

# The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities

Robert L. Schalock<sup>a,\*</sup>, Gordon S. Bonham<sup>b</sup>, Miguel A. Verdugo<sup>c</sup>

<sup>a</sup>Hastings College (Nebraska), P.O. Box 285, Chewelah, Washington, DC 99109, USA

<sup>b</sup>Bonham Research, Baltimore, MD, USA

<sup>c</sup>Department of Psychology, Institute for Community Inclusion, University of Salamanca, Spain

Received 17 September 2007; received in revised form 2 February 2008; accepted 2 February 2008

## Abstract

The concept of quality of life (QOL) is increasingly being used in the field of intellectual disabilities as a conceptual and measurement framework for program planning and evaluation. This article describes the development of a QOL conceptual and measurement framework, and summarizes how this framework is currently being used both nationally and internationally to assess and report personal QOL-related outcomes, to guide quality improvement strategies, and to evaluate the effectiveness of those strategies. Implications of such use are discussed, including those related to understanding mental models, developing internal data systems, supporting organization change, and building on current public policies. The article concludes with reference to the evolving nature of the QOL concept and the impact of this on model development and transdisciplinary research.

© 2008 Elsevier Ltd. All rights reserved.

**Keywords:** Quality of life application; Quality of life conceptual framework; Quality of life measurement framework; Personal outcomes; Quality improvement

## 1. Introduction

Historically, the concept of quality of life (QOL) has been used in the field of intellectual and closely related developmental disabilities (IDD) primarily as a sensitizing notion that during the 1980s and 1990s grounded and guided what an individual valued and desired. During the past decade, its role has expanded to include: (a) a conceptual framework for assessing personal outcomes; (b) a social construct that guides program practices and quality improvement (QI) strategies; and (c) a criterion for assessing the effectiveness of those practices and strategies. As such, it has become an agent for social change that at its core makes us think differently about persons with IDD and how we might reform policy and practices to enhance QOL-related personal outcomes. Basic to that process is a

desire among stakeholders for quality services and personal outcomes; a focus on providing individualized supports within inclusive (i.e. community) environments; an emphasis on key performance indicators and evidence-based practices; and the use of best practices regarding skill training, assistive technology, and environmental accommodation (Schalock, Gardner, & Bradley, 2007).

Despite the appeal of the QOL concept in the field of IDD, it has yet to be fully integrated into current policy and practices due to a number of issues related to its conceptualization, measurement, and application. In addition, the ecological and consumer empowerment emphasis of the QOL movement is frequently at odds with models of disablement that focus on defectology (Devlieger, Rusch, & Pfeiffer, 2003) and models of care that focus on control, power, health, safety, and categorization (De Walle, van Loon, van Hove, & Schalock, 2005).

The major purpose of this article is to discuss how QOL investigators in the field of IDD are addressing these issues.

\*Corresponding author. Tel.: +1 509 935 8176; fax: +1 509 935 6101.  
E-mail address: rschalock@ultraplix.com (R.L. Schalock).

Specifically, in subsequent sections, we summarize the development of a QOL conceptual and measurement framework and then explain how this framework is currently being used both nationally and internationally to: implement QOL-related program practices, assess and report personal outcomes, guide QI strategies, and evaluate the effectiveness of those practices and strategies. The article is primarily relevant to: program service managers who are striving to make organization conditions more congruent with the mental model that already governs ‘support thinking’; to professional in their efforts to implement QOL-focused program practices and individualized supports; and to researchers who can use the conceptual and measurement frameworks to guide their research and evaluation studies. The article also reflects the emerging transdisciplinary approach to research that involves researchers and practitioners working jointly in the production of both scientific understanding and societal application effects (Walter, Helgenberger, Wiek, & Scholz, 2007).

Although the article is based primarily on the work of the authors, details about parallel developments in individual-referenced QOL research and application can be found in the published work of Cummins (1997, 2004), Perry and Felce (2005) and Wehmeyer and Schwartz (1998). Parallel developments in the field of family QOL can be found in the published work of Brown, Anand, Fung, Isaacs, and Braum (2003), Poston et al. (2003), and Summers et al. (2005).

## 2. Conceptual framework

The conceptual QOL conceptual framework presented in Table 1 has three key components: factors, domains, and indicators. This framework has been developed by the authors over the last two decades using three sequential steps (Shoemaker, Tankard, & Larorsa, 2004): observing and describing the phenomenon, concept mapping, and empirically testing the framework in a series of studies described in this and subsequent sections. The importance of this conceptual framework is that it has explanatory

power and thus provides: a firm foundation for the measurement of QOL-related personal outcomes; and the use of QOL-related factors, domains, and indicators as a focus of individualized supports, program policy and practices, and QI supports. The net effect of a conceptual framework such as that described in Table 1 is that it has advanced the field in two ways: from a *concept* of QOL to a QOL *construct* with associated measurement properties; and from a conceptual framework to the initial work on *model development* and evaluation. As discussed by Kalafat, Illback, and Sanders (2007), by understanding the conceptual framework of a phenomenon, one can identify its core components or mediators, and distinguish these from more changeable or adaptable features of the environment.

### 2.1. QOL factors

In our research to date, ‘QOL’ has been considered to be an overall latent construct. Beneath this are the three factors listed in Table 1: Independence, Social Participation, and Well-Being. These three higher order constructs (i.e. factors) have been identified on the basis of structural equation modeling employing a cross-cultural survey instrument (Verdugo & Schalock, 2001) based on the 24 core indicators and eight domains identified from the international QOL literature and listed in Table 1 (right column). The survey instrument employs a 4-point Likert scale to measure the dimensions for both sets of questions: (a) importance: from ‘not important’ (1) to ‘very important’ (4); and (b) use: from ‘never’ (1) to ‘always’ (4). The instrument has been administered to date in 10 countries representing three continents. Survey data have been obtained from 900 consumers with intellectual disability/mental retardation, 900 parents/guardians of these consumers, and 900 professionals providing services and supports to those consumers (Jenaro et al., 2005; Schalock et al., 2005; Wang, Schalock, Verdugo, & Jenaro, in press). These three factors align well with stated public policies and goals related to personal well-being (Schalock et al., 2007; Walsh, Erickson, Bradley, Moseley, & Schalock, 2006).

Table 1  
Quality of life conceptual model: factors, domains, and indicators

Factor	Domain	Exemplary indicators
Independence	Personal development Self-determination	Education status, personal skills, adaptive behavior (ADLs & IADs) Choices/decisions, autonomy, personal control, personal goals
Social participation	Interpersonal relations Social inclusion Rights	Social networks, friendships, social activities, interactions, relationships Community integration/participation, community roles, supports Human (respect, dignity, equality) Legal (legal access, due process)
Well-being	Emotional well-being Physical well-being Material well-being	Safety & security, positive experiences, contentment, self-concept, lack of stress Health & nutrition status, recreation, Leisure Financial status, employment status, housing status, possessions

## 2.2. QOL domains

The eight domains listed in Table 1 are the dimensions composing personal well-being. The set represents the range over which the QOL concept extends and thus defines the multi-dimensionality of a life of quality. These eight domains emerged from a synthesis of international QOL literature (Schalock & Verdugo, 2002), and have subsequently been validated in reference to both domain structure and stability in a series of cross-cultural studies (Bonham et al., 2004; Jenaro et al., 2005; Schalock et al., 2005; Verdugo, Gomez, Arias, & Martin, 2006).

## 2.3. QOL indicators

The exemplary indicators listed in Table 1 are QOL-related perceptions, behaviors, and conditions that give an indication of a person's well-being. They define operationally each QOL domain, and *their measurement results in personal outcomes*. The exemplary indicators listed in Table 1 are the most common indicators based on an international review of QOL literature in the areas of education, special education, intellectual disability/mental retardation, mental/behavioral health, and aging (Schalock et al., 2007; Schalock & Verdugo, 2002). Personal outcomes are measured at the indicator item level, but are typically aggregated for reporting and analysis purposes at the domain and factor levels.

## 3. Measurement framework

In this section of the article we present one approach to QOL measurement based on the assessment of indicator items associated with the domains and indicators summarized in Table 1. In understanding this measurement framework, three points are important to keep in mind. First, the measurement of indicator items results in what are commonly referred to in the field as 'personal outcomes' (Gardner & Carran, 2005). Second, measuring both subjective ('self-report') and objective ('direct observation') indicators on the same item overcomes many of the problems associated with either focusing on only subjective or objective measures (which typically are not highly correlated) or combining subjective and objective measures into the same measurement scale (Cummins, 1997, 2004; Schalock & Felce, 2004). Third, QOL measurement needs to be sensitive to both the etic (universal) and emic (culture-bound) properties of QOL domains and indicators (Keith & Schalock, 2000). In reference to the latter point, a series of cross-cultural studies based on the conceptual framework presented in Table 1 suggests that the eight listed domains have etic properties in regard to rated importance, but emic properties in regard to rated use (Jenaro et al., 2005; Schalock et al., 2005).

## 3.1. QOL indicator items

Indicator items associated with each QOL domain listed in Table 1 are used to assess either the person's perceived well-being on the item ('self-report') or an objective indication of the person's life experiences and circumstances ('direct observation'). An example is shown in Table 2.

## 3.2. Item selection

A concept mapping approach is typically used to select specific items, depending on the organization, state, country, or region. This concept mapping approach to item selection involves the following eight steps that have been used in multiple efforts to develop QOL domain/indicator-referenced measurement items and scales: (a) the item pool is derived from previous research and published literature; (b) expert judges in the field evaluate each item in reference to domain specificity, importance, and observability; (c) focus groups composed of important stakeholders (e.g. professionals, organization personnel, consumers, and families) evaluate each item in reference to its value and importance to them; (d) a pilot scale is developed based on an analysis of information obtained from steps b and c; (e) the pilot scale is administered to a representative sample of the population(s) for whom the scale will be used; (f) pilot study data are analyzed to confirm the reliability, domain loading, robustness, and etic (i.e. universal) property of the respective item; (g) final items are selected that meet the criteria listed in step f; and (h) the assessment instrument is finalized, including administration and scoring instructions. Based on these eight steps, QOL-related personal outcome scales have been developed that typically use a 3–5 point Likert scale to rate either the person's perception of their status on the respective indicator item ('self-report') and/or the direct observation of the person's life experiences and circumstances ('direct observation'). Typically, the scale includes 5–7 indicator items per domain (Bonham et al., 2004; Van Hove & van Loon, 2007; Verdugo, Schalock, Gomez, & Arias, 2007).

## 3.3. Item selection criteria

Criteria for selecting specific indicators/personal outcomes are that those indicator items selected: reflect what people want in their lives, relate to current and future policy issues, are those that the service provider has some control over, and can be used for reporting and QI purposes (Walsh et al., 2006). Depending on intended use, an additional criterion is that the items selected have etic properties—that is, are relevant to different diagnostic groupings and persons without disabilities. This criterion is consistent with both the QOL conceptual principle that 'QOL has the same components for all people' (Schalock, Verdugo, Bonham, Fantova, & van Loon, 2008), and the

Table 2  
Exemplary items used to measure QOL indicators and domains

---

<i>Domain: personal development; Indicator: adaptive behavior</i>	
Self-report:	To what degree are you able to feed yourself, get up and down, toilet, and dress yourself? (independent, with assistance, cannot)
Direct observation:	ADL status: How would you rate the degree to which the person does these activities of daily living? (generally independent, generally with assistance, cannot do on own)
<i>Domain: self-determination; Indicator: choices</i>	
Self-report:	Are you offered choices (e.g. what to wear, what to eat, places to go)? (yes, not sure, no)
Direct observation:	To what degree is the person offered choices as to what to wear, what to eat, places to go etc.? (considerable, some, little or none)
<i>Domain: interpersonal relations; Indicator: friendships</i>	
Self-report:	Do you have friends? (yes, not sure, no)
Direct observation:	Has the person identified persons as friends and refers to them as such? (yes, not sure, no)
<i>Domain: social inclusion; Indicator: community participation</i>	
Self-report:	Do you take part in activities within the town where you live? (yes, not sure, no)
Direct observation:	How often is the person involved in activities within the community? (frequently (weekly), sometimes (1–2/week), never)
<i>Domain: rights; Indicator: dignity and respect</i>	
Self-report:	Do people around you allow privacy, ask what you think, leave you alone while bathing? (yes, not sure, no)
Direct observation:	How much respect and dignity is shown this person by staff and others? (considerable, some, very little)
<i>Domain: emotional well-being; Indicator: safety and security</i>	
Self-report:	Do you feel safe and secure? (yes, not sure, no)
Direct observation:	How would you rate the safety and security of the person's living and work/school environments? (very safe, somewhat safe, not safe)
<i>Domain: physical well-being; Indicator: health status</i>	
Self-report:	What about your health? How do you feel? (very good, okay, not good/ill)
Direct observation:	How would you evaluate the physical health of this person? (good, fair, poor)
<i>Domain: material well-being; Indicator: possessions</i>	
Self-report:	Do you have personal possessions such as a radio, TV, stereo, pictures? (yes, not sure, no)
Direct observation:	How many personal possessions does the person have? (many, some, few or none)

---

current efforts to develop empirical benchmarks that involve comparisons of personal QOL-related outcomes across different diagnostic groups and the general population (Keith & Bonham, 2005; Schalock et al., 2007; Verdugo, Schalock, Keith, & Stancliffe, 2005).

### 3.4. Measurement guidelines

Four key guidelines for the measurement of personal outcomes are that: (a) objective indicators of personal experiences and circumstances are better than subjective measures to use for the purpose of program evaluation and QI (Cummins, 1997; Emerson et al., 2001; Schalock & Felce, 2004; Verdugo et al., 2005); (b) Likert-type scales, which are easily understandable and meaningful to the respondent and thus can be used to capture a wide range of variance in attitudes and behaviors, provide an efficient and reliable method for assessing personal outcomes in psychometrically sound ways (Hartley & MacLean, 2006); (c) if the person cannot respond for themselves, proxies can be used, but their effect on the obtained information needs to be built into the data analysis (Bonham et al., 2004; Schalock & Bonham, 2003; Stancliffe, 2000; Verdugo et al., 2005); and (d) personal outcomes can be analyzed at the level of the individual, aggregated at the organization or systems level, and complemented by other performance measures such as health and safety indicators, client movement patterns, staff turnover, and unit costs (Gardner

& Carran, 2005; Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, 2003).

## 4. Application

To date, the authors have been involved in four applications in the field of IDD of the QOL conceptual and measurement frameworks just described. Although apparent in other education, rehabilitation, and health areas (cf. Schalock, 2004; Schalock et al., 2007) the following discussion focuses on those within the IDD field: planning and providing individualized supports, establishing benchmarks, identifying and targeting significant predictors of QOL-related personal outcomes, and implementing QI strategies.

### 4.1. Individualized supports within a QOL framework

Since the mid-1980s the supports paradigm has made at least three significant impacts on policies and practices regarding persons with IDD. First, the supports orientation has brought together the related practices of person-centered planning, personal growth and development opportunities, community inclusion, self-determination, and empowerment. Second, the implementation of individualized supports has led to the expectation of enhanced personal outcomes, which are typically related to QOL

domains and indicators such as those listed in Table 1. Third, the level or intensity of a person's support needs is being used as a basis for agency and systems planning and funding models.

The Individual Supports Plan (ISP) and caretaker provided supports are two key components of applying the supports paradigm to persons with IDD. Increasingly, we are seeing the integration of the QOL framework into the ISP process so as to align support provision to the QOL framework and thus focus on the role that individualized supports play in the enhancement of personal, QOL-related outcomes. For example, in the Arduin Program in The Netherlands, the content of the individual's service plan is constructed using a 'logic model' that is aligned with the QOL conceptual and measurement framework discussed earlier in this article. Specifically, the *input* is the goals and perspective of the person and their assessed support needs; the *throughput* specifies individual support activities related to each of the eight QOL domains listed in Table 1; and the *output* is personal outcomes as assessed on a Personal Outcomes Scale patterned after the approach summarized in Table 2 (Van Loon, 2008; Van Hove & van Loon, 2007).

Since most supports are provided by care takers (e.g. family members or direct care/support staff) it is important for these individuals to see the relationship between the QOL concept and the focus and importance of the supports the person provides. Table 3 shows a 'QOL Support Framework' that is currently used in education and rehabilitation programs to align QOL domains to potential individualized supports (Schalock, 2004).

#### 4.2. Benchmarks

Benchmarks have been developed and used out of a desire for organizations to achieve quality outcomes (Center for the Study of Social Policy, 1996; Tucker &

Codding, 1998). The following two examples exemplify how *empirical benchmarks can be based on assessed QOL-domain scores*.

Since 1998, the Nebraska Department of Health and Human Services has assessed the QOL of service recipients with intellectual disabilities on eight domains similar to those listed in Table 1. These scores are totaled to produce an index of perception of well-being (Keith & Bonham, 2005; Nebraska Health and Human Services, 2006). Average scores for each domain and index are reported annually for each service provider agency in the state, along with the state average for each domain, and also for a random sample of persons without disabilities living in the same community as the provider agency. Thus, there are three empirical benchmarks: one based on the yearly trended scores for the agency, the second represented by the statewide average scores per domain and total score, and the third by those living in the community without disabilities. Each empirically derived benchmark provides both a point of reference and a standard by which agencies can compare themselves with others providing similar services. The importance of the third (community-referenced) benchmark is that it provides an index of the discrepancy between personal, QOL-related outcomes for persons with disabilities and community QOL indicators.

The second approach to benchmarking comes from the Ask Me! Project. As with Nebraska, Provider Profiles are also used in Maryland to report annual average QOL scores for all community agencies (Bonham, Basehart, & Marchand, 2005). These data are used by agencies for QI purposes, and in the case of the Personal Development domain for state administration (DDA) to develop state-level goals and monitor achievements. Two state/system-level benchmarks have been established based on assessed personal outcomes: maintaining threshold percents of people who report positive QOL in the 8 domains, and increasing the average QOL scores reported in at least one domain (in this case, Personal Development).

#### 4.3. Outcome predictors

Personal outcomes can be used for both reporting purposes and guiding organization improvements (Chorpita, 2003; Gambill, 1999; Kazdin & Weisz, 2003; Keith & Bonham, 2005; Langberg & Smith, 2006; Schalock & Bonham, 2003; Veerman & van Yperen, 2007). Over the last decade, a number of research studies have identified the statistically significant predictors of assessed QOL-related outcomes in persons with IDD. Each of these studies has generally used a total or composite measure of QOL based on a QOL conceptual framework such as that previously discussed in reference to Table 1. Table 4 provides a summary of this work. It is important to note that some of these predictors are person-referenced; others are organization, system, or community referenced. As discussed next, data tutorials can focus on how an understanding of these significant predictors can be used

Table 3  
QOL supports framework

Domain	Exemplary individualized supports
Personal development	Functional skill training, assistive technology, communication systems
Self-determination	Choices, personal control, decisions, personal goals
Interpersonal relations	Foster friendships, encourage intimacy, support families and community interactions/relationships
Social inclusion	Community roles, community activities, volunteerism, social supports
Domain: rights	Privacy, due process, civic responsibilities, showing respect and dignity
Emotional well-being	Increased safety, stable environments, positive feedback, predictability, self identify mechanisms (e.g. mirrors, name tags)
Physical well-being	Health care, mobility, wellness, exercise, nutrition
Material well-being	Ownership, possessions, employment

Table 4  
Significant predictors of QOL-related outcomes

Outcome variable	Significant predictor(s)
QOL composite score	IQ and adaptive behavior scores (Schalock, Lemanowicz, Conroy, & Feinstein, 1994) Living & employment status (Schalock, Bonham, & Marchand, 2000) Self-determination level (Wehmeyer & Schwartz, 1998) State funded employment services, geographical location, availability of transportation, agency staffing patterns (Bonham et al., 2005)
Social inclusion	IQ and AB level (Perry & Felce, 2005; Stancliffe & Lakin, 1998)
Interpersonal relations	IQ and AB level (Stancliffe & Lakin, 1998)
Self-determination	IQ and AB level (Perry & Felce, 2005) Setting size (Tossebro, 1995) Service model (Walsh et al., 2006)
Personal development	Setting size (Perry & Felce, 2005) Staff attention (Emerson et al., 2001; Perry & Felce, 2005) Organization culture (Perry & Felce, 2005)
Personal outcomes	Choices, rights, community interaction, respect (Gardner & Carran, 2005)

to enhance personal outcomes and in the process produce knowledge about linkages among multiple input and process variables (Corley, 2007).

#### 4.4. QI strategies

The term QI—a term used extensively in the IDD field—refers to an organization or system's capacity to improve performance and accountability through systematically collecting and analyzing data and information, and implementing action strategies (hereafter referred to QI strategies) based on the analysis. The goal of QI is to enhance personal outcomes and program accountability. QI is different from quality assurance (QA) that addresses a service provider's demonstrated ability to guarantee basic assurances in the areas of health, safety, and continuity. Three QI strategies employed nationally and internationally by the authors and their colleagues are described next: providing data tutorials, building learning teams, and evaluating progress and reporting feedback.

##### 4.4.1. Data tutorials

Three realities are found in many service provider organizations: first, staff generally do not understand data and data analyses; second, most personnel are afraid of data due to its frequent negative association with evaluation and its potential consequences in regards to licensing,

funding, certification, or investigation; and third, data management has frequently not been handled well in the past which impacts how the organization accepts information and its willingness to act on it. Hence, we have found that providing data tutorials as a QI strategy has been very productive when the tutorials: (a) increase the understanding of statistical concepts and research designs; (b) involve stakeholders in the generation of research/evaluation questions, data collection, and utilization of the information; (c) clarify the questions being asked of data, the alignment of those questions to the data analyzed, and how well the data answer the questions; (d) help personnel understand the contextual factors affecting the obtained results; (e) provide personnel with specific suggestions as to how the data/can be used to enhance personal outcomes or other performance indicators; (f) stress that the primary purpose of data collection and analysis is for QI purposes and not to evaluate the goodness (or badness) of the program or services provided; and (g) emphasize that any evaluation represents only 'a point in time' and that using data for QI is a continuous process that requires a long-term commitment.

##### 4.4.2. Learning teams

Much of what happens in education and rehabilitation programs is based on the planning, implementation, and evaluation strategies developed by a team. We are beginning to see in the field of IDD a transformation to what many in the field refer to as 'learning teams' that are based on the concept of synergy and whose efforts are enhanced by the team being self-directed, setting and focusing on challenging new goals, and thinking insightfully (and outside the box) about complex issues (Isaacs, 1999; Lick, 2006; Senge, 2006).

Learning teams (generally composed of middle level managers, clinicians, direct care/support personnel, and consumers) are increasingly focusing on inputs such as those predictor variables listed in Table 4 that might lead to desired personal outcomes. When they do so, they instill *right to left thinking that requires that one specifies desired outcomes first* and then ask, "What needs to be in place within the organization or community for these outcomes to occur?" (Andrews, 2004; Drucker, 1994). Once the significant predictors of personal outcomes are identified, resources can be allocated to maximize their positive impact on desired personal outcomes. Based on the research findings summarized in Table 4, for example, an effective QI strategy would be for program personnel to direct resources and individual supports to: (a) improve the level of adaptive behavior, employment status, self-determination, and personalized staff assistance; (b) reduce setting size; and (c) increase the availability of transportation.

##### 4.4.3. Progress and feedback

QOL-related feedback can occur at two levels in addition to that provided to service recipients. At the agency level,

both assessed QOL scores for service recipients and the predictors of personal outcomes are shared by agency personnel. As part of the data tutorial in Maryland, for example, agency staff is asked first to compare the average QOL score reported by their consumers to that of all consumers in the state, and hypothesize why the people they support have higher, lower, or the same scores as the comparison group. Second, the staff is asked to look for any trends in the data, and relate these trends to agency goals and/or recent service delivery changes. Third, participants are asked to think about how they might target significant predictors of personal outcomes and commit additional resources, expertise, and/or time to influence these predictors.

Feedback can also be provided to a larger stakeholder constituency through the publication and wide distribution of Provider Profiles such as those described earlier for Nebraska and Maryland. These Provider Profiles have common goals that include assessing the QOL status and needs of large numbers of people, and reporting the QOL of individuals served by various service providers. Thus, each, in its own way, opens the system to scrutiny by citizens with and without disabilities in an effort to allow improved access and decision making. The availability of these profiles has potential to significantly alter the relationship between individual consumers and service providers (Keith & Bonham, 2005).

In summary, these four application examples (individualized supports, benchmarks, outcome predictors, and QI strategies) show how IDD service/supports providers are responding to two major trends in the field impacting program planning and evaluation. The first trend involves current program evaluation concepts and methods that involve: the use of logic models that provide a framework for seeing the relationships among inputs, processes, and outcomes (Donaldson & Gooler, 2003; Dwyer & Makin, 1997); the application of evidence-based practices (Chorpita, 2003; Veerman & van Yperen, 2007); an emphasis on performance measurement (McDavid & Hawthorne, 2006); and a focus on developmental evaluation with its emphasis on making organizational learning and capacity building the primary objective of evaluation information and its use (Schalock, 2001; Westley, Zimmerman, & Patton, 2006). The second trend involves the significant changes that have occurred during the last decade in the disability service delivery system. Chief among these changes has been the movement from: (a) easy to identify and describe systems of public support for people with disabilities to highly complex networks composed of widely varying levels and types of providers, settings, and structures; (b) traditional standards and methods associated with compliance and documentation to a quality assessment and improvement methodology; (c) organization-based programs to community-based individualized support systems; and (d) organizations as primary service providers to organizations as bridges to the community.

## 5. Implications

The four applications discussed in Section 4 also have significant implications for the IDD field and how we approach program planning and evaluation. Four of these implications that the authors are most aware of—and involved in—are discussed next.

### 5.1. Understand mental models

Mental models are deeply ingrained assumptions, generalizations, and images we have to understand the world (Senge, 2006). They form the vision and culture of an organization and serve as the basis for leadership, values training, service delivery, outcomes evaluation, and QI. In the field of disabilities, a number of mental models have historically inhibited change. Chief among these are: (a) models of disablement that focus on personal defectology rather than human potential and ameliorating environmental factors (Devlieger et al., 2003; Schalock, 2004); (b) an over emphasis on *quality of care* that focuses on control, power, health, safety, and categorization as opposed to *QOL* that focuses on social inclusion, self-determination, personal development, community inclusion, and the provision of individualized supports (de Walle et al., 2005); and (c) organizations as mechanistic entities rather than organizations as self-organizing systems that reinforce thinking and doing, creativity, coordination, priority setting, and communication patterns (Gardner & Carran, 2005). It is important to identify and understand these three inhibiting models because they are frequently the limiting factors to change. As stated by Senge (2006, p. 100), “to change the behavior of a system requires that one identify and change the limiting factor(s) and thereby increase one’s leverage”. It is also important to bring mental models to the surface, discuss them and show the relationship between the QOL concept and the supports paradigm, and in the process hopefully bring about changes within a culture that promotes inquiry and commitment to QOL-focused policies and practices.

### 5.2. Develop an internal data system

Using QOL-related personal outcomes for reporting and QI requires thinking and acting beyond *external monitoring and evaluation* (the historical approach) and focusing instead on an *internal information collection and use process* that provides the basis for evidence-based practices, organization development, and QI. Developing such a system poses at least three challenges and opportunities. First, the development and use of an internal system in addition to an external monitoring process involves risks, and getting ‘on board’ will take time for many organizations. In the meantime, external validation and the use of quality and performance indicators will be necessary—combined with technical assistance provided to organizations and systems. Second, providers and policy makers

need to see the relevance of using the assessment of personal outcomes and feedback as an integral part of how their organization or systems operates. Third, the costs (in terms of time, resources, and expertise) of collecting and analyzing multiple data sources need to be minimized by asking the right questions, making data-based decisions, and using integrated, computerized, real-time, and seamless management information systems. Through these processes, organizations will be less likely to be data rich and information poor.

### 5.3. Support organization change

As discussed earlier, organizations and systems providing services and supports to persons with IDD are in the process of redefining their roles as they respond to the challenges of the quality revolution, the community-based movement, and the reform movement with its emphasis on measurability, reportability, and accountability. In this process, organizations are: shifting from organization-based programs to community-based support systems, changing from organizations as primary service providers to organizations as bridges to the community, and emphasizing the critical role that direct support staff play in enhancing personal outcomes. These changes pose the following three challenges (and opportunities). First, organizations will need to provide individualized supports to maximize personal outcomes within the context of community environments. Second, organizations will need to understand better the community to which the organization is bridging. Nationally and internationally current policy and practices are designed to promote the acceptance, integration, and inclusion of people with ID into their communities. Thus, organization personnel need to understand community attitudes, develop community-based living and work opportunities, and access natural support networks. The third challenge relates to the role played by the direct support personnel. As organizations become more horizontal and engage in QI activities, direct care/support staff will play an increasingly valued role in the planning, delivery, and evaluation of services and supports. Organization managers need to recognize their contribution and develop a cadre of direct support personnel who are aware of the QOL concept and QOL-related program practices.

### 5.4. Build on current public policy

Although the term ‘QOL’ is seldom used in public policy, QOL-related concepts and programmatic requirements are. For example, many public laws related to persons with ID (e.g. [Developmental Disabilities Act, 2000](#); [Individuals with Disabilities Education Act, 2004](#)) require individual support plans that can be developed within a QOL conceptual and measurement framework that aligns support needs to QOL domains, and includes the assessment of QOL-related personal outcomes. Similarly, the US

Government Accounting Office (1998) has issued a number of guidelines related to managing for results, including ways to develop performance indicators and outcome measures, which also can be aligned with a QOL framework and used for reporting and QI purposes. Finally, the US Centers for Medicare and Medicaid (which is a primary funding source for community services and supports for persons with ID) has recently implemented a quality framework that focuses on participant outcomes and the use of that information for quality assurance and improvement ([US Department of Health and Human Services, 2005](#)). Each of these public policies offers an opportunity to integrate a QOL conceptual and measurement framework into current public policies and programmatic practices.

In conclusion, the application examples described in this article, and the implications just discussed, reflects the evolutionary nature of the QOL concept. Specifically, over the last three decades, the concept has ‘evolved’ from: a concept to a measurable construct, a model that describes what to a framework that suggests how, an idiographic (microsystem) focus to a multi-systems perspective, and an idea to an action-oriented change agent. As a result of these changes, we are moving towards a more detailed model of QOL and its use in program planning and evaluation. Such a model will need to be comprised of a mixture of causal and indicator variables as well as including inputs, outputs, and a clear delineation of mediator and moderator variables. In this process, it is anticipated that a transdisciplinary approach ([Walter et al., 2007](#)) will increasingly be used that jointly involves researchers and practitioners. Such an approach will result in both scientific (understanding) and social (application) effects, and allow the field to better integrate principles and methods into program practices and standards.

## References

- Andrews, A. B. (2004). Start at the end: Empowerment evaluation product planning. *Evaluation and Program Planning*, 27(3), 275–285.
- 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. G., Kirchner, N., & Rumenap, J. M. (2004). Consumer-based quality of life assessment: The Maryland Ask Me! Project. *Mental Retardation*, 42(5), 338–355.
- Brown, I., Anand, S., Fung, W. L. A., Isaacs, B., & Braum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities*, 15, 207–229.
- Center for the Study of Social Policy (1996, August). *Beyond lists: Moving to results-based accountability*. Washington, DC: Author.
- Chorpita, B. F. (2003). The frontier of evidence-based practice. In A. E. Kazdin, & J. R. Weisz (Eds.), *Evidence-based psychotherapies for children and adolescents* (pp. 42–59). New York: Oxford.
- Corley, E. A. (2007). A use-and-transformation model for evaluating public R & D. *Evaluation and Program Planning*, 30(1), 21–35.
- Cummins, R. A. (1997). Assessing quality of life. In R. I. Brown (Ed.), *Assessing quality of life for people with disabilities: Models, research, and practice* (pp. 16–150). London: Stanley Thornes Publishers Ltd.

- Cummins, R. A. (2004). Issues in the systematic assessment of quality of life. In J. H. Hogg, & A. Langa (Eds.), *Approaches to the assessment of adults with intellectual disabilities: A service provider's guide* (pp. 140–172). London: Blackwell.
- De Walle, I., van Loon, J., van Hove, G., & Schalock, R. L. (2005). Quality of life vs. quality of care: Implications for people and programs. *Journal of Policy and Practice in Intellectual Disabilities*, 2(3/4), 229–239.
- Developmental Disabilities Assistance and Bill of Rights Act of 2000 (2000). Publ. L. No. 106-402, 114 Stat. 1678.
- Devlieger, J. P., Rusch, F., & Pfeiffer, D. (2003). Rethinking disability as same and different: Towards a cultural model of disability. In J. P. Devlieger, F. Rusch, & D. Pfeiffer (Eds.), *Rethinking disability: The emergence of new definitions, concepts, and communities* (pp. 9–16). Antwerp, Belgium: Garant Publishers.
- Donaldson, S. E., & Gooler, L. E. (2003). Theory-driven evaluation and action. *Evaluation and Program Planning*, 26(4), 355–366.
- Drucker, P. F. (1994). *Managing for results*. New York: Harper and Row.
- Dwyer, J., & Makin, S. (1997). Using a program logic model that focuses on performance measurement to develop a program. *Canadian Journal of Public Health*(November/December), 421–425.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., et al. (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, 106, 401–415.
- Gambill, E. (1999). Evidence-based practice: An alternative to authority-based practice. *Families in Society*, 80, 341–350.
- Gardner, J. F., & Carran, D. (2005). Attainment of personal outcomes by people with developmental disabilities. *Mental Retardation*, 43(3), 157–174.
- 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.
- Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services. (2003). *National core indicators: 5 years of performance measurement*. Cambridge, MA, Alexandria, VA: Authors.
- Individuals with Disabilities Education Act (IDEA), 70 USC. 1400 et seq. (2004).
- Isaacs, W. (1999). *Dialogue and the art of thinking together*. New York: Currency.
- Jenaro, C., Verdugo, M. A., Caballo, C., Balboni, G., Lachappele, Y., Otbrebski, W., et al. (2005). Cross-cultural study of person-centered quality of life domains and indicators: A replication. *Journal of Intellectual Disability Research*, 49(Part 10), 734–739.
- Kalafat, J., Illback, R. J., & Sanders, D., Jr. (2007). The relationship between implementation fidelity and educational outcomes in a school-based family support program: Development of a model for evaluating multidimensional full-service programs. *Evaluation and Program Planning*, 30(2), 136–148.
- Kazdin, A. E., & Weisz, J. R. (2003). *Evidence-based psychotherapies for children and adolescents*. New York: The Guilford Press.
- 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., & Schalock, R. L. (2000). *Cross-cultural perspectives on quality of life*. Washington, DC: American Association on Mental Retardation.
- Langberg, J. M., & Smith, B. H. (2006). Developing evidence-based intervention for deployment into school settings: A case example highlighting key issues of efficacy and effectiveness. *Evaluation and Program Planning*, 29(4), 323–334.
- Lick, D. W. (2006). A new perspective on organizational learning: Creating learning teams. *Evaluation and Program Planning*, 29(1), 88–96.
- McDavid, J. C., & Hawthorne, L. L. (2006). *Program evaluation and performance measurement*. Thousand Oaks, CA: Sage Publications.
- Nebraska Department of Health and Human Services. (2006). *2006 Nebraska developmental disabilities provider profiles: Information on Nebraska's community-based service providers*. Lincoln, NE: Author.
- Perry, J., & Felce, D. (2005). Factors associated with outcomes in community group homes. *American Journal on Mental Retardation*, 110, 121–135.
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: a qualitative inquiry. *Mental Retardation*, 41, 313–328.
- Schalock, R. L. (2001). *Outcomes-based evaluation* ((2nd ed.)). New York: Kluwer.
- Schalock, R. L. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies*, 14, 204–215.
- 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, G. S., & Marchand, C. R. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction. *Evaluation and Program Planning*, 23(1), 77–88.
- 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. R. Parmenter (Eds.), *International handbook of applied research in intellectual disabilities* (pp. 261–279). London: Wiley.
- Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life for 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., Lemanowicz, J., Conroy, J., & Feinstein, C. (1994). A multivariate investigative study of the correlates of quality of life. *Journal on Developmental Disabilities*, 3, 59–73.
- 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(1), 18–28.
- Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., et al. (2005). A cross-cultural study of quality of life indicators. *American Journal on Mental Retardation*, 110, 298–311.
- Senge, P. M. (2006). *The fifth discipline: The art and practice of the learning organization* (revised ed.). New York: Doubleday.
- Shoemaker, P. J., Tankard, J. W., Jr., & Larorsa, D. L. (2004). *How to build social service theories*. Thousand Oaks, CA: Sage Publications.
- Stancliffe, R. (2000). Proxy respondents and quality of life. *Evaluation and Program Planning*, 23(1), 89–93.
- Stancliffe, R., & 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.
- 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 Disabilities Research*, 49(10), 777–783.
- Tossebo, J. (1995). Impact of size revised: Relation of number of residents to self-determination and deprivation. *American Journal on Mental Retardation*, 100, 59–67.
- Tucker, M. S., & Coddling, J. B. (1998). *Standards for our schools: How to set them, measure them, and reach them*. San Francisco: Jossey-Bass Publishers.
- US Department of Health and Human Services, Centers for Medicare and Medicaid Services. (2005). Quality letters (1–9). Retrieved December 1, 2007, from <<https://cms>>, <[hhs.gov/medicaid/waiversqcom.asp](https://hhs.gov/medicaid/waiversqcom.asp)>.
- Van Hove, G., & van Loon, J. (2007). *Personal outcomes scale*. Department of Special Education, University of Gent, Gent, Belgium.
- 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.
- 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., Gomez, L., Arias, B., & Martin, J. C. (2006). Validation of the eight domain model of quality of life. Presentation at the symposium on quality of life outcomes: Their empirical development, verification, and use. *International symposium on social inclusion*, Montreal, CA, May 2–6.
- Verdugo, M. A., & Schalock, R. L. (2001). *Cross-cultural survey of quality of life indicators*. Salamanca, Spain: Institute on Community Integration, Faculty of Psychology, University of Salamanca.
- Verdugo, M. A., Schalock, R. L., Gomez, L., & Arias, L. (2007). Developing multi-dimensional 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. (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). *Quality of life report: Ireland*. Dublin: Irish Department of Human Services.
- Walter, A. I., Helgenberger, S., Wiek, A., & Scholz, R. W. (2007). Measuring societal effects of transdisciplinary research projects: Design and application of an evaluation model. *Evaluation and Program Planning*, 30(4), 325–338.
- Wang, M., Schalock, R. L., Verdugo, M. A., & Jenaro, C. (in press). The cross-cultural validation and analysis of quality of life domains: Demonstrating construct comparability and measurement equivalence. *American Journal on Mental Retardation*.
- 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.
- Westley, B., Zimmerman, B., & Patton, M. Q. (2006). *Getting to maybe: How the world is changed*. Toronto: Random House.
- Robert L. Schalock**, Ph.D., is the Professor Emeritus at Hastings College in Hastings, Nebraska.
- Miguel Angel Verdugo**, Ph.D., is the Director at the Institute for Community Inclusion and Professor of Psychology at the University of Salamanca, Spain.
- Gordon S. Bonham**, Ph.D., is CEO of Bonham Research in Baltimore, Maryland.