CHAPTER 2

The Concept of Quality of Life: Its Meaning, Importance, and Our Approach to It

Overview

Over the past few decades, the concept of quality of life (QOL) has increasingly become a focus for research and application in the fields of education and special education, health care (physical and behavioral), social services (mental retardation and intellectual disabilities and aging), and families. Although it might surprise the reader, we will not begin with a definition of *quality of life*. Rather, we will describe its meaning and importance in regard to what we will call (and define) as core domains and indicators. As stated in chapter 1, there are more than 100 definitions of the term, and the interested reader can find a summary and critique of these definitions in Cummins (1996) and Goode (1994). Our strong belief is that an operational description of the term and its meaning will be a better way to provide to our readership practical assessment, application, and evaluation information and strategies.

To appreciate fully the importance of the QOL concept, it is necessary to understand its semantic meaning and use throughout the world. In reference to its meaning, *quality* makes us think of the excellence or "exquisite standard" associated with human characteristics and positive values such as happiness, success, wealth, health, and satisfaction; *of life* indicates that the concept concerns the very essence or essential aspects of human existence (Lindstrom, 1992). This semantic meaning explains why the concept is impacting the *Handbook's* areas, because it makes us think about individuals, policies, and practices that change people's lives and their perception of a life of quality. Thus it has been our experience that throughout the world the QOL concept is being used as a:

- sensitizing notion that gives us a sense of reference and guidance from the individual's perspective, focusing on the core domains to a life of quality

- social construct that provides a model for assessing the core QOL domains
- unifying theme that provides a systematic framework to apply QOL-oriented policies and practices

Quality of life has been construed by some as an "inner sense" (Taylor & Bogdan, 1996), as a correlate of temperament or personality (Edgerton, 1996), as a construct sensitive to anthropological, sociological, and psychological influences (R. I. Brown, 2000a), or as a product of interaction between person and environment (Rapley, 2000). The nature of the QOL construct, as opposed to a simple definition, is important in the literature for a central compelling reason: If, as Edgerton (1996) has suggested, "features of a person's environment are less important in bringing about a sense of well-being than are aspects of that person's personality or temperament" (p. 88), the response of the field will be quite different than if Schalock (1997) is correct when, in identifying the best predictors of quality of life, he noted, "these are factors that programs can do something about" (p. 252). However, despite Edgerton's caution that environmental change may not change quality of life, he nevertheless identified a list of improvements (e.g., housing, health care, employment, recreation) that any society should provide — a list very much like the QOL predictors enumerated by Schalock (1997). Thus, while there may be disagreement on the relative weight of individual versus environmental contributors to quality of life, the importance of improving environmental situations for individuals is not in dispute.

In addition, the meaning and application of quality of life differ according to the discourse in which the QOL concept is expressed. Quality of life can be expressed, for example, in the context of program evaluation or evaluation research. Then its meaning will be "outcome" among other valued outcomes of services or programs. If we look at quality of life in the context of social policy, its meaning can be defined as a common target to guarantee a good life and equal opportunities for all citizens. In the context of disability, health care, and rehabilitation politics, the meaning of quality of life can be seen as enhancing or improving equality for all people, despite their condition. Quality of life in the context of individual preferences produces perhaps the most popular meaning of the concept, namely individually varying experiences of one's life. This discourse can be named "how to get all good things that a person appreciates" (L. Matikka, personal correspondence, 2000).

Thus discourses about the QOL concept need to be based on its conceptualization, plus a clear understanding of significant contextual factors that are driving its application to people in education, health, and social services environments. Contextual factors such as those summarized in Table 1.1 are very important, especially when we define disability, health impairments, and aging as problematic

fits between a person and his or her environment. Additional contextual factors include (Schalock, 2000):

- a transformed vision of what constitutes the life possibilities of people who are disabled, of ill health, or aged
- a new way of thinking about such individuals that focuses on the person, the environmental variables that influence one's functioning, and the feasibility of change at both the individual and societal levels
- the current paradigm shift with its emphasis on inclusion, equity, empowerment, and community-based supports
- the quality revolution, with its emphasis on quality management, and valued person-referenced outcomes
- the evidence that individuals can be more independent, productive, community integrated, and satisfied when education, health care, and habilitation services and supports are based on QOL-oriented policies and practices

At its core the QOL concept makes us think differently about people at the margin of society and how we might bring about change at both the individual and societal level to enhance people's well-being and to reduce their exclusion from the mainstream of society. To that end, this chapter discusses three key aspects about the QOL concept: (a) its meaning from the perspective of core domains and indicators; (b) its importance as an overarching framework and set of principles and techniques to enhance a person's or family's sense of well-being; and (c) a heuristic model that explains our approach to its assessment, application, and evaluation. Throughout the chapter the reader is encouraged to think about his or her own quality of life and the factors that both define and enhance it. In that process we predict a number of questions will come to mind:

- What are the key descriptors of a life of quality?
- What are the major indicators of a life of quality?
- How do these descriptors and indicators vary across people, communities, and countries?
- How can one's quality of life be enhanced?.

The Meaning of Quality of Life

Defining and conceptualizing quality of life has been, and remains, a complex process that presents numerous technical and philosophical problems. This state of affairs has prompted us to suggest that we are better off not to define the term, but rather to agree about the core domains and indicators of a life of quality and

a number of principles that define how quality of life should be conceptualized. Throughout the *Handbook,* core QOL domains are defined as "the set of factors composing personal well-being." Core QOL indicators are defined as "QOL domain-specific perceptions, behaviors, or conditions that reflect a person's well-being."

Quality of Life Domains and Indicators

Traditional belief has held that objective factors, such as the elimination of poverty, would enhance personal well-being. However, for general populations the correlation between income and sense of well-being is modest (Myers, 2000). Recognition of this fact led Campbell, Converse, and Rodgers (1976) to observe that "there is not much doubt that the central issue confronting any examination of the perceived quality of life involves the relationship between subjective and objective indicators of well-being" (p. 474). In distinction, Edgerton (1996) has questioned the nature of the relationship between objective and subjective factors and cautioned that, at least for some people, the subjective perception of well-being may not be closely linked to objective standards of quality. As noted by both Edgerton and Goode (1997a, 1997b), the nature of this relationship between the objective and the subjective is a difficult empirical question.

Parmenter and Donelly (1997) reviewed several studies that support Edgerton's view, revealing variable and often low correlation between objective and subject indicators of quality of life. There is currently no clear objective standard by which to assess quality of life, and researchers seem to agree that subjective assessment of individual perceptions of life experiences in areas such as relationships, community activity, physical and material well-being, personal development, satisfaction, and happiness needs to be considered. However, as pointed out by Hatton (1998), Edgerton (1990, 1996), and Stancliffe (2000), there are potentially some serious problems with assessing subjective quality of life: the difficulty in interviewing individuals who lack communication skills; the different meanings attributed to quality of life interviews by different individuals; and the concern that subjective well-being may be as much a product of individual disposition or personality as of discernible changes in life circumstances.

Felce (1997; Felce & Perry, 1996) has proposed a three-part model that attempts to integrate an objective description of life conditions and a subjective assessment of satisfaction with a third dimension: personal values and aspirations. The importance of personal values and the weighting of ratings of life experiences have been recognized and discussed by Campbell et al. (1976), Cummins (1997a, 1997b), and Renwick, Brown, and Raphael (2000). One could argue, however, that such influences as personal values are simply another feature of the subjective dimensions, just as Rapley (2000) asserted the contribution of social relationships to estimates of subjective well-being. The key point of consensus is that no cur-

rent author fails to include a subjective dimension in any formulation of quality of life, and typical models (e.g., Cummins, 1996; Schalock & Keith, 1993) present subjective quality of life as their central outcome.

In an effort to move beyond this objective-subjective debate, Schalock (1996b) suggested a move to consensus on core QOL domains and indicators that might be measured at three levels: (a) personal, (b) functional or objective, and (c) social. This suggestion is consistent with Felce (1997), who proposed that the structure of QOL domains should meet two criteria: (a) in recognition of the complexity of life they must reflect the possibility of a multi-element, multiple-focus approach to assessment; and (b) they must generally reflect a broad knowledge of those things important to all of us.

The search for core QOL domains goes back to the pioneering work of Campbell et al. (1976). Subsequently, other investigators have suggested a number of core QOL domains that are quite similar (Hughes et al., 1996). This consistency is shown in Table 2.1. We feel that the eight core domains suggested by Schalock and listed at the end of Table 2.1 are quite consistent with those proposed by others, as well as being both empirical and experiential. These eight core domains lend themselves to multiple approaches to measurement, as each can be examined via multiple exemplary indicators. Such an approach also makes clear the artificial nature of the distinction between objective and subjective indicators of quality of life.

People live in a number of systems that influence the development of their values, beliefs, behaviors, and attitudes. This notion is probably best described in the work of Bronfenbrenner (1979), Cullen (1999), Dagnan, Ruddick, and Jones (1998), and Keith and Schalock (2000), who suggest an ecological perspective in describing the many contexts of human behavior. Throughout the *Handbook* we suggest that three levels of systems affect one's quality of life:

- the microsystem, or the immediate social settings, such as family, home, peer group, and workplace, that directly affect the person's life

- the mesosystem, or the neighborhood, community, service agencies, and organizations that directly affect the functioning of the microsystem

- the macrosytem, or the overarching patterns of culture, social-political trends, economic systems, and society-related factors that directly affect one's values, assumptions, and the meaning of words and concepts

This ecological approach makes a strong statement about including core QOL domains and indicators that reflect the multiple systems within which all people live: micro, meso, and macro. This concept is shown in Figure 2.1. Note that across the top one sees listed the eight core QOL domains; down the left side are listed the three levels of analysis, with the respective approaches to measurement

TABLE 2.1
Exemplary Quality of Life Domains

Investigator	Core Domains
Flanigan (1982)	Physical and material well-being Relations with other people Social, community, and civic activities Personal development and fulfillment Recreation
World Health Organization (1997)	Physical health Psychological Level of independence Social relations Environment Spirituality; religion; personal beliefs
Cummins (1996)	Material well-being Health Productivity Intimacy Safety Place in community Emotional well-being
Felce (1997)	Physical well-being Material well-being Social well-being Productive well-being Emotional well-being Rights or civic well-being
Schalock (1996b, 2000)	Emotional well-being Interpersonal relations Material well-being Personal development Physical well-being Self-determination Social inclusion Rights

that will be described in chapters 10 and 11; and within each cell are exemplary QOL indicators that are clarified further in chapters 3 through 8 for each of the *Handbook's* focus areas. As we will see in these chapters, although the core domains and indicators appear to be quite invariant across cultures, their importance varies according to one's life stage and whether one is focusing on the person, community, or larger society-culture.

Quality of Life Principles

The QOL principles that have guided us throughout this project have arisen not just from the QOL movement and literature but also from the "quality revolution." The quality revolution, with its emphasis on quality products and quality outcomes, emerged rapidly during the 1980s, when we were sensing the increased attention given to the QOL concept. One of the main products of the quality revolution was a "new way of thinking" about people at the margin of society that was guided significantly by the QOL concept. This new way of thinking stressed person-centered planning, the supports model, quality enhancement techniques, and person-referenced quality outcomes. More specifically, this new way of thinking allowed:

- service providers to reorganize resources around individuals rather than rearranging people in program slots

- consumers and service providers to embrace the supports paradigm

- program evaluation to shift its focus to person-referenced outcomes that could be used to improve organizational efficiency and enhance person-referenced services and supports

- management styles to focus on learning organizations, reengineered corporations, entrepreneurship, and continuous quality improvement

The QOL concept has had two significant impacts on the text's focus areas. First, embracing the concept has become a sensitizing notion, social construct, and unifying theme. Second, a number of principles have emerged that give additional meaning to the QOL concept and around which QOL application can be organized. The development of these principles has emerged from the international consensus work done by the Special Interest Research Group on Quality of Life of the International Association for the Scientific Study of Intellectual Disabilities. Table 2.2 summarizes five key QOL conceptualization principles (Schalock et al., in press).

In summary, the QOL concept is better understood today than it was yesterday, and its core domains and indicators are becoming well accepted. As we have just seen, the concept of quality of life cannot be separated from the context within which people with special needs live and interact. We have also seen that a

Level of Analysis

Core Quality of Life Domains

Level of Analysis	Emotional Well-Being	Interpersonal Relations	Material Well-Being	Personal Development	Physical Well-Being	Self-Determination	Social Inclusion	Rights
Macrosystem (Social Indicators)	Religious Freedom; Family Life Legislation	Public Safety	Economic Assistance (Social Insurance); Vocational Rehabilitation Legislation; Social Economic Status	Equal Opportunity Legislation; Education Rehabilitation Funding Legislation; Educational Statistics	Housing Statistics; Health Insurance	Guardianship Laws; Consumer Empowerment	Zoning Laws (Opportunity)	Public Laws (e.g., IDEA, ADA, Civic Rights Act); Human Rights Legislation
Mesosystem (Functional Assessment)	Safety; Freedom from Stress; Freedom to Worship; Supports	Interactions; Family Life; Affection; Group membership; Social supports; Marital Status	Ownership; Employment Opportunities; Supported Employment; Shelter	Person-Centered Planning; Advancement Opportunities; Opportunity for Development; Education & Rehabilitation Programs; Augmentative Technology	Health Care; Physical Rehabilitation; Food & Nutrition; Recreational & Leisure	Opportunities for Choice Making/Decisions; Allowance for Choices/Personal Control; Person-Centered Planning	Community Access/Barrier Free Environments; Normalized & Integrated Environments; Community Participation Opportunities; Social Acceptance; Transportation; Role Status; Community Supports	Self-Control & Responsibility; Protection & Advocacy Policies; Due Process; Access; Advocacy; Self-Advocacy Training & Development
Microsystem (Personal Appraisal)	Self-Concept; Happiness; Spirituality; Contentment; Satisfaction; Feeling of Well-Being; Mental Health Status	Friendships; Intimacy	Possessions; Income/Salary; Savings; Investments; Standard of Living	Educational Level; Adaptive Behavior Skills; Activities of Daily Living Skills; Instrumental Activities of Daily Living; Personal Competence	Health Status; Nutritional Status; Mobility	Autonomy; Self-Direction; Personal Control; Preferences; Choice	Community Participation/Activities; Circle of Friends; Access/Participation Opportunities; Natural Supports; Accepted Social Roles	Voting; Privacy; Self-Determination; Ownership; Personal Values; Sense of Dignity; Personal Freedom

Figure 2.1. Ecological approach: Exemplary quality of life indicators.

TABLE 2.2
Quality of Life Conceptualization Principles

Quality of life:

1. is composed of those same factors and relationships for people in education or special education, physical health, mental and behavioral health, mental retardation and intellectual disabilities, aging, and families that are important to all people

2. is experienced when a person's needs are met and when one has the opportunity to pursue life enrichment in major life settings

3. has both subjective and objective components, but is primarily the perception of the individual that reflects the quality of life he or she experiences;

4. is based on individual needs, choices, and control

5. is a multidimensional construct influenced by personal and environmental factors such as intimate relationships, family life, friendships, work, neighborhood, city or town of residence, housing, education, health, standard of living, and the state of one's nation

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complete understanding of the concept requires a systems perspective wherein one is sensitive to the micro-, meso-, and macrolevel influences on a life of quality — and one's perception of such. And we have also seen that our search has revealed eight core domains of a life of quality: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. By embracing an ecological model such as that shown in Figure 2.1, one becomes sensitive to factors that affect life at different proximal levels to the person. At the same time, one glimpses the importance of the QOL concept — a topic to which we now turn.

The Importance of the Concept of Quality of Life

Although quality of life is critically important to each of us, its importance to education, health care, social services, and families has been most evident during the past two decades, which in turn were influenced by the quality revolution and the reform movement. Generally speaking, the importance of the QOL concept is that it provides an overarching person- or family-centered framework and set of principles to enhance people's psychological and subjective well-being. Five application principles, which are based on our work with the international consensus group (Schalock et al., in press), are summarized in Table 2.3.

TABLE 2.3
Quality of Life Application Principles

Quality of life application should:

1. enhance a person's well-being

2. be applied in light of the individual's cultural and ethnic heritage

3. collaborate for change at the personal, program, community, and national levels

4. enhance the degree of personal control and individual opportunity exerted by the individual in relation to his or her activities, interventions, and environments

5. occupy a prominent role in gathering evidence, especially in identifying the significant predictors of a life of quality and the impact of targeting resources to maximize positive effects

As shown clearly in Table 2.3, the importance and significance of the QOL concept is evident at the three systems levels: micro, meso, and macro. This section of the chapter sensitizes the reader to a number of important applications that will be described more fully in part 4. Each application reflects the concept's importance to those with whom we work and associate.

Microsystem: Personal Growth and Development Opportunities

There are currently four major thrusts at the microsystem level to enhance a person's perceived quality of life. First, there is strong advocacy for increased opportunities to participate in the mainstream of life, associated with increased inclusion, equity, choices, and self-determination (Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1998). Second, consumers are working jointly with researchers to determine the relative importance or value of the QOL core domains. Third, consumers are increasingly becoming involved in assessing their own quality of life (Schalock, Bonham, & Marchand, 2000). And fourth, the area of personal development and wellness training is becoming a major thrust in service and supports delivery (Schalock & Faulkner, 1997).

Mesosystem: Program and Environment Enhancement Techniques

We are also seeing service and support providers implementing quality enhancement techniques that focus on either the environment or the service and supports program (Schalock, 1994). Environmentally based enhancement techniques involve designing environments that are user friendly and reduce the mismatch between the person and the environment. Examples include (Ferguson, 1997): opportu-

nity for involvement (e.g., meal preparation); easy access to the outdoor environment, modification to stairs, water taps, door knobs; safety (e.g., handrails, safety glass, nonslip walking surfaces); convenience (e.g., orientation aids such as color coding or universal pictographs); accessibility to home and community; sensory stimulation (e.g., windows, less formal furniture); prosthetics (e.g., personal computers, specialized assistive devices, high-technological environments); and opportunity for choice and control (e.g., lights, temperature, privacy, and personal space).

Program-based enhancement techniques are currently being built around the core domains of a life of quality. In reference to the eight core domains used in this handbook, for example, (a) emotional well-being can be enhanced by increased safety, stable and predictable environments, and positive feedback; (b) interpersonal relationships by fostering friendships, encouraging intimacy, and supporting families; (c) material well-being by supporting ownership, and employment; (d) personal development by fostering education and functional rehabilitation and by using augmentative technology; (e) physical well-being by ensuring adequate health care, mobility, wellness, and proper nutrition; (f) self-determination by encouraging choices, personal control, decisions, and personal goals; (g) social inclusion by emphasizing community roles, community integration, and volunteerism; and (h) rights by ensuring voting access, due process, and opportunities to assume civic responsibilities.

Macrosystem: Social Policies

There are currently more than 40 worldwide treaties or conventions of human rights. The 1990s witnessed a major initiative by the international community to improve the legal status and enhance the situation of people with special needs. Reflective of this initiative, the United Nations General Assembly adopted in 1993 the *United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations, 1993). Eight of the 22 rules can be considered "enabler standards" that deal with issues such as international cooperation (technical and economic), information and research, policymaking and planning, coordination of work, personnel training, and monitoring and evaluation. Significantly, the 14 "outcome standards" are congruent with the eight proposed core QOL domains, as follows:

1. emotional well-being: reflected in the rule regarding religion
2. interpersonal relations: reflected in rules relating to family life and personal integrity
3. material well-being: employment, income maintenance, and social services
4. personal development: education and rehabilitation
5. physical well-being: medical care and recreation and sports

6. self-determination: self-advocacy organizations

7. social inclusion: support services

8. rights: awareness raising, accessibility, equal rights to participate

In summary, the importance of the QOL concept is both personal and societal. At the personal level, the concept makes us think about the excellence associated with human characteristics and positive values such as happiness, success, wealth, health, and satisfaction; at the societal level, the concept makes us sensitive to the needs of others and the potential discrepancy between what people need and what they have. Thus its importance to each reader is that it is both a sensitizing notion and a social construct that can be used as an overarching framework to make a significant difference in people's lives. The chapter's concluding section presents and discusses a heuristic QOL model that provides such a framework, which we use throughout the *Handbook* to explain further the assessment, application, and evaluation of QOL concepts, policies, and practices.

Our Heuristic Quality of Life Model

The 1990s and early 21st century have seen a significant change in how we view education, health care, and social service programs, including their values, purposes, character, responsibility, and intended outcomes. This change is referred to as the reform movement. Major characteristics include (Schalock, 2001) focusing on outputs rather than inputs; redefining clients as customers; decentralizing authority; using market rather than bureaucratic mechanisms; catalyzing public, private, and volunteer sectors; empowering citizens; and introducing private finance. Two aspects of the reform movement have a direct bearing on our heuristic model: its accountability dimension and its quality dimension.

Current accountability initiatives seek to improve management, increase efficiency and effectiveness, and improve public confidence in private and public programs. Throughout the world, governments are asking education, health care, and social service programs and providers to articulate goals and report results through the three processes of strategic plans, performance plans, and program performance reports. Analogously, public and private funding agencies are increasing their attention to the use of performance information in the budget process, moving toward full-scale implementation of results-based accountability and budgeting. These efforts are giving increased prominence to value for money, including the responsibility of managers at all levels to make the best use of resources and the need for good output and performance information, including consumer satisfaction and QOL-related outcomes.

In reference to the quality dimension, two phenomena are significantly influ-

encing current education, health care, and social service programs: (a) the movement toward assessing the value and quality of respective programs on the basis of consumer satisfaction, and (b) the development of new models of service delivery that reflect quality enhancement, the devolution of government, the homogenization of services, and the community-based movement in human services. In this regard, contemporary discussions of quality outcomes are no longer grounded in the industrial-regulatory perspective wherein quality was defined as conformity with regulation and specification. In contrast, current definitions of quality are rooted in the postindustrial, knowledge-based society (Gardner, 1999). The worldwide growth of service economies and the information revolution have elevated the importance of customer service and the measurement of personal and consumer-referenced outcomes.

These two quality phenomena — the movement toward assessing the value and quality of respective programs on the basis of consumer satisfaction and person-referenced outcomes, and the development of new QOL-referenced models of intervention and service delivery — have impacted the area of quality of life in three significant ways.

1. They have provided a catalyst to develop methodological pluralism, which reflects the postmodernist's emphasis on responsive, constructive evaluation (Guba & Lincoln, 1989).

2. They emphasize the need to incorporate the systems perspective into one's QOL work, as people live in several systems (micro, meso, and macro) that influence the development of their values, beliefs, behaviors, and attitudes.

3. The concern for quality outcomes within a devolution environment has resulted in the development of practice guidelines that reflect quality programming and intervention.

These three impacts are reflected in our heuristic QOL model shown in Figure 2.2. As shown, the model has three major components: QOL domains (and indicators), a social systems perspective, and three potential foci (measurement, application, and evaluation). An overview of each component is presented next.

Quality of Life Domains and Indicators

A number of domains of personal well-being have been identified in the international QOL literature. Although the number varies slightly (see Table 2.1), the core domains (sometimes referred to as "dimensions") include the desired states of emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. Many QOL investigators suggest that the actual number of domains is perhaps
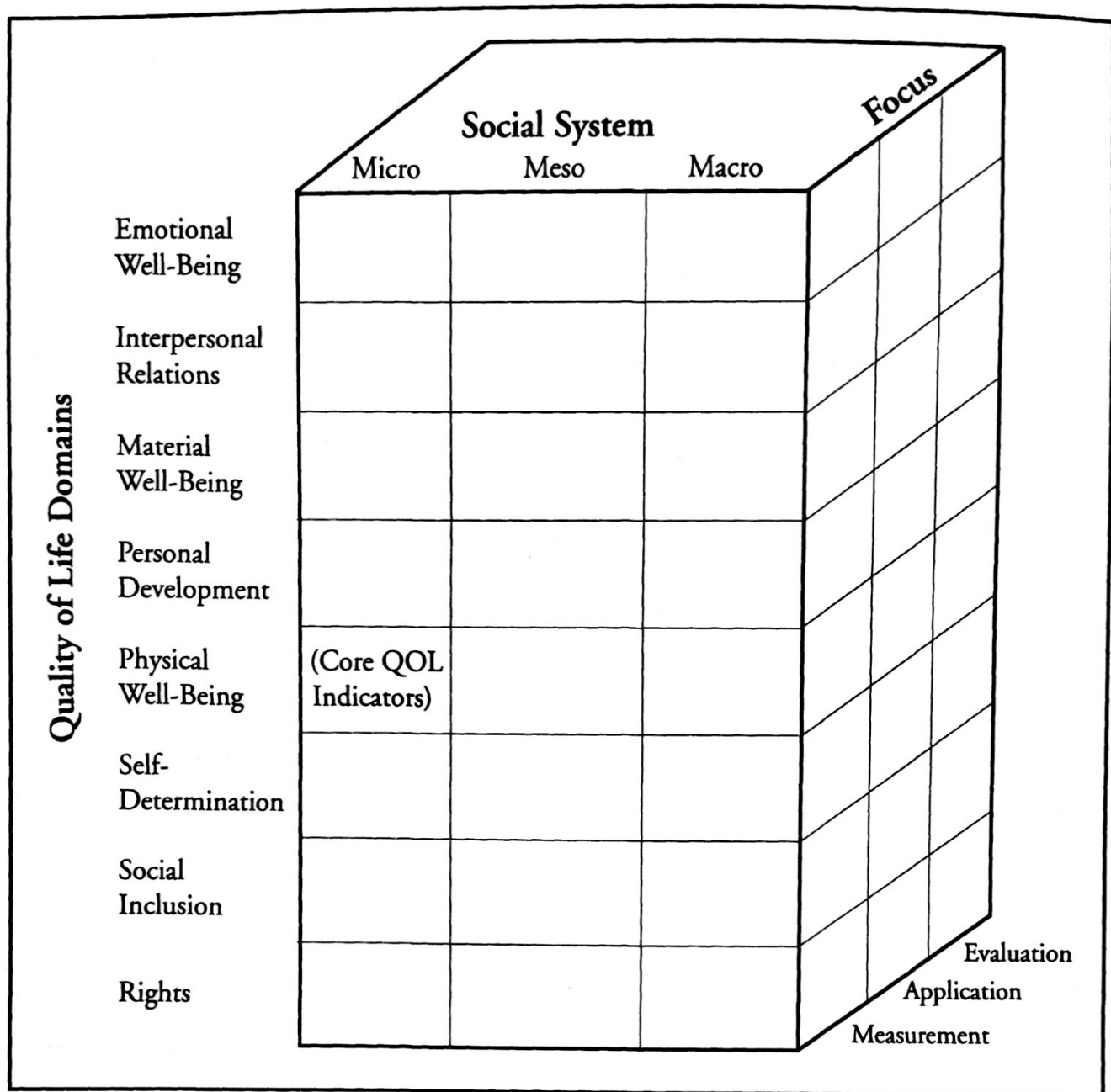
Figure 2.2. Heuristic model: Quality of life measurement, application, and evaluation.

less important than the recognition (a) that any proposed QOL model must recognize the need for a multi-element framework, (b) that people know what is important to them, and (c) that any set of domains must represent in aggregate the complete QOL construct. As noted above:

- Core QOL domains are: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. These domains represent in aggregate the complete QOL construct presented throughout the *Handbook.*

- Core QOL indicators are: QOL domain-specific perceptions, behaviors, or conditions that reflect a person's perceived or real quality of life. Criteria for the

selection of an indicator are that it is functionally related to the respective QOL domain, measures what it is supposed to measure (validity), is consistent across people or raters (reliability), measures change (sensitivity), reflects changes only in the situation concerned (specificity), is affordable, timely, person-referenced, can be evaluated longitudinally, and is culturally sensitive.

Social Systems Perspective

By way of review, people live in several systems that influence the development of their values, beliefs, behaviors, and attitudes. As assumed throughout the *Handbook*, three system levels affect one's quality of life:

- the microsystem, or the immediate social settings, such as family, home, peer group, and workplace, that directly affect the person's life
- the mesosystem, or the neighborhood, community, service agencies, and organizations that directly affect the functioning of the microsystem;
- the macrosystem, or the overarching patterns of culture, social-political trends, economic systems, and society-related factors that directly affect one's values, assumptions, and the meaning of words and concepts

The systems perspective emphasizes the need to view quality of life from a broader perspective than just the individual. Indeed, as shown in Figure 2.2, core QOL domains and indicators can be defined and measured in reference to each system level. In addition, Figure 2.2 indicates that the application of the QOL concept in reference to measurement, application, and evaluation should also encompass each of the three system levels.

Foci

As QOL research and discussions have evolved, international consensus has moved away from thinking there is one definition or application of quality of life and toward describing and understanding its core domains and the conditions that promote and enhance a good life. Quality of life encompasses the basic conditions of life (e.g., adequate food, shelter, and safety) plus life enrichers (e.g., inclusive social, leisure, and community activities). These enrichers are based on the individual's values, beliefs, needs, and interests.

As we have seen, meanings of quality of life also differ according to the field of discourse. The QOL concept, for example, can be expressed in the context of its measurement as an outcome. It can also be expressed in the context of social policy as a common application target to guarantee a good life and equal opportunities for all citizens. Or it can be expressed in the context of individual preferences, which is perhaps its most popular meaning.

As the previous section of this chapter discussed a number of systems-level

applications of the QOL concept and parts 3 and 4 focus in detail on its measurement and application, we discuss in the remainder of this chapter a concept pertinent to each of the three foci (measurement, application, evaluation): methodological pluralism. Our use of methodological pluralism is based on four premises:

1. Quality of life is a multidimensional construct in which culturally consensual values and shared attributes are reflected.

2. One's life of quality has both subjective and objective components.

3. People use QOL data for different purposes, including self-report, description, evidence, evaluation, and comparison.

4. The use of QOL data can be understood and applied within micro-, meso-, and/or macrosystems.

Measurement, application, and evaluation theory and strategies have undergone tremendous changes over the past 30 years. At least four stages can be identified (Shadish, Cook, & Leviton, 1991):

1. The 1960s, which stressed the assessment of program effectiveness at solving social problems.

2. The 1970s, which focused on how information is used in the design and modification of social programs.

3. The 1980s, wherein the major focus was to integrate work from the previous two stages.

4. The late 1980s and 1990s (called the postmodernist period) was characterized by minimizing the roles of science-based, quantitative research methodology and maximizing a social constructivist, qualitative, and pluralistic approach. Currently, this approach stresses that (Schalock, 2001): the pragmatic evaluation paradigm, ideographic research, context-specific knowledge, decision-oriented evaluation, and a combination of qualitative and quantitative research/evaluation designs.

In reference to our heuristic model (Figure 2.2), methodological pluralism is reflected primarily in the measurement and evaluation foci. Each approach, in its own way, recognizes the critical role that the person, those closest to the person, and the person's environments play on an individual's perceived quality of life. This notion is very consistent with the ecological approach to quality of life presented in this *Handbook* and necessitates the measurement and evaluation of QOL indicators across all systems levels proposed below.

Microsystem: Personal Appraisal

This measurement and evaluation level addresses the subjective nature of quality of life, typically asking the person how satisfied he or she is with the cell-specific exemplary indicator(s) (see Figure 2.2). For example, one might ask, "How satisfied are you with the skills and experiences you have gained or are gaining from your job?" or "How happy are you with your home or where you live?" Although the person's responses are subjective, responses need to be measured in psychometrically sound ways. A three-point Likert scale can be used both to indicate the level of expressed satisfaction and to demonstrate reliability and validity of measurement.

Increasingly, a person's measured level of satisfaction (i.e., personal appraisal) is a commonly used dependent measure in evaluating core QOL domains and indicators. It has several evaluative advantages: (a) satisfaction is a commonly used aggregate measure of individual life domains and demonstrates a trait-like stability over time (Andrews, 1974; Edgerton, 1996); (b) there is an extensive body of research on level of satisfaction across populations and service delivery recipients (Cummins, 1996); and (c) satisfaction as a dependent variable allows one to assess the relative importance of individual QOL domains and thereby assign value to the respective domain. The major disadvantages of using only satisfaction as a measure of quality of life include (a) the reported low or lack of correlation between subjective and objective measures of quality of life, (b) its limited utility for smaller group comparisons, (c) its tendency to provide only a global measure of perceived well-being, and (d) its discrepancy with the multidimensional nature of quality of life (Schalock, 2001). Because of these disadvantages, the general recommendation among QOL researchers is to include personal appraisal (i.e., subjective), functional assessment (i.e., objective), and social indicators as measures of the core QOL domains.

Mesosystem: Functional Assessment

This measurement and evaluation level addresses the objective nature of quality of life and reflects the person's interaction with neighborhood, community, or organization. The most typical formats used in functional assessment include rating scales, participant observation, and/or questionnaires. Each attempts to document a person's functioning across one or more core QOL domains. To accomplish this, most instruments employ an ordinal rating scale to yield a profile of the individual's functioning across major life activity areas such as home, work, school, or community.

There are advantages to using functional assessments to evaluate the core QOL domains: (a) objective measures can confirm results from the personal appraisal strategy; (b) adding objective measures to personal appraisal overcomes the commonly reported low correlation between subjective and objective measures of

quality of life; (c) their use allows for the evaluation of outcomes across groups; and (d) objective measures provide important feedback to service providers, funders, and regulators as to how they can change or improve their services to enhance the recipient's functioning level.

There are also disadvantages to functional assessment: (a) it must be balanced with other considerations, such as the fact that not all outcomes related to one's perceived quality of life can be measured; (b) it can be costly, and one needs to be cautious that the functional assessment system does not consume in resources more than its information is worth; (c) it is useful to management or the decision-making process only to the extent that it answers the right questions; and (d) users of functional assessment data need to understand the role that many factors play in one's perceived quality of life and not focus exclusively on the service provider.

Macrosystem: Social Indicators

Social indicators generally refer to external, environmentally based conditions such as health, social welfare, friendships, standard of living, education, public safety, housing, neighborhood, and leisure. These indicators may be defined as a statistic of direct normative interest that facilitates concise, comprehensive, and balanced judgments about the conditions of major aspects of society (Andrews & Whithey, 1976). Such indicators are good for measuring the collective quality of community or national life; however, they are probably insufficient to measure either an individual's perceived quality of life or functional behavior(s). Campbell et al. (1976), for example, argue that social indicators reflect only an outsider's judgment of quality as suggested by external, environmentally based conditions. Thus "because we are accustomed to evaluating people's lives in terms of their material possessions, we tend to forget that satisfaction is a psychological experience and that the quality of this experience may not correspond very closely to these external conditions" (p. 3).

In summary, the methodological pluralism approach proposed in this *Handbook* combines personal appraisal, functional assessments, and social indicators. This approach to QOL measurement and evaluation has become a widely accepted strategy for three reasons. First, all activity focuses clearly on the multidimensional, core QOL domains and indicators. Thus one need not use different indicators for subjective versus objective measurement; rather, the core domains and indicators remain constant; what varies is whether one focuses on micro-, meso-, or macrolevel of measurement. Second, it allows one to incorporate multiple perspectives and systems-level analysis into the measurement, application, and evaluation of quality of life. And third, methodological pluralism allows researchers to meet the following objectives of using mixed-method evaluations: triangulation, or the determination of correspondence of results across personal appraisal and functional assessment strategies; complementarity, or the use of

qualitative and quantitative methods to measure the overlapping but distinct facets of the QOL construct; and initiation, which allows one to recast questions or results from one strategy with questions or results from the contrasting strategy (Schalock, 2001).

Conclusion

In conclusion, a number of important ideas reflect the emerging framework for conceptualizing, measuring, applying, and evaluating quality of life. Quality of life is a rich and varied concept that draws on the resources of both science and art and is manifested not only in the data of research and measurement but also in a variety of personal expressions consistent with individual being, belonging, and becoming. It follows, therefore, that most conceptions of quality of life share common features and core ideas such as general feelings of well-being, feelings of positive social involvement, opportunities to achieve personal potential, choices and personal control, self-image, and a life-span perspective.

Our belief is that the meaning of quality of life is understood best in regard to its core domains and indicators that reflect a life of quality. We are seeing throughout the world its importance reflected in quality enhancement techniques being applied locally, nationally, and internationally on behalf of people with special needs and their families. As Renwick et al. (2000) remind us, a full picture of quality of life includes the interactions among factors at various degrees of immediacy to the person, and it is necessary to understand how factors at all levels affect a person's experienced quality of life. As stated so well by Rapley (2000), quality of life is "the product of interaction in community with others" (p. 157).

Throughout this first part, we have stressed the importance of approaching the QOL concept from an ecological perspective that results in both a better understanding of the factors that impact a person's perceived quality of life and the application of potential strategies to enhance one's life of quality. Our heuristic QOL model presented in Figure 2.2 incorporates our understanding of the QOL concept, the reform movement with its accountability and quality dimensions, methodological pluralism, and the key concepts discussed thus far: the core QOL domains and indicators, the systems perspective, and the foci for our collaborative work (measurement, application, and/or evaluation). We use this model throughout the rest of the *Handbook* to guide our efforts to provide effective techniques and strategies that the reader of a *Handbook on Quality of Life for Human Service Practitioners* should expect.

At this point, we need to share a word of caution with our readers: There is a lot of information included in parts 2 through 4. We have done our best to organize the key ideas and data into easy-to-read tabular and graphic formats. We have striven hard to ensure that the reader will neither get lost nor have the feeling

that either we do not know where we are going in the *Handbook* or that the text is data rich and information poor. To that end, we have followed our own admonition to "know where you are going so you will end up in the right place." Part 2, "The Integration of Research on Quality of Life," presents our first major challenge and the reader's first opportunity to evaluate our clarity and organizational abilities. We trust we have succeeded.