



From a concept to a theory: The six eras of quality of life research and application

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ABSTRACT

This article describes the evolution of the quality of life concept through the lens of six distinct eras. Each era reflects a shared process in which multiple stakeholders, including persons with intellectual and developmental disabilities and researchers, have played a significant role. Across these six eras, research on quality of life has evolved from operationalizing a concept to developing a theory. As described in the article, the first three eras resulted in formulating conceptualization, measurement, and application principles; developing quality of life conceptual and operational models; and constructing reliable and valid instruments to assess quality of life domains or domain-referenced indicators. The application era has focused on applying the concept of quality of life and its measurement, supports provision, conceptualization and theory, and systemic change. The final two eras have involved theory development and theory confirmation.

1. Introduction and overview

Over the past 40 + years, the concept of quality of life (QOL) has evolved from a concept to a model, and from a model to a theory. This Special Issue of *RIDD* provides an excellent opportunity to summarize this evolution and to build on the conceptual and empirical work done to date to ensure a firm foundation for empirically-based theory development and confirmation.

As a brief overview, although the concept of quality of life has been around since antiquity, the concept emerged in the field of intellectual and developmental disabilities (IDD) during the 1980s. Its emergence reflected the goal of the civil rights and deinstitutionalization movements to enhance the rights, autonomy, inclusion, equity, and empowerment of a group of people who had previously experienced exclusion, segregation, discrimination, and the denial of basic human and civil rights.

The critical work to bring about systemic change and implement a “quality of life mentality” was a shared journey, and involved multiple stakeholders including policy makers, service/support providers, professionals, and people with IDD and their families. Starting with the philosophical concept of a life of quality, this evolutionary journey began with developing a set of principles to guide the concept’s operationalization, measurement, and application. These principles laid the foundation for the development of QOL models, which in turn were operationalized through the development of QOL assessment instruments. Armed with these principles, models, and tools, people and organizations began to apply them to develop policies and practices across the micro, meso, and macro systems for multiple purposes, including providing individualized services and supports, transforming organizations, bringing about

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systems and societal change, and moving from a concept to a theory. Throughout this process, researchers played a critical role.

This article describes the evolution of the QOL concept through the lens of six distinct eras. These eras involve formulating principles, model development, instrument construction, QOL application, theory development, and theory confirmation. As discussed throughout the article, these six eras also encompass the goals of this special issue of RIDD: measurement of QOL, factors influencing QOL, interventions to improve QOL, cultural and contextual factors, and methodological issues.

2. Era 1: formulating principles

This first era began in the field of IDD in the early 1990s when concept mapping was used to formulate a set of principles related to the conceptualization, measurement, and application of the QOL concept. These principles were initially published in Schalock et al. (2002), validated in Brown et al. (2004) and updated through a consensus conference in 2019 (Lombardi, Claes, Bradley, & Schalock, 2024). The updating that occurred in 2019 was necessary due to a number of factors. Chief among these were the significant international research and publications regarding the QOL concept; the development and application of both individual and family-referenced QOL models; the significant work done demonstrating the role of context in policies, practices, and human behavior; organizational and systems change supporting “QOL thinking”; and the increasing application of the QOL concept to groups other than people with IDD. The impacts of these developments are shown in column 2 of Tables 1–3.

2.1. Conceptualization principles

The original conceptualization principles captured the changing vision of persons with IDD and their personal well-being, the emerging social-ecological model of disability, and the multi-dimensional nature of human functioning. These conceptualization principles also led to the use of the QOL concept as a social construct to improve and enhance a person or family’s well-being, and provided a QOL framework for the planning and delivery of services, supports, and the evaluation of QOL-related outcomes. The updated conceptualization principles shown in column 2 validate the principles enunciated in Schalock et al. (2002), and reflect the universal nature of QOL, its subjective and objective aspects, its multidimensionality, its being influenced by contextual factors and their interaction, and its potential for change (Lombardi et al., in press).

2.2. QOL measurement principles

The original measurement principles summarized in Table 2 established a research-based framework to develop and standardize instruments to assess QOL domains and their associated indicators (see following era on “Model Development”). The updated measurement principles described in column 2 reflect the significant post-2002 developments in the measurement of the QOL construct and its application to service delivery and program practices. This increased use and understanding of the measurement of QOL also underlies the emergence of additional measurement guidelines listed in column 3 (Table 2).

2.3. QOL application principles

As shown in the first column in Table 3, the original QOL application principles provided the parameters around which the QOL concept and QOL-related outcomes can be used as a basis for policies and practices, professional education and training, research, and outcome evaluation. As noted in column 2, the QOL application principles were expanded in 2019 to include three conditions associated with a person or family-centered approach to QOL: value-based preconditions, contextual analysis, and support strategies. These three components emphasize: (a) the role that context and value-based preconditions play in human functioning and the enhancement of valued outcomes; (b) the adoption of the supports paradigm into disability-related policies and practices; and (c) the social, political, and financial landscape currently facing individuals with IDD and their families. This landscape is characterized by its significant movement toward highly complex service/support delivery networks that comprise widely varying levels and types of providers, settings, and structures; its focus on assessing personal outcomes and organization outputs; its emphasis on an internally based performance monitoring and quality improvement process; and its provision of community-based, individualized systems of supports. In addition, in some jurisdictions, one finds government as a contractor, monitor, and standards setter for individualized services and supports; and/or an emphasis on quality of care rather than quality of life.

Table 1

Original and updated QOL conceptualization principles.

<i>Original principles (2002)</i>	<i>Updated principles (2019)</i>
1. Quality of life has the same components for all people.	1. Quality of life domains are the same for all people.
2. Quality of life is multidimensional and influenced by personal and environmental factors and their interaction.	2. Quality of life is composed of multiple dimensions that are interconnected and influenced by contextual factors and their interaction.
3. Quality of life has both subjective and objective components.	3. Quality of life is both subjective and objective.
4. Quality of life is enhanced by self-determination, resources, purpose in life, and a sense of belonging.	4. Quality of life is dynamic and is subject to change.

Table 2
Original and updated QOL measurement principles and guidelines.

<i>Original measurement principles (2002)</i>	<i>Updated principles (2019)</i>	<i>Additional guidelines (2019)</i>
<ol style="list-style-type: none"> 1. Measurement in QOL involves the degree to which people have life experiences that they value. 2. Measurement in QOL reflects the domains that contribute to a full and interconnected life. 3. Measurement in QOL considers the physical, social, and cultural environments that are important to people. 4. Measurement in QOL includes measures of experiences both common to all humans and those unique to individuals. 	<ol style="list-style-type: none"> 1. QOL measurement focuses on experiential outcomes, with the person as the primary and preferred respondent. 2. QOL measurement results in information that can be used at the individual, family, community, organization, and systems level for multiple purposes. 3. Measurement in QOL requires a multidimensional perspective. 4. The primary use of QOL scores is to address contextual inhibitors and improve the individual's or family's life, and not to compare individuals or families. 5. At the organization or systems level objective QOL indicators can be aggregated and used for multiple purposes including monitoring, reporting, quality improvement and research. 	<ol style="list-style-type: none"> 1. QOL measurement and scale development should be based on a validated QOL conceptual model and/or QOL theory that is inductively developed. 2. Indicators (i.e., items) used to assess QOL domains/dimensions should be culturally sensitive and constructed in a methodologically sound way, including the demonstration of reliability and validity. 3. QOL assessment should include both subjective and objective QOL indicators. 4. The indicators used to assess QOL may differ depending on the target population. 5. A QOL assessment instrument should be administered by a person who is familiar with the QOL concept and competent in assessment strategies.

Table 3
QOL application principles and conditions.

<i>Application principles (2002 and 2019)</i>	<i>Conditions associated with a person or family-centered approach to QOL</i>
<ol style="list-style-type: none"> 1. QOL application enhances well-being within cultural contexts. 2. QOL principles should be the basis for interventions and supports. 3. QOL application should be evidence-based. 4. QOL principles should take a prominent place in professional education and training. 	<ol style="list-style-type: none"> 1. Value-based preconditions that support the application of the QOL concept/framework: participating in community, promoting sense of belonging, maximizing capabilities, freedom to engage in major life activities, commitment to the goals that are important to the person or family, respect for enhancement of differences, and valued social roles of persons with disability in the community. 2. Analysis to address contextual factors that facilitate or inhibit change and personal outcomes. 3. Support strategies based on systems of supports: natural supports, technology, prosthetics, education across the life span, reasonable accommodation, strengths and respect, and professional services.

3. Era 2: model development

Concept mapping, which is a type of structural conceptualization that is useful for multiple purposes including model development, was used in this second era of the evolution of the QOL concept. This work, which began in the mid to late 1980s, involved three activities: (a) generating ideas and listing potential domains and indicators based on the input from focus groups, personal interviews, national and international surveys, and published literature; (b) sorting the potential domains and indicators into groups that made conceptual sense and reflected both the values and aspirations of individuals with IDD and community QOL standards; and (c) defining each domain on the basis of measurable indicators. This approach to model development was used by IDD researchers/investigators such as [Brown and Faragher \(2014\)](#), [Brown et al. \(2010, 2013\)](#), [Buntinx and Schalock \(2010\)](#), [Felce \(1997\)](#), [Gómez et al. \(2015\)](#), and [Verdugo et al. \(2005\)](#) to operationalize the QOL concept into a QOL model.

The present authors also used concept mapping, but developed their operational QOL model based on the integration of published literature in the fields of education, special education, intellectual disability, mental/behavioral health, and aging. Based on that integrative process, we developed and published ([Schalock & Verdugo, 2002](#)) the QOL Model summarized in [Table 4](#). The cross-cultural validation and the hierarchical structure of the model are described in [Jenaro et al. \(2005\)](#) and [Wang et al. \(2010\)](#), respectively. Based on the widespread use of the QOL concept and the supports model, the two have been integrated into the QOL

Table 4
QOL model.

QOL domain	Literature-based indicators*
Personal Development	Education, personal competence, performance
Self-Determination	Autonomy/personal control, goals and personal values, choices
Interpersonal Relations	Interactions, relationships, supports
Social Inclusion	Community integration and participation, valued community roles, social supports
Rights	Human (respect, dignity, equality) and legal (citizenship, access, due process)
Emotional Well-Being	Contentment, self-confect, lack of stress
Physical Well-Being	Health and health care, activities of daily living, leisure
Material Well-Being	Financial status, employment, housing

*Note. The three indicators listed for each domain were the most commonly cited indicators across the fields surveyed in the literature review.

Supports Model that provides a major component in applying the QOL paradigm (Verdugo et al., 2024) and a vehicle for implementing rights (Morán et al., 2023).

Subsequent to the model's development, its framework has been used for multiple purposes. These involve the construction of QOL assessment instruments (see next era); a vehicle for implementing human rights (e.g., Morán et al., 2023); implementing quality enhancement strategies (e.g., Reinders & Schalock, 2014); outcome measurement, planning individualized supports, and organization/systems change (e.g., Baker et al., 2016; Schalock & Keith, 2016); and aligning QOL domains with UNCRPD articles (e.g., Claes et al., 2016; Gómez et al., 2024).

4. Era 3: instrument construction

Once QOL models were developed and validated, wide-spread efforts emerged to construct reliable and valid QOL assessment instruments. The construction of many of these instruments was guided by the measurement principles listed in Table 2, and were organized around model-specific domains and indicators, such as those found in Table 4. Examples of QOL assessment instruments can be found in Brown et al. (2006), Claes et al. (2009), Cummins (2004), Gómez and Verdugo (2016), Gómez et al. (2015), Petry et al. (2009), Summers et al. (2005), Van Hecke et al. (2018), and Verdugo et al. (2010, 2014).

In addition to the measurement principles described in Table 2, the construction and standardization of QOL assessment instruments also strove to meet best practice assessment standards. As described in Claes et al. (2009) and Verdugo et al. (2005), these standards relate to: (a) aligning with professionally based assessment practices (e.g., The Standards of Educational and Psychological Testing; American Educational Research Association et al., 2014); (b) involving the degree to which people have life experiences they value; (c) reflecting the domains that contribute to a full and interconnected life; (d) considering physical, social, and cultural environments/contexts; (e) focusing on experiential outcomes, with the person as the primary and preferred respondent; (f) using a culturally sensitive reliable and valid instrument; (g) using qualitative and quantitative data collection methods; (h) using some combination of self-report and report by others; and (i) using 3–5 point Likert type scales to quantify a respondent's response.

5. Era 4: QOL application

Once principles were formulated, models developed, and instruments constructed, the field evolved to the application era. Since its original conceptualization, there were multiple areas related to the application of the QOL concept. These involve enhancing a person's well-being within a cultural context; measuring QOL domains and indicators and using this information for formative feedback and systemic change; furthering the understanding of the QOL construct and its integrative components; and guiding the development of policies and practices. To determine the extent and focus of the application of the QOL concept, a systematic literature search was performed in the EBSCO, WOS and SciELO databases since 1990. Search terms were *intellectual disabilities*, *developmental disabilities* and

Table 5
QOL application areas and focus areas (2017–2024).

Application area	Major focus
Measurement (37 % of articles)	<ul style="list-style-type: none"> – Personal, cultural, and contextual factors – Comparing types of services and residences – Cross-cultural comparisons – Model to predict QOL dimensions – Development and validation of measures – Communicating support needs – Level of ID – Adaptive behavior influence – QOL and special needs populations (e.g., cerebral palsy, aging, Down Syndrome, psychiatric diagnosis) – Congruency between reports
Individualized supports (27 % of articles)	<ul style="list-style-type: none"> – Life coaching – Positive behavior supports – Social inclusion intervention – Deinstitutionalization – Supporting people with specialized needs (e.g., elderly, severe/ profound limitations, people with complex needs) – Person-centered planning – Supported employment – Self-determination – Physical activity
Conceptualization, Theory (23 % of articles)	<ul style="list-style-type: none"> – Conceptualization, model, paradigm, theory – Moderators and mediators – Disability rights – Disability policy – Shared citizenship
Organization/systems change (12 % of articles)	<ul style="list-style-type: none"> – Organization transformation – Supported accommodation impact – Changes in the provision of supports – Systems change

cognitive disabilities, cross-referencing these words always with *quality of life*, and crossing also with: *personal characteristics, environmental factors, support services and intervention, enhancement, programs*. The initial search years were 1997 - 2024, and resulted in a total of 7327 references. Since a large proportion of these references centered on health-related QOL, focused on a unidimensional approach to disease and its improvement, and used the term QOL without definition and a model or theoretical basis, the search period was limited to 2017–2024, and focused on QOL, IDD, and multidimensionality only. Based on these parameters, 73 published articles were retrieved and analyzed.

The analysis of the 73 articles was completed by one of the authors and one research assistant who read each article's abstract (and article if necessary to complete the analysis). The analytic taxonomy included both the article's application area and major focus. The application areas involved: (a) the conceptualization and evolution of the theoretical development up to the connection with the supports paradigm and the incorporation of rights from a citizenship perspective; (b) the measurement of quality of life in different contexts such as the personal, social and cultural factors that influence it, on populations with different etiologies, and on consideration of the type of measure to use; (c) the strategies and support conditions that facilitate improvement in QOL; and (d) the organizational and system changes necessary to implement good professional and organizational practices. Results of the analysis are found in Table 5. Specific references associated with the major focus found in column 2 of Table 5 are available on line at: <https://gredos.usal.es/handle/10366/157127>.

As noted in Table 5, the major application areas related to measurement, followed by supports provision and conceptualization/model development. Less frequent was organization/ systems change. In reference to the major focus within each application area (column 2 in Table 5), the variety of applications was impressive. This heterogeneity and diversity of the current application of the QOL concept reflects both its attractiveness to stakeholders and flexibility, but also the fact that there is still no clear consensus regarding its intended use and application. In the long run, this lack of consensus may well cause the diminution of the potential and utility of the concept. Thus, the relevance of the article's next section: Theory Development.

6. Era 5: theory development

Moving from the QOL concept to a theory of QOL was first suggested by Cummins (2005). That same suggestion was made by Zuna et al. (2010) regarding family QOL. In regard to the author's work in theory development, we published an article in 2016 entitled, "Moving Us towards a Theory of Individual QOL." In the article, and based on the work of Donaldson and Gooler (2003), and Bortolotti (2008), we defined a theory as an "integrative construct based on facts and experiences that reflects a set of principles upon which the theory is based and applied, and generates hypotheses that can be tested and used as a basis for explanation" (Schalock et al., 2016, p.2). Furthermore, in the article we described how the development of a theory: (a) starts with a conceptual model that can be used to explain a particular phenomenon, explores the impact of various factors influencing the phenomenon, and provide the basis for its application; (b) involves inductive reasoning that incorporates observation and results from scientific inquiry; (c) meets theory standards related to utility, testability, feasibility, applicability, and generalizability; and (d) explains how the theory can be applied and used to generate hypotheses that can be tested and whose results can be used for explanation and application. These same components are evident in the development of a theory of family QOL (e.g., Zuna et al., 2010).

Subsequent material in this section is based on our current understanding of the influence of quality enhancement strategies and the roles that moderator and mediator factors/variables play in impacting one's quality of life. This material encompasses points a-d above, and emphasizes that developing an individual QOL theory involves the following two critical aspects: defining the theory and describing the operational components of the theory.

6.1. Theory definition

Individual QOL is a multidimensional phenomenon composed of core domains that constitute personal well-being. These domains are impacted by personal characteristics and environmental/contextual factors. These characteristics and factors operate at the level of the micro, meso, and macro system levels and can be impacted through three theory-based operational components: quality

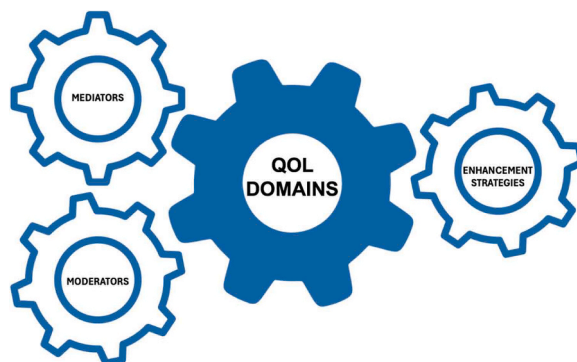


Fig. 1. Operational components of the individual QOL theory.

enhancement strategies, moderator factors, and mediator factors.

6.2. Operational components

As depicted in Fig. 1, the individual QOL theory has three operational components: quality enhancement strategies, moderator factors, and mediator factors. These three components can impact QOL domains and domain-referenced indicators through: (a) direct action (as is the case of quality enhancement strategies); (b) altering the relation between two variables and thus modify the form or strength of the relation (as is the case of moderator factors); and/or (c) influencing the relation between an independent and outcome variable and thus exhibit indirect causation, connection, or relation (as in the case of mediator factors).

6.2.1. Quality enhancement strategies

Quality enhancement strategies are the vehicle through which QOL domains and indicators can be directly impacted. Enhancement strategies involve a number of actions that incorporate QOL principles and systemic changes that can be applied across ecological systems. As synthesized from the current literature and summarized in Reinders and Schalock (2014), Schalock et al. (2016), and Verdugo et al. (2022), exemplary quality enhancement strategies are summarized in Table 6.

6.2.2. Moderating factors

In addition to quality enhancement strategies, and as depicted in Fig. 1, QOL domains and their respective measurable indicators are also impacted by moderators. A *moderating factor* alters the relation between two variables and thus modifies the form or strength of the relation. A *moderator effect* is an interaction in which the effect of one variable is dependent on the level of the other variable (Farmer, 2012; Gómez et al., 2020). Based on current literature (summarized in Gómez et al., 2020) a list of potential moderating factors is provided in Table 7 (top row). As noted in Table 7, moderator factors typically pertain to personal characteristics and family-unit factors.

6.2.3. Mediating factors

A *mediating factor* influences the relation between an independent and outcome variable, and exhibits indirect causation, connection, or relation (Farmer, 2012; Gómez et al., 2020). A *mediator effect* is created when a third factor (e.g., residential status, organization culture, type and frequency of supports provided, or community factor) intervenes between the independent variable (e.g., personal characteristics) and outcome variable (e.g., QOL domain and/or QOL domain indicators). As noted in Table 7 (bottom row), mediating factors typically pertain to an individual's current status, organization culture, provider system, and community factors.

7. Era 6: theory confirmation

Once a theory is developed in reference to its definition and operational components, it needs to be implemented and confirmed. Theory confirmation is a deductive, evidence-based process in which theory-related implementation variables are evaluated to verify and substantiate the theory's status and impact.

Researchers will play a significant and critical role in this confirmation process. To be most effective, researchers will need to employ both qualitative and quantitative research designs to be comprehensive. They will also need to accommodate their research practices to conform to characteristics of the current transformation in the field of IDD. As described by Kover and Abbeduto (2023), Luckasson et al. (in press), MacDonald et al. (2023), and Shogren (2023), these transformational research practices encompass changing perceptions and distinguishing between the context of discovery and the context of justification; increasing allyship and anti-ableism; implementing equity research practices; and centering people with IDD in the process and outcomes of science.

Table 6
Exemplary quality enhancement strategies.

System level	Exemplary quality enhancement strategy
Microsystem (Individual and Family)	<ul style="list-style-type: none"> – Involve the person in developing, implementing, and evaluating person-centered services and supports – Foster decision making, choice making, goal setting, self-advocacy, self-management – Incorporate into research practices the practice of co-engagement and co-production
Mesosystem (Organization and Community)	<ul style="list-style-type: none"> – Implement person-centered planning and evaluation through “My Support Teams” – Conduct contextual analysis to identify context-based factors that facilitate or hinder systemic change – Ensure opportunity development and safe and secure environments – Align support needs with individualized supports provided, with desired outcomes – Build organization and system capacity to bring about meaningful change through workforce development, technology, partnerships, community involvement, and multiple types of resources (e.g., time, money, and expertise)
Macrosystem (Larger System and Society)	<ul style="list-style-type: none"> – Develop policies that embody the conceptualization, measurement, and application principles listed in Tables 1–3 – State measurable indicators associated with the QOL domains incorporated into the QOL model underlying the theory (Table 4) – Develop policies that mandate person-centered planning and evaluation – Enrich peoples' environments to ensure proper nutrition, clean air and sanitation; reduce abuse and neglect; and maximize housing and income

Table 7
QOL moderators and mediators.

Factor	Influence	Variables studied to date
Moderator	Alters the relation between two variables and thus modified the form or strength of the relation	<i>Personal characteristics:</i> Gender, age, intellectual functioning, adaptive behavior, socio-economic status <i>Family-unit factors:</i> Family income, size of family, geographical location, religious preference, family structure
Mediator	Influences the relation between an independent and outcome variable and exhibits indirect causation, connection, or relation	- <i>Current status:</i> Residential platform, employment status, health status, and level of self-determination - <i>Organization culture:</i> Level of personal involvement with the client, level of growth opportunities - <i>Provider system:</i> Type of service, individualized supports - <i>Community factors:</i> Normative expectations, attitudes, media impact

Knowledge is cumulative. Thus, the four theory-related confirmation areas discussed next may well change over time. At this point, we suggest that the theory-related verification and substantiation process focus on: (a) fidelity to theory standards, (b) utilization of the theory, (c) the role of moderating and mediating factors, and (d) testing theory-based hypotheses.

7.1. Fidelity to theory standards

A number of theory standards were mentioned previously regarding utility, testability, cohesiveness, feasibility, applicability, and generalizability. To evaluate the individual QOL theory's fidelity to one or more of these standards, researchers will need to operationally define the respective standard and then determine how the theory's application can best meet the respective standard. Several research techniques, including participant action research, focus groups, or case studies can be used to make the determination and to substantiate the degree to which the respective standard is met. To the authors' knowledge, such research has not been done.

7.2. Utilization of the theory

The focus of this verification and substantiation research area is to describe and evaluate the theory's use in guiding the development and implementation of quality enhancement strategies, person-centered outcome evaluation, and/or policy development. A number of potential utilization-focused research designs can be used, including grounded theory, ethnography, participant action research, focus groups, and/or case studies (Patton, 2008).

7.3. The role of moderating and mediating factors

As discussed above, a moderating factor alters the relation between two variables and thus modifies the form or strength of the relation. In reference to the operational components of the individual QOL theory depicted in Fig. 1, and the moderators listed in Table 7, a moderator effect is an interaction in which the effect of one variable (e.g., QOL domain score or domain indicator scores) is dependent on the level of the other variable (e.g., personal characteristics or family-unit factor). A number of potential research designs can be used to determine these interactions and their effect. These include quasi-experimental designs such as multiple baseline studies, multivariate designs, descriptive designs, correlational designs, and surveys.

In reference to mediating factors, which influence the relation between an independent and outcome variable, and exhibits indirect causation, connection, or relation, a mediator effect is created when a third factor (e.g., residential or employment status) intervenes between the independent variable (e.g., personal characteristics) and outcome variable (e.g., QOL domain and/or QOL domain indicators). As noted in Table 7 (bottom row), mediator factors typically pertain to an individual's current status, organization culture, provider system, and community factors. Since mediating factors are more amenable to systemic change, a number of quantitative research designs are appropriate to use to determine their impact on QOL-related measures. These include between subject designs, randomized control trials, within-subjects designs (repeated measures), and experimental/control designs.

7.4. Testing theory-based hypotheses

The individual QOL theory can also be used for prediction that involves the generation of hypotheses that can be tested, and whose results can be used for explanation and/or application. Hypotheses can focus on the impact of quality enhancement strategies, the role of moderate or mediator factors; or other aspects of the theory, including its definition and application. Exemplary theory-based hypotheses include:

- Personal growth opportunities provided by family members increases the QOL domain scores of personal development, social inclusion, rights, and emotional well-being.
- Individuals who play an active role in their Personal Support Plan's development and implementation will have increased motivation and enhanced QOL domain scores on personal development, self-determination, social inclusion, rights, and emotional well-being.

- An organization that aligns resources with individualized support strategies that focus on the 8 QOL domains (see Table 4) will achieve enhanced QOL domain-referenced outcomes for their clientele.
- Individuals who use assistive technology devices will exhibit higher QOL domain scores related to personal development, interpersonal relations, and self-determination.
- Improving levels of adaptive behavior will result in higher scores in the QOL domains of emotional, physical, and material well-being.
- Significant differences in QOL domain scores are related to the frequency and type of supports provided.

8. Conclusion

This article has described the six eras in QOL research and application. Beginning with embracing a concept and its potential to make life better for persons with IDD, multiple stakeholders worked together to formulate guiding principles regarding the concept's conceptualization, measurement, and application. Once the principles were formulated, concept mapping was used to develop operational models. These models guided the construction of assessment strategies and instruments and provided the framework for application.

More recently, emphasis has focused on theory development and theory confirmation. This focus presents new challenges and opportunities to both researchers and practitioners. The challenges relate to developing a QOL theory that meets standards related to utility, testability, feasibility, applicability, and generalizability, while at the same time working with stakeholders and the community to communicate a clear description of the theory and its potential, and evaluate its impact on the lives of people with IDD and their families. The opportunities involve applying our understanding of quality enhancement strategies and the critical role played by moderator and mediator factors to bring about significant change in the services and supports provided to people with IDD. Collectively, these challenges and opportunities will not only positively affect peoples' lives, but will also move the field into its next (the 7th) significant era. What this era will encompass and reflect is our collective challenges and opportunities.

Research on QOL has been prolific for decades, and in recent years advances in the concept and theory of QOL have converged with a focus on person-centered supports, contextual factors, and the exercise of rights in the community. Measuring and improving the QOL of people with disabilities provides the roadmap for increasing independent living, self-determination, social participation, and shared citizenship of people with IDD.

The societal changes needed to make significant progress in improving the personal well-being of people with significant physical or cognitive limitations are linked to the need for cultural change, based on the assumption of different values regarding the consideration of people belonging to minority groups. And the key is to adopt a systemic approach aimed at synchronizing changes in professional practices, organizational and system practices, support services, and public policies focused on rights and social inclusion.

What This Paper Adds

This article presents an up-to-date review of research concerning the conceptual development of quality of life for individuals with intellectual and developmental disabilities, as well as its measurement and applications in professional, organizational, and public policy practices. It identifies six distinct periods of research focus in recent history. The connection between quality of life approaches and the supports paradigm is underscored, along with the inclusion of contextual factors and the exercise of rights aimed at fostering independent living, self-determination, social participation, and shared citizenship of people with intellectual and developmental disabilities. Finally, emphasis is also placed on the development of theory, its validation, and expectations for the future.

CRedit authorship contribution statement

Robert Logan Schalock: Writing – review & editing, Writing – original draft, Supervision, Investigation, Conceptualization.
Miguel Angel Verdugo: Writing – review & editing, Writing – original draft, Supervision, Investigation, Conceptualization.

Declarations of interest

None.

Data availability

We have shared a permanent link to data within the article.

References

- American Educational Research Association, & American Psychological Association (2014). National Council on Measurement in Education, Joint committee on Standards (for. Standards for Educational and Psychological Testing. Washington, DC: AERA.
- Baker, A., Salisbury, B., & Collins, D. (2016). Changing service delivery systems: An example from Community Living-British Columbia. In R. L. Schalock, & D. Keith Ken (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual disability* (pp. 149–166). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Bortolotti, L. (2008). *An introduction to the philosophy of science*. Maiden, MA: Polity Press.

- Brown, I., Brown, R., Baum, N. T., Isaacs, B. J., Myerscough, T., & Neikrug, S. (2006). *Family quality of life survey: Main caregivers of people with intellectual or developmental disabilities*. Toronto, CA: Surrey Place Centre.
- Brown, I., Hatton, C., & Erickson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practices. *Intellectual and Developmental Disabilities, 51*, 316–332.
- Brown, I., Keith, K. D., & Schalock, R. L. (2004). Quality of life conceptualization, measurement, and application: Validation of the SIRG-QOL consensus principles. *Journal of Intellectual Disability Research, 48*, 451.
- Brown, R. I., & Faragher, R. (2014). *Quality of life and intellectual disability: Knowledge applications to other social and educational challenges* (Eds.). New York: Nova Science.
- Brown, R. I., Hong, K., Shearer, J., Wang, M., & Wang, S. (2010). Family quality of life in several countries: Results and discussion of satisfaction in families where there is a child with a disability. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disability. From theory to practice* (pp. 377–398). New York, NY: Springer.
- Buntinx, W. H. E., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in ID. *Journal of Policy and Practice in Intellectual Disabilities, 7*, 283–294.
- Claes, C., van Hove, G., van Loon, J., Vandeveld, S., & Schalock, R. L. (2009). Quality of life measurement in the field of intellectual disabilities: Eight principles for assessing quality of life-related personal outcomes. *Social Indicators Research, 98*, 61–72.
- 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 disability* (pp. 167–174). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Cummins, R. A. (2004). Instruments for assessing quality of life. In J. H. Hoag, & A. Lange (Eds.), *Approaches to assessing adults with intellectual disabilities: A service provider guide*. London, UK: Blackwell.
- Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research, 49*, 699–706.
- Donaldson, S. I., & Gooler, L. E. (2003). Theory-driven evaluation in action: Lessons from a \$20 million statewide work and health initiative. *Evaluation and Program Planning, 26*(4), 355–366.
- Farmer, C. (2012). Demystifying moderators and mediators in intellectual and developmental disabilities research: A primer and review of the literature. *Journal of Intellectual Disability Research, 56*, 1148–1160.
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research, 41*, 126–135.
- Gómez, L. E., Arias, B., Verdugo, M. A., Tasse, M. J., & Brown, I. (2015). Operationalization of quality of life for adults with severe disabilities. *Journal of Intellectual Disability Research, 59*, 925–994. <https://doi.org/10.3390/healthcare11121748>
- Gómez, L. E., Morán, M. L., Navas, P., Verdugo, M.Á., Schalock, R. L., Lombardi, M., & Brown, I. (2024). Using the quality of life framework to operationalize and assess the CRPD articles and the Sustainable Development Goals. *Journal of Policy and Practice in Intellectual Disabilities, 21*(1), Article e12470. <https://doi.org/10.1111/jppi.12470>
- Gómez, L. E., Schalock, R. L., & Verdugo, M. A. (2020). 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., & Verdugo, M. A. (2016). Outcomes evaluation. In R. L. Schalock, & Ken D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual disability* (pp. 71–80). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Jenaro, C., Verdugo, M. A., Caballo, C., Balboni, G., Lachapelle, Y., Otrebski, W., & Schalock, R. L. (2005). Cross-cultural study of person-centered QOL domains and indicators: A replication. *Journal of Intellectual Disability Research, 49*, 734–739.
- Kover, S. T., & Abbeduto, L. (2023). Toward equity in research on intellectual and developmental disabilities. *American Journal of Intellectual and Developmental Disabilities, 128*, 388–392.
- Luckasson, R., Schalock, R. L., & Bradley, V. J. (2024). Diffusion of the Shared Citizenship Paradigm: Strategies and next steps. *American Journal on Intellectual and Developmental Disabilities*. (in press).
- Lombardi, M., Claes, C., Bradley, V., & Schalock, R. L. (2024). The influence of context on the conceptualización, measurement, and application of the concept of quality of life. *Journal of Policy and Practice in Intellectual Disabilities, 21*(2), Article e12508.
- MacDonald, K. E., Schwartz, A. E., Feldman, M. F., Nelis, T., & Raymaker, D. M. (2023). A call-in for allyship and anti-ableism in ID research. *American Journal of Intellectual and Developmental Disabilities, 128*, 398–410.
- Morán, L., Gómez, L. E., Verdugo, M.Á., & Schalock, R. L. (2023). The quality of life supports model as a vehicle for implementing rights. *Behavioral Sciences, 13*, Article e365. <https://doi.org/10.3390/bs13050365>
- Patton, M. Q. (2008). *Essentials of utilization-focused evaluation*. Sage. Guilford Press.
- Petry, K., Maes, B., & Vlaskamp, C. (2009). Psychometric evaluation of a questionnaire to measure the quality of life of people with profound multiple disabilities (QOL-PMD). *Research in Developmental Disabilities, 30*, 1326–1336.
- Reinders, H. J., & Schalock, R. L. (2014). How organizations can enhance the quality of life of their clients and assess their results: The concept of QOL enhancement. *American Journal on Intellectual and Developmental Disabilities, 119*, 291–302.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., & Paramenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation, 40*, 457–470.
- Schalock, R. L., & Keith, K. D. (2016). The evolution of the quality of life concept. In R. L. Schalock, & D. Keith Ken (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual disability* (pp. 3–12). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners* (pp. 1–430). Washington, DC: American Association on Mental Retardation.
- Schalock, R. L., Verdugo, M. A., Gómez, L. E., & Reinders, H. S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities, 121*(1), 1–12. <https://doi.org/10.1352/1944-7558-121.1.1>
- Shogren, K. A. (2023). The right to science: Centering people with ID in the process and outcome of science. *Intellectual and Developmental Disabilities, 61*, 172–177.
- Summers, J. A., Poston, D., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual and Disability Research, 49*, 777–783.
- Van Hecke, N., Claes, C., Vanderplasschen, W., De Maeyer, J., De Witte, N., & Vandeveld, S. (2018). Conceptualisation and measurement of quality of life based on Schalock and Verdugo's model: A cross-disciplinary review of the literature. *Social Indicators Research, 137*(1), 335–351.
- 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 people 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., Schalock, R. L., & Gómez, L. E. (2024). The quality of life supports model as a major component in applying the quality of life paradigm. *Journal of Policy and Practice in Intellectual Disabilities, 21*(1), Article e12468. <https://doi.org/10.1111/jppi.12468>.
- Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research, 49*, 707–717.
- Wang, M., Schalock, R. L., Verdugo, M. A., & Jenaro, C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. *American Journal on Intellectual and Developmental Disabilities, 115*, 218–233.
- 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). Dordrecht, the Netherlands: Springer.