Three Decades of Quality of Life
Robert L. Schalock

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What is This?
Three Decades of Quality of Life

Robert L. Schalock

Over the last few decades, the field of mental retardation has embraced the concept of quality of life as both a sensitizing notion and an overarching principle for service delivery. This article summarizes the current understanding of the quality of life construct by examining previous efforts at defining and clarifying the concept, and examines issues that will affect the utility of the construct well into the new century.

Recent published a chapter (Schalock, 1997a) in which I discussed the concept of quality of life in 21st-century disability programs. In that chapter, I suggested that these programs incorporate an ecological conception of disability, focus on quality of life, base their services on a supports model, and be committed to evaluating person-referenced outcomes. In the present article, I want to discuss the concept of quality of life in the 21st century from a slightly different perspective. First, I summarize where we have been (which I refer to as "embracing the concept"); second, I discuss where we are now ("clarifying the concept"); third, I project where I think we are going with the concept in the 21st century ("pursuing the concept"); and, finally, I offer 10 guidelines to help in our efforts.

I suggest at the outset of our consideration of three decades of quality of life that the importance of the concept of quality of life to persons with mental retardation is reflected well in the following three statements:

1. The concept of quality of life is a social construct that is affecting program development and service delivery in the areas of education (Halpern, 1993; Snell & Vogtle, 1997), health care (Coulter, 1997; Renwick, Brown, & Nagler, 1996), mental retardation (Brown, 1997; Schalock, 1996b, 1997b), and mental health (Lehman, Rachuba, & Postrado, 1995).
2. The concept of quality of life is being used as the criterion for assessing the effectiveness of services to people with disabilities (Felce & Perry, 1996; Gardner, Nudler, & Chapman, 1997; Perry & Felce, 1995; Rapley & Hopgood, 1997; Schalock, 1995b).
3. The pursuit of quality is apparent at three levels of today's human service programs: in persons who desire a life of quality (Ward & Keith, 1996; Whitney-Thomas, 1997), in providers who want to deliver a quality product (Albin-Dean & Mark, 1997), and in evaluators (policy makers, funders, and consumers) who want quality outcomes (Gardner & Nudler, 1997; Schalock, 1999).

How did we get to where we are in reference to the concept of quality of life, and where are we going as we embark on the 21st century? In the following three sections of this article, I suggest that we got here by embracing during the decade of the 1980s the concept of quality of life; during the 1990s we attempted to clarify the concept; and I predict that during the next decade the concept will be pursued even more intensely by (a) individuals advocating for a life of quality, (b) service and support providers focusing on ways to produce quality products, and (c) evaluators analyzing quality outcomes.

Embracing the Concept (the 1980s)

During the 1980s the field of mental retardation and closely related disabilities embraced the concept of quality of life as both a sensitizing notion and an overarching principle for service delivery. Why? Because the concept captured the changing vision of persons with disabilities, provided a common language for persons across disciplines and functional statuses, and was consistent with the larger "quality revolution."

The Changing Vision

Over the last two decades, there has been a significant change in the way we view persons with disabilities. This transformed vision of what constitutes the life possibilities of persons with mental retardation is reflected in terms that are familiar to the reader: self-determination, strengths and capabilities, the importance of normalized and typical environments, the provision of individualized support...
The Quality Revolution

The quality revolution, with its emphasis on quality products and quality outcomes, was emerging rapidly during the 1980s. One of the main products of this revolution was a new way of thinking that was guided largely in the mental retardation field by the concept of quality of life, which became the unifying theme around which programmatic changes were organized. This new way of thinking stressed person-centered planning, the supports model, quality-enhancement techniques, and person-referenced quality outcomes (Schalock, 1999). More specifically, this revolutionary approach, based on the unifying theme of quality of life,

- allowed service providers to reorganize resources around individuals rather than rearranging people in program slots (Albin-Dean & Mank, 1997; Albrecht, 1993; Edgerton, 1996; Gardner & Nudler, 1997; Schalock, 1994);
- encouraged consumers and service providers to embrace the supports paradigm (Schalock, 1995a);
- shifted the focus of program evaluation to person-referenced outcomes that could be used to improve organizational efficiency and enhance person-referenced services and supports (Clifford & Sherman, 1983; Mathison, 1991; Schalock, 1995b; Torres, 1992); and
- allowed management styles to focus on learning organizations (Senge, 1990), reengineered corporations (Hammer & Champy, 1993), entrepreneurship (Osborne & Gaebler, 1992), and continuous quality improvement (Albin-Dean & Mank, 1997).

Thus, by the end of the 1980s, we had embraced the concept of quality of life for at least the three reasons just mentioned. However, embracing a concept and fully understanding it are two different things. Before considering the decade of the 1990s, during which we made significant progress in understanding and applying the concept, it is important to mention two additional phenomena regarding the concept of quality of life that were evident by the end of the 1980s. These two phenomena became significant catalysts to the work that was to be carried out during the 1990s. First, the concept of quality of life was being used in at least three different ways:

- as a sensitizing notion that was giving us a sense of reference and guidance from the individual’s perspective, focusing on the person’s environment;
- as a social construct whose overriding principle was to improve and enhance a person’s quality of life; and
- as a unifying theme that provided a systematic or organizing framework to focus on the multidimensionality of the concept.

Second, the field was beginning to agree on a number of quality of life principles. These 11 principles, which are summarized in Table 1, were based on considerable discussion and input from all stakeholders (Goode, 1990; Schalock, 1990).

Clarifying the Concept (the 1990s)

During the 1980s the field of mental retardation embraced a concept that was neither well defined (hence the presence of more than 100 definitions of quality of life) nor completely understood. Thus, the 1990s began with investigators and advocates attempting to answer a number of questions about the conceptualization and measurement of quality of life (Raphael, 1996; Schalock, 1996b). Chief among these questions were the following:

Conceptual issues—How is it best to conceptualize indicators of quality of life? Is quality of life a single, unitary entity, or a multidimensional, interactive concept? Is quality of life the same for all individuals?

Measurement issues—What should be measured? How do we measure quality of life? What psychometric standards
TABLE 1
Fundamental Quality of Life Principles (1980s Decade)

<table>
<thead>
<tr>
<th>Principle</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. For persons with disabilities is composed of those same factors and relationships that are important to persons without disabilities.</td>
</tr>
<tr>
<td>2. Is experienced when a person’s basic needs are met and when he or she has the same opportunity as anyone else to pursue and achieve goals in the major settings of home, community, and work.</td>
</tr>
<tr>
<td>3. Factors vary over the life span of a person.</td>
</tr>
<tr>
<td>4. Is related to a person’s and group’s cultural and ethnic heritage.</td>
</tr>
<tr>
<td>5. Is based on a set of values that emphasize consumer and family strengths.</td>
</tr>
<tr>
<td>6. Is determined by the congruence of public policy and behavior.</td>
</tr>
<tr>
<td>7. Is a concept that can be consensually validated by a wide range of persons representing a variety of viewpoints of consumers and their families, advocates, professionals, and providers.</td>
</tr>
<tr>
<td>8. Study requires an in-depth knowledge of people and their perspectives.</td>
</tr>
<tr>
<td>9. Measurement requires multiple methodologies.</td>
</tr>
<tr>
<td>10. Has both objective and subjective components, but it is primarily the individual’s subjective view that determines the quality of life he or she experiences.</td>
</tr>
<tr>
<td>11. Variables should occupy a prominent role in overall program evaluation.</td>
</tr>
</tbody>
</table>

As we begin this decade, these questions are beginning to be answered, thanks largely to a number of significant conceptual shifts regarding how we view and assess quality of life. In this section I discuss five of these concepts: (a) the multidimensional nature of quality of life, (b) satisfaction as the primary measure of quality of life, (c) the hierarchical nature of quality of life, (d) the use of multivariate research designs to study important correlates of quality of life, and (e) the use of multiple methods to assess one’s perceived quality of life.

**Multidimensional Nature**

There is increasing agreement that quality of life is a multidimensional concept that precludes reducing it to a single “thing,” of which the person may have a considerable amount, some amount, or none. Current and ongoing research in this area has identified eight core quality of life dimensions (Schalock, 1996c): emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. Although the number and configuration of these core dimensions vary slightly among investigators, the summary presented in Table 2 indicates quite clearly the generality of these dimensions. These core dimensions are based on the work of Cummins (1996, 1997a); Felce (1997); Felce and Perry (1996, 1997b); Hughes and Hwang (1996); and Schalock (1996c). Similar listings can be found in Heal, Khoju, Rusch, and Harnisch (in press); Parmenter and Donnelly (1997); Renwick and Brown (1996); and Stark and Goldsby (1990).

**Focus on Satisfaction**

Increasingly, we are seeing that a person’s measured level of satisfaction is the most commonly used dependent measure in evaluating his or her perceived quality of life. One might well ask, “Why this emphasis on satisfaction?” Actually, there are a number of reasons, including the following:

- It is a commonly used aggregate measure of individual life domains (Andrews, 1974).
- It demonstrates a traitlike stability over time (Diener, 1984; Edgerton, 1990, 1996; Heal, Borthwick-Duffy, & Saunders, 1996).
- There is an extensive body of research on level of satisfaction across populations and service delivery recipients (Cummins, 1997b; Halpern, 1993; Harner & Heal, 1993; Heal & Chadesy-Rusch, 1985; Heal, Rublin, & Park, 1995; Schalock & Faulkner, 1997).
- It allows one to assess the relative importance of individual quality of life dimensions and thereby assign value to the respective dimensions (Cummins, 1996; Felce & Perry, 1996, 1997b; Flanagan, 1978, 1982; Schalock, Bontham, & Marchant, in press).

Thus, the major advantages of using satisfaction as an indicator of one’s perceived quality of life are its usefulness in (a) comparing population samples; (b) providing a common language that can be shared by consumers, providers, policymakers, regulators, and researchers; (c) assessing consumer needs; and (d) evaluating organizational outputs. Its major disadvantages include its limited utility for smaller group comparisons that might provide only a global measure of perceived well-being, and its discrepancy with current multidimensional theories of quality of life (Cummins, 1996). For these reasons, other dependent measures of quality of life are needed, and these are described in a later section of this article.

**Hierarchical Nature**

There is good agreement in the quality of life literature about three things: First, quality of life, by its very nature, is subjective; second, the various core dimensions are valued by persons differently; and third, the value attached to each core dimension varies across one’s life. These three points of agreement strongly indicate that the concept of quality of life must be viewed from a hierarchical perspective. A model that allows one to integrate these three factors is presented in Figure 1, which is based on the work of Elorriaga, Garcia, Martinez, and Unamunza (in press); Flanagan (1978); Maslow (1954); and Verdugo (in press). The model depicts a hypothetical, hierarchical arrangement of the various core quality of life dimensions listed in Table 2.
Multivariate Research Design

One of the biggest stumbling blocks overcome during the decade of the 1990s was shifting our mind-set regarding the research and statistical design used to study the quality of life concept. Specifically, we saw a significant shift from a “between” to a “multivariate/within” approach. Historically, the study of quality of life was approached from a between-groups (or between-conditions) perspective; hence, investigators sought to find factors, such as social economic status and large demographic population descriptors, that could discriminate between those persons or countries with a higher and those with a lower quality of life. This “between” mentality spilled over to our early work on quality of life in subtle ways, as reflected in the attitude expressed by some that we need to have different measures or quality of life indices for those who are higher functioning and for those who are either nonverbal or lower functioning.

Shifting to a multivariate research design has a number of heuristic and practical advantages. First, it allows one to focus on the correlates and predictors of a life of quality, rather than comparing quality of life scores or statuses. More specifically, one can use multivariate research designs to determine the relationship between a number of measured predictor variables and one’s perceived quality of life. This approach has been one that I have used to evaluate the relative contribution to one’s assessed quality of life of a number of personal characteristics, objective life conditions, and provider characteristics. Across a number of studies (e.g., Schalock, DeVries, & Lebsack, 1999; Schalock & Faulkner, 1997; Schalock, Lemanowicz, Conroy, & Feinstein, 1994), personal factors (e.g., health status and adaptive behavior level), environmental variables (e.g., perceived social support, current residence, earnings, home type, and integrated activities), and provider characteristics (e.g., worker stress and job satisfaction) have been shown to be significant predictors of quality of life. Second, once these significant predictors are identified, programmatic changes can be made to enhance a person’s quality of life through techniques such as personal development and wellness training, quality enhancement techniques, and quality management techniques (Schalock, 1994; Schalock & Faulkner, 1997). Third, multivariate research designs help us better understand the complexity of the concept of quality

| TABLE 2 |
| Core Quality of Life Dimensions (1990s Decade) |
|-----------------|-------------|---------------|------------------------|
| Emotional well-being | X | X (Intimacy) | | |
| Interpersonal relations | X (Social) | X (Intimacy) | | |
| Material well-being | X | X | | |
| Personal development | X (Productive) | X (Productivity) | | |
| Physical well-being | X | X | | |
| Self-determination | X (Productive) | X (Productive) | | |
| Social inclusion | X (Social) | X | | |
| Rights | X (Civic) | X (Safety) | X (Civic responsibility) | |

**FIGURE 1.** Hierarchical nature of core quality of life dimensions.
of life and the role that a number of contextual variables play in the perception of a life of quality. Finally, these designs shift the focus of our thinking and intervention from personal to environmental factors as major sources of quality of life enhancement.

**Quality of Life Assessment**

One of the most significant changes during the 1990s was the shift toward outcome-based evaluation and person-referenced outcomes. This emerging focus on person-referenced outcomes reflects not only the subjective and personal nature of one’s perceived quality of life, but also the quality revolution that we are currently experiencing; consumer empowerment with the associated expectation that human service programs will result in an improved quality of life for service recipients; the increased need for program outcome data that evaluate the effectiveness and efficiency of intervention and rehabilitation programs; the supports paradigm, which is based on the premise that acquiring needed and relevant supports will enhance one’s quality of life; and the pragmatic evaluation paradigm, which emphasizes a practical, problem-solving orientation to program evaluation.

The quality of life assessment approach discussed in this section of the article is based on three assumptions made in the current literature on quality of life conceptualization and measurement: (1) Quality of life is composed of eight core dimensions (see Table 2 and Figure 1); (2) the focus of quality of life assessment should be on person-referenced outcomes; and (3) assessment strategies should use either personal appraisal or functional assessment measures reflecting one or more of the eight core dimensions. A model that incorporates these three assumptions is presented in Figure 2. As shown in the model, each of the eight core dimensions is defined operationally in terms of a number of specific indicators that include attitudinal, behavioral, or performance factors representing one or more aspects of each core dimension. The following criteria should guide one’s selection of specific indicators (Anastasi, 1982; Schalock, 1995b): The indicator is valued by the person, multiple indicators are used, the indicator is measurable and has demonstrated reliability and validity, the indicator is connected logically to the service or support received, and the indicator is evaluated longitudinally. Exemplary quality of life indicators are listed in Table 3.

The indicators listed in Table 3 can be measured using either the personal appraisal or the functional assessment strategies described next. The reader should also note that the personal appraisal strategy should be equated to the historical notion of subjective indicators, whereas the functional assessment strategy should be equated to the historical notion of objective indicators.

**Personal Appraisal.** The personal appraisal strategy addresses the subjective nature of quality of life, typically asking the person how satisfied he or she is with the various aspects of his or her life. For example, this is the approach we used in the Quality of Life Questionnaire (Schalock & Keith, 1993), wherein we asked questions such as, “How satisfied are you with your current home or living situation?” and “How satisfied are you with the skills and experience you have gained or are gaining from your job?” Although the person’s responses are subjective, they need to be measured in psychometrically acceptable ways. Thus, a 3- to 5-point Likert scale can be used to indicate the level of expressed satisfaction. The advantages to this approach to measurement are that it encompasses the most common dependent measure used currently in quality of life assessments, it allows one to measure those factors that historically have been considered to be major subjective indicators of a life of quality, and it allows one to quantify the level of expressed satisfaction.

**Functional Assessment.** The most typical formats used in functional assessment include rating scales, participant observation, and questionnaires (Schalock, 1996c). Each attempt to document a person’s functioning across one or more core quality of life dimensions and the respective indicator. To accomplish this, most instruments employ some form of an ordinal rating scale to yield a profile of the individual’s functioning. For example, one might ask, “How frequently do you use health-care facilities?” or “How many civic or community clubs do you belong to?” The advantages of functional assessments are that they are more objective and performance based, allow for the evaluation of outcomes across groups, and thus provide important feedback to service providers, funders, and regulators as to how they can change or improve their services to enhance the recipients’ perceived quality of life.

As mentioned previously, historically, the subjective indicators used to assess one’s quality of life have been different from the objective ones. The advantage of using the approach to quality of life assessment depicted in Figure 2 is that one need not use different indicators for subjective versus objective measurement; rather, the core dimensions remain constant, and what varies is whether one uses a personal appraisal or a functional assessment approach to assessing the respective indicators. Thus, all assessment is focused clearly on the eight core dimensions of quality of life.

It is apparent that some of the domains are more amenable to personal appraisal, and others to functional assessment. For example, personal appraisal might best be used for the core dimensions of emotional well-being, self-determination, rights, and interpersonal relations, whereas functional assessment might better be used for the core dimensions of material well-being, personal development, physical well-being, and social inclusion. Hence, there is a definite need to use multiple measures of one’s perceived quality of life.

Despite the conceptual breakthrough regarding the assessment of quality of life just described, to date no single instrument fully implements the assessment model depicted in Figure 2. The interested reader is referred to Cummins (1997a) and Schalock (1996c) for reviews of the most commonly used in-

Instruments and advancements in the area of quality of life assessment.

Pursuing Quality (the Next Decade)

The discerning reader will have noticed that quality of life has yet to be defined in this article. And that is by design, because one needs to understand the concept fully in order to define it. And that may well explain why one can find more than 100 definitions of quality of life in the literature today. Over the years I have consistently referred to quality of life as “a concept that reflects a person’s desired conditions of living” (Schalock, 1994, p. 121). Given the five significant changes that occurred during the 1990s, I am now ready to modify my definition slightly:

Quality of life is a concept that reflects a person’s desired conditions of living related to eight core dimensions of one’s life: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

With this definition clearly in mind, I suggest that the concept of quality of life will be pursued in the first decade of the 21st century from the following three perspectives: individuals pursuing a life of quality, service and support providers producing quality products, and evaluators (policymakers, funders, and consumers) analyzing quality outcomes.

Individuals Pursuing a Life of Quality

I anticipate that there will be at least three major thrusts by persons pursuing a life of quality. First, we will continue to see strong advocacy for increased opportunities to participate in the mainstream of life, associated with increased inclusion, equity, and choices. Related efforts will involve advocating for increased individual supports within regular environments; seeking inclusion in major activities such as decision making, person-centered planning, and participatory action research (Whitney-Thomas, 1997); and incorporating the concept of quality of life into international and national disability policies (Goode, 1997a, 1997b). With these increased opportunities and involvement, more positive personal appraisals and functional assessments—that is, an enhanced quality of life—should result.

Second, consumers will work jointly with researchers in assessing the relative importance of the core dimensions depicted in Figure 1. Referring to Figure 1, for children and youth, for example, the most important dimensions may well be personal development, self-determination, interpersonal relationships, and social inclusion (Schalock, 1996a; Stark & Goldsbury, 1990); for adults, the hierarchy as shown in Figure 1 may well reflect the ordering of many peoples’ valued dimensions; and for the elderly, physical well-being, interpersonal relationships, and emotional well-
TABLE 3
Quality of Life Indicators

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Exemplary indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional well-being</td>
<td>Safety, Spirituality, Happiness</td>
</tr>
<tr>
<td></td>
<td>Freedom from stress, Self-concept, Contentment</td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td>Intimacy, Affection, Family</td>
</tr>
<tr>
<td></td>
<td>Interactions, Friendships, Supports</td>
</tr>
<tr>
<td>Material well-being</td>
<td>Ownership, Financial, Security, Food</td>
</tr>
<tr>
<td></td>
<td>Employment, Possessions, Socioeconomic status, Shelter</td>
</tr>
<tr>
<td>Personal development</td>
<td>Education, Skills, Fulfillment</td>
</tr>
<tr>
<td></td>
<td>Personal competence, Purposeful activity, Advancement</td>
</tr>
<tr>
<td>Physical well-being</td>
<td>Health, Nutrition, Recreation, Mobility</td>
</tr>
<tr>
<td></td>
<td>Health care, Health insurance, Leisure, Activities of daily living</td>
</tr>
<tr>
<td>Self-determination</td>
<td>Autonomy, Choices, Decisions</td>
</tr>
<tr>
<td></td>
<td>Personal control, Self-direction, Personal goals/values</td>
</tr>
<tr>
<td>Social inclusion</td>
<td>Acceptance, Status, Supports, Work environment</td>
</tr>
<tr>
<td></td>
<td>Community activities, Roles, Volunteer activities, Residential environment</td>
</tr>
<tr>
<td>Rights</td>
<td>Privacy, Voting, Access</td>
</tr>
<tr>
<td></td>
<td>Due process, Ownership, Civic responsibilities</td>
</tr>
</tbody>
</table>

being may be the most important dimensions (Schalock et al., 1999). The net result of these efforts should be the development of relevant quality of life outcome categories across the life span. Third, consumers will increasingly become involved in assessing their own quality of life. For example, we (Schalock et al., in press) have recently shown that consumers are excellent surveyors and can assess other consumers’ quality of life with highly acceptable reliability and validity.

Service Providers Producing Quality Products

This first decade of the 21st century will see service providers implementing quality-enhancement techniques that focus on what program personnel and services or supports can do to enhance a person’s perceived quality of life. As we move into the 21st century, I predict that these techniques will be either environmentally or program based.

Environmentally Based Enhancement Techniques. The implementation of two concepts related to environmentally based quality-enhancement techniques will characterize the first decade of the 21st century. One is the belief that an enhanced quality of life is the result of a good match between a person’s wants and needs and his or her fulfillment (Cummins, 1996; Michalos, 1985; Murrell & Norris, 1983; Schalock, Keith, Hoffman, & Karan, 1989); the second is the corollary that it is possible to assess the match between persons and their environments (Schalock & Jensen, 1986). The importance of these two concepts is supported by data suggesting that reducing particular discrepancies between a person and his or her environment increases that person’s quality of life (Schalock et al., 1989).

Page constraints limit a thorough discussion of these environmentally based enhancement techniques. However, the following two examples will indicate how two such techniques might be used in the 21st century. One technique involves the assessment of particular environmental characteristics as reflected in the Program Analysis of Service System (PASS 3; Felce & Perry, 1997a; Wolfensberger & Glenn, 1975) and allows one to evaluate the following aspects of rehabilitation-oriented environments: physical integration, social integration, age-appropriate interpretations and structures, culture-appropriate interpretations and structures, model coherency, developmental growth orientation, and quality of setting. The second technique involves the design of environments that are user friendly and evidence the following (Ferguson, 1997): opportunity for involvement (e.g., food preparation); easy access to the outdoor environment; modifications to stairs, water taps, and door knobs; safety (e.g., handrails, safety glass, nonslip walking surfaces); convenience (e.g., orientation aids such as color coding or universal pictographs); accessibility; sensory stimulation (windows, less formal furniture); prosthetics (personal computers, specialized assistive devices, high-technology environments); and opportunity for choice and control (e.g., lights, temperature, privacy, personal space, personal territory).

Program-Based Enhancement Techniques. Once the core dimensions of quality of life have been assessed, then it becomes possible to implement a number of program-based quality-enhancement techniques. Examples include the following:

- Emotional well-being—increased safety, stable and predictable environments, positive feedback
- Interpersonal relations—friendships and intimacy are fostered, families supported
• Material well-being—ownership, possessions, employment
• Personal development—education and functional rehabilitation, augmentative technology
• Physical well-being—health care, mobility, wellness, nutrition
• Self-determination—choices, personal control, decisions, personal goals
• Social inclusion—community role, community integration, volunteerism
• Rights—privacy, voting, due process, civic responsibilities

In addition to pursuing these quality-enhancement techniques, service providers will need to evaluate the impact of these strategies. Thus, during the first decade of the 21st century, service providers will need also to pursue the quality outcomes discussed in the next section. In this process, they will need to evaluate where they are, where they want to be, and what organizational changes will be required to increase both person-referenced and program-referenced outcomes.

**Evaluators Analyzing Quality Outcomes**

Human service organizations throughout the world are currently being challenged to provide quality services that result in quality outcomes. This is a challenging task because of two powerful, potentially conflicting forces: person-centered values and economically based restructured services. The focus on person-centered values stems from the quality of life movement; the human rights and self-advocacy movements' emphasis on equity, inclusion, empowerment, respect, and community living and work options; numerous public laws that stress opportunities and desired person-referenced outcomes related to independence, productivity, community integration, and satisfaction; and research demonstrating that persons can be more independent, productive, community integrated, and satisfied when quality of life concepts are the basis of individual services and supports. Conversely, the focus on restructured services stems from economic restraints, an increased need for accountability, and the movement toward a market economy in health care and rehabilitation services.

How can service providers adapt to these two potentially conflicting forces and still focus on valued, person-referenced outcomes? A heuristic model for doing so is presented in Figure 3, which outlines the three components of an outcomes-focused evaluation model: standards, focus, and critical performance indicators. Standards reflect the current emphasis on efficiency and value. Efficiency standards are based on the economic principles involved in increasing the net value of goods and services available to society; value standards reflect what is considered good, important, or of value to the person. Focus represents the current accountability emphasis on programmatic outputs and person-referenced outcomes. In the model, outputs reflect the results of organizational processes, and outcomes represent the impact of services and supports on the person. Critical performance indicators for the organization ("outputs") include responsiveness, consumer satisfaction, quality improvements, staff competencies, normalized environments, user-friendly environments, placement rates, unit costs, recidivism, bed days, and waiting lists; for the person ("outcomes"), critical performance indicators include activities of daily living, self-direction, functional skills, community living and employment status, home ownership, decision making, self-esteem, social relations, education, health, and wellness.

The reader may ask a very basic question at this point: "How might this model be used to analyze quality outcomes within the current environment that stresses person-referenced outcomes and program-referenced efficiency measures?" I would suggest the use of one or more of the following types of outcome-based evaluation analyses (described in more detail elsewhere: Schalock, 1995b; Schalock, 1999). Each analysis summarized below is related to a respective cell in the model shown in Figure 3.

- Efficiency outputs can be determined by using either allocation efficiency analysis or benefit–cost analysis that evaluates whether the program used its allocation well, whether the program's benefits outweigh the costs, or both.
- Efficiency outcomes can be determined through impact analysis that determines whether the program made a difference compared to either no program or an alternative program.
- Value outputs can be determined through effectiveness analysis that determines whether the service or support in question meets its stated goals and objectives.
- Value outcomes can be determined through participant analysis such as that described in reference to the quality of life assessment model presented in Figure 2.

The primary challenge to service providers and evaluators alike is to reach a balance in their evaluation efforts among the four types of analyses summarized above, and to recognize that different constituents will emphasize their respective desired analysis. Funders, for example, will most likely focus on efficiency outputs, whereas advocacy groups will stress the importance of evaluating value and efficiency outcomes. Those emphasizing public policy might stress efficiency outcomes and value outputs. A second challenge for each of us will be to reach a reasonable balance between accountability demands and available evaluative resources so that we can use the resulting outcome data to do the following: (a) determine whether functional limitations have been reduced and the person's adaptive behavior and role status enhanced; (b) provide feedback to decision makers about the effectiveness and efficiency of the respective services or supports provided; (c) provide the basis for program changes and improvements; (d) target those areas where increased resources can be applied to improve the match between persons and environments; and (e) show consumers that we are serious about program evaluation and that we are willing to involve them in the evaluation activities.
As we embark on the 21st century and undoubtedly continue to pursue both the concept of quality of life and an enhanced life of quality for persons with mental retardation, what guidelines might assist our efforts? I propose 10 guidelines that need to be understood within the context of the three decades of quality of life just discussed. As a quick summary of those decades, remember that during the 1980s we embraced the concept of quality of life as a sensitizing notion, social construct, and unifying theme; during the 1990s we came to a better understanding of the conceptualization and measurement of quality of life; and during the first decade of the 21st century, I predict, we will see individuals pursuing a life of quality, service providers producing quality products, and evaluators analyzing quality outcomes. Thus, in addition to reaffirming the 10 fundamental quality of life principles summarized in Table 1, I offer the 10 guidelines summarized in Table 4 for our work during the ensuing decade.

In conclusion, the first decade of the 21st century will be an exciting and active time as we jointly “pursue quality.” This pursuit will involve individuals’ desiring and advocating for a life of quality, service and support providers’ producing quality products, and evaluators’ analyzing quality outcomes. However, despite the optimism expressed in the above predictions and guidelines, we should never forget that the first decade of the 21st century will probably continue to reflect the value clashes that we experienced during the 1990s. Thus, considerable hard work, advocacy, and risk lie ahead.

The last two decades saw considerable progress in understanding the significant role that the concept of quality of life has played in the lives of persons with mental retardation and the systems that interact with those lives. Indeed, the concept of quality of life has extended beyond the person and now affects an entire service delivery system because of its power as a social construct, unifying notion, and integrating concept. But what about the third decade? Will the concept of quality of life be the same as it is today? Only time will tell. What is certain is that, because of this concept, the lives and hopes of people with mental retardation will never be the same. And that is a lot to ask of any concept.

### FIGURE 3. Outcome-focused evaluation model.

<table>
<thead>
<tr>
<th>Focus</th>
<th>Efficiency</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outputs</td>
<td>Indicators: Support Intensity, Staff Turnover, Waiting Lists, Unit Costs, Bed Days, Number Served</td>
<td>Indicators: Responsiveness, Customer Satisfaction, Normalized Environments, User-Friendly Environments, Staff Competencies, Quality Enhancement</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Indicators: Health Status (Morbidity Rates), Wellness Indicators, Activities/Instrumental Activities of Daily Living, Employment Status, Living Status</td>
<td>Indicators: Decision Making, Self-Esteem, Independence, Inclusion, Social Relations, Rights and Dignity</td>
</tr>
</tbody>
</table>

21st Century Guidelines

As we embark on the 21st century and undoubtedly continue to pursue both the concept of quality of life and an enhanced life of quality for persons with mental retardation, what guidelines might assist our efforts? I propose 10 guidelines that need to be understood within the context of the three decades of quality of life just discussed. As a quick summary of those decades, remember that during the 1980s we embraced the concept of quality of life as a sensitizing notion, social construct, and unifying theme; during the 1990s we came to a better understanding of the conceptualization and measurement of quality of life; and during the first decade of the 21st century, I predict, we will see individuals pursuing a life of quality, service providers producing quality products, and evaluators analyzing quality outcomes. Thus, in addition to reaffirming the 10 fundamental quality of life principles summarized in Table 1, I offer the 10 guidelines summarized in Table 4 for our work during the ensuing decade.

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TABLE 4
21st Century Quality of Life Guidelines

1. Consider that quality of life for persons with mental retardation is composed of those same core dimensions that are valued by all of a nation's citizens.
2. Base public policies and service delivery principles on the concept of quality of life and the enhancement of a life of quality for all people.
3. Realize that the value ascribed to the various core quality of life dimensions will probably vary over a person's life span, but, regardless of age, an enhanced quality of life is experienced when a person's basic needs are met and when he or she has the same opportunities as anyone else to pursue and achieve goals in the major life domains and settings.
4. Focus evaluation activities on both consumer outcomes and system performance.
5. Stress that continuous quality improvement is a fundamental aspect of an organization's culture.
6. Have evaluation activities play a complementary and supportive role that is consistent with the changing concept of disability as resulting from the interaction of the person and his or her environment.
7. Identify the significant predictors of a life of quality and evaluate the impact of targeting resources to maximize their positive effect(s).
8. Help consumers, policymakers, funders, service providers, and advocates to understand the multidimensionality of the concept of quality of life (see Figure 1) and its assessment (see Figure 2).
9. Use multivariate statistical and research designs to determine the effectiveness and efficiency of quality of life-focused education and rehabilitation programs (see Figure 3).
10. Integrate subjective and objective quality of life indicators into a unified concept of the core dimensions of quality of life, realizing that some aspects of each core dimension can be evaluated best via personal appraisal strategies and other aspects through objective functional assessments (see Figure 2).

ABOUT THE AUTHOR

Robert L. Schlalock, PhD, is a professor of psychology at Hastings College and adjunct professor of pediatrics and psychiatry at the University of Nebraska Medical Center. His current interests are in the areas of planning and evaluation, focusing on the topical areas of quality of life and outcomes-based evaluation. Address: Robert L. Schlalock, Box 285, Chewelah, WA 99109-0285.

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