

A New Paradigm in the Field of Intellectual and Developmental Disabilities: Characteristics and Evaluation

Laura E. Gómez¹, Robert L. Schalock², and Miguel Ángel Verdugo³

¹ Universidad de Oviedo, ² University of Nebraska, and ³ INICO, Universidad de Salamanca

Abstract

Background: A new paradigm, which we refer to as The Quality of Life Supports Paradigm, is emerging internationally in the field of intellectual and developmental disabilities. The new paradigm integrates the key concepts of 'quality of life' and 'supports'. This article addresses the question of how one evaluates a new paradigm. **Method:** This is a conceptual work that describes five characteristics of a paradigm. The characteristics are based on the groundbreaking work of relevant authors in the field of intellectual and developmental disabilities, quality of life, supports, and evaluation. **Results:** The five characteristics are that a paradigm is theory driven, ethical, flexible, adaptable, and measurable. The article especially delves into the fifth characteristic and provides specific examples of how to evaluate the new paradigm. **Conclusions:** The new paradigm encompasses core values, accommodates contextual factors, and can be used for multiple purposes to positively impact the development and implementation of value-based policies and practices that enhance the quality of life and personal well-being of people with intellectual and developmental disabilities.

Keywords: Intellectual disability; Developmental disability; Quality of life; Quality of Life Supports Paradigm; Convention on the Rights of People with Disabilities.

Resumen

Un Nuevo Paradigma en el Ámbito de la Discapacidad Intelectual y del Desarrollo: Características y Evaluación. Antecedentes: en el ámbito internacional de las discapacidades intelectuales y del desarrollo está surgiendo un nuevo paradigma, el Paradigma de Calidad de Vida-Apoyos, que integra los conceptos clave "calidad de vida" y "apoyos". Este artículo aborda la cuestión de cómo se evalúa un nuevo paradigma como este. **Método:** este es un trabajo conceptual que describe cinco características de un paradigma. Estas características están basadas en el trabajo innovador de autores relevante en el ámbito de las discapacidades intelectuales y del desarrollo, la calidad de vida, los apoyos y la evaluación. **Resultados:** las cinco características de un paradigma son que este es impulsado por la teoría, ético, flexible, adaptable y medible. En el artículo se profundiza especialmente en la quinta característica y se proporcionan ejemplos específicos sobre cómo evaluar el nuevo paradigma. **Conclusiones:** el nuevo paradigma abarca valores fundamentales, incorpora factores contextuales y se puede utilizar para múltiples propósitos para favorecer el desarrollo y la implementación de políticas y prácticas basadas en valores que mejoran la calidad de vida y el bienestar personal de las personas con discapacidades intelectuales y del desarrollo.

Palabras clave: discapacidad intelectual; discapacidad del desarrollo; calidad de vida; Paradigma de Calidad de Vida y Apoyos; Convención sobre los Derechos de las Personas con Discapacidad.

A paradigm can be defined as the collective set of beliefs, assumptions, policies, and practices shared by individuals that guide the collective efforts of multiple stakeholders to solve problems, develop new knowledge, and make change. According to Kuhn (1970), the acceptance of a new paradigm is based on its attracting converts, its being sufficiently open-ended to be testable, and its potential to provide a more successful approach to—and explanation of—a phenomenon or field of endeavor.

Currently in the field of Intellectual and Developmental Disabilities (IDD) a new paradigm is emerging internationally. This new *Quality of Life Supports Paradigm* (QOLSP) integrates

the key concepts of quality of life (QOL) and supports (Schalock et al., 2020a, 2020b, 2020c; Schalock & Keith, 2016; Verdugo et al., in press). In this emerging paradigm, the QOL concept provides a framework for policy development, best practices, and outcome evaluation due to the concept's universal property, values, focus on the individual, and emphasis on valued outcomes (Gómez & Verdugo, 2016; Mittler, 2015; Schalock & Verdugo, 2019). The concept of supports promotes the development, education, and interests of the person, and provides a framework to enhance an individual's functioning and personal well-being through the planning and delivery of a coordinated set of person-referenced support strategies that prevent or mitigate one's disability (Stancliffe et al., 2016; Thompson et al., 2009, 2014).

Organizations and systems that have adopted and implemented one or more characteristics of the QOLSP have changed their policies and practices and thereby transformed in significant ways. These changes have involved implementing systems of supports, aligning an individual's support needs with personalized

support strategies and valued outcomes, connecting practices at the individual level with priorities and missions of organizations, aligning quality of life and supports-related policies and decision making at the organization and systems level, developing a quality of life-supports based framework for disability policies and practices and conducting quality of life-focused outcomes evaluation (Amor et al., 2018, 2020; Baker et al., 2016; Schalock & Keith, 2016; Schalock & Verdugo, 2013; Schalock et al., 2018; Thompson et al., 2014).

This article identifies characteristics of a paradigm such as the QOLSP and describes how a new paradigm can be evaluated. We propose that evaluating a paradigm involves a clear understanding of the characteristics of the paradigm in question, and a paradigm-driven evaluation framework. The five characteristics of a paradigm are described in subsequent sections are based on the work of Chen (1990), DeWitt (2010), Kuhn (1970), Gómez et al. (2020a), Schalock et al. (2020a, 2020b, 2020c), Shogren et al. (2020), Thompson et al. (2014), Wasserman (2010), and Weiss (1997). These five characteristics are that a paradigm is: (1) *theory driven* (i.e., based on a validated conceptual model); (2) *ethic* (i.e., encompasses core values); (3) *flexible* (i.e., can be used for multiple purposes); (4) *adaptable* (i.e., provides a framework to accommodate contextual factors); and (5) *measurable* (i.e., can be evaluated).

Theory Driven: A QOL Support Model

A new paradigm must be theory driven; in other words, it must be based on a validated conceptual model. Figure 1 depicts a QOL Supports model that integrates quality of life domains, systems of supports elements (choice and personal autonomy, inclusive environments, generic supports, and specialized supports), and context-based implementation and evaluation factors (QOL principles and facilitating conditions and support values and facilitating conditions). The model was developed by the authors based on a synthesis of international disability literature related to the concepts of quality of life and supports (Schalock & Keith, 2016; Verdugo et al., in press). Its essential components include QOL domains, systems of support elements, and context-based implementation and evaluation factors.

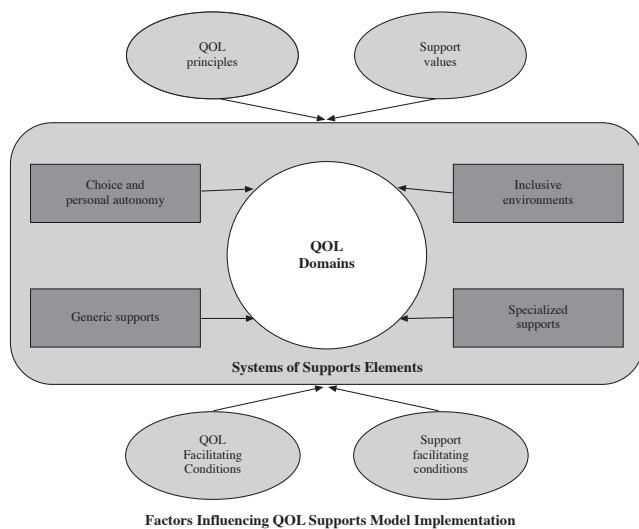


Figure 1. Quality of Life Support Model

QOL Domains

There are numerous individual and family-referenced quality of life models. Examples are found in the work of Felce (1997), Gómez et al. (2011), Isaacs et al., (2007), Petry et al. (2007), Schalock et al. (2016), and Summers et al. (2005). The “QOL domains” component of the QOL Supports Model is flexible enough to incorporate domains referenced in different QOL models. Although the authors have employed in their work the eight-domain QOL conceptual model developed by Schalock et al. (2016), domains are quite similar across QOL models, and encompass four basic principles in their development. These are that quality of life: (a) is composed of several dimensions (i.e., multidimensional) that are the same for all people (but may be valued differently) and reflect an individual’s or family’s well-being; (b) is influenced by personal and environmental factors (Gómez et al., 2016); (c) has both objective and subjective components (Cummins, 2000); and (d) is enhanced by individualized, person-centered supports (Consortium on QOL, 2019; Gómez et al., 2020a).

Systems of Supports

Systems of supports are a broad range of resources and strategies that prevent or mitigate a disability, promote the development, education, and interests of a person, and enhance an individual’s functioning and personal well-being. Since the introduction of the concept of supports into the IDD field in the mid-1980s, our understanding has increased significantly regarding systems of supports elements. As depicted in Figure 1, a frequently used categorization of systems of supports elements include (Lombardi et al., 2020; Schalock et al., 2021; Verdugo et al., in press): (a) choice and personal autonomy opportunities (i.e., opportunities to make choices and exercise self-determination); (b) inclusive environments (i.e., natural environments in which people with a disability and those without a disability are included and valued); (c) generic supports (i.e., supports that are available to all); and (d) specialized supports (i.e., professionally-based interventions, therapies, and strategies).

Context-Based Implementation and Evaluation Factors

The four contextual factors depicted in Figure 1 influence the successful implementation of a QOL Supports Model and guide collective efforts. The identification and description of these factors is based on the work of the Buntinx et al. (2018), Consortium on QOL (2019), Onken (2018), Qian et al. (2019), Schalock and Keith (2016), Thompson et al. (2014), and Verdugo et al. (in press). These four factor contextual factors are (Schalock et al., 2020c): (a) QOL principles (aforementioned); (b) QOL facilitating conditions (e.g., maximizing capabilities and opportunities); (c) support values (e.g., conceptualizing supports as a bridge between “what is” and “what can be”), and (d) support facilitating conditions (e.g., availability and accessibility of supports).

Ethic: Encompasses Core Values

Core values reflect a paradigm’s collective set of beliefs, assumptions, policies, and practices. The QOLSP rejects a defectology and segregation/devaluing paradigm, and replaces it with a paradigm that consolidates core values related to the

social-ecological model of disability, the capacities approach to human development and disability, the supports model, and human rights and quality of life principles. More specifically, the QOLSP incorporates core values related to (Schalock et al., 2020c): (a) the human and legal rights of persons with a disability (Claes et al., 2016; Gómez et al., 2020b; Harpur, 2012; Mittler, 2015; Verdugo et al., 2012); (b) the capacities approach to human development and disability (Nussbaum, 2011) and the principles of positive psychology (Wehmeyer, 2013); (c) the emphasis on self-determination and decision-making supports (Morán et al., 2019; Schalock et al., 2019; Shogren et al., 2017); (d) the cross-cultural emphasis on inclusion and equity for individuals with a disability and their families (Consortium on QOL, 2019; Isaacs et al., 2007; Schalock & Keith, 2016); and (e) the use of best practices and value-based outcomes-based evaluation (Gómez et al., 2012; Gómez & Verdugo, 2016; Schalock et al., 2011).

Flexible: Used for Multiple Purposes

To evaluate a paradigm, it needs to be flexible enough “to be used for multiple purposes”. As discussed in detail by Verdugo et al. (in press), one or more components of the QOLSP has been used for multiple purposes that involve supports provision, organization transformation, and systems change.

Supports Provision

Systems of support are an interconnected network of resources and strategies that promote the development and interests of a person and enhance an individual’s functioning and personal well-being. Systems of supports are based on the premise that a person’s support needs reflect the current mismatch between one’s personal competence and the environmental demands within which a person lives, works, learns, interacts, and recreates. The essential purpose of systems of supports is to reduce the discrepancy between an individual’s functional limitations and environmental demands, and thereby enhance their functioning and personal well-being. As referenced, the elements of a systems of support include: (a) choice and personal autonomy opportunities (i.e., opportunities to make choices and exercise self-determination); (b) inclusive environments (i.e., natural environments in which people with a disability and those without a disability are included and valued); (c) generic supports (i.e., supports that are available to all); and (d) specialized supports (i.e., professionally-based interventions, therapies, and strategies).

Organization Transformation

In addition to either providing or coordinating the systems of supports elements just described, transformed organizations also engage in “*quality of life and supports thinking*” that is based on the contextual factors represented in Figure 1. Specifically, organization transformation based on the QOLSP involves:

- Promoting the QOL principles and facilitating conditions that involve participation in the community, promoting a sense of belonging, maximizing the person’s capabilities, allowing freedom to engage in major life activities, being committed to the goals that are important to the person or family, and respecting human and legal rights and individual differences.

- Incorporating into the organization’s service delivery system support values that recognize and respect the individual’s capacities, understand the person’s support needs, foster opportunities, conceptualize supports as a bridge between “what is” and “what can be”, and believe that with appropriate individualized supports over a sustained period, an individual’s quality of life and functioning generally will improve.
- Implementing policies and practices that include the availability and accessibility of supports, safe and secure environments, information about systems of supports elements, competent and knowledgeable support providers, consistency and stability of support provision, and coordination and management of supports.

Systems Change

The QOLSP provides a framework to produce the systems change that is envisioned in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006). As discussed by Mittler (2015), Convention Articles incorporate the principles and values embedded in the QOL concept, and Convention Goals encourage signatories to make ‘reasonable accommodation’ in their support delivery systems to enable people with disabilities to exercise their rights. For example, systems change can be based on the alignment of QOL domains, UNCRPD articles, and systems of supports elements (Claes et al., 2016; Gómez et al., 2020a; Lombardi et al., 2019, 2020; Verdugo et al., 2012).

Adaptable: A Framework to Accommodate Contextual Factors

A paradigm needs to provide a framework that accommodates contextual factors that influence a person’s functioning and well-being and impact an organization or system’s effectiveness and efficiency (Thompson et al., 2014). Despite the widespread use of the term “context” in the field of IDD, until recently there has been a limited understanding of—and specificity regarding—the term and its application. Based on recent work (e.g., Schalock et al., 2020a, 2020c; Shogren et al., 2018, 2020a, 2020b) has increased our understanding of the contextual factors that affect a paradigm’s implementation and evaluation.

The four clusters of contextual factors (i.e., QOL principles, QOL facilitating conditions, support values, and support facilitating conditions) can be used as a framework to accommodate the multidimensional properties of context. Specifically:

- *In reference to support provision*, the opportunities and specific supports provided to a person will depend heavily on: (a) the degree to which the QOL concept and its associated principles are reflected in a society’s values and an organization/system’s culture; and (b) the support values that support providers incorporate into supports planning and implementation.
- *In reference to organization transformation and systems change*, the quality and quantity of the transformation or change will depend on the degree to which policy makers and support providers successfully unfreeze the status quo and implement policies and practices that unfreeze the status quo and influence positively the QOL and support facilitating conditions.

Measurable: It Can be Evaluated

As discussed by Gullickson (2020) and Ozeki et al. (2019), an evaluation framework delineates the process involved in measuring the impact of a paradigm. In this last section of the article we describe a paradigm-driven evaluation framework that involves four types of evaluation: principle-focused, utilization-focused, outcomes-focused, and process focused. The components of this framework are summarized in Table 1.

Principle-Focused Evaluation

According to Patton (2018, p. 3), *principle-focused evaluation* informs about which principles are appropriate for what purposes in what contexts. From this perspective, principles are hypotheses, not truths. Based on the evidence, principle-focused evaluation examines whether principles are clear, meaningful, and actionable; if so, whether they are being followed; and, if so, whether they are leading to desired outcomes. Principles operate at different levels, which might be derived from experience, expertise, values or research. A good principle provides guidance for making choices and decisions, is useful in setting priorities, and inspires and supports ongoing development and adaptation (p. 9). Patton also discusses 10 ways in which principles operate (p. 10): (1) informing choices at forks in the road; (2) being grounded in values about what matters to those who develop, adopt, and attempt to follow them; (3) providing direction, but not detailed description, so they offer opportunities to adapt to different contexts; (4) being interpreted and applied contextually; (5) being the rudder for navigating complex dynamic systems; (6) enhancing their effectiveness when based on experience, knowledge, and evidence about how to be effective; (7) requiring judgement in application (effectiveness is somewhat dependent on the quality of decision making and judgment in applying and evaluating them); (8) having competing principles; (9) pointing to consequences, outcomes, and impacts; and (10) being evaluated for process (implementation) and results (outcomes).

As discussed by Patton (2018, p. 20), the emergent challenges for these principle-focused evaluations have to do with the new

units of analysis and broader areas of focus for evaluation (i.e., the ‘evaluand’ or what is evaluated; Scriven, 1995, p. 68). Tools such as logic models work well for program evaluations in which we work with ‘closed systems’, established boundaries and some kind of control, but not so well with this kind of open systems that are characterized by volatility, uncertainty, and unpredictability. In this sense, Patton enhances the importance of principles because they are “the primary way of navigating complex dynamic systems and engaging in strategic initiatives” (p. 21).

Within the IDD field, a principle-focused evaluation may be applied in four ways. The first is to determine whether value-based disability policies and practices incorporate QOL domains, systems of supports elements, QOL principles and facilitating conditions, and support values and facilitating conditions, together with core values such as human and legal rights, the capacities approach to disability, the principles of positive psychology, and the principles of equity, empowerment, and inclusion. A second way is to determine the degree of implementation (i.e., implementation fidelity) to which support providers (a) use QOL domains and system of support elements in support provision, (b) conduct outcome evaluation, and (c) address QOL and support facilitating conditions. A third way is to check if core values and principles such as human and legal rights, inclusion, equity and empowerment lead to enhanced QOL outcomes. A fourth way is to empirically test the efficacy of adopting a human and legal rights perspective (such the assumption of the UNCRPD when providing supports to people with IDD), while QOL-related personal outcomes would be the measurable desired outcomes.

Given the complexity of testing open and complex hypotheses like the one formulated in the above example in which there is a great lack of control, qualitative designs are recommended, with the recommended evaluation standard being the *quality of the evidences*. Based on Lincoln and Guba (1985), there are five quality criteria that can be used in qualitative research: (a) credibility: confidence that can be placed in that the research findings represent plausible information drawn from the participants’ data and is a correct interpretation of the participants’ views; (b) transferability: the degree to which the results can be transferred to other contexts or settings with other respondents, which is

Table 1
Type of evaluations for the New Paradigm-Driven Evaluation Framework in IDD

Type of Evaluation	Definition	Research Design	Evaluation Standard
Principle-focused (Patton, 2018)	Assessing whether principles and values are clearly stated, implemented and lead to desired outcomes.	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)	Assessing whether uses of the evaluation are important, useful and stated by people with IDD	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)	Assessing change and benefits accruing from services/supports and identifying moderators and mediators of the change.	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 Systematic reviews and Meta-analyses	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)	Assessing the degree of flexibility, predictive accuracy, and explanatory power of the paradigm’s components and application.	Quantitative designs (e.g. structural equation modeling)	Robustness of evidences (e.g., model-data fit, predictive accuracy, explanatory power) Fidelity and Flexibility of model implementation

facilitated by a thick description; (c) dependability: the stability of findings over time, it involves participants' evaluation of the findings; (d) confirmability: the degree to which the findings could be confirmed by other researchers; and (e) reflexivity: the process of critical self-reflection about oneself as researcher (e.g., biases, preferences) and the research (e.g., biases, degree of control, quality of the instruments, expertise of interviewers). The checklist developed by Chacón-Moscoso et al. (2019) might be extremely useful to consider in observational studies (e.g., between-observer reliability or within-observer reliability).

Utilization-Focused Evaluation

Utilization-focused evaluation (Patton, 2008) is an approach based on the principle that an evaluation should be judged on its usefulness to its intended users. Therefore, evaluations should be planned and conducted in ways that enhance the likely utilization of both the findings and the process itself to inform decisions and improve valued outcomes for people with IDD and their families. There are two key elements in this approach: (a) people with IDD (i.e., the intended users of the evaluation) must be clearly identified and actively engaged from the beginning of the evaluation process to ensure that their primary intended uses are identified; (b) evaluators must ensure that these intended uses of the evaluation that have been pointed out as relevant by people with IDD guide all other decisions that will be made about the evaluation process.

In the field of IDD, there is a growing interest and imperative about *inclusive research* and engaging people with IDD as more than research subjects or respondents. Inclusive research designs align with the UNCRPD values such as ensuring that research is accessible to people with disabilities (Article 31) and involving people with disabilities in the monitoring and evaluation of the UNCRPD implementation process (Article 33). There are many ways of involving people with IDD in inclusive research. As discussed by Bigby et al. (2014), these involve: (a) advisory or reference groups: people with IDD as advisors to researchers, organizations and governments about research agendas, conducts or dissemination; (b) leading and controlling research: people with IDD taking charge; and (c) collaborative: people with IDD collaborating in specific studies with researchers without IDD. The most common research designs in inclusive research with people with IDD are based on team approaches, using focus groups, individual or shared interviews, and workshops of researchers with ID and their supporters.

Although the evaluation standard for inclusive research is emerging, we can highlight some key aspects that have been identified in the recent scientific literature: (a) feasibility: key aspects that allow or facilitate the viability of the research, such as active supporters, a team approach and experienced researchers (García et al., 2014); (b) content-based evidences about the usefulness and relevance of the evidence from people with IDD's perspective (e.g., mean scores and standard deviations on importance degree, adequacy, utility, etc.; degree of concordance); (c) impact of the inclusive research from the perspectives of researchers with IDD and intended users of the evaluation (e.g., QOL-related personal outcomes, self-advocacy skills, level of satisfaction before, during and after the development of the research). Our challenge is to evolve from "best practices" in inclusive research to research-based knowledge about specific actions that have been proven to produce desired outcomes across contexts.

Outcome-Focused Evaluation

In research and theory, a distinction is made between thinking of the outcomes, what we want to achieve (ends), and the process, how to achieve them (means). In this new paradigm in the IDD field, an *outcome-focused evaluation* assesses change, benefits, costs, efficiency and efficacy of services, supports, programs and specific interventions provided to people with IDD, and identifies moderators and mediators of the change (Gómez et al., 2020b). In this type of evaluation, it is important to fully define the characteristics of the recipients (e.g., age, gender, level of support needs, communication skills), together with the characteristics and the procedure of implementation of supports, services and interventions that we want to test. In this sense, the purposes of outcome-focused is to: (a) assess QOL-related personal outcomes domain indicators that can be reported at the individual level and aggregated for use at the organization and systems level —see Gómez et al. (2013), Gómez and Verdugo (2016) for illustrative examples and further details—; and (b) determine the relation among demographic (e.g., gender, age, level of support needs), independent (e.g., interventions, services), moderators and mediators (e.g., level of supports), and dependent variables (i.e. QOL-related personal outcomes).

When testing specific hypothesis related to an outcomes-focused evaluation such as the ones just mentioned, quantitative designs and economic studies are the most recommended, together with systematic reviews and meta-analyses of these two types of studies. In this regard, experimental studies with randomized controlled trials (RCT) would be the golden standard proving the best quality of evidences. However, in the field of IDD, this kind of designs are not always possible to implement in real contexts, and therefore other experimental and observational designs with less level of control are also recommended. For example, economic studies can be conducted in order to test not only the efficacy of supports, services and interventions, but also the balance between their costs and benefits, consequences, effectiveness and utility.

When quantitative designs are carried out, it is fundamental to provide robust evidences of high quality related to the internal and external validity of the study (see, e.g., Muñiz & Fonseca-Pedrero, 2019; Rdz-Navarro & Fan Yang-Wallentin, 2020). Meta-analysis may be appropriate if treatment, intervention or type of support estimates of the same outcome from more than one study are available. In this sense, we encourage evaluators to use systems to rating the quality and strength of evidence such as GRADE ('Grading of Recommendations Assessment, Development and Evaluation'; GRADE Working Group, 2004) that uses four categories—high, moderate, low, and very low—that are applied to a body of evidence, and then moving from the quality of evidence to indicate the strength of the recommendation (National Institute for Health and Care Excellence [NICE], 2012). An illustrative example of the use of these kinds of ratings of the quality of the evidence and strength of the recommendation of psychological treatments for people with IDD and comorbid mental health problems can be found in Gómez and Navas (2021).

Process-Focused Evaluation

Process evaluation focuses on the implementation process and attempts to determine the degree of flexibility, predictive accuracy, and explanatory power of the paradigm's components and application. As opposed to outcome evaluations, a process-focused

evaluation emphasizes and pays attention not only to outcomes but especially inputs, activities and outputs, together with the potential relationships between all of them. This process and the process of testing the hypothesized relationships among the elements should be theory driven. In this way, process-focused evaluations that are theory-based allow us to distinguish between implementation failures and theory failures. They help us understand how and why a program, interventions service, or support works or fails. Thus, they allow revision and give new opportunities for improvement and change (Weiss, 1997).

In the IDD field, this type of evaluation might be used for two relevant purposes: (a) to assess the extent to which QOL domains, system of support elements, QOL principles and facilitating conditions, and support values and facilitating conditions are used in supports provision, organization transformation, and systems change; and (b) to explain how multilevel and multifactorial contextual factors related to QOL principles, support values, QOL facilitating conditions, and support facilitating conditions moderate or mediate QOL outcomes. The methods or research designs that we recommend evaluating these complex models are quantitative, such as structural equation modeling (explanatory and predictive modeling). For this theory-driven process evaluation approach that is a critical research approach in the broader field of IDD, the robustness of the evidence (e.g. model-data fit) shouldn't be the only evaluation standard. It is essential here to open the "black box" (i.e., the causal mechanisms) in order to evaluate the new paradigm and illuminate the processes by which we are able to achieve the desired impact. For that reasons, it will be indispensable—also challenging—to provide adequate evidences about a good balance between fidelity (i.e., detailed standardized designs and implementation procedures that make it replicable)

and flexibility of model implementation (i.e., adaptations and accommodations that will be needed to apply it in different contexts and to a heterogeneous population of people with IDD who have exceptional support needs).

Conclusion

According to Kuhn (1970), the acceptance of a new paradigm is based on its attracting new converts, its potential to promote a more successful approach to an endeavor, and its being sufficiently open ended to be testable. There is no question, based on the extent of published literature, that the QOLSP has attracted converts who believe that it encompasses core values, accommodates contextual factors, and can be used for multiple purposes to positively impact the development and implementation of value-based policies and practices that enhance the quality of life and personal wellbeing of people with IDD.

Although the QOLSP is sufficiently open-ended to be testable, the evaluation of its full impact is still "a work in progress." The authors hope that understanding the characteristics of a paradigm and the paradigm-driven evaluation framework described above will facilitate both the application of the new paradigm and measuring its impact through the use of evaluation strategies that encompass principles, utilization, process, and outcomes.

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References

- Amor, A.M., Fernández, M., Verdugo, M.A., Aza, A., & Schalock, R.L. (2020). Shaping the faces of the prism: Rights, supports, and quality of life for enhancing inclusion and opportunities in students with intellectual disability. *Disability & Society*, *49*(3), 5-33. <https://doi.org/10.5604/01.3001.0014.3573>
- Amor, A.M., Verdugo, M.A., Calvo, M. I., & Navas, P. (2018). Psychoeducational assessment of students with intellectual disability: Professional-action framework analysis. *Psicothema*, *30*(1), 39-45. <https://doi.org/10.7334/psicothema2017.175>
- 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.
- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, *27*(1), 3-12. <https://doi.org/10.1111/jar.12083>
- Buntinx, W.H., 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>
- Chacón-Moscoso, S., Anguera, M.T., Sanduvete-Chaves, S., Losada, J.L., Lozano-Lozano, J.A., & Portell, M. (2019). Methodological quality checklist for studies based on observational methodology (MQCOM). *Psicothema*, *31*(4), 458-464. <https://doi.org/10.7334/psicothema2019.116>
- Chen, H.T. (1990). *Theory-driven evaluation*. Sage.
- Claes, C., Vandenbussche, H., & Lombardi, M. (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.
- Consortium on Quality of Life (2019). *Towards a consensus document regarding the conceptualization, measurement, and application of the quality life concept*. University of Gent.
- Cummins, R.A. (2000). Objective and subjective quality of life: An interactive model. *Social Indicators Research*, *52*(1), 55-72. <https://doi.org/10.1023/A:1007027822521>
- DeWitt, R. (2010). *World views: An introduction to the history and philosophy of science*. Wiley-Blackwell.
- 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>
- García, E., O'Brien, P., & Darren, C. (2014). Involving people with intellectual disabilities within research teams: Lessons learned from an Irish experience. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(2), 149-157. <https://doi.org/10.1111/jppi.12081>
- 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, Article 5123. <https://doi.org/10.3390/ijerph17145123>
- Gómez, L.E., & Navas, P. (2021). Tratamientos psicológicos para personas con discapacidad intelectual y problemas de salud mental [Psychological treatments for people with intellectual disability and mental health problems]. In *Manual de tratamientos psicológicos*. Pirámide.
- 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/s10882-019-097202-3>.
- 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 people with intellectual disability* (2nd Ed.) (pp. 71-80). American Association on Intellectual and Developmental Disabilities.
- 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>
- GRADE Working Group (2004). Grading quality of evidence and strength of recommendations. *BMJ*, 328, Article 1490. <https://doi.org/10.1136/bmj.328.7454.1490>
- 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 and Society*, 27, 1-14. <https://doi.org/10.1080/09687599.2012.631794>
- Isaacs, B.J., Brown, I., Brown, R.I., Baum, N., Myserscough, T., Neikrug, A., Roth, D., Shearer, J., & Wang, M. (2007). The International Family Quality of Life Project: Goals and description of a Survey Tool. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 177-185. <https://doi.org/10.1111/j.1741-1130.2007.00116.x>
- Kuhn, T. (1970). *The structure of scientific revolutions* (2nd Ed.). University of Chicago Press.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Sage.
- Lombardi, M., Chu, C., Claes, C., & Schalock, R.L. (2020). Towards an international definition of supports, systems of supports, and elements of systems of supports. *Submitted for publication*.
- Lombardi, M., Vandebussche, H., Claes, C., Schalock, R.L., De Maeyer, J., & Vandevelde, S. (2019). The concept of quality of life as a framework for implementing the UNCRPD. *Journal of Policy and Practice in Intellectual Disabilities*, 16(3), 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>
- 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>
- Muñoz, J., & Fonseca-Pedrero, E. (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>
- National Institute for Health and Care Excellence (2102). *The guidelines manual*. <https://www.nice.org.uk/process/pmg6/chapter/developing-and-wording-guideline-recommendations>
- 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.
- Petry, K., Maes, B., & Vlaskamp, C. (2007). Operationalizing quality of life for people with profound multiple disabilities: A Delphi study. *Journal of Intellectual Disability Research*, 52, 34-39. <https://doi.org/10.1111/j.1365-2788.2006.00882.x>
- Qian, X., Larson, S.A., Ticha, R., & Stancliffe, R., & 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>
- Rdz-Navarro, K., & Yang-Wallentin, F. (2020). Specification issues in nonlinear SEM: The moderation that wasn't. *Psicothema*, 32(1), 115-121. <https://doi.org/10.7334/psicothema2019.235>
- Schalock, R.L., Gómez, 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/10.1352/1944-7558-121.1.1>
- 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., & Keith, K.D. (Eds.) (2016). *Cross-cultural quality of life: Enhancing the lives of people with intellectual disabilities*. American Association on Intellectual and Developmental Disabilities.
- Schalock, R.L., Luckasson, R., & Shogren, K.A. (2020a). Going beyond environment to context: Leveraging the power of context to produce change. *International Journal of Environmental Research and Public Health*. <https://doi.org/10.3390/ijerph17061885>.
- Schalock, R.L., Luckasson, R., & Tassé, M.J. (2019). The contemporary view of intellectual and developmental disabilities. Implications for psychologists. *Psicothema*, 31, 223-228. <https://doi.org/10.7334/psicothema2019.119>
- Schalock, R.L., Luckasson, R., & Tassé, M.J. (2020b). Ongoing transformation in the field of IDD: Taking action for future progress. *Submitted for publication*.
- Schalock, R.L., Luckasson, R., & Tassé, M.J. (2021). *Intellectual disability: Definition, diagnosis, classification, and planning supports*. AAIDD.
- Schalock, R.L., & Verdugo, M.A. (2013). The transformation of disabilities organizations. *Intellectual and Developmental Disabilities*, 51, 273-286. <https://doi.org/10.1352/1934-9556-51.4.273>
- Schalock, R.L., & Verdugo, M.A. (2019). International developments influencing the field of intellectual and developmental disabilities. In K.A. Keith (Ed.), *Cross-cultural psychology: Contemporary themes and perspectives* (2nd Ed.) (pp. 309-323). Wiley-Blackwell.
- 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., & Gómez, L.E. (2020c). The Quality of Life Supports Paradigm: Its description and application in the field of intellectual and developmental disabilities. *Submitted for publication*.
- Schalock, R.L., Verdugo, M.A., & van Loon, J. (2018). Understanding organization transformation in evaluation and program planning. *Evaluation and Program Planning*, 67, 53-60. <https://doi.org/10.1016/j.evalprogplan.2017.11.003>
- Shogren, K.A., Luckasson, R., & Schalock, R.L. (2020a). 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>

- Shogren, K.A., Luckasson, R., & Schalock, R.L. (2020b). Leveraging the power of context in disability policy development, implementation, and evaluation: Multiple applications to enhance personal outcomes. *Journal of Disability Policy Studies*. Advance on line publication. <https://doi.org/10.1177/1044207320923656>
- Shogren, K.A., Schalock, R.L., & Luckasson, R. (2018). The use of a context-based change model to unfreeze the status quo and drive change to enhance personal outcomes of people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 15*, 101-109. <https://doi.org/10.1111/jppi.12233>
- Shogren, K.A., Wehmeyer, M.L., Uyanik, H., & Heidrich, M. (2017). Development of the support decision making inventory system. *Intellectual and Developmental Disabilities, 47*, 220-233. <https://doi.org/10.1352/1934-9556-55.6.432>
- 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.
- Summers, J.A., Poston, D., Turnbull, A., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research, 49*, 777-783. <https://doi.org/10.1111/j.1365-2788.2005.00751.x>
- Thompson, J.R., Bradley, V.J., Buntinx, W., Schalock, R.L., Shogren, K.A., Snell, M.E., Wehmeyer, M.L., Borthwick-Duffy, S., Coulter, D.L., Craig, E.P.M., Gómez, S.C., Lachapelle, Y., Luckasson, R.A., Reeve, A., Spreat, S., Tassé, M.J., Verdugo, M.A., & Yeager, M.H. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities, 47*, 135-146. <https://doi.org/10.1352/1934-9556-47.2.135>
- Thompson, J.R., Schalock, R.L., Agosta, J., Teninty, L., & Fortune, J. (2014). How the supports paradigm is transforming the developmental disabilities service system. *Inclusion, 2*, 86-99. <https://doi.org/10.1352/2326-6988-2.2.86>
- 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., 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*, 1036-1045. <https://doi.org/10.1111/j.1365-2788.2012.01585.x>
- Verdugo, M.A., Schalock, R.L., & Gómez, L.E. (in press). 25 years of parallel paths of the paradigms of quality of life and supports: Coming to the end. *Siglo Cero*.
- Wasserman, D.L. (2010). Using a systems orientation and foundational theory to enhance theory-driven human service program evaluation. *Evaluation and Program Planning, 33*, 67-80. <https://doi.org/10.1016/j.evalprogplan.2009.06.005>
- Wehmeyer, M.L. (Ed.) (2013). *The Oxford handbook of positive psychology and disability*. Oxford University Press.
- 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>