioned, but their responses are almost always interpreted without them. In short, inclusive research for people with ID in the field of human rights is strikingly scarce and exceptional (Strnadová and Walmsley, 2018).

The scientific literature has identified a number of barriers to carrying out inclusive research on human rights with people with ID. The main ones are the lack of relationships between academic institutions and self-advocates with ID, as well as a lack of funding to cover their participation, both of which can lead to a rejection of collaboration opportunities (Petri, 2021). Therefore, the first conclusion of this study highlights the need to include people with ID as co-researchers, with an active role in all phases of the research process. To achieve this, collaboration payments should be included in research budgets, although this is challenging in the current climate, especially in Spain, as research grant calls rarely allow for the inclusion of funding for the research team, and the funding granted for research projects is usually much less than what was requested.

The small number of participants with ID in the qualitative study could be considered as one of the main limitations of this research, as it would be desirable for the sample to be much larger and more representative. Despite this limitation, our study represents a first approach to inclusive research on human rights in Spain. With the participation of three self-advocates with ID, who were compensated for their work in validating the easy-to-read version (not as researchers), we have sought to highlight their views on the need to investigate and monitor compliance with the CRPD, giving their opinions fundamental weight. The ID participants in this study defended their right to equality and nondiscrimination, indicating that their views were rarely heard, and they appreciated that this research considered and valued their opinion. Likewise, their participation demonstrated that the #Rights4MeToo Scale, adapted for easy reading, enables people with ID to assume an active role in understanding and defending their own rights. In fact, the participants highlighted the importance of validating the scale in easy-to-read format to ensure that no one misses out on opportunities due to cognitive accessibility barriers (a right recently recognized in Spain with Law 6/2022, of March 31, which regulates cognitive accessibility and establishes its requirements and application conditions). Additionally, the participants were aware that, as the ultimate experts in their lives, they are not merely part of the change but have an essential role in it. Through their active involvement, the people with ID improved their knowledge about the research process and the rights contained in the CRPD, in such a way that their participation in this study contributes to their empowerment to claim their rights in the first person.

Our study underlines the importance of including people with ID in research, providing them with an active role and the necessary support to contribute to all phases of an investigation focused on issues that concern them. Our study also stresses the need to teach not only the person with ID but also society and support providers that people with ID have the same rights as any citizen. In this respect, the pilot version of the #Rights4MeToo Scale is the first step toward providing society with a tool that facilitates (a) learning about rights; (b) compliance monitoring the CRPD; (c) the detection and reporting of unjust, abusive, or discriminatory situations; and (d) guidance on the protection and defense of rights for organizations and public policies. Analyses of the internal consistency of the scale's pilot version have been highly satisfactory, which bodes well for the next steps. With further refinement of the items in the validation process, less reliable and less valid items will be eliminated from the scale, so the coefficients will likely improve in the final version of the instrument.

Sufficient evidence of the instrument's content and face validity has already been provided. The main limitations of the quantitative study should however be noted. These include the characteristics of the sample, which although very large was still a convenience sample. It was also a largely homogeneous sample, as it was accessed through service provider organizations, meaning that persons with ID who were not users of their services are not represented. Mention should also be made of the difficulties associated with the recruitment of participants with ID who are minors, who have descendants, or who are in employment. For this reason, the field-test continues at present.

We believe that the #Rights4MeToo Scale will be an important milestone in the field of ID, serving as a basis for relevant national studies, and with its adaptation to the legal and cultural context of other countries, it will enable international comparative studies, which are essential to help identify variables that facilitate or hinder full citizenship for persons with ID (Houseworth *et al.*, 2019). In future studies, with the final validation sample, we will refine the tool and continue to provide evidence of its reliability and validity based on its internal structure and relationship with other variables, making the scale available free of charge to interested parties on the INICO website (https://inico.usal.es/instrumentos-de-evaluacion/).

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