



ELSEVIER

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

A quality of life supports model: Six research-focused steps to evaluate the model and enhance research practices in the field of IDD

Laura E. Gómez^{a,*}, Robert L. Schalock^b, Miguel Ángel Verdugo^c

^a Departamento de Psicología. Universidad de Oviedo, Spain

^b Hastings College, United States

^c INICO, Universidad de Salamanca, Spain

ARTICLE INFO

No. of reviews completed is 2

Keywords:

Quality of life
Supports
Quality of life supports model
Developmental disabilities
Intellectual disability
Research
Methodology

ABSTRACT

In the field of intellectual and developmental disabilities (IDD) the constructs of quality of life and supports have been combined into a Quality of Life Supports Model (QOLSM) that is currently used internationally for supports provision, organization transformation, and systems change. With the model's increasing and widespread use in research and practice, there is a need to evaluate the model's impact at the individual, organization, and systems levels. The purpose of this article is to outline six specific research-focused evaluation steps that allow researchers to evaluate the model and thereby enhance research practices in the field of IDD. These steps involve: (1) operationalizing components of the QOLSM; (2) relating QOLSM components to the type of research planned and intended outcome indicators; (3) gathering evidence and establishing its credibility; (4) interpreting and communicating the results; (5) implementing research outcomes at the level of the microsystem, mesosystem and macrosystem; and (6) judging the impact of the model. These steps delineate a research framework that is based on a systematic approach to evidence-based practices and enhanced research practices in the field of IDD.

What this paper adds?

This article describes the components of a value-based conceptual model that integrates the construct of quality of life and the supports paradigm. This model is used internationally as a new approach and framework to guide the development and implementation of individualized supports and services to persons with IDD, and to evaluate the impact of these supports and services on an individual's personal well-being/quality of life. The six steps summarized in the article articulate specific activities required to evaluate the model and its application, and thereby enhance research practices in the field of IDD.

1. Introduction

The constructs of quality of life and individualized supports are currently providing a value-based best practices framework for planning, providing and evaluating individualized supports and services for people with intellectual and developmental disabilities (IDD). Within this framework: (a) the assessment of personal outcomes related to quality of life (QOL) are essential for developing

* Corresponding author at: Faculty of Psychology, University of Oviedo, Plaza Feijoo, s/n., 33003, Oviedo, Spain.

E-mail address: gomezlaura@uniovi.es (L.E. Gómez).

<https://doi.org/10.1016/j.ridd.2021.104112>

Received 30 July 2021; Received in revised form 3 October 2021; Accepted 8 October 2021

Available online 14 October 2021

0891-4222/© 2021 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license

(<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

evidence-based interventions and practices that enhance the personal well-being and quality of life of people with IDD (Gómez, Verdugo, Arias, Navas, & Schalock, 2013; Gómez, Arias, Verdugo, & Navas, 2012; Gómez, Peña, Arias, & Verdugo, 2016; Schalock, Verdugo, & Gómez, 2011; Schalock, Gómez, Verdugo, & Claes, 2017), and (b) the assessment of the pattern and intensity of support needs and planning individualized supports based on the assessment are essential for implementing individualized support strategies that enhance an individual's personal well-being/quality of life (Schalock, Luckasson, & Tassé, 2021). That is, the QOL construct serves as a guide to obtain valuable information about what is important in the person's life ('what' and 'how much'), while the supports paradigm is a powerful tool to achieve valued outcomes ('how').

Recently, the quality of life construct and the supports paradigm have been merged into a Quality of Life Supports Model (QOLSM; Gómez, Schalock, & Verdugo, 2021; Verdugo, Schalock, & Gomez, 2021). The QOLSM, which will be described in the following section, is composed of four key components: core values, QOL domains, systems of support, and facilitating conditions. The QOLSM is an emergent and helpful framework for policy development, supports provision, organization transformation, systems change, and outcome evaluation. Additionally, the model integrates significant characteristics of the current transformation in the field of IDD. These characteristics encompass a holistic and integrated approach to IDD, a focus on the human and legal rights of people with a disability, the eligibility for services and supports based on significant limitations in major life activity areas, an emphasis on individualized supports provided within inclusive community-based environments, and the evaluation of valued personal outcomes (Schalock & Luckasson, 2021, this volume; Schalock et al., 2021b; Schalock, Luckasson, & Tassé, 2021, in press).

With its increasing use in supports provision, organization transformation, and systems change (Verdugo et al., 2021), there is a need to evaluate the model's impact at the individual, organization, and systems levels. The purpose of this article is to outline six specific research-focused steps that address this evaluation need. These steps will help to delineate a systematic approach to—and framework for—enhancing research practices in the field of IDD. In subsequent sections of the article, each of the sequential steps depicted in Fig. 1 is described.

2. Research-focused evaluation steps

2.1. STEP 1: operationalize components of the QOLSM

Operationalizing the components of the QOLSM facilitates the description and visualization of the model, including its critical elements, and how those elements can be used to apply the model (Gómez, Schalock, & Verdugo, 2020a). As shown in Fig. 2, the four key components of the QOLSM are core values, individual and family quality of life domains, systems of support, and facilitating conditions.

2.1.1. Core values

Core values stem from the beliefs and assumptions that people have about individuals with IDD and their individual worth and potential. These core values guide policies and practices regarding people with IDD and their roles in society. The core values incorporated into the QOLSM are: (a) the new disability rights paradigm created by the Convention on the Rights of Persons with

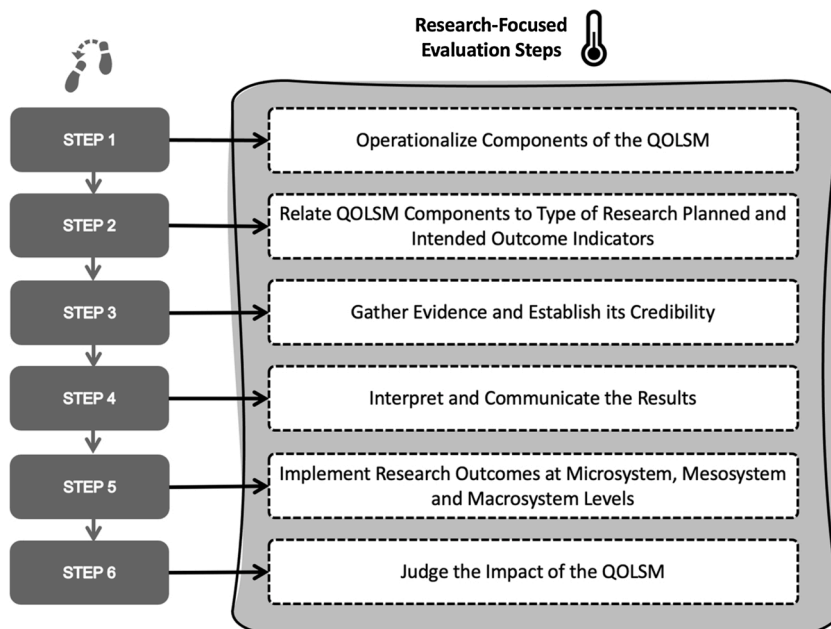


Fig. 1. Six Research-Focused Evaluation Steps to evaluate the QOLSM.

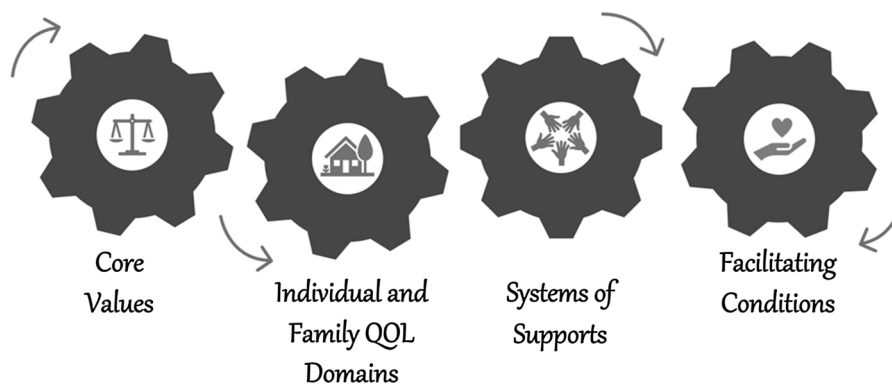


Fig. 2. The Quality of Life Supports Model (QOLSM).

Disabilities (CRPD; United Nations, 2006) that emphasize legal, economic, social, and cultural rights (Claes, Vandenbussche, & Lombardi, 2016; Esteban, Navas, Verdugo, & Arias, 2021; Gómez et al., 2020b; Gómez, Morán, Alcedo, Arias, & Verdugo, 2020c; Harpur, 2012; Mittler, 2015; Morales, Morán, & Gómez, 2021; United Nations, 2006; Verdugo, Navas, Gómez, & Schalock, 2012); (b) the capacity and potential of individuals to grow and develop (Nussbaum, 2011; Wehmeyer, 2013); (c) the emphasis on self-determination, inclusion, and equity for individuals with disabilities and their families (Vicente, Verdugo, Guillén, Martínez, & Gómez, 2020; Morán, Gómez, & Alcedo, 2019; Vicente, Guillén, Gómez, Ibáñez, & Sánchez, 2019; Wehmeyer, 2020); and (d) the commitment to address a person's support needs and foster opportunities to enhance individual functioning and personal well-being (Buntinx, Tu Tan, & Aldenkamp, 2018; Schalock et al., 2021b; Thompson et al., 2015, 2016).

2.1.2. Individual and family QOL domains

Early work regarding the construct of QOL led to the development and publication of a consensus document regarding principles underlying its conceptualization, measurement, and application (Schalock et al., 2002). Based on this early work and these principles, a number of QOL conceptual models have been developed that focus on either individual-referenced or family-referenced QOL (Brown et al., 2006; Giné et al., 2013; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Zuna, Summers, Turnbull, Hu, & Xu, 2010). QOL domains encompassing commonly referenced QOL models are quite similar, as discussed by Francisco-Mora, Ibáñez, and Balcells-Balcells (2020), Gómez, Verdugo, and Arias (2010), and Gómez, Verdugo, Arias, and Arias (2011).

In the field of IDD, commonly used individual QOL models are those proposed by Cummins (2005); Felce (1997), and Schalock and Verdugo (2002). The latter model proposes eight domains that include the interrelated dimensions of personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, and material well-being. This model has solid evidence about its validity and use not only in the field of IDD (Arias et al., 2018; Gómez, Arias, Verdugo, Tassé, & Brown, 2015; Gómez et al., 2011, 2016, 2020c, 2020d; Gómez, Verdugo, Arias et al., 2015; Jenaro et al., 2005; Schalock et al., 2005; Schalock, Gomez, Verdugo, & Reinders, 2016; Verdugo, Gómez, Arias, Navas, & Schalock, 2014), but also in other groups at risk of social disadvantage (Aza, Verdugo, Orgaz, Fernández, & Amor, 2020; Fernández, Verdugo, Gómez, Aguayo, & Arias, 2018, 2019; Gómez et al., 2012, 2016; Swerts, Gómez, de Maeyer, Goedele, & Vandersplasschen, 2021; Verdugo, Arias, Gómez, & Schalock, 2010).

This eight-dimensional QOL conceptual model also operationalizes one of the core values of the QOLSM: the new disability rights paradigm established within the CRPD (Verdugo et al., 2012). Its operationalization has been supported by: (a) a Delphi study (Lombardi et al., 2019) in which 153 international experts agreed on the relationship between the CRPD Articles, the eight QOL domains and numerous QOL indicators; (b) a systematic review of the scientific literature (Gómez et al., 2020b) in which indicators and personal outcomes related to the eight domains of QOL and the Articles of the CRPD were identified; and (c) a consultation with 32 expert judges (Gómez et al., 2021b) on an extensive pool of items that can be used to evaluate the indicators and personal outcomes related to the Articles of the CRPD organized around the eight domains of QOL.

2.1.3. Systems of supports

Systems of supports provide the framework for improving individual or family functioning and well-being. According to Schalock et al. (2021b), systems of supports are a broad range of resources and strategies that prevent or mitigate a disability or its effects; promote the development, education, interests, and welfare of individuals with IDD or their families; and enhance individual or family functioning and well-being. Table 1 presents a commonly used grouping of the elements of a system of supports (Schalock et al., 2021b).

Application of the supports paradigm results in one's ability to assess the pattern and intensity of support needs and using this information for subgroup classification, aligning support needs to support strategies, and identifying and operationalizing systems of support elements (see Table 1). A description of the standardized assessment of support needs can be found in the work of Aguayo, Verdugo, Arias, Guillen, and Amor (2019); Amor, Verdugo, Arias, Fernández, and Aza (2021); Chou, Lee, Chang, and Yu (2013); Claes,

Table 1
Systems of Supports Elements.

Systems of Supports Element	Examples
Choice and personal autonomy	Having opportunities to make choices and exercise self-determination, being recognized as a person before the law, and enjoying legal capacity on an equal basis with those without a disability. Choice and personal autonomy are facilitated through decision making supports
Inclusive environments	Educational, living, and work environments that provide accesses to resources, information, and relationships, encourage growth and development, support people, and accommodate the psychological needs of autonomy, competence, and relatedness
Generic supports	Supports that are widely available to the general population, including natural supports, technology, prosthetics, life-long learning opportunities, reasonable accommodation, dignity and respect, and personal strengths/assets
Specialized supports	Supports that are professionally-based interventions, strategies, and therapies

Van Hove, Vandeveld, van Loon, and Schalock (2009); Dizdarevic et al. (2020); Kuppens et al. (2010); Lamoureux-Hébert and Morin (2009); Stancliffe, Arnold, and Riches (2016); Thompson et al. (2015, 2016), and Verdugo, Aguayo, Arias, and García-Domínguez (2020), among others.

2.1.4. Facilitating conditions

Facilitating conditions are contextual factors that influence the successful application of the QOLSM. The identification of these conditions allows the identification and subsequent evaluation of relevant valued outcomes for people with IDD. These contextual factors are influenced by—and interact with—properties of the micro, meso, and macrosystem (Onken, 2018; Qian, Larson, Ticha, Stancliffe, & y Pettingell, 2019; Shogren, Luckasson, & Schalock, 2020; Shogren, Luckasson, & Schalock, 2020). In reference to QOL, facilitating conditions include participating in the community, promoting a sense of belonging, maximizing capabilities and opportunities, freedom to engage in major life activities, safe and secure environments, and a commitment to the goals that are important to the person or family. In reference to supports provision, facilitating conditions include understanding the person's support needs, being committed to addressing the person's support needs and enhancing their personal goals, maximizing the availability and accessibility of supports, being knowledgeable about the elements of supports utilizing competent and knowledgeable support providers, ensuring the consistency and stability of supports provision, and coordinating and managing supports.

2.2. STEP 2: relate QOLSM components to type of research planned and intended outcome indicators

As discussed by Gullickson (2020) and Ozeki, Coryn, and Schroter (2019), an evaluation framework delineates the process and types of research involved in evaluating a conceptual model. According to Gómez et al. (2021a), four types of research can be used to test hypothesis related to evaluating the QOLSM: principle-focused (Patton, 2018), utilization-focused (Patton, 2008), outcome-focused (Gómez & Verdugo, 2016), and process-focused (Weiss, 1997). The selection of which type of evaluation one uses should be based on the goal of the research, the essential components of the QOLSM on which the research focuses, and the selected outcome indicators. Details regarding each of these types of research are summarized in Table 2.

The type of research/evaluation selected will determine which outcome indicators are required for measurement, and what outcomes are assessed. This, in turn, allows one to specify which evaluation questions one wants to answer; which hypotheses one is going to test; and whether one intends to make causal explanations, predictions, or descriptions. These questions and hypotheses can be formulated through the use of a program logic model. In a program logic model, direct and specific causal relations can be tested between input variables (like targeted people), process variables (like individual support strategies), short term effects (like quality of life-related personal outcomes) and long term impacts (like subjective well-being). As discussed by Gómez et al. (2020a) and Schalock et al. (2016), the relationships between these variables can be further understood when multivariate and indirect relationships are tested. Schalock & Luckasson (2021, this volume) describe how a person-centered outcome evaluation model is used to conceptualize,

Table 2
Types of evaluations for assessing the QOLSM.

Type of Evaluation	Definition	Relevant QOLSM Component(s)	Exemplary Outcome Indicators
Principle-focused (Patton, 2018)	Assessing whether principles and values are clearly stated, implemented, and lead to desired outcomes	Core Values	Core values and their documented incorporation into organization, systems policies or practices
Utilization-focused (Patton, 2008)	Assessing whether the model is used for multiple purposes including supports provision, organization transformation, and/or systems change	Systems of supports	Evidence that the model's components are used in supports provision, organization transformation, or systems change
Outcome-focused (Gómez & Verdugo, 2016)	Assessing change and benefits accruing from supports and identifying moderators and mediators of change	Quality of life domains	Changes in individual and family-referenced quality of life domains
Process-focused (Weiss, 1997)	Assessing the degree to which flexibility (in terms of addressing facilitating conditions), prediction accuracy, and explanatory power of the model and its application	Facilitating conditions Contextual factors	Evidence that the organization or system has addressed QOL and supports facilitating conditions

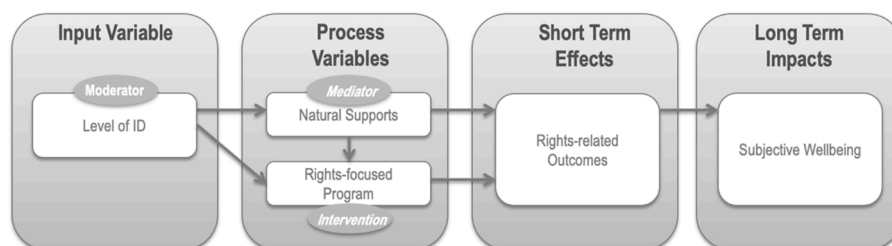


Fig. 3. Example of how to formulate complex hypothesis within the framework of a program logic model.

operationalize, and measure valued outcomes related to human functioning and personal well-being.

Fig. 3 illustrates how hypotheses (that are developed jointly with persons with IDD) regarding the QOLSM can be formulated by using a logic model:

- 1 The level of disability (evaluated through an adaptive behavior scale; e.g., Balboni et al., 2014; Tassé et al., 2019) will moderate the effect of an intervention focused on people with IDD who know what their rights are and how they can advocate for themselves.
- 2 This intervention will improve rights-related personal outcomes (evaluated through the rights subscale of a quality of life instrument; e.g., Gómez et al., 2020d).
- 3 The natural supports that each person receives will mediate the impact of the rights-centered intervention: The impact will be greater for those with more and better natural supports involved in the intervention.
- 4 The intervention will improve the subjective well-being of the participants (evaluated through a quality of life scale answered by the person with IDD; e.g., Gómez, Arias, Verdugo, Tassé, & Brown, 2015, Gómez, Verdugo et al., 2015).

2.3. STEP 3: gather evidence and establish its credibility

Gathering evidence and establishing its credibility involves choosing the most suitable research design, determining the data collection methods, and completing the data analysis. The research design is the plan for integrating all elements of an empirical study so that the evidence collected and the conclusions made are credible, unbiased, and generalizable (Dannels, 2010). Commonly used research designs that incorporate qualitative, quantitative or mixed methods include experimental, quasi-experimental, single-case, comparative, predictive, explanatory, observational, or selective studies (Ato, López, & Benavente, 2013; Gómez et al., 2021a). In Table 3, we summarize exemplary research designs, and the most suitable techniques and subsequent evaluation standards to evaluate the quality and robustness of the evidences gathered.

In reference to data collection methods, it is essential to select a relevant sample in terms of representativeness and size (Muñiz & Fonseca-Pedrero, 2019). Although probability sampling is usually preferable to non-probability sampling, in the field of IDD, obtaining representative sample is not only difficult to achieve, but is also often difficult to justify from an ethical point of view (especially when it comes to interventions where we have to randomly assign vulnerable people to a control group). In this sense, although randomized controlled trials may be the most recommended from a methodological point of view due to the quality of the evidence it provides, in most cases the needs and well-being of the people should prevail, so conducting quasi-experimental studies and single subject designs is highly valued, but bearing in mind that the quality of the evidence they provide is weaker.

Once the sample has been selected, the next step is to select the measuring instruments. These instruments should be standardized on the relevant population and have adequate evidences of reliability and validity. The data collection instrument(s) selected will lead

Table 3

Types of research designs for assessing the QOLSM (Gómez et al., 2021a).

Type of Evaluation	Research Design	Evaluation Standard
Principle-focused (Patton, 2018)	Qualitative designs (e.g., grounded theory, ethnography, phenomenology, participatory action research, case studies, emancipatory research)	Quality of evidences (i.e., credibility, transferability, dependability, confirmability, and reflexivity)
Utilization-focused (Patton, 2008)	Inclusive research (e.g., focus groups, workshops, interviews)	Feasibility Content-based evidences: Usefulness and relevance of the evidence from people with IDD's perspective Impact: Satisfaction
Outcome-focused (Gómez & Verdugo, 2016)	Quantitative designs (e.g., descriptive information obtained from between group or within group designs and using bivariate statistics; multivariate designs such as multiple discriminant analysis, multiple/hierarchical regression analysis). Economic studies	Quality of evidences related to internal and external validity (e.g., GRADE or NICE systems) Robustness of evidences (e.g., statistical significance, effect size, percent of variance explained) Relationship between cost and benefits, consequences, effectiveness and utility
Process-focused (Weiss, 1997)	Systematic reviews and Meta-analyses	Robustness of evidences (e.g., model-data fit, predictive accuracy, explanatory power) Fidelity and Flexibility of model implementation

to collecting evidence of greater or lesser quality and evidence that is of greater or lesser relevance to the person. In the field of IDD, where the assessment of support-needs and personal goals play a fundamental role, it is essential to achieve the best possible balance between the quality and relevance of the evidence.

Depending on the research design, participants, instruments and procedures used, the best and most suitable techniques of data analyses need to be selected. In this regard, when one tests hypotheses, it is not only necessary to report the level of significance used (e.g., $p < .05$), but it is also essential to calculate and provide the estimated effect size and the confidence intervals for each inference test performed.

2.4. STEP 4: interpret and communicate the results

After conducting the data analyzes, the research results need to be interpreted and communicated. In this process, it is crucial to keep in mind the quality and relevance of the evidence collected in order to not commit bias. Interpreting and communicating research results is an ethical duty that must be done rigorously and without exaggeration or creating false expectations. Therefore, it is important to interpret and communicate the results in reference to the following guidelines:

- The measurement instruments have standard measurement errors. True scores of the evaluated constructs are within a confidence interval that must be made explicit.
- Generalization of the results should not be done if representative samples are not used. Extrapolation of research results with small and convenience samples should always be done with great caution.
- Reporting on interventions that have not led to the expected results is as important as publishing interventions that can be considered successful or effective.
- Any bias or systematic errors in research that leads to inaccurate deductions should be avoided.
- Any condition(s) that may be relevant when interpreting the results must be communicated. Additionally, any conflict of interest that may exist must be made explicit.

In evaluating the QOLSM, it is essential to indicate the role that consumers (i.e., people with IDD) have played in the implementation and evaluation process (see [Schalock & Luckasson, 2021, this volume](#)), and to establish and maintain community stakeholder engagements and partnerships. In this sense, scientific papers published in prestigious peer-reviewed journals are necessary, but they are only the first step or the initial tool to translate findings to the end-users. [Rickinson \(2016\)](#) provides a series of very useful techniques to be successful in maintaining community stakeholder involvement:

- Knowing your audience: who is this research for? Who are the users of the research? How can one engage with them and understand their needs, concerns, interests, communication preferences and time-scales?

Table 4

Multisystem Uses of the QOLSM and Exemplary Evaluation Activities and Associated Outcome Indicators.

Current Uses of the QOLSM	Utilization Focus	Exemplary Research Evaluation Activities and Associated Outcome Indicators
Supports Provision (Microsystem)	<ul style="list-style-type: none"> • Provide individualized supports • Align personal goals and support needs with elements of a system of supports • Use QOL framework for supports planning and implementation 	<ul style="list-style-type: none"> • Determine the type and intensity of the supports provided • Determine the alignment of support needs to support strategies in Individual Supports Plans (ISP) • Determine the relation between supports provided and QOL outcomes
Organization Transformation (Mesosystem)	<ul style="list-style-type: none"> • Implement a system of supports delivery system (see Table 1) • Use support teams that develop and implement ISPs that align personal goals and support needs with elements of a system of supports and QOL domains • Base organization policies and practices on the QOLSM • Conduct QOL-focused outcomes evaluation 	<ul style="list-style-type: none"> • Determine the extent to which systems of supports are used • Evaluate ISPs to determine the alignment of personal goals and support needs with elements of a system of supports and QOL domains • Determine the extent to which the QOLSM is integrated into organization policies and practices • Use the results of the QOL-focused evaluation for reporting, monitoring, and continuous quality improvement
Systems Change (Macrosystem)	<ul style="list-style-type: none"> • Develop systems-wide policies and practices that incorporate QOL and supports values and facilitating conditions (see Step 1) • Align systems-level policies and practices based on components of the QOLSM 	<ul style="list-style-type: none"> • Determine the extent to which the system incorporates systems-wide policies and practices that are based on QOL and supports values and facilitating conditions • Determine the extent to which systems-level policies and practices are aligned with components of the QOLSM

Table 5
The QOLSM Self-Assessment Template.

QOLSM Component	Component Indicators	Primary Evidence Sources	Current Status	Proposed Quality Improvement Strategy
Core Values	<p>QOL principles related to equity, inclusion, self-determination, and empowerment are applied</p> <p>Support values are implemented that involve:</p> <ul style="list-style-type: none"> • the anticipation of improved functioning • recognition of the person's capabilities • understanding the person's support needs • fostering opportunities to enhance the person's functioning and well-being 	<p>Mission Statement</p> <p>Organization written policies</p> <p>Observable practices</p>		
Quality of Life Domains	<p>Assessment of Quality of Life Domains</p> <p>Respect for the individual's worth and personal autonomy</p> <p>Joint development and implementation of the Personal Support Plan</p> <p>Assessment and use of valued personal outcomes</p>	<p>Content analysis of Personal Support Plans</p> <p>Quality of life scales</p> <p>Content analysis of Personal Support Plans</p> <p>Observation of actual practices</p>		
Systems of Supports	<p>Assessment of the pattern and intensity of the individual's support needs</p> <p>Provision of support strategies that:</p> <ul style="list-style-type: none"> • promote the person's development, education, and interests • lessen or mitigate the individual's disability/limitations • align individual support needs and personal goals with specific support strategies and valued outcomes are evidence-based <p>Implementation of systems of supports:</p> <ul style="list-style-type: none"> • autonomy and personal control • inclusive environments • generic supports • specialized supports <p>Demonstration of support relationships:</p> <ul style="list-style-type: none"> • respect • responsiveness • reliability • communication • commitment • understanding • empathy 	<p>Support recipient interview</p> <p>Family interview</p> <p>Case record (e.g., supports needs assessment profile; professional evaluations of support needs; self-assessment interview)</p> <p>Content analysis of Personal Support Plans</p> <p>Observation</p> <p>Support recipient/ family interview</p> <p>Support staff interviews</p>		
Facilitating Conditions	<p>Addresses QOL facilitating conditions:</p> <ul style="list-style-type: none"> • participation in the community • promoting a sense of belonging • maximizing capabilities and opportunities • having the freedom to engage in major life activities • experiencing safe and secure environments • being committed to the goals that are important to the person <p>Addresses support facilitating conditions:</p> <ul style="list-style-type: none"> • the availability and accessibility of supports • knowledge about specific support strategies • competent and knowledgeable support providers • consistency and stability of supports provision • coordination and management of supports 	<p>Organization policies</p> <p>Organization practices</p> <p>Interagency agreements</p> <p>Local/generic working agreements</p> <p>Service recipient/ family interview</p> <p>Analysis of specific support strategies employed in the Personal Support Plan</p> <p>Support staff interviews</p>		

- Highlighting key messages: focus on the main findings and enumerate clearly their implications. This might include the use of bullets, case studies and scenarios to highlight qualitative findings, tables and numbers to highlight quantitative findings, images, diagrams and videos to bring ideas to life, and accessible and jargon-free language.
- Tailoring outputs: use a wide range of mechanisms for presenting and sharing information (e.g., newsletters, oral and online presentations, audiovisual materials, infographics, fact sheets, podcasts, videos, blog posts, workshops, webinars, toolkits). Make use of user-friendly and easy reading.
- Supporting uptake and use: Examples include telling key audiences about the intended or desired outputs well before completion, linking them to well-known topical issues or initiatives, getting support for the outputs from respected opinion makers, emphasizing how the outputs can help them, or publicizing them in relevant networks and social media.

2.5. STEP 5: implement research outcomes at microsystem, mesosystem and macrosystem levels

As discussed earlier, the QOLSM is currently used primarily to guide supports provision (microsystem), to provide a framework for organization transformation (mesosystem), and to encourage systems change (macrosystem). To assist the reader in understanding these multi-system applications, [Table 4](#) summarizes the relationship between each of the current uses of the QOLSM and the primary utilization's focus, and exemplary research/evaluation activities and associated outcome indicators. This table, which is based on the work of [Amor et al. \(2021\)](#); [Baker, Salisbury, and Collins \(2016\)](#); [Gómez et al. \(2021a\)](#); [Schalock and Keith \(2016\)](#), and [Verdugo et al. \(2021\)](#), can be used in conjunction with [Tables 2, 3, and 5](#) to guide research/evaluation activities including the selection of potential outcome indicators and implementing research outcomes at the micro, meso, and macrosystem levels.

2.6. STEP 6: judge the impact of the QOLSM

The acceptance of a new service delivery model, such as the QOLSM, is based on its potential to be more successful than previous approaches in solving problems, developing new knowledge, and facilitating positive change. The research-focused evaluation steps outlined above will allow researchers to evaluate these criteria related to the impact of the QOLSM through one or more of the types of evaluation summarized in [Tables 2 and 3](#) (i.e., principle-focused, utilization-focused, outcome-focused, process focused). Across the types of evaluation, the impact of the QOLSM will be judged based on the degree to which: (a) core values are manifest in organization and system policies and practices; (b) the model's components are used for multiple purposes, including supports provision, organization transformation, and/or systems change; (c) quality of life-related personal outcomes are enhanced; and (d) organizations and systems successfully address those contextual factors that enhance human functioning and personal well-being. This process requires that personal well-being/quality of life outcomes are monitored longitudinally, and there is a continual focus on relating the QOLSM components to the type of research planned and intended outcome indicators (see Step 2).

The suggested *QOLSM Self-Assessment Template* presented in [Table 5](#) can also be used by researchers to judge the impact of the QOLSM. This template is completed by researchers who work with organization personnel who are familiar with and have access to both the organization's policies and practices, and the support recipient's case file and Individual Supports Plan. The user-friendly Template facilitates process and outcome assessment by initially listing the specific measurable indicators (column 2) associated with each of the QOLSM core components (column 1). The actual assessment process involves: (a) identifying organization-based evidence sources (Column 3) that can be used to assess the current status of the indicators associated with each QOLSM component; (b) using the information obtained from those evidence sources to assess the presence or absence of indicators associated with the respective QOLSM component (column 4); (c) determining, based on the component's current status and the organization's Mission Statement and priorities, whether the organization will commit to implementing one or more quality improvement strategies to enhance those desired QOLSM components where there is little or no evidence indicating their incorporation into the organization's current policies and practices; and (d) identifying specific quality improvement strategies that will enhance the specific indicators associated with the targeted QOLSM component (column 5).

3. Conclusions

The field of IDD has recently seen an increased use of person-centered outcome evaluation strategies that are employed to meet the expectation that the outcomes and impacts of IDD-related policies and practices be assessed and acted on ([Schalock & Luckasson, 2021, this volume](#)). As proposed in this article, this call for accountability and professional responsibility is facilitated through the use of a conceptual and measurement framework such as the QOLSM that provides a systematic approach to the evaluation process. Specifically, and as summarized in [Fig. 1](#), the process involves operationalizing the components of the QOLSM model, relating these components to the type of research intended and associated outcome indicators, gathering evidence and establishing its credibility, interpreting and communicating the results, implementing those outcomes across system levels, and judging resulting impacts.

In conclusion, successfully implementing these six steps will involve a collaborative effort among key stakeholders, including people with IDD, advocates, supports providers, relatives, researchers, and policy makers. This effort requires that special attention be paid to the research methodologies employed and the quality of the evidences gathered, keeping in mind a person-centered research approach that focuses on what is relevant to the person. In addition, the research-focused evaluation steps discussed in this article delineate a research framework that results in a systematic approach to enhancing research practices in the field of IDD.

Author contributions

Laura E. Gómez: Conceptualization, Methodology, Writing – Original Draft, Visualization, Project Administration, Funding acquisition. **Robert L. Schalock:** Conceptualization, Methodology, Visualization, Writing- Review & Editing. **Miguel Á. Verdugo:** Conceptualization, Methodology, Writing- Review & Editing, Funding acquisition.

Acknowledgements

The manuscript has not been published elsewhere, is not currently submitted elsewhere, and is significantly different from other manuscripts that have been submitted elsewhere. Ethics procedures have been followed and the standards governing research involving human participants in force in Spain have been met. There is not any financial or any other kind of conflicts of interest for the authors of this manuscript. Neither the funding bodies of this research have imposed any restrictions on free access to or publication of these research data. Its publication is approved by all authors and by the responsible authorities where the work was carried out. If accepted, it will not be published elsewhere including electronically in the same form, in English or in any other language, without the written consent of the copyright-holder. The authors ensure that writing is free from bias by using people-first language. This work was supported by the Ministry of Science, Innovation, and Universities (R&D Projects, 2019) (grant numbers PID2019-105737RB-I00/AEI/10.13039/501100011033 and PID2019-110127GB-I00/AEI/10.13039/501100011033).

References

- Aguayo, V., Verdugo, M. A., Arias, V. B., Guillen, V. M., & Amor, A. M. (2019). Assessing support needs in children with intellectual disability and motor impairments: Measurement invariance and group differences. *Journal of Intellectual Disability Research*, 63(12), 1413–1427. <https://doi.org/10.1111/jir.12683>
- Amor, A. M., Verdugo, M. A., Arias, B., Fernández, M., & Aza, A. (2021). Examining the suitability of the list of indicators describing age-related typical support needs. *International Journal of Environmental Research and Public Health*, 18, 764. <https://doi.org/10.3390/ijerph18020764>
- Arias, V. B., Gómez, L. E., Morán, L., Alcedo, M. A., Monsalve, A., & Fontanil, Y. (2018). Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to children without autism? *Journal of Autism and Developmental Disorders*, 48(1), 123–136. <https://doi.org/10.1007/s10803-017-3289-8>
- Ato, M., López, J. J., & Benavente, A. (2013). A classification system for research designs in psychology. *Anales de Psicología*, 29(3), 1038–1059. <https://doi.org/10.6018/analesps.29.3.178511>
- Aza, A., Verdugo, M. A., Orgaz, M. B., Fernández, M., & Amor, A. M. (2020). Adaptation and validation of the self-report version of the scale for measuring quality of life in people with acquired brain injury (CAVIDACE). *Quality of Life Research*, 29, 1107–1121. <https://doi.org/10.1007/s11136-019-02386-4>
- Baker, A., Salisbury, B., & Collins, D. (2016). Changing service delivery systems: An example from Community Living British Columbia. In R. L. Schalock, & K. D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual disability* (pp. 149–166). American Association on Intellectual and Developmental Disabilities.
- Balboni, G., Tassé, M. J., Schalock, R. L., Borthwick-Duffy, S. A., Spreat, S., Thissen, D. M., et al. (2014). The diagnostic adaptive behavior scale: Evaluating its sensitivity and specificity. *Research in Developmental Disabilities*, 35, 2884–2893. <https://doi.org/10.1016/j.ridd.2014.07.032>
- Brown, I., Brown, R., Baum, N. T., Isaacs, B. J., Myerscough, T., Neikrug, S., et al. (2006). *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities*. Surrey Place Centre.
- Buntinx, W. H. E., Tu Tan, I., & Aldenkamp, A. P. (2018). Support values through the eyes of the patient: An exploratory study into long-term support for persons with refractory epilepsy. *Epilepsy and Behavior*, 82, 155–163. <https://doi.org/10.1016/j.yebeh.2018.02.031>
- Chou, Y. C., Lee, Y. C., Chang, S. C., & Yu, A. P. L. (2013). Evaluating the Supports Intensity Scale as a potential assessment instrument for resource allocation for persons with intellectual disability. *Research in Developmental Disabilities*, 34(6), 2056–2063.
- Claes, C., Van Hove, G., Vandevelde, S., van Loon, J., & Schalock, R. (2009). Evaluating the inter-respondent (consumer vs. staff) reliability and construct validity (SIS vs. Vineland) of the Supports Intensity Scale on a Dutch sample. *Journal of Intellectual Disability Research*, 53, 329–338.
- Claes, C., Vandenbussche, H., & Lombardi, L. (2016). Human rights and quality of life domains: Identifying cross-cultural indicators. In R. L. Schalock, & K. D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual and developmental disabilities (2nd Ed.)* (pp. 167–174). American Association on Intellectual and Developmental Disabilities.
- Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49, 699–706.
- Dannels, S. A. (2010). Research design. In G. R. Hancock, & R. O. Mueller (Eds.), *The reviewer's guide to quantitative methods in the social sciences* (pp. 343–355). Routledge.
- Dizdarevic, A., Ahmetovic, Z., Malec, D., Mujezinovic, A., Ahmetovic, M., Zilic, F., et al. (2020). Analysis of factor validity of the support intensity scale on Bosnian–Herzegovinian sample. *Advances in Cognitive Psychology*, 16(2), 117.
- Esteban, L., Navas, P., Verdugo, M. A., & Arias, V. B. (2021). Community living, intellectual disability and extensive support needs: A rights-based approach to assessment and intervention. *International Journal of Environmental Research and Public Health*, 18(6), e3175. <https://doi.org/10.3390/ijerph18063175>
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41, 126–135. <https://doi.org/10.1111/j.1365-2788.1997.tb00689.x>
- Fernández, M., Gómez, L. E., Arias, V. B., Aguayo, V., Amor, A. M., Andelic, N., et al. (2019). A new scale for measuring quality of life in acquired brain injury. *Quality of Life Research*, 28(3), 801–814.
- Fernández, M., Verdugo, M. A., Gómez, L. E., Aguayo, V., & Arias, B. (2018). Core indicators to assess quality of life in population with brain injury. *Social Indicators Research*, 137, 813–828. <https://doi.org/10.1007/s11205-017-1612-6>
- Francisco-Mora, C., Ibáñez, A., & Balcells-Balcells, A. (2020). State of the art of family quality of life in early care and disability: A systematic review. *International Journal of Environmental Research and Public Health*, 17(19), e7220. <https://doi.org/10.3390/ijerph17197220>
- Giné, C., Vilaseca, R., Gràcia, M., Mora, J., Orcasitas, J. R., Simón, C., et al. (2013). Spanish family quality of life scales: Under and over 18 years old. *Journal of Intellectual and Developmental Disabilities*, 38, 141–148. <https://doi.org/10.3109/13668250.2013.774324>
- Gómez, L. E., & Verdugo, M. A. (2016). Outcomes evaluation. In R. L. Schalock, & K. D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of persons with intellectual disability (2a ed.)* (pp. 71–80). American Association on Intellectual and Developmental Disabilities.
- Gómez, L. E., Arias, B., Verdugo, M. A., & Navas, P. (2012). An outcomes-based assessment of quality of life in social services. *Social Indicators Research*, 106, 81–93. <https://doi.org/10.1007/s11205-011-9794-9>
- Gómez, L. E., Monsalve, A., Morán, L., Alcedo, M. A., Lombardi, M., & Schalock, R. L. (2020b). 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. <https://doi.org/10.3390/ijerph17145123>. Article 5123.
- Gómez, L. E., Morán, L., Al-Halabí, S., Swerts, C., Verdugo, M. A., & Schalock, R. L. (2021b). *How to implement and monitor the United Nations Convention on the Rights of Persons with Disabilities? A consensus for its evaluation in people with intellectual and developmental disabilities [Manuscript submitted for publication]*.

- Gómez, L. E., Morán, M. L., Alcedo, M. A., Arias, V. B., & Verdugo, M. A. (2020c). Addressing quality of life of children with autism spectrum disorder and intellectual disability. *Intellectual and Developmental Disabilities*, 58(5), 393–408. <https://doi.org/10.1352/1934-9556-58.5.393>
- Gómez, L. E., Peña, E., Arias, B., & Verdugo, M. A. (2016). Impact of individual and organizational variables on quality of life. *Social Indicators Research*, 125(2), 649–664. <https://doi.org/10.1007/s11205-014-0857-6>
- Gómez, L. E., Schalock, R. L., & Verdugo, M. A. (2020a). The role of moderators and mediators in implementing and evaluating intellectual and developmental disabilities-related policies and practices. *Journal of Developmental and Physical Disabilities*, 32, 375–393. <https://doi.org/10.1007/s10882-019-09702-3>
- 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., Verdugo, M. A., & Arias, B. (2010). Calidad de vida individual: avances en su conceptualización y retos emergentes en el ámbito de la discapacidad [Individual quality of life advances in the conceptualization and emerging challenges in the disability field]. *Behavioral Psychology-Psicología Conductual*, 18(3), 453–472.
- Gómez, L. E., Verdugo, M. A., Arias, B., & Arias, V. B. (2011). A comparison of alternative models of individual quality of life for social service recipients. *Social Indicators Research*, 101, 109–126. <https://doi.org/10.1007/s11205-010-9639-y>
- Gómez, L. E., Verdugo, M. A., Arias, B., Navas, P., & Schalock, R. L. (2013). The development and use of provider profiles at the organization and systems level. *Evaluation & Program Planning*, 40, 17–26. <https://doi.org/10.1016/j.evalprogplan.2013.05.001>
- Gómez, L. E., Verdugo, M. A., Rodríguez, M., Morán, L., Arias, V. B., & Monsalve, A. (2020d). Adapting a measure of quality of life to children with Down syndrome for the development of evidence-based interventions. *Psychosocial Intervention*, 29, 39–48. <https://doi.org/10.5093/pi2019a17>
- Gómez, L. E., Arias, B., Verdugo, M. A., Tassé, M. J., & Brown, I. (2015). Operationalisation of quality of life for adults with severe disabilities. *Journal of Intellectual Disability Research*, 59(19), 924–941. <https://doi.org/10.1111/jir.12204>
- Gómez, L. E., Verdugo, M. A., & Arias, B. (2015). Validity and reliability of the INICO-FEAPS scale: An assessment of quality of life for people with intellectual and developmental disabilities. *Research in Intellectual and Developmental Disabilities*, 36, 600–610. <https://doi.org/10.1016/j.ridd.2014.10.049>
- Gullickson, A. M. (2020). The whole elephant: Defining evaluation. *Evaluation and Program Planning*, 79, 100–121. <https://doi.org/10.1016/j.evalprogplan.2020.101787>
- Harpur, P. (2012). Embracing the new disability rights paradigm: The importance of the convention on the rights of persons with disabilities. *Disability & Society*, 27(1), 1–14. <https://doi.org/10.1080/09687599.2012.631794>
- Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and the Family*, 68, 1069–1083. <https://doi.org/10.1111/j.1741-3737.2006.00314.x>
- Jenaro, C., Verdugo, M. A., Caballo, C., Balboni, G., Lachapelle, Y., Otbreski, W., et al. (2005). Cross-cultural study of person-centered quality of life domains and indicators: A replication. *Journal of Intellectual Disability Research*, 49, 734–739.
- Kuppens, S., Bossaert, G., Buntinx, W., Molleman, C., Van den Abbeele, A., & Maes, B. (2010). Factorial validity of the Supports Intensity Scale (SIS). *American Journal on Intellectual and Developmental Disabilities*, 115(4), 327–339. <https://doi.org/10.1352/1944-7558-115.4.327>
- Lamoureux-Hébert, M., & Morin, D. (2009). Translation and cultural adaptation of the supports intensity scale in French. *American Journal on Intellectual and Developmental Disabilities*, 114(1), 61–66.
- Lombardi, M., Vandenbussche, H., Claes, C., Schalock, R. L., De Maeyer, J., & Vandeveld, 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>
- Mittler, P. (2015). The UN convention on the rights of persons with disabilities: Implementing a paradigm shift. *Journal of Policy and Practice in Intellectual Disabilities*, 12, 79–89. <https://doi.org/10.1111/jppi.12118>
- 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.
- Morán, L., Gómez, L. E., & Alcedo, M. A. (2019). Inclusión social y autodeterminación: los retos en la calidad de vida de los jóvenes con autismo y discapacidad intelectual [Social inclusion and self-determination: the challenges in the quality of life of youth with autism and intellectual disability]. *Siglo Cero*, 50(3), 29–46. <https://doi.org/10.14201/scero20195032946>
- Muñiz, J., & Fonseca-Pedrero. (2019). Diez pasos para la construcción de un test [Ten steps for test development]. *Psicothema*, 31(1), 7–16. <https://doi.org/10.7334/psicothema2018.291>
- Nussbaum, M. C. (2011). *Creating capabilities: The human development approach*. Belknap Press of Harvard University.
- Onken, S. J. (2018). Mental health consumer concept mapping of supported community. *Evaluation and Program Planning*, 71, 36–45. <https://doi.org/10.1016/j.evalprogplan.2018.08.001>
- Ozeki, S., Coryn, C. L. S., & Schroter, D. C. (2019). Evaluation logic in practice. Findings from two empirical investigations of American Evaluation Association members. *Evaluation and Program Planning*, 76, 1–7. <https://doi.org/10.1016/j.evalprogplan.2019.101681>
- Patton, M. Q. (2008). *Essentials of utilization-focused evaluation*. Sage.
- Patton, M. Q. (2018). *Principle-focused evaluation: The GUIDE*. Guilford Press.
- Qian, X., Larson, S. A., Ticha, R., Stancliffe, R., & y Pettingell, S. L. (2019). Active support training, staff assistance, and engagement of individuals with intellectual and developmental disabilities in the United States: Randomized controlled trial. *American Journal on Intellectual and Developmental Disabilities*, 124, 157–173. <https://doi.org/10.1352/1944-7558-124.2.157>
- Rickinson, M. (2016). Communicating research findings. In D. Wyse, E. Smith, L. E. Suter, & N. Selwyn (Eds.), *The BERA/Sage handbook of educational research* (pp. 973–997). Sage.
- Schalock, R. L., & Keith, K. D. (2016). *Cross-cultural quality of life: Enhancing the lives of people with intellectual disability (2nd Ed.)*. American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., & Luckasson, R. (2021). Enhancing research practices in intellectual and developmental disabilities through person-centered outcome evaluation. *Research in Developmental Disabilities*.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. American Association on Mental Retardation.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., et al. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disability: Report of an international panel of experts. *Mental Retardation*, 40, 457–470.
- Schalock, R. L., Gómez, L. E., Verdugo, M. A., & Claes, C. (2017). Evidence and evidence-based practices: Are we there yet? *Intellectual and Developmental Disabilities*, 55, 112–119. <https://doi.org/10.1352/1934-9556-55.2.112>
- Schalock, R. L., Gomez, L. E., Verdugo, M. A., & Reinders, H. S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities*, 121, 1–12. <https://doi.org/10.1352/1944-7558-121.1.12016>
- Schalock, R. L., Verdugo, M. A., & Gómez, L. E. (2011). Evidence-based practices in the field of intellectual and developmental disabilities: An international consensus approach. *Evaluation and Program Planning*, 34, 273–282. <https://doi.org/10.1016/j.evalprogplan.2010.10.004>
- Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., et al. (2005). A cross-cultural study of quality of life indicators. *American Journal on Mental Retardation*, 110, 298–311.
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021a). Ongoing transformation in the field of intellectual and developmental disabilities: Taking action for future progress (in press) *Intellectual and Developmental Disabilities*.
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021b). *Intellectual disability: Definition, diagnosis, classification, and planning supports*. AAIDD.
- Shogren, K. A., Luckasson, R., & Schalock, R. L. (2020a). Leveraging the power of context in disability policy development, implementation, and evaluation: Multiple applications to enhance personal outcomes. *Journal of Disability Policy Studies*, 31(4), 230–243. <https://doi.org/10.1177/1044207320923656>
- Shogren, K. A., Luckasson, R., & Schalock, R. L. (2020b). Using a multidimensional model to analyze context and enhance personal outcomes. *Intellectual and Developmental Disabilities*, 58, 95–110. <https://doi.org/10.1352/1934-9556-58.2.95>

- Stancliffe, R. J., Arnold, S. R. C., & Riches, V. C. (2016). The supports paradigm. In R. L. Schalock, & K. D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual disabilities* (pp. 133–142). American Association on Intellectual and Developmental Disabilities.
- Swerts, C., Gómez, L. E., de Maeyer, J., Goedele, D. N., & Vandersplasschen, W. (2021). Development of the Quality of Life in Youth Services Scale (QOLYSS): content-related validity evidence based on adolescents. *Applied Research in Quality of Life*. <https://doi.org/10.1007/s11482-021-09921-x>
- Tassé, M. J., Balboni, G., Navas, P., Luckasson, R. A., Nygren, M. A., Belacchi, C., et al. (2019). Developing behavioural indicators for intellectual functioning and adaptive behaviour for ICD-11 disorders of intellectual development. *Journal of Intellectual Disability Research*, 63(5), 386–407. <https://doi.org/10.1111/jir.12582>
- Thompson, J. R., Bryant, B. R., Schalock, R. L., Shogren, K. A., Tasse, M. J., Wehmeyer, M. L., et al. (2015). *Supports intensity scale—Adult version user’s manual*. American Association on Intellectual and Developmental Disabilities.
- Thompson, J. R., Wehmeyer, M. L., Hughes, C., Shogren, K. A., Seo, H., Little, T. D., et al. (2016). *Supports Intensity Scale-Children’s version (SIS-C)*. American Association on Intellectual and Developmental Disabilities.
- United Nations. (2006). *United Nations convention on the rights of persons with disability*. Author. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>.
- Verdugo, M. A., Aguayo, V., Arias, V. B., & García-Domínguez, L. (2020). A systematic review of the assessment of support needs in people with intellectual and developmental disabilities. *International Journal of Environmental Research and Public Health*, 17(24), e9494. <https://doi.org/10.3390/ijerph17249494>
- Verdugo, M. A., Arias, B., Gómez, L. E., & Schalock, R. L. (2010). Development of an objective instrument to assess quality of life in social services: Reliability and validity in Spain. *International Journal of Clinical and Health Psychology*, 10(1), 105–123.
- Verdugo, M. A., Gómez, L. E., Arias, B., Navas, P., & Schalock, R. L. (2014). Measuring quality of life in persons with intellectual and multiple disabilities: Validation of the San Martín Scale. *Research in Developmental Disabilities*, 35(1), 75–86. <https://doi.org/10.1016/j.ridd.2013.10.025>
- 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). El Modelo de Calidad de Vida y Apoyos: La unión tras veinticinco años de caminos paralelos [The Quality of Life Supports Model: Twenty-five years of parallel paths have come together]. *Siglo Cero*, 52(3), 9–28.
- Vicente, E., Guillén, E. V., Gómez, L. E., Ibáñez, A., & Sánchez, S. (2019). What do stakeholders understand by self-determination? Consensus for its evaluation. *Journal of Applied Research in Intellectual Disabilities*, 32, 206–218. <https://doi.org/10.1111/jar.12523>
- Vicente, E., Verdugo, M. A., Guillén, M. V., Martínez, A., & Gómez, L. E. (2020). Advances on the assessment of self-determination: Internal structure of a scale for people with intellectual disabilities aged 11 to 40. *Journal of Intellectual Disability Research*, 64, 700–712. <https://doi.org/10.1111/jir.12762>
- Wehmeyer, M. L. (2013). *The Oxford handbook of positive psychology and disability*. Oxford University Press.
- Wehmeyer, M. L. (2020). The importance of self-determination to the quality of life of people with intellectual disability: A perspective. *International Journal of Environmental Research on Public Health*, 17(19), e7121. <https://doi.org/10.3390/ijerph17197121>
- Weiss, C. H. (1997). Theory-based evaluation: Past, present, and future. *New Directions for Evaluation*, 76, 41–55. <https://doi.org/10.1002/ev.1086>
- Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disability: From theory to practice* (pp. 241–278). Springer.