Ralph Kober
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Chapter 2
Quality of Life Model Development and Use in the Field of Intellectual Disability

Robert L. Schalock, Kenneth D. Keith, Miguel Á. Verdugo, and Laura E. Gómez

Introduction and Overview

Models are helpful in understanding a phenomenon and identifying critical components or factors involved in its application. In program development and evaluation, for example, *logic models* provide a visual map or narrative description of how specific program components are related to a program's desired results. A logic model has many uses, including presenting a program's underlying assumptions, rationale, or theory; explaining the connections between inputs and outcomes; identifying critical factors that affect variation in program outcomes; and providing a systems approach to portraying the path toward a desired outcome. Logic model construction is an important first step in program monitoring, performance management, and evaluation (Frechtling, 2007; Kaplan & Garrett, 2005; Millar, Simeone, & Carnevale, 2001).

As distinct from a logic model, an *operational model* depicts key concepts and variables involved in understanding, operationalizing, and applying a phenomenon or, in the case of the present chapter, the quality of life (QOL) construct. An operational model allows one to operationalize a construct in regard to its definition, conceptual and measurement framework, components, and potential application. Thus, the development and evaluation of an operational model is an important first step in QOL assessment, application, and theory construction.

Although the model development and application work we describe in this chapter is based primarily on the authors' research on *individual-referenced QOL* over the last two decades, details about analogous efforts can be found elsewhere. Specifically, the interested reader can find similar model development and evaluation efforts described for (a) individual-referenced QOL (e.g., Cummins, 1996, 2005; Felce & Perry, 1995, 1996, 1997; Petry, Maes, & Vlaskamp, 2005, 2007); (b) family QOL (e.g., Summers et al., 2005; Chapter 15 by Zuna et al.); (c) health-related QOL (e.g., Byrne-Davis, Bennett, & Wilcock, 2006; Rahtz, Sirgy, & Lee,

R.L. Schalock (✉)
Hastings College, Hastings, NE, USA
e-mail: rschalock@ultraplix.com

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2004; Taillefer, Dupuis, Roberge, & LeMay, 2003); and (d) QOL of older people (e.g., Bowling & Gabriel, 2004). Across these QOL model development and evaluation efforts, one finds reference to the need to focus on the parameters of a QOL model; understand better the relationship between domain-specific factors and external variables; develop more sophisticated models, including a better definition of the content and boundaries of the QOL concept; and validate the factor structure and hierarchical nature of the QOL construct.

This chapter has four major sections. In the first, we describe how we have approached the first step in model development: formulating and validating a QOL conceptual and measurement framework. In the second section, we describe how the model has been operationalized through its definition, components (concepts, indicators, and moderator–mediator variables), and premises. In the third section, we suggest a number of criteria that can be used to evaluate any empirically derived model. In the final section, we reference how the model has been applied in four areas important to the application of the QOL construct in the ID field. We do not suggest that the QOL operational model presented in this chapter is the only way to understand and apply the QOL construct; however, we hope it will provide an example and catalyst for discussion and further QOL model development efforts.

Formulating and Validating a QOL Conceptual and Measurement Framework

Model development involves combining sources of information including existing definitions, literature, and logical reasoning (Shoemaker, Tankard, & Lasorsa, 2004; Chapter 15 by Zuna et al.). In our case, the major source of information has come from two decades of research that has resulted in (a) identifying core QOL domains that have etic properties (Jenaro et al., 2005; Keith, Heal, & Schalock, 1996; Schalock et al., 2005); (b) developing and evaluating of domain-referenced and culturally sensitive QOL indicators used to assess QOL-related personal outcomes (van Loon, van Hove, Schalock, & Claes, 2008; Verdugo, Arias, Gómez, & Schalock, 2008a; Verdugo, Arias, Gómez, & Schalock, 2009); and (c) identifying a number of personal characteristics and environmental variables associated with QOL-related personal outcomes (Keith, 2007; Schalock & Bonham, 2003; Schalock, Gardner, & Bradley, 2007). Our approach to model development has included two steps that reflect the seminal work of Carlisle and Christensen (2006), Fawcett (1999), and Shoemaker et al. (2004): formulating the conceptual and measurement framework, and validating the conceptual and measurement framework.

Formulating the Conceptual and Measurement Framework

Observation and description. The concept of QOL became a widely used notion in national and international arenas during the 1960 and 1970s, and began to seriously influence the field of ID in the 1980s. During these three decades, observation

and description concerning the QOL concept generally fit into either a social indicator/environmental perspective (e.g., Andrews & Whithey, 1976; Davis & Fine-Davis, 1991; Parmenter & Donelly, 1997) or a personal well-being/individual perspective (e.g., Brown, 1997; Cummins, 1997; Goode, 1990). Initially, this perspective incorporated personal values and satisfaction measures; gradually, however, it became apparent that the QOL concept implies some combination of subjective and objective variables and therefore researchers considered more objective indicators reflecting life events and circumstances (Cummins, 2000; Keith, 2001; Schalock, 1999).

Concept mapping. Concept mapping is a type of structural conceptualization that is useful for multiple purposes, including model development, theory construction, and program evaluation (Kane & Trochim, 2007; Rosas & Camphausen, 2007; Sutherland & Katz, 2005). Beginning in the mid to late 1980s, researchers used concept mapping to identify and define core QOL domains and their respective indicators and to develop a conceptual framework based on core domains and indicators. This work involved three activities: (a) generating ideas and listing potential domains and indicators based on input from focus groups, personal interviews, 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 disabilities and community QOL standards; and (c) defining each domain operationally on the basis of measurable indicators (Cummins, 1997; Felce & Perry, 1997; Gardner & Carran, 2005; Hughes & Hwang, 1996; Hughes, Hwang, Kim, Eisenman, & Killian, 1995; Schalock & Keith, 1993; Schalock & Verdugo, 2002).

The net result of these activities for us was the development of the QOL conceptual and measurement framework shown in Table 2.1. In reference to this framework,

Table 2.1 Quality of life conceptual and measurement framework

Domain	Literature-based indicators
Emotional well-being	Contentment, self-concept, lack of stress
Interpersonal relations	Interactions, relationships, supports
Material well-being	Financial status, employment, housing
Personal development	Education, personal competence, performance
Physical well-being	Health and health care, activities of daily living, leisure
Self-determination	Autonomy/personal control, goals and personal values, choices
Social inclusion	Community integration and participation, community roles, social supports
Rights	Human (respect, dignity, equality) and legal (citizenship, access, due process)

The indicators listed are a synthesis of the international QOL literature in education, special education, intellectual disability/mental retardation, mental/behavioral health, and aging (Schalock & Verdugo, 2002). The three indicators listed in each domain are the three most commonly cited indicators across the five areas.

- QOL core domains represent the range over which the QOL concept extends and thus define the multidimensionality of a life of quality.
- QOL indicators are QOL-related perceptions, behaviors, and conditions that operationally define each QOL domain. Their measurement results in QOL-related personal outcomes.

Concept mapping also allowed QOL investigators to develop assessment instruments based on QOL domains and measurable indicators (see Cummins, 2004 for a review). As this work has continued, and as researchers have refined assessment instruments and strategies and made them more reliable and valid, they have laid a foundation to validate the conceptual and measurement framework.

Validating the Conceptual and Measurement Framework

A number of studies have validated the QOL conceptual and measurement framework shown in Table 2.1 by demonstrating the factor structure of the domains and determining the etic (universal) and emic (culture-bound) properties of the domains and indicators. Specifically, a series of cross-cultural studies (Jenaro et al., 2005; Schalock et al., 2005) used the *Cross-Cultural Survey of QOL Indicators* (Verdugo & Schalock, 2003) to survey three respondent groups (consumers, family/advocates, and professionals) representing four geographical groupings (Europe, Central and South America, North America, and Mainland China; 10 countries) on the *importance and use* (three-point Likert ratings) of the 24 core QOL indicators listed in Table 2.1. The total sample across the studies was 2823 (approximately equal numbers in each respondent group). Results indicated that (a) the factor structure and factor stability of the eight core QOL domains listed in Table 2.1 was confirmed; (b) there were similar domain profiles on importance and use across respondent and geographical groups, thus supporting the etic property of the QOL domains; and (c) there were significant group and geographical differences on indicator items, thus supporting the emic property of domain indicators.

Additional confirmation of the eight-domain factor structure shown in Table 2.1 is found in the recent work of Verdugo, Arias, Gómez, and Schalock (2008b, 2009, in press) and Wang, Schalock, Verdugo, and Jenaro (2010). Table 2.2 summarizes the results of this more recent causal modeling analysis that has evaluated

Table 2.2 Quality of life factors and domains

Factor	Domains
Independence	Personal development
	Self-determination
Social participation	Interpersonal relations
	Social inclusion
	Rights
Well-being	Emotional well-being
	Physical well-being
	Material well-being

via structural equation modeling the factor structure and hierarchical nature of the conceptual model summarized in Table 2.1. Note that in Table 2.2 the eight core domains listed in Table 2.1 are aggregated into three higher order factors: independence, social participation, and well-being.

In summary, the development and validation of a QOL conceptual and measurement framework is the first step in developing an operational QOL model. As discussed above, this three-step process involved observation and description, concept mapping, and validating the conceptual and measurement framework. The net result is that we understand better the construct's meaning and boundaries. As the first step in model development, this process also establishes the foundation for operationalizing the model's parameters. We discuss three such parameters next: an operational definition of individual-referenced quality of life, the model's components, and the model's premises.

Operationalizing the QOL Model

As noted previously, we define an operational QOL model as a way to depict key concepts and variables in understanding, operationalizing, and applying the QOL construct. Here we discuss operationalizing the QOL model, including a definition, model components, and model premises.

Definition of Individual-Referenced QOL

The grounded theory approach to model development derives directly from data, rather than a priori assumptions or untested hypotheses (Donaldson & Gooler, 2003; Taylor & Bogdan, 1998). This approach, which we used to develop the operational definition of individual-referenced quality of life that follows, incorporates three primary data sets: (a) identification and validation of core QOL domains that have etic properties (Tables 2.1 and 2.2); (b) demonstration of the cultural sensitivity of the QOL indicators used to assess each domain; and (c) identification of a number of personal and environmental variables that moderate or mediate QOL-related personal outcomes. The QOL definition

> Individual quality of life is a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they may vary individually in relative value and importance. Assessment of QOL domains is based on culturally sensitive indicators.

Model Components

Three principal components allow operationalization of a model: (a) concepts that provide a way to organize the phenomenon; (b) indicators that provide measures of the phenomenon; and (c) variables that allow explanation of factors influencing the

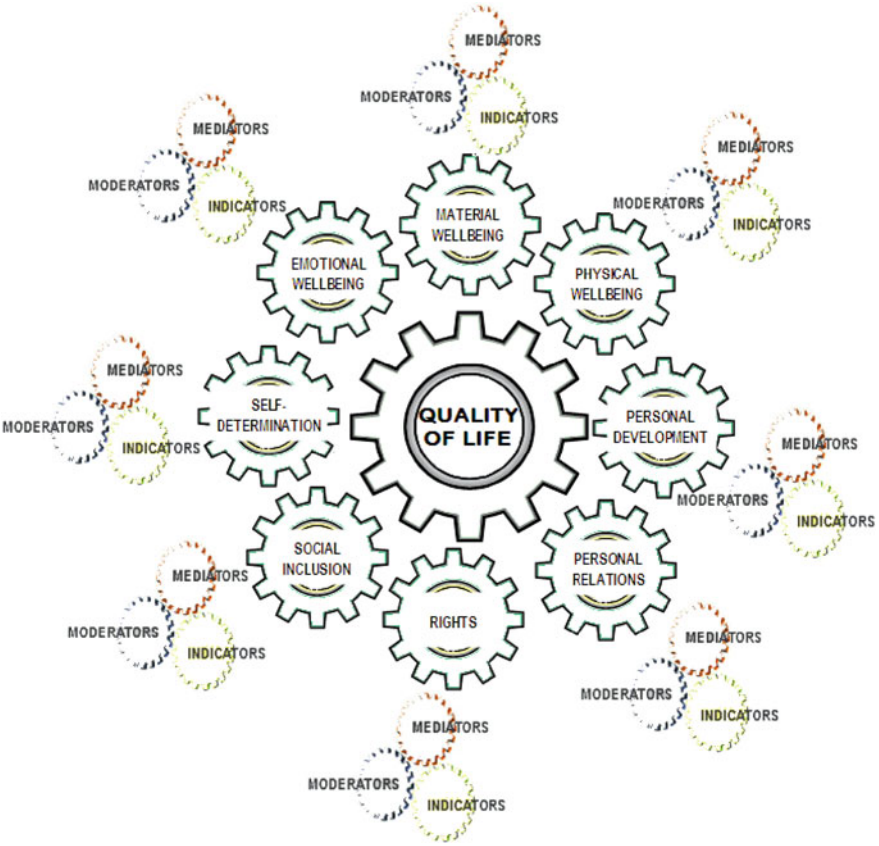

Fig. 2.1 Quality of life operational model

phenomenon. In our work to date (Fig. 2.1), *the operational model, including core QOL domains* (*i.e., the concept*)*, indicators* (*measures*)*, and variables* (*moderators and mediators*)*, operates at the QOL domain level*.

Concepts. The QOL conceptual and measurement framework presented in Table 2.1 and the operational definition of individual-referenced QOL presented above provide the conceptual basis for an operational QOL model: QOL is multidimensional, is composed of eight core domains that are measured on the basis of personal and culturally relevant indicators, and is influenced by personal and environmental factors that act potentially as moderators or mediator. The importance of this framework and operational definition is that the QOL operational model has explanatory power and thus allows one to not only better understand essential characteristics of the QOL construct, but also better understand the role of indicators, moderator variables, and mediator variables.

Indicators. QOL indicators are quality of life-related perceptions, behaviors, and conditions that define operationally each QOL domain. *Their measurement*

results in personal outcomes. For consistency and standardization purposes, indicators are selected on the basis of published research, expert panels, and stakeholder focus groups. Criteria for selecting specific indicators are that those indicator items selected: reflect what people want in their lives, are culturally sensitive, are related to current and future policy issues, are those that the individual (or service provider) has some control over, and can be used for quality improvement purposes (Verdugo, Schalock, Gomez, & Arias, 2007; Verdugo, Schalock, Keith, & Stancliffe, 2005; Walsh, Erickson, Bradley, Moseley, & Schalock, 2006).

Because there is a low correlation between subjective and objective assessments of QOL indicators (Cummins, 1997; Schalock & Felce, 2004), most current QOL assessment instruments use some combination of self-report (subjective) and directly observable (objective) indictors/measures. Both approaches *quantify the respondent's responses*, generally using a 3- to 5-point Likert scale. Such scales are easily understood and meaningful to the respondent. In the area of QOL assessment with persons with ID, Likert-type scales capture a wide range of variance in attitudes and behaviors and provide an efficient and reliable method for assessing domain-referenced indicators in psychometrically sound ways (Bonham et al., 2004; Hartley & MacLean, 2006).

The indicators used to assess a QOL domain will affect our understanding of the domain. The following three examples from four different countries reflect the emic nature of QOL indicators – even though the same criteria listed earlier were used in their selection. *Each of the three examples is referenced to the same domain*: *Personal Development*. In the first example, the six indicators used on the *Ask Me*! *Survey* are (a) "does your job and what you do make you feel important; (b) are you getting the training that will help you get a job or a better job; (c) do others give you a chance to become what you want to be; (d) are you learning things that will make you a better person; (e) do you get the information you need about sexuality; and (f) do you get the services you need?" (Bonham, Basehart, & Marchand, 2005). By comparison, the six indicators used in the *Personal Outcomes Scale* (van Loon et al., 2008), developed in Belgium and The Netherlands, uses a 3-point Likert scale to record self-report and direct observation assessments of activities and instrument activities of daily living; the learning of skills or involvement in some type of educational program; opportunities to demonstrate skills; access to information (e.g., newspaper, TV); and use of a computer, cell phone, and/or calculator. In a similar way, the *Integral Scale* (Verdugo et al., 2009), developed in Spain, uses a 4-point Likert scale to record self-report and a yes–no scale to record direct observation assessments of daily activities and involvement in educational programs and work activities. These three examples show clearly that the indicators used to assess a QOL domain will influence both our understanding of the domain and the meaning of the resultant personal outcomes.

Moderator variables. Investigators working to operationalize models typically use two classes of variables: moderators and mediators. A *moderator variable* is a qualitative (e.g., gender or race) or quantitative (e.g., IQ or SES) variable that alters the direction or strength of the relation between a predictor and an outcome (Baron & Kenny, 1986). A moderator effect is an interaction in which the

effect of one variable depends on the level of the other (Frazier, Tix, & Barron, 2004; Hair, Black, Babin, Anderson, & Tatham, 2006). In reference to individual-referenced QOL outcomes research, intellectual functioning, adaptive behavior level, and level of self-determination are frequently considered moderator variables (Felce & Emerson, 2001; Gardner & Carran, 2005; Lachapelle et al., 2005; Perry & Felce, 2005; Schalock, Bonham, & Marchand, 2000; Stancliffe & Lakin, 1998; Stancliffe, Abery, & Smith, 2000; Wehmeyer & Schwartz, 1998).

Mediator variables. A *mediator* variable influences the relation between an independent variable and an outcome and exhibits indirect causation, connection, or relation (Baron & Kenny, 1986). A mediating effect is created when a third factor intervenes between the independent and outcome variable (Frazier et al., 2004; Hair et al., 2006). In the field of ID, policies, practices, services, and supports can be thought of as mediator variables. Within the individual-referenced QOL outcome research literature, residential setting, employment status, service model, organization culture and operation, and community interactions are mediator variables that affect the level of assessed personal outcomes (Bonham et al., 2004; Gardner & Carran, 2005; Perry & Felce, 2005; Tossebro, 1995; Walsh et al., 2006). An evolving literature (e.g., Cummins, 2005) suggests that at least one personal characteristic – subjective well-being homeostasis – may well serve as a mediator.

The role that moderator and mediator variables play in QOL domains and personal outcomes is not completely clear at this time. For example, Neeley-Barnes, Marcenko, and Weber (2008) reported recently that living in the community (representing a residential setting and thus a mediator variable) influenced three QOL domains: community inclusion, rights, and interpersonal relations. Analogously, particular aspects of a QOL domain may act as a mediator. For example, self-determination (a core QOL domain that includes one or more indicators related to choice, which one might consider a moderator variable) may also act as a mediator that has a causal relation to QOL-related personal outcomes (Cummins, 2005). Furthermore, in reference to logic models, mediators can act as intervening variables between inputs and outcomes (Chen, 2005; Frechtling, 2007). As research in this area continues, it is important to keep in mind that understanding the role of important moderators and mediators of personal outcomes indicates the maturity of a discipline (Aguinis, Boik, & Pierce, 2001; Hoyle & Robinson, 2003) and is also at the heart of model development and theory construction in social science (Cohen, Cohen, West, & Aiken, 2003).

Model Premises

Published literature and logical reasoning influence a model's premises. Table 2.3 summarizes the six premises that have guided this third phase of our work related to operationalizing and applying the model. These six premises not only describe key assumptions regarding the model's development but also provide the basis for evaluating and applying the model.

Table 2.3 Model premises

1. The indicators used to assess a QOL domain will affect our understanding of the domain
2. Both self-report (subjective) and direct observation (objective) measures should be obtained, because there is a low correlation between subjective and objective indicators/QOL measures (Cummins, 1997; Schalock & Felce, 2004)
3. Objective indicators of life experiences and circumstances are better than subjective measures to use for the purposes of model development and program evaluation (Cummins, 2005; Schalock & Felce, 2004; Verdugo et al., 2005)
4. Moderators and mediators are defined in reference to personal characteristics and environmental factors; can operate at any systems level (micro, meso, macro); represent a potential dynamic relationship; and can be considered as intervening variables in logic modeling that includes inputs, throughputs, outputs, and outcomes (Frazier et al., 2004; Frechtling, 2007)
5. Each QOL domain can be a moderator or mediator of any other domain and these inter-correlations are dynamic (Baron & Kenny, 1986)
6. QOL-related models are similar to a middle-range theory that consists of a limited number of concepts and propositions that are generated and tested by means of empirical research. Thus, the concepts and propositions of middle-range theories may be translated, just as with the use of a model, into variables and testable hypotheses (Fawcett, 1999)

Criteria to Evaluate an Operational Model

As the field of ID encounters more models related to constructs such as quality of life, we need to think about the criteria used to evaluate the utility and effect of models, like the one described in this chapter. In an effort to stimulate thought and discussion about relevant criteria for such models, we suggest the following questions and criteria:

1. Is the model credible? That is, is it meaningful and does it describe the phenomenon? Specific criteria would include (Hunter, 2006; Schalock & Luckasson, 2005) the following: the model is systematic (i.e., organized, sequential, logical), formal (i.e., explicit and reasoned), and transparent (i.e., apparent and clearly communicated).
2. Is the model accepted? The literature on diffusion of ideas and innovations (e.g., Rogers, 1995) has identified four key diffusion/acceptance processes: innovation; communication channels; time to involve knowledge transfer, persuasion, decision, implementation, and confirmation; and the system into which the information/idea/model is to be infused. A related series of questions include whether the model is *plausible* so that it can be followed and implemented and *practical and realistic* in taking account of the organization and system's capacities in relation to the environment (Hunter, 2006). Specific criteria include that the model is referenced in academic journals, replicated in cross-cultural studies, and used as a framework for public policy and services delivery practices.
3. Is the model testable? Criteria would include that the model generates hypotheses (e.g., of the role that moderator and mediator variables play in personal outcomes) and is modified on the basis of new information (Keith, 2001, 2007).

4. Does the use of the model change anything? Criteria would include that the model explains how program inputs, processes, and external factors potentially influence outcomes; identifies and prioritizes evaluation questions and helps align evaluation methodology to answer those questions; expands our ability to explain causality and predict results; helps to develop evidence-based practices; and facilitates capacity building for organizations and systems (Carlisle & Christensen, 2006; Corley, 2007; Rogers & Bozeman, 2001; Veerman & van Yperen, 2007).

Applying a QOL Operational Model

We have previously published application examples in four areas related to the operational QOL model presented in this chapter: (a) assessment of personal outcomes (Bonham et al., 2004; Keith, 2007; Schalock, Bonham, & Verdugo, 2008; Schalock, Verdugo, Bonham, Fantova, & van Loon, 2008; van Loon et al., 2008; Verdugo et al., 2007, 2008a, 2008b, 2009); (b) as a basis for agency reporting and provider profiles (Keith & Bonham, 2005; Keith & Ferdinand, 2000; State of Nebraska, 2008); (c) as a basis for quality improvement strategies (Bonham et al., 2005; Schalock, Verdugo, et al., 2008); and (d) as a framework for desired policy outcomes (Shogren et al., 2009) and individual support plans (van Loon, 2008). These applications are occurring at the same time that the field is discussing and evaluating the utility of logic models to both explain the connection between inputs and outcomes and identify critical factors that affect variation in quality of life-related outcomes (Isaacs, Clark, Correia, & Flannery, 2007; Schalock & Bonham, 2003; Schalock et al., 2007).

Because of this convergence, it is important to understand clearly the relationship between operational and logic models. Both have comparable developmental phases (Gugiu, Rodriguez, & Campos, 2007), provide an integrative framework for assessment and evaluation strategies (Cooksy, Gill, & Kelly, 2001), assume that information without use is information without value (Corley, 2007), and can be used as a planning and performance management tool (Kaplan & Garrett, 2005; Millar et al., 2001). Their differences lie in their intended purpose or focus. A logic model can present a program's underlying rationale, theory, and assumptions, including explaining connections between inputs and outcomes, identifying critical factors affecting variation in program outcomes, and providing a systems approach portraying the path toward a desired outcome. In distinction, an operational model operationalizes a construct, including its definition, conceptual and measurement framework, components, and potential application.

Logic and operational models intersect at the outcomes level of the logic model. The viability and strength of a logic [program] model is heavily dependent on the conceptual soundness and validity of the outcome variable(s) used, which underscores the critical need to develop QOL-related personal outcome measures based on an operational model that is formulated and validated through processes such

as those discussed in this chapter. As Stancliffe and Lakin (2005) and Isaacs et al. (2007) have noted, the lack of a robust outcome measure (i.e., dependent variable) has limited both the utility of logic models in the field of IDand the generalizations that can be made about the relationship between inputs and outcomes. Furthermore, in our view, an empirically derived and validated QOL-related operational model provides the conceptual and measurement basis and framework for QOL-related theory development and QOL-related evidence-based practices.

Conclusion

Over the last three decades, we have seen significant conceptual and empirical work clarifying the concept of quality of life. Specifically, we have moved from a philosophical concept to a measurable construct, and from a measurable construct to an operational model that is supported by considerable data and serves as a basis for application and hypothesis testing. The operational QOL model presented in this chapter (a) defines QOL in terms of its empirically derived domains and measurable indicators; (b) measures QOL-related outcomes on the basis of these domain-referenced indicators; (c) operationalizes and assesses moderator and mediator variables that potentially affect variation in QOL-related personal outcomes; and (d) depicts how one or more of the model's components can be used as a basis for service delivery, program practices, and program evaluation.

Based on our experience to date, use of such a model has three implications and potential impacts. First, there should be an increased confidence (by policy makers and service delivery providers) that the QOL construct provides a valid framework for service delivery policies and program practices. Second, an operational model explains how program inputs, processes, and external factors act as moderator or mediator variables that impact QOL domain-referenced personal outcomes. Third, such a model provides an application and research framework for the emerging *trans-disciplinary approach to research and application* that involves researchers and practitioners working jointly in the production of both scientific understanding and societal application effects.

Considerable work remains to be done to evaluate this and similar operational models. This work will entail the continued exploration and identification of culturally sensitive domain-referenced indicators and the best way(s) to assess them, the identification of significant QOL domain-referenced moderator and mediator variables, and the testing of hypotheses that are based on the model. These efforts reflect the next phase in model development and theory construction in the fields of quality of life and intellectual disability.

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References

Aguinis, H., Boik, R. J., & Pierce, C. A. (2001). A generalized solution for approximating the power to detect effects of categorical moderator variables using multiple regression. *Organizational Research Methods*, *4*, 291–323.

Andrews, F. M., & Whithey, S. B. (1976). *Social indicators of well-being: Americans' perception of life quality*. New York: Plenum Press.

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173–1182.

Bonham, G. S., Basehart, S., & Marchand, C. B. (2005, December). *Ask Me! FY 2006: The QOL of Marylanders with developmental disabilities receiving DDA funded supports*. Annapolis, MD: Bonham Research.

Bonham, G. S., Basehart, S., Schalock, R. L., Marchand, C. B., Kirchner, N., & Rumenap, J. M. (2004). Consumer-based quality of life assessment: The Maryland Ask Me! Project. *Mental Retardation*, *42*(5), 338–355.

Bowling, A., & Gabriel, Z. (2004). An intergrational model of quality of life in older age. Results from the ESRC/MRC HSRC quality of life survey in Britain. *Social Indicators Research*, *69*, 1–36.

Brown, R. I. (1997). Quality of life: The development of an idea. In R. I. Brown (Ed.), *Quality of life for people with disabilities: Models, research and practice* (2nd ed., pp. 1–10). Cheltnham: Stanley Thornes.

Byrne-Davis, L. M. T., Bennett, P. D., & Wilcock, G. K. (2006). How are quality of life ratings made? Toward a model of quality of life in people with dementia. *Quality of Life Research*, *15*, 855–865.

Carlisle, P. R., & Christensen, C. M. (2006). *The cycles of theory building in management research*. Boston: School of Management-Boston University and Harvard Business School.

Chen, H. (2005). Theory-driven evaluation. In J. Mathison (Ed.), *Encyclopedia of evaluation* (pp. 415–419). Thousand Oaks, CA: Sage.

Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.). Mahwah, NJ: Erlbaum.

Cooksy, L. J., Gill, P., & Kelly, P. A. (2001). The program logic model as an integrative framework for a multimethod evaluation. *Evaluation and Program Planning*, *24*(2), 119–128.

Corley, E. A. (2007). A use-and-transformation model for evaluation public R & D. *Evaluation and Program Planning*, *30*(1), 21–35.

Cummins, R. A. (1996). The domains of life satisfaction: An attempt to order chaos. *Social Indicators Research*, *52*, 55–72.

Cummins, R. A. (1997). Assessing quality of life. In R. I. Brown (Ed.), *Quality of life for people with disabilities: Models, research and practice* (2nd ed., pp. 116–150). Cheltenham: Stanley Thornes.

Cummins, R. A. (2000). Objective and subjective quality of life: An interactive model. *Social Indicators Research*, *52*, 55–72.

Cummins, R. A. (2004). Instruments for assessing quality of life. In J. H. Hogg & A. Langa (Eds.), *Approaches to the assessment of adults with intellectual disabilities: A service providers guide* (pp. 130–152). London: Blackwell.

Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, *49*(10), 699–706.

Davis, E., & Fine-Davis, M. (1991). Social indicators of living conditions in Ireland with European comparisons. *Social Indicators Research*, *25*(2–4), 318–353.

Donaldson, S. E., & Gooler, L. E. (2003). Theory-driven evaluation and action. *Evaluation and Program Planning*, *26*(4), 355–366.

Fawcett, J. (1999). *The relationship of theory and research* (3rd ed.). Philadelphia, PA: F.A. Davis.

Felce, D., & Emerson, E. (2001). Living with support in a home in the community: Predictors of behavioural development and household and community activity. *Mental Retardation and Developmental Disabilities Research*, *34*(2), 23–41.

Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, *16*(1), 51–74.

Felce, D., & Perry, J. (1996). Assessment of quality of life. In R. L. Schalock (Ed.), *Quality of life: Vol. I: Conceptualization and measurement* (pp. 63–72). Washington, DC: American Association on Mental Retardation.

Felce, D., & Perry, J. (1997). Quality of life: The scope of the term and its breadth of measurement. In R. I. Brown (Ed.), *Quality of life for persons with disabilities: Models, research and practice* (2nd ed., pp. 56–71). Cheltenham: Stanley Thornes.

Frazier, P. A., Tix, A. P., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology research. *Journal of Counseling Psychology*, *51*, 115–134.

Frechtling, J. A. (2007). *Logic modeling methods in program evaluation*. San Francisco: Jossey-Bass.

Gardner, J. F., & Carran, D. (2005). Attainment of personal outcomes by people with developmental disabilities. *Mental Retardation*, *43*(3), 157–174.

Goode, D. A. (1990). Thinking about and discussing quality of life. In R. L. Schalock (Ed.), *Quality of life: Perspectives and issues* (pp. 41–57). Washington, DC: American Association on Mental Retardation.

Gugiu, P. C., Rodriguez, G., & Campos, L. (2007). Semi-structured interview protocol for constructing logic models. *Evaluation and Program Planning*, *30*(4), 339–350.

Hair, J. F., Jr., Black, B., Babin, B., Anderson, R., & Tatham, R. (2006). *Multivariate data analysis* (6th ed.). Upper Saddle River, NJ: Prentice Hall.

Hartley, S. L., & MacLean, W. E., Jr. (2006). A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research*, *50*(Part II), 813–827.

Hoyle, R. H., & Robinson, J. I. (2003). Mediated and moderated effects in social psychological research: Measurement, design, and analysis issues. In C. Sansone, C. Morf, & A. T. Panter (Eds.), *Handbook of methods in social psychology*. Thousand Oaks, CA: Sage.

Hughes, C., & Hwang, B. (1996). Attempts to conceptualize and measure quality of life. In R. L. Schalock (Ed.), *Quality of life: Volume I: Conceptualization and measurement* (pp. 51–61). Washington, DC: American Association on Mental Retardation.

Hughes, C., Hwang, B., Kim, J.-H., Eisenman, L. T., & Killian, D. J. (1995). Quality of life in applied research: A review and analysis of empirical measures. *American Journal on Mental Retardation*, *99*(6), 623–641.

Hunter, D. E. K. (2006). Using a theory of change approach to build organizational strength, capacity, and sustainability with not-for-profit organizations in the human services sector. *Evaluation and Program Planning*, *29*(2), 193–200.

Isaacs, B., Clark, C., Correia, S., & Flannery, J. (2007). The utility of logic models to plan quality of life outcomes evaluations. *Journal of Policy and Practice in Intellectual Disabilities*, *4*, 177–185.

Jenaro, C., Verdugo, M. A., Caballo., C., Balboni, G., Lachapelle, Y., Otrebski, W., et al. (2005). Cross-cultural study of person-centered QOL domains and indicators: A replication. *Journal of Intellectual Disability Research*, *49*(10), 734–739.

Kane, M., & Trochim, W. (2007). *A review of concept mapping for planning and evaluation*. Thousand Oaks, CA: Sage Publications.

Kaplan, S. A., & Garrett, K. E. (2005). The use of logic models by community-based initiatives. *Evaluation and Program Planning*, *28*(2), 167–172.

Keith, K. D. (2001). International quality of life: Current conceptual, measurement, and implementation issues. *International Review of Research in Mental Retardation*, *24*, 49–74.

Keith, K. D. (2007). Quality of life. In A. Carr, G. O'Reilly, P. N. Walsh, & J. McEvoy (Eds.), *The handbook of intellectual disability and clinical psychology practice* (pp. 143–168). London: Routledge.

Keith, K. D., & Bonham, G. S. (2005). The use of quality of life data at the organization and systems level. *Journal of Intellectual Disability Research*, *49*(Part 10), 799–805.

Keith, K. D., & Ferdinand, L. R. (2000). *Project to compare quality of life of Nebraskans with developmental disabilities and citizens without disabilities*. Lincoln, NE: Governor's Planning Council on Developmental Disabilities.

Keith, K. D., Heal, L. W., & Schalock, R. L. (1996). Cross-cultural measurement of critical quality of life concepts. *Journal of Intellectual and Developmental Disability*, *21*, 273–293.

Lachappelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R. L., et al. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research*, *49*(10), 740–744.

Millar, A., Simeone, R. S., & Carnevale, J. T. (2001). Logic models: A systems tool for performance management. *Evaluation and Program Planning*, *24*(1), 73–81.

Neeley-Barnes, S., Marcenko, M., & Weber, L. (2008). Does choice influence quality of life for people with mild intellectual disability? *Intellectual and Developmental Disabilities*, *46*(1), 12–26.

Parmenter, T. R., & Donelly, M. (1997). An analysis of the dimensions of quality of life. In R. I. Brown (Ed.), *Quality of life for people with disabilities: Models, research and practice* (2nd ed., pp. 91–115). Cheltenham: Stanley Thornes.

Perry, J., & Felce, D. (2005). Factors associated with outcomes in community group homes. *American Journal on Mental Retardation*, *110*, 121–135.

Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, *18*, 35–46.

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*, *51*(5), 334–349.

Rahtz, D. R., Sirgy, M. J., & Lee, D.-J. (2004). Further validation and extension of the quality of life/community-health care model and measures. *Social Indicators Research*, *69*, 167–198.

Rogers, E. M. (1995). *Diffusion of innovations* (4th ed.). New York: Free Press.

Rogers, J. D., & Bozeman, B. (2001). Knowledge value alliances: An alternative to the R & D project focus in evaluation. *Science Technology and Human Values*, *26*(1), 23–55.

Rosas, S. R., & Camphausen, L. C. (2007). The use of concept mapping for scale development and validation in evaluation. *Evaluation and Program Planning*, *30*(2), 125–135.

Schalock, R. L. (1999). Three decades of quality of life. In M. L. Wehmeyer & J. R. Patton (Eds.), *Mental retardation in the 21st century* (pp. 335–358). Austin, TX: Pro-Ed.

Schalock, R. L., & Bonham, G. S. (2003). Measuring outcomes and managing for results. *Evaluation and Program Planning*, *26*(3), 229–235.

Schalock, R. L., Bonham, C. B., & Marchand, C. B. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction. *Evaluation and Program Planning*, *23*(1), 77–88.

Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, *31*(2), 181–190.

Schalock, R. L., & Felce, D. (2004). Quality of life and subjective well-being: Conceptual and measurement issues. In E. Emerson, C. Hatton, T. Thompson, & T. Parmenter (Eds.), *Handbook of applied research in intellectual disabilities* (pp. 261–279). New York: Wiley.

Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life of persons with intellectual and other developmental disabilities: Applications across individuals, organizations, communities, and systems*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schalock, R. L., & Keith, K. D. (1993). *Quality of life questionnaire manual*. Worthington, OH: IDS.

Schalock, R. L., & Luckasson, R. (2005). *Clinical judgment*. Washington, DC: American Association on Mental Retardation.

Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

Schalock, R. L., Verdugo, M. A., Bonham, G. S., Fantova, F., & van Loon, J. (2008). Enhancing personal outcomes: Organizational strategies, guidelines, and examples. *Journal of Policy and Practice in Intellectual Disabilities*, *5*(4), 276–285.

Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, W., Wehmeyer, M., Xu, J., et al. (2005). A cross-cultural study of quality of life indicators. *American Journal on Mental Retardation*, *110*, 298–311.

Shoemaker, P. J., Tankard, J. W., Jr., & Lasorsa, D. L. (2004). *How to build social science theories*. Thousand Oaks, CA: Sage Publications.

Shogren, K. A., Bradley, V. J., Gomez, S. C., Yeager, M. H., et al. (2009). Public policy and the enhancement of desired public policy outcomes for persons with intellectual disability. *Intellectual and Developmental Disabilities*, *47*, 307–319.

Stancliffe, R., Abery, B., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation*, *105*, 431–454.

Stancliffe, R. J., & Lakin, C. K. (1998). Analysis of expenditures and outcomes of residential alternatives for persons with developmental disabilities. *American Journal on Mental Retardation*, *102*, 552–568.

Stancliffe, R. J., & Lakin., K. C. (2005). *Costs and outcomes of community services for people with intellectual disabilities*. Baltimore, MD: Paul H. Brookes.

State of Nebraska Health and Human Services. (2008). *2008 Nebraska developmental disabilities provider profiles*. Lincoln, NE: Author (Division of Developmental Disabilities).

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., et al. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research*, *49*(10), 777–783.

Sutherland, S., & Katz, S. (2005). Concept mapping methodology: A catalyst for organizational learning. *Evaluation and Program Planning*, *28*(3), 257–269.

Taillefer, M.-C., Dupuis, G., Roberge, M.-A., & LeMay, S. (2003). Health-related quality of life models: Systematic review of the literature. *Social Indicators Research*, *64*, 293–323.

Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource* (3rd ed.). New York: Wiley.

Tossebro, J. (1995). Impact of size revised: Relation of number of residents to self-determination and deprivation. *American Journal on Mental Retardation*, *100*, 59–67.

Van Loon, J. (2008). Aligning quality of life domains and indicators to support intensity scale data. In R. L. Schalock, J. R. Thompson, & M. J. Tasse (Eds.), *Supports intensity scale companion guide: A resource for SIS users* (pp. 80–87). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Van Loon, J., van Hove, G., Schalock, R. L., & Claes, C. (2008). *Personal Outcomes Scale*. Middleburg, NL/Gent: Arduin Steichlich/Department of Special Education, University of Gent.

Veerman, J. W., & van Yperen, T. A. (2007). Degrees of freedom and degrees of certainty: A developmental model for the establishment of evidence-based youth care. *Evaluation and Program Planning*, *30*(2), 136–148.

Verdugo, M. A., Arias, B., Gómez, L. E., & Schalock, R. L. (2008a). *GENCAT Scale. Formulary of the Gencat Scale. Application Manual of the Gencat Scale*. Barcelona: Department of Social action and Citizenship, Generalitat of Catalonia.

Verdugo, M. A., Arias, B., Gómez, L. E., & Schalock, R. L. (2008b). *GENCAT Scale. Final report about the development of a multidimensional scale for assessing the quality of life of human services users in Catalunya*. Barcelona: Department of Social action and Citizenship, Generalitat of Catalonia.

Verdugo, M. A., Arias, B., Gómez, L. E., & Schalock, R. L. (2009). *The integral scale*. Madrid: CEPE.

Verdugo, M. A., Arias, B., Gómez, L. E., & Schalock, R. L. (in press). 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*.

Verdugo, M. A., & Schalock, R. L. (2003). *Cross-cultural survey of QOL indicators*. Salamanca: Institute on Community Integration-Faculty of Psychology-University of Salamanca.

Verdugo, M. A., Schalock, R. L., Gomez, L. E., & Arias, B. (2007). Developing multidimensional quality of life scales focusing on the context: The Gencat Scale. *Siglo Cero*, *38*(4), 57–72.

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*(10), 707–717.

Walsh, P., Erickson, E., Bradley, V., Moseley, C., & Schalock, R. L. (2006). *Supported accommodation services for people with intellectual disabilities: A review of models and instruments used to measure quality of life in various settings*. Dublin: National Disability Authority.

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.

Wehmeyer, M., & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, *31*(1), 3–12.

Chapter 3
Measuring Subjective Wellbeing: The Personal Wellbeing Index – Intellectual Disability

Robert A. Cummins, Anna L.D. Lau, Gareth Davey, and Jane McGillivray

Introduction

The past few decades have seen an exponential growth in quality of life (QOL) research. The results of these endeavors now form an increasingly coherent body of literature that has generated widespread interest in the wellbeing of populations and individuals. This interest is evident not just among researchers, but also in the increasing use of QOL measures as outcome indicators, and as information upon which to make policy decisions regarding the allocation of resources. However, all such applications depend critically on an understanding of the QOL construct and on the instruments used to make the necessary measurements.

Advancing a common understanding within this area has proved very challenging, not least because the field involves three disciplinary areas, and hence three different orientations to QOL measurement. These are economics, which continues to regard money as proxy for happiness (for a discussion see Ott, 2005); medicine, which regards QOL as centered on health and employs a measured construct called Health Related Quality of Life (for a critique see Cummins, Lau, & Stokes, 2004). And then there are the social sciences within which QOL is seen as an overarching construct incorporating matters of money and health, but not restricted to these variables. It is this latter tradition that forms the basis of the following discussion.

Within the social sciences, QOL has been a topic of systematic study for over 30 years. The area was launched into scientific prominence by the publications of Andrews and Withey (1976) and Campbell, Converse, and Rodgers (1976). Both texts demonstrated the importance of clearly differentiating between the objective and the subjective dimensions of QOL. This distinction has now become the cornerstone of theory development but had to initially overcome the prejudice against subjective measurement, as being inherently unreliable.

R.A. Cummins (✉)
School of Psychology, Deakin University, Geelong, VIC, Australia
e-mail: cummins@deakin.edu.au

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