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SPECIAL ISSUE ARTICLE



Using the quality of life framework to operationalize and assess the CRPD articles and the Sustainable Development Goals

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Abstract

This article describes how rights, the United Nations Sustainable Development Goals (SDGs), and the quality of life (QOL) framework are closely interrelated. Although legislation can be used as a tool for the practical application of QOL principles, QOL assessment information is required to further develop legislation and monitor the fulfillment of laws, policies, and the SDGs. A validated QOL model, which provides a set of concepts that can be one useful way for understanding and assessing QOL, can also function to assess many of the rights and goals promulgated in the Convention on the Rights of Persons with Disabilities (CRPD) and in the SDGs. This article illustrates the overlap between the CRPD, SDGs and QOL using the *#Rights4MeToo Scale*, a new measurement instrument for people with intellectual and developmental disabilities (IDD). The

Abbreviations: CRPD, Convention on the Rights of Persons with Disabilities; IDD, intellectual and developmental disabilities; QOL, quality of life; SDGs, Sustainable Development Goals.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2023 The Authors. *Journal of Policy and Practice in Intellectual Disabilities* published by International Association for the Scientific Study of Intellectual and Developmental Disabilities and Wiley Periodicals LLC. instrument's value lies in its potential to: (a) raise awareness about the rights enshrined in the CRPD; (b) design, implement, and evaluate the effectiveness of interventions aimed at facilitating the exercise of those rights and the achievement of the SDGs; and (c) ultimately improve the QOL of people with IDD.

KEYWORDS

Convention on the Rights of Persons with Disabilities, developmental disabilities, intellectual disability, quality of life, sustainable development goals

"As we embark on this great collective journey, we pledge that no one will be left behind. Recognizing that the dignity of the human person is fundamental, we wish to see the goals and targets met for all nations and peoples and for all segments of society. And we will endeavor to reach the furthest behind first."

United Nations (2015, p. 35).

These words show the current commitment of society in general—and the *Sustainable Development Goals* (SDGs; United Nations, 2015) in particular—to ensure that all people, including those with intellectual and developmental disabilities (IDD) living in vulnerable situations or in the world's least developed countries, have rights and responsibilities to fulfill their potential in dignity and equality in healthy environments (Büschi et al., 2022; Didi et al., 2018; Murphy & Bantry-White, 2021; Simpson & Chan, 2021). To realize these goals for people with IDD, efforts need to be stepped up in line with the *Convention on the Rights of Persons with Disabilities* (CRPD; United Nations, 2006) and the SDGs (United Nations, 2015).

Translating the rights of people with IDD into concrete measures, practices, and policies begins with understanding and operationalizing the Articles of the CRPD and the SDGs. The CRPD is society's great international milestone on disability and is unarguably the most widely recognized international treaty that has been produced in relation to this population. The 17 SDGs define the actions that all countries would be required to take to improve health and education, reduce inequality, and speed economic growth so that "no one will be left behind" (United Nations, 2015).

As discussed in this article, there is a close relationship between the SDGs, the CRPD Articles, and the QOL paradigm, since all three undertake to prevent anyone from being relegated to a non-citizenship status, and to enhance human rights and the inclusion of people with IDD into the mainstream of life. They also emphasize valued outcomes such as equality; health and well-being; independent living; sexual and reproductive health and rights; inclusive education; gender equality and empowerment of women and girls; material wellbeing; employment and decent work; access to information and justice systems; inclusive societies and institutions; supported decision-making; and protection from all forms of exploitation, violence, and abuse.

OPERATIONALIZING THE CRPD AND SDGS USING QOL

Well before the introduction of the CRPD and the SDGs, the construct of QOL had been conceptualized in ways that overlap considerably with many of the values set out in CRPD and SDGs. It had also already been operationalized and applied in a variety of ways and using a variety of models to pursue, defend, and evaluate the aforementioned values and outcomes. A major strength of the operationalization of QOL is its focus on context, the measurement of personal and valued outcomes, and the power to reflect the perspective of people with IDD and what is truly important to them. QOL operational models have a crucial role to play in enhancing stated values in IDD (as set out by the CPRD, the SDGs, and QOL conceptual principles) since they translate abstract social and political values and goals into evidence-based practices (Gómez, 2022).

Using a QOL framework to operationalize and assess the Articles of the CRPD was initially proposed by Verdugo et al. (2012), who argued that the specific rights listed in the CRPD could be aligned with QOL domains recognized in QOL models, thereby operationalizing the CRPD by providing objective and measurable domain-referenced indicators of personal outcomes. This line of work has continued since then, as reflected in Gómez et al. (2020), Lombardi et al. (2019), and Schalock et al. (2018).

In Spain, an initiative that emerged in line with this progression of work resulted in the most advanced operationalized alignment of the CRPD Articles and QOL (Gómez et al., 2022). Here, 21 CRPD-specific rights are aligned with the 17 SDGs, and both are operationalized through 41 QOL indicators, using the eight domains of one
 TABLE 1
 Overlap among QOL domains, CRPD Articles, and CRPD-related SDGs.

| QOL domains | CRPD Articles | QOL indicators | SDGs |
|--------------------------------|--|--|--|
| Personal development | 24 (education) | Educational setting Involvement in an educational program Lifelong learning Personal skills Supports for personal growth and development | 4. Quality education |
| Self-determination | 14 (liberty and security of person)21 (freedom of expression and opinion) | Freedom of movement Freedom of choice Personal autonomy Personal control Realizing personal goals Access to information Level of understanding the information | 17. Partnerships for the goals |
| | | Using information | |
| Interpersonal relationships | 23 (respect for home and the family) | Opportunities to express opinion Right to set up their own family Right to be a parent Dating people of own choice | Good health and wellbeing Gender equality |
| Social inclusion | 8 (awareness-raising) 9 (accessibility) | Acts of awareness to increase social inclusion Accessibility in streets, transportation, and community buildings | 9. Industry, innovation and infrastructure11. Sustainable cities and communities13. Climate action |
| | 19 (living independently and being included in the community) | • Living in a home with minimum intrusion from others | |
| | 20 (personal mobility) | Ways to be mobileOpportunity to travel | |
| | 29 (participation in political and public life) | Voting Participation in groups, boards/ committees, and public office | |
| | 30 (participation in cultural life) | Participation in cultural events (e.g., concerts, theaters, movies, museums), and in recreational or leisure events (e.g., hobbies, sports) | |
| Rights | 5 (equality and non-discrimination) | Non-discrimination | Reduced inequalities Peace, justice and strong institutions |
| | 10 (right to life) | Making choices about end-of-life decisions | |
| | 12 (equal recognition as persons before the law) | Legal competence (supported decision-making) | |
| | 13 (access to justice) | Accommodations in the defense of rights, the judicial and penitentiary system | |
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| QOL domains | CRPD Articles | QOL indicators | SDGs |
|------------------------|---|--|--|
| | 15 (freedom from torture or cruel, inhuman or degrading treatment or punishment) | Personal injuries caused by others | |
| | 22 (respect for privacy) | Control over personal areas | |
| | | Confidentiality of information | |
| Emotional wellbeing | 16 (freedom from exploitation, violence and abuse) | • Living in a safe environment (i.e., not being abused by others) | 3. Good health and wellbeing |
| | 17 (protecting the integrity of the person) | • Experiencing respect and dignity | |
| Physical wellbeing | 26 (habilitation and rehabilitation) | Medical and emotional interventions if neededAppropriate therapies | Good health and wellbeing Clean water and sanitation Life below water Life on land |
| Material wellbeing | 27 (work and employment)28 (adequate standard of living and social protection) | Paid employment Job training programs Annual income covers basic expenses and allows for discretionary spending Adequate housing Public assistance | Non poverty Zero hunger Affordable and clean energy Decent work and economic growth Industry, Innovation and Infrastructure. Responsible consumption and production |
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Abbreviations: CRPD, Convention on the Rights of Persons with Disabilities; QOL, quality of life; SDGs, Sustainable Development Goals.

OOL model described by Schalock and Verdugo (2002). A further five transversal CRPD Articles (Article 6: women with disabilities: Article 7: children with disabilities: Article 11: situations of risk and humanitarian emergencies; Article 18: liberty of movement and nationality; and Article 25: health) are operationalized through sociodemographic data (i.e., gender, age, country of birth, and health conditions) given that they reflect conditions that can have a crosscutting influence on all the other rights and cannot be manipulated or changed from the microsystem or mesosystem levels. Table 1 shows the considerable overlap between the eight QOL domains selected, the 26 CRPD Articles, and the 17 SDGs, highlighting how both the CRPD Articles and the SDGs are operationalized through objective and measurable QOL indicators. These indicators have been designed to assess both the overlap and the unique aspects inherent in the QOL domains, CRPD Articles, and SDGs.

THE #RIGHTS4METOO SCALE

Implementing the CRPD and achieving the SDGs for people with IDD is a clear and critical priority pursued at the international level. To this end, QOL-based measurement instruments with adequate evidence of reliability and validity are needed. *The* #Rights4MeToo Scale ("#YoTambién Tengo Derechos"; Gómez et al., 2023) is such an instrument. This validated and standardized instrument operationalizes the CRPD Articles and SDGs through the assessment of QOL-related personal outcomes (Gómez et al., 2021a, 2021b; Morales et al., 2021; Morán et al., 2023; Verdugo et al., 2021) and contextual factorsnamely, the 41 QOL indicators listed in Table 1. The purpose of the instrument is to: (a) give a voice to people with IDD regarding their personal values, their lived experience, and everyday situations in their daily lives; (b) 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) serve as a guide for organizations to identify the strengths and greatest needs of this population in relation to rights and, therefore, in QOL.

CONTRIBUTIONS TO THE QOL FRAMEWORK

This article contributes to the QOL framework by:

• Highlighting the considerable overlap between the QOL paradigm, the CRPD, and the SDGs—three major international initiatives with a shared philosophy.

- Highlighting the importance of operationalizing values and principles, and exploring how QOL operational models can serve to this purpose.
- Proposing a set of indicators that capture much of what is intended in all three initiatives and using measured outcomes to assess QOL, specific human rights in the CRPD, and many aspects of the SDGs.
- Providing a strong rationale for how we develop policy, provide services, and regard people with disability, ultimately improving the QOL of people with disability.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

ETHICS STATEMENT

This research was authorized and supported by the Consejería de Derechos Sociales y Bienestar of Principado de Asturias, as well as the Research Ethics Committee of the Universidad de Oviedo (17_RRI_2021). All participants provided their informed consent.

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REFERENCES

- Büschi, E., Antener, G., & Parpan-Blaser, A. (2022). Intellectual disability in Switzerland: The UN convention on the rights of persons with disabilities, as a vehicle for progress. *Tizard Learning Disability Review*, 27(1), 31–39. https://doi.org/10.1108/TLDR-07-2021-0019
- Didi, A., Dowse, L., & Smith, L. (2018). Intellectual disability and complex support needs: Human rights perspective for policy and practice. *The International Journal of Human Rights*, 22(8), 989–1006. https://doi.org/10.1080/13642987.2018.1485653

- Gómez, L. E. (2022). Quality of life in people with intellectual and developmental disabilities. *Developmental Medicine & Child Neurology*, 64(9), 1056–1057. [Commentary on Jacoby et al. (2022). Modelling quality of life in children with intellectual disability using regression trees. *Developmental Medicine & Child Neurology*, 64(9), 1145–1155. https://doi.org/10.1111/dmcn.15209
- Gómez, L. E., Monsalve, A., Morán, L., Alcedo, M. A., Lombardi, M., & Schalock, R. L. (2020). Measurable indicators of CRPD for people with intellectual and developmental disabilities within the framework of quality of life. *International Journal of Environmental Research and Public Health*, 17, 5123. https://doi.org/10.3390/ijerph17145123
- Gómez, L. E., Morán, L., Al-Halabí, S., Swerts, C., Verdugo, M. A., & Schalock, R. L. (2022). Quality of life and the international convention on the rights of persons with disabilities: Consensus indicators for assessment. *Psicothema*, 34(2), 182–191. https://doi.org/10.7334/psicothema2021.574
- Gómez, L. E., Morán, M. L., Navas, P., Vicente, E., Guillén, V. M., Monsalve, A., Alcedo, M. A., Al-Halabí, S., Balboni, G., Lombardi, M., Swerts, C., Schalock, R. L., & Verdugo, M. A. (2023). Escala #YoTambién Tengo derechos [#Rights4MeToo scale]. INICO.
- Gómez, L. E., Schalock, R. L., & Verdugo, M. A. (2021a). A new paradigm in the field of intellectual and developmental disabilities: Characteristics and evaluation. *Psicothema*, 33(1), 28–35. https://doi.org/10.7334/psicothema2020.385
- Gómez, L. E., Schalock, R. L., & Verdugo, M. A. (2021b). A Quality of Life Supports Model: Six research-focused steps to evaluate the model and enhance research practices in the field of IDD. *Research in Developmental Disabilities*, 119, 104112. https://doi. org/10.1016/j.ridd.2021.104112
- Lombardi, M., Vandenbussche, H., Claes, C., Schalock, R. L., De Maeyer, J., & Vandevelde, S. (2019). The concept of quality of life as framework for implementing the UNCRPD. Journal of Policy and Practice in Intellectual Disabilities, 16, 180–190. https://doi.org/10.1111/jppi.12279
- Morales, L., Morán, L., & Gómez, L. E. (2021). Evaluación de resultados personales relacionados con derechos en jóvenes con discapacidad intelectual y TEA [Assessment of rights-related personal outcomes in young people with autism spectrum disorder and intellectual disability]. Siglo Cero, 52(3), 81–99. https://doi.org/10.14201/scero20215238199
- Morán, L., Gómez, L. E., Verdugo, M. A., & Schalock, R. L. (2023). The quality of life supports model as vehicle for implementing rights. *Behavioral Sciences*, 13(5), 365. https://doi.org/10.3390/ bs13050365
- Murphy, K., & Bantry-White, E. (2021). Behind closed doors: Human rights in residential care for people with an intellectual disability in Ireland. *Disability & Society*, 36(5), 750–771. https://doi.org/10.1080/09687599.2020.1768052
- Schalock, R. L., Baker, A., Claes, C., Gonzalez, J., Malatest, R., van Loon, J., Verdugo, M. A., & Wesley, G. (2018). The use of quality of life scores for monitoring and reporting, quality improvement, and research. *Journal of Policy and Practice in Intellectual Disabilities*, 15, 176–182. https://doi.org/10.1111/jppi.12250
- Schalock, R. L., & Verdugo, M. A. (2002). Handbook on quality of life for human service practitioners. American Association on Mental Retardation.

- Simpson, J., & Chan, H. S. (2021). From rights to results: Systemic advocacy and leadership by people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 8(1), 87–98. https://doi.org/10.1080/23297018.2021.1878927
- United Nations. (2006). Convention on the Rights of Persons with Disabilities (CRPD). https://www.un.org/development/desa/disabilities/ convention-on-the-rights-of-persons-with-disabilities.html
- United Nations. (2015). Transforming our world: the 2030 Agenda for Sustainable Development. https://www.unfpa.org/sites/ default/files/resource-pdf/Resolution_A_RES_70_1_EN.pdf
- Verdugo, M. A., Navas, P., Gómez, L. E., & Schalock, R. L. (2012). The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, 56(2), 1036–1045. https://doi.org/10. 1111/j.1365-2788.2012.01585.x
- Verdugo, M. A., Schalock, R. L., & Gomez, L. E. (2021). The quality of life supports model: Twenty-five years of parallel paths have

come together. Siglo Cero, 53(3), 9–28. https://doi.org/10.14201/ scero2021523928

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