Quality of Life as Context for Planning and Evaluation of Services for People with Disabilities

RUTH E. DENNIS
WES WILLIAMS
MICHAEL F. GIANGRECO
CHIGEE J. CLONINGER
University of Vermont

ABSTRACT: *Quality of life has become a dominant theme in planning and evaluating services for people with disabilities. This article reviews definitions of quality of life, explores the concept from the perspective of the optimal theory of personal well-being, and surveys the research on the concept and its implications for planning and evaluating services. This article explores the subjective nature of life quality, particularly for people with disabilities, and relates the concept to both cultural norms and universal human values and needs. Each person experiences life, and disability, in unique ways. Practitioners need to consider quality-of-life issues as a context in planning and evaluating quality services.*

Every person is like all other persons, like some persons and like no other persons. (Speight, Myers, Cox, & Highlen, 1991, p. 32)

□ In the past decade, quality of life has emerged as an important theme in planning and evaluating services for people with disabilities (Goode, 1990; Schalock, Keith, Hoffman, & Karen, 1989). The theme is reflected in programs and policies intended to enhance full community membership and participation. There is a growing emphasis on the creation of formal and informal support networks to meet the needs of people with disabilities and to ensure they have a quality of life that is congruent with how that concept is defined by the individual and society (Fabian, 1991; Roessler, 1990). This article presents definitions of quality of life, explores the concept from a framework based on "optimal theory" of personal well-being, surveys the source and use of research, and discusses implications for planning and evaluation.

DEFINITIONS OF QUALITY OF LIFE

The term quality of life is emerging ever more frequently in professional literature; in public policy; and in the popular language of business, consumer satisfaction, advertising, health, the environment, politics, and education. There is no single definition of the term, but researchers have agreed that any assessment of life quality is essentially subjective (Blatt, 1987; Edgerton, 1990; Schalock, 1990a; Taylor & Racino, 1991). Definitions offered recently (Schalock & Bogale, 1990) have included the following:

• Satisfaction with one's lot in life and a sense of contentment with one's experiences of the world (Taylor & Bogden, 1990).

• A sense of personal satisfaction that is more than contentment and happiness but less than "meaning" or fulfillment (Coulter, 1990).

• A general well-being that is synonymous with overall life satisfaction, happiness, contentment, or success (Stark & Goldsbury, 1990).

- The ability to adopt a lifestyle that satisfies one's unique wants and needs (Karen, Lambour, & Greenspan, 1990).

- Blatt (1987) emphasized the temporal, relative, and individual nature of the definition of quality of life:

> There will be necessarily empty places, as it is equally certain that there will be times when there seems to be too much. . . . The brimming cup has little to do with the size of the cup or the temporary nature of its contents. . . . It is all in the mind and, for sure, in the soul. (p. 358)

Goode (1990) reported several principles regarding quality of life (QOL) for people with disabilities. Consumers with disabilities and service providers identified the following principles:

1. QOL for persons with disabilities is made up of the same factors and relationships that have been shown to be important for persons without disabilities.
2. QOL is experienced when a person's basic needs are being met and when he or she has the opportunity to pursue and achieve goals in major life settings.
3. The meaning of QOL in major life settings can be consensually validated by a wide array of persons representing the viewpoints of persons with disabilities, including their families, professionals, service providers, advocates and others.
4. The QOL of an individual is intrinsically related to the QOL of other persons in her or his environment.
5. QOL of a person reflects the cultural heritage of the person and of those surrounding him or her. (p. 54)

Many researchers have concurred that quality of life for people with disabilities comprises the same factors as quality of life for people without disabilities (Blatt, 1987; Devereux, 1988; Goode, 1990; Schalock, 1990b; Turnbull & Brunk, 1990; Weick, 1988). However, Taylor and Racino (1991) noted that philosophers throughout the ages have failed to agree on the meaning of quality of life. They cautioned that such a complex issue is no easier to describe for people with disabilities than it has been for others. Because of the variety of approaches to quality of life, we need to draw on a broad-based literature to gain understanding and perspective regarding life quality for people with disabilities.

A QUALITY-OF-LIFE FRAMEWORK: OPTIMAL THEORY MODEL

Optimal theory is a concept discussed by Speight et al. (1991) in the literature of counseling and development. Optimal theory, rooted in traditional African culture, suggests a holistic view of health and well-being that provides a balance between the values of diversity and the values of commonality. Speight et al. suggested that by adopting an optimal world view, we can move beyond a fragmented view of individuals who experience different external realities and challenges, toward a more holistic view. Their model, referenced to the work of Cox (1982), depicts an individual's world view as a Venn diagram of three overlapping circles: individual uniqueness, human universality, and cultural specificity. Speight et al. indicated that the area of overlap between the three broadly defined spheres is most interesting and illuminating because only in their combination can we begin to understand the blending of influences on individuals' world views. Figure 1 provides a similar framework for considering subjective quality-of-life values as they relate to people with disabilities.

Individual Values and Needs

Within the individual sphere (see Figure 1), *every person is like no other person.* For example, people's experience of disability and their individual needs, strengths, and talents can contribute to a unique world view that underlies subjective assessments of life quality. People with disabilities may have unique needs related to their condition, such as a need for communication, mobility, support, and technology. They may also have unique life experiences, such as having people equate their differences with deficiency; being labeled, stereotyped, and stigmatized; being segregated and having a very limited social network; being moved frequently from one living situation to another; and being given little or no choice about their associates or where they live, work, and recreate.

Shared Human Values and Needs

Within the sphere of common human experience (see Figure 1), *every person is like all other persons.* Weick (1988) urged that, in addition to the specific needs of people with disabilities, we

FIGURE 1
Optimal Framework for Subjective Quality-of-Life Values and Needs
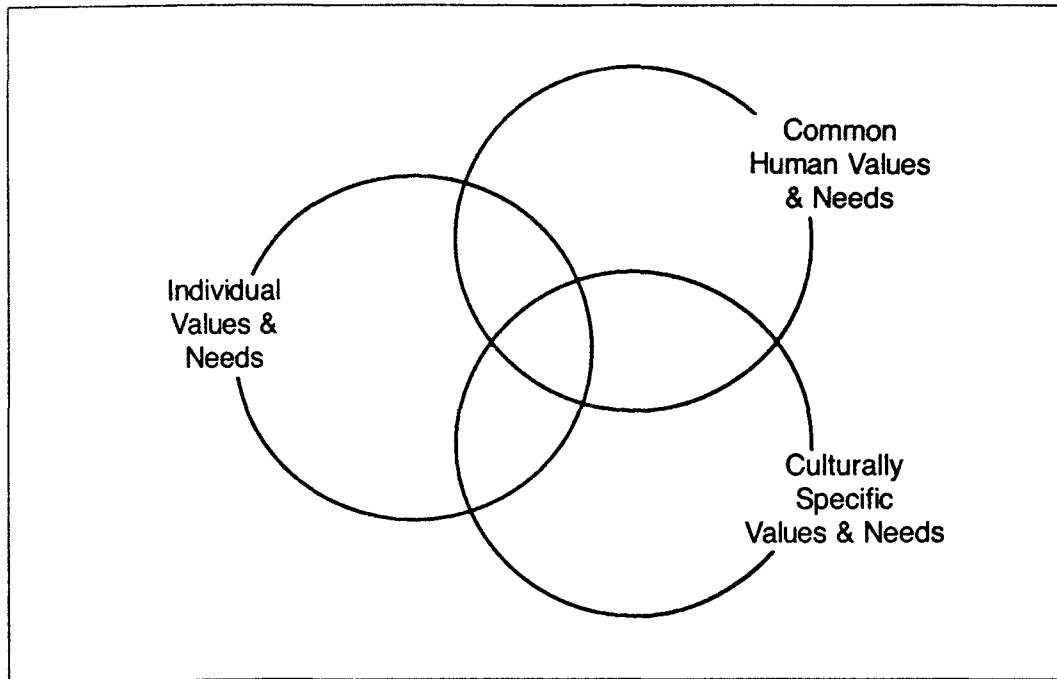
must address common and basic human needs in any discussion of quality of life. She wrote:

> People with developmental disabilities have special needs. Funding, policies and services have often focused on these special needs. . . . As a result, basic needs have gone unmet. Their basic needs are the same as ours. (pp. 12-13)

The search for a balance between individual values and shared human values and needs that underlie differing views has been a traditional subject of social, political, and educational philosophers (Maguire, 1982). Many have suggested that the common values held by a society are often related to the context out of which they grew, particularly the common *needs* perceived by people living in that context.

Values of Independence and Interdependence. Western values and beliefs regarding common human values and needs include the values of both personal independence and social interdependence. Bellah, Madsen, Sullivan, Swidler, and Tipton (1985) identified "radical individualism" as a dominant and sometimes problematic theme in U.S. society and concluded that there is

a tendency to ignore how individual autonomy is ultimately supported by the common human values of society.

The struggle of Americans to achieve a balance related to values of independence and interdependence is reflected in U.S. social institutions, including schools (Ravitch, 1986; Schlechty, 1990). Many argue that today's schools may be overemphasizing individualism and independence at the expense of interdependence and social relationships that underlie some concepts of quality of life (Fullan, 1991; Noddings, 1984). Educational goals for people with disabilities also reflect the struggle to achieve a balance related to values of independence and interdependence (Haring, 1991). Educators and others have often set as a primary goal "independent living through skill acquisition" for people with disabilities. Such goals seldom acknowledge that quality of life for people both with and without disabilities also requires social relationships and levels of interdependence, ranging from reliance on basic community services (e.g., mass transportation, police, fire) to extensive reliance on social service agencies (e.g., housing,

income support, medical support, legal aid, and guidance in activities of daily living).

Influence of Social Theories. Our view of common human characteristics and values has been reflected in, and enhanced by, theories of human development and the "principle of normalization" (Nirje, 1976; Wolfensberger, 1977). The study of human development is rooted in humanistic thought, which asserts the dignity and worth of humankind and its capacity for self-realization through reason. Popular theories of human development express valued life outcomes in terms that include *skills, potential, reason, growth, satisfaction,* and *fulfillment.* These concepts underlie other current definitions of quality of life (Rosenthal, 1984). Developmental theory, in its focus on human potential, has been a seminal concept in the articulation of, and advocacy for, common human rights and values. These values gave rise to many positive social policies, including protective public policy and services for children, the civil rights movement in the United States, and the expansion of educational opportunity through public education.

Some researchers, however, hold that developmental theory has not always had positive effects for people with disabilities. An emphasis on successive developmental stages, phases, or steps often implies that people who fail to pass through these stages are somehow less human (Ferguson, P., 1987). Many researchers have criticized this emphasis on stages and steps as reflecting both cultural and gender biases (Gilligan, 1979; McIntosh, 1983; McLaren, 1989; Sassen, 1980) and not reflecting the developmental experiences of people with disabilities (Berkeley & Ludlow, 1989; Dunn, 1991; Ferguson, D., & Baumgart, 1991).

The normalization principle, which extends humanistic thought about what normal development and life mean to people with disabilities, has had a significant effect on our concept of quality of life for people with disabilities. The term *normalization* became popular in the United States after Wolfensberger (1977) defined it simply as "letting the mentally retarded obtain an existence as close to normal as possible" (p. 305). Nirje (1976) defined normalization as, "The opportunity to undergo the normal developmental experiences of the life cycle" (p. 173). The normalization principle supports many current articulations of rights of people with disabilities and gave rise to practices such as deinstitutionalization, educa-

tional placement in the least restrictive environment, and national and international policy statements and indicators intended to enhance access to quality of life in community environments.

Culturally-Based Values and Needs

Within the sphere of cultural influence (see Figure 1), *every person is like some other person* through experiences and meanings that groups of people share. Cultural anthropologists and sociologists have traditionally studied the values and beliefs of different groups and subgroups of the world's population that underlie different concepts of quality of life (Donegan & Potts, 1988; Glesne & Peshkin, in press). These values and beliefs are embedded in the group's customs, language, traditions, literature, religion, art, and other day-to-day practices that take on shared meaning and value for members of the group. Many writers point out that cultural values are not static, but fluid and responsive to the political and historical context that groups of people experience; and these values reflect the efforts of members of the groups to actively make sense of their experiences (Ericson, 1990; Freire, 1970; Greene, 1990; McLaren, 1989). Most social groups today are affected by the mingling of their cultures with that of other groups and experience subcultural and individual diversity within their own groups, as well (Ericson, 1990; Mead, 1943).

We are probably most familiar with values and beliefs common to modern, white, middle-class American culture, as it is idealized and popularized by our political, media, and educational institutions. Any discussion of quality of life for people with disabilities in the United States, however, must attend to the variation in quality-of-life standards and values among groups, families, and individuals with differing life experiences. American Indians, African Americans, Latinos, and Asians, women and men, children and adults, rural and urban, rich and poor, blue-collar and executives, and so forth—all these groups experience life and culture differently; white, middle-class values and lifestyle are not universally favored (Edgerton, 1990). Our increasing awareness of cultural differences and the influences of cultural beliefs and values on perceptions of quality of life lead us to cautiously approach generalized definitions and standards for people with disabilities.

Implications of the Framework

Although quality of life for individuals and groups may consist of similar factors and relationships, the optimal theory model indicates that the determination of what constitutes quality of life for individuals and groups of people both with and without disabilities is complex. The interactions among individual uniqueness, human universality, and cultural specificity influence each individual and group as they select and set different priorities for quality-of-life factors at different times.

The literature indicates that an examination of quality-of-life issues should include the following factors:

1. *There is no single definition of quality of life.*
2. *Potential for bias exists, even for researchers.* Partly because of the undefined and subjective nature of quality of life, each person who studies this concept must guard against being unknowingly influenced by his or her own values, experiences, and culture.
3. *The quality of life of individuals is related to that of those around them.* For example, the quality of life of an individual can be intrinsically related to that of her family; and efforts to address the individual's quality of life must include consideration of the family's interpretation of quality of life.
4. *Quality-of-life factors are temporal, or fluid, and are affected by context.* Factors for individuals and groups change in response to life experiences, political and historical contexts, and specific needs that arise out of those contexts. That individuals and groups can subscribe to a multitude of quality-of-life factors or values, many of which may be contradictory and difficult to reconcile, increases the complexity of determining which factors are operating in a given context. For example, as discussed earlier, individuals can value both independence and interdependence. Thus, they may desire either independence *or* interdependence in some contexts—and a compromise between the two in others.

An analysis of quality-of-life factors for individuals or groups is a snapshot frozen in time and context. Time moves on and the context changes. Researchers and practitioners desiring to use quality-of-life factors as a basis for planning and evaluating services should carefully analyze different methodologies for examining quality of life and select factors that have the most potential for adequately addressing the problems listed previously.

APPROACHES TO QUALITY-OF-LIFE RESEARCH

The theoretical approaches to quality-of-life research are varied (Bradley & Knoll, 1990; Speight et al., 1991). Some researchers see value in an attempt to objectify and quantify quality of life (Stark & Goldsbury, 1990), whereas others believe that quality of life remains, by its very nature, an individually unique and subjective concept that defies objective measurement and demands qualitative approaches (Edgerton, 1990). Many others use a combination of approaches to gain knowledge regarding quality of life (Bradley & Knoll, 1990; Cameto, 1990; Conroy & Feinstein, 1990; Schalock, 1990a; Stainback & Stainback, 1989). A few researchers believe that the term *quality of life* should be abandoned (Luckasson, 1990).

Quantitative Approaches

Quantitative approaches to quality-of-life research have been used by social science researchers for more than 50 years (Goode, 1990), whereas emphasis on quantitative research related to people with disabilities is a more recent phenomena (Stark & Goldsbury, 1990). The primary purpose in operationalizing or quantifying quality of life for people both with and without disabilities has been to compare and plan services, programs, and policies referenced to quality of life for specific populations. Social scientists have studied quality-of-life indicators using different approaches:

- The study of social indicators.
- The study of psychological indicators.
- Ecological analysis.

Social Indicators. Social-indicator studies usually measure the collective quality of community living for groups or populations (e.g., nations, cities). Social-indicator factors typically refer to external, environmentally-based conditions, such as health, social welfare, friendships, standard of living, education, public safety, housing, marital status, work, tax rate, family, and children (Cameto, 1990; Roessler, 1990; Schalock, 1990b; Zantura & Goodhart, 1979). Such indica-

tors are often considered insufficient for assessing an individual's quality of life or for evaluating the outcomes of services because they only reflect an outsider's judgment of quality, as suggested by external factors. These indicators do not address individual psychological experiences of satisfaction, which may not correlate to external conditions (Campbell, Converse, and Rodgers, 1976; Schalock et al., 1989).

Psychological Indicators. Psychological-indicator studies measure the individual's subjective reactions to the presence or absence of certain life experiences. Psychological-indicator studies concerned with quality of life focus on psychological well-being and personal satisfaction. For example, Flanagan (1976) found that factors important to an adult American's well-being include physical and material well-being, relations with other people, social community and civic activities, personal development and fulfillment, and recreation. Campbell (1981) identified the following factors: education, marriage, family life, friendship, health, standard of living, the country, neighborhood, residence, and work. Social and psychological indicators of quality of life for people with disabilities have been studied in relation to community residential programs (Burchard et al., 1989), jobs and social relations (Chadsey-Rusch, 1990; Heal & Chadsey-Rusch, 1985), supported employment (Wehman et al., 1988), medical rehabilitation programs (Roessler, 1990), and the follow-up status of students graduating from special education (Hasazi, Gorden & Roe, 1985; Hasazi, Hock, & Cravedi-Cheng, 1992; Scuccimarra & Speece, 1990).

Ecological Analysis/Goodness-of-Fit. Schalock (1990b) noted that social and psychological indicators do not reliably correlate with each other or with an individual's overall assessment of quality of life. He argued that we need to use ecological analyses to measure the "goodness-of-fit" between the environment and an individual's resources or stressors. From an ecological perspective, quality of life is optimal when the individual's needs and wants can be met by society and the individual has adequate resources to meet the demands of the environment (Cameto, 1990). Other researchers have proposed that a quality-of-life index be used as an outcome measure for services and as the criterion for goodness-of-fit between individuals and their

environment (Murrell & Norris, 1983; Schalock et al., 1989).

Methodologies in Quantitative Quality-of-Life Research

Quantitative methodologies for assessing quality of life use objective and subjective measures, self-report and report by familiar others, and researcher- and subject-generated interview questions (Heal & Sigelman, 1990). Because of the advantages and limitations of each method, some researchers use a combination of methods.

Many studies of quality of life for people with physical disabilities have used self-reports (Stensman, 1985). This approach has the advantage of directly accessing quality-of-life factors for the individual. Fabian (1991) noted, however, that the self-report approach is problematic when interviewees, such as young children and people with cognitive impairments, lack a range of life experiences with which to compare their own experience of quality of life, or when they experience difficulties making judgments and communicating their views. These problems have led some researchers to adapt the measurement tools to simplify and pictorialize response options (Heal & Sigelman, 1990; Newton, Horner, & Lund, 1991). Researchers have also used reports of familiar others and objective measures of adaptive functioning (Fabian, 1991).

Using reports of family members, caretakers, and friends who are familiar with the individual's values, circumstances, experiences, and preferences has the advantage of addressing some of the problems of the self-report approach. However, the perceptions of these familiar others are not necessarily the same as the individual's perceptions of his or her own quality of life. Satir (1972) noted that familiar others do not have identical experiences—that "each group has a world that members of the other group [do] not share" (p. 121). Heal and Sigelman (1990) indicated that the use of multiple methodologies, including the combination of interviews with the individual with disabilities and familiar others, may be a viable approach to addressing this problem.

The practice of using objective measures of adaptive functioning to address problems of self-report and reports of familiar others is supported by the view that higher levels of adaptive functioning allow for greater integration in community life and for greater personal competence,

which results in a better quality of life. Fabian (1991) noted that one problem with this approach is the assumption that there is a relationship between functioning and well-being. There is no empirical base to support the assumption that higher or increased levels of functioning are related to quality of life.

In the majority of the literature, the assessment items were derived by researchers from reviews of the previous literature concerning the quality of life of people both with and without disabilities. Because of this circuitous process, as well as the undefined and subjective nature of quality of life, researchers may be unknowingly influenced by their own individual experiences and culture. New concepts of participatory research have asserted that to increase the validity of research on quality of life, those who are affected by the research, including people with disabilities, their families, researchers, service providers, and organizations that represent these people, should participate with researchers and funding agencies in determining research purposes, quality-of-life factors, questions, methods, and dissemination of results. Participatory research has recently become the focus of studies conducted by the National Institute on Disability and Rehabilitation Research (NIDRR) and by the Association for the Care of Children's Health (McGonigel, 1988). Goode (1990) described an example of a participatory research approach in which consumers and professionals participated in the review, development, and revision of a model of quality of life.

Through the use of a combination of approaches (e.g., self-report, reports by familiar others, participatory research) quantitative methodologies have the potential to begin to resolve issues concerning the definition of quality of life, the potential for bias on the part of researchers, and the quality of life of individuals in relation to that of those around them. However, it is less clear how quantitative methodologies can be constructed to more adequately address the problem of quality-of-life factors being temporal and affected by context.

Qualitative Approach

The qualitative approach to research on quality of life assumes that by listening to people with disabilities relate their experiences, we can better understand the challenges and issues they face and how services can support them more effec-tively (Bogden & Taylor, 1976, 1982; Covert & Carr, 1988; Crutcher, 1990; Devereux, 1988; Weick, 1988). Edgerton (1990) stated that any discussion of quality of life is culturally and individually interpreted by both the researcher and the respondent, and he argued for longitudinal ethnographic and naturalistic studies of quality of life. The qualitative approach appears to have advantages in considering the quality of life of individuals in relation to that of those around them, as well as its temporal and contextual nature. Qualitative descriptions of quality of life for people with disabilities, however, are, by definition, limited in their generalizability.

Quantitative Versus Qualitative

The ongoing controversy between quantitative and qualitative researchers (Guba & Lincoln, 1989; Popkewitz, 1984) complicates the selection of appropriate methodologies for studying quality of life. Quantitative researchers reject qualitative methodology because it is too subjective and fails to demonstrate reliability and generalizability of findings. Qualitative researchers reject quantitative methodology because it oversimplifies complex phenomena and objectifies human experience; and this process can lead to the depersonalization and devaluing of life experiences.

The controversy is exacerbated when researchers and policy-makers attempt to use quantitative-based constructs of quality of life to prescribe, plan, and evaluate services. This quantification has led to the generation of a number of conceptual models of quality of life for people with disabilities (Borthwick-Duffy, 1990; Goode, 1990; Stark & Goldsbury, 1990). One of the most controversial constructs of quality of life was described in the medical literature by Gross, Cox, Tatyrek, Pollay, and Barnes (1983). The construct is $QOL = NE (H + S)$. The concept that quality of life is the product of natural endowment (NE) and the sum of contributions of home and society (H + S) was proposed to assist medical personnel in determining whether to provide lifesaving medical intervention to infants born with myelomeningocele. This proposed quantification of quality of life has triggered strong debate (Miller, 1984; Orelove & Sobsey, 1991; Powell & Hecimovic, 1985). Coulter's (1990) caution regarding this attempt to formulate a quality-of-life construct applies to other constructs of quality of life: "Even if this formula

were conceptually sound, there is no evidence that we have methodologically valid means for measuring its components" (p. 62).

Edgerton (1990) noted the futility of the "American passion for reducing complex qualitative concepts to simple scalar instruments" (p. 150). He argues that quantitative measures of quality of life are only a temporal phenomena and that long-term involvement with the individual is essential to ascertaining a better picture of quality of life. Edgerton cautioned, "If individual choice is replaced by a 'Quality of Life Quotient,' the result will not only be absurd, it may be tragic as well" (p. 158). Quality of life for people with disabilities, in Edgerton's view, does not depend on an individual's availing himself or herself of certain programs and services, but in making choices to find satisfaction in his or her own way, which may sometimes be seen as unrealistic by their families and service providers. Edgerton has stated that society should provide options for people with disabilities without imposing standards for a quality life.

Qualitative descriptions of quality of life for people with disabilities are, by definition, limited in their generalizability. Quantitative measures, constructs, and scales to determine quality of life for people with disabilities remain plagued by questions of validity (Fabian, 1991). Any method that attempts to quantify or formulate quality of life or to measure or accredit services according to their ability to provide quality of life for people with disabilities, must respond to the issue that what they are measuring may not, in fact, reflect quality of life for people with disabilities.

Many researchers have acknowledged that no single measure of quality of life is sufficient (Fabian, 1991; Turnbull & Brunk, 1990). Schalock (1990a) reminded us: "We are just beginning to understand the concept of quality of life and are probably not doing a very good job at this time in measuring it" (p. 139). Jamieson and Sneed (1989) acknowledged that any definition of quality of life implies value judgments about how people should live their lives, that definitions of quality of life are different at different times and in different circumstances, and that no indicators can be definitive of quality of life. They have asserted, nevertheless, that there is still some need to attempt to assess quality of life to inform decision making and public policy. This rationale supports the continued efforts to refine quality-of-life measurements and identify outcomes. Many researchers have agreed that the identifica-

tion of quality-of-life outcomes that reflect both subjective and objective assessments is a promising means of planning and evaluating the effect of services, programs, and public policy for persons with disabilities (Conroy & Feinstein, 1990; Fabian, 1991; Horner, 1991; Jamieson & Sneed, 1989; Roessler, 1990; Turnbull & Brunk, 1990).

Other researchers have remained convinced that the attempts to assess quality of life for individuals are dangerous. Luckasson (1990), who addressed the issue from a legal perspective, wrote: "I urge the disability community to reject the use of the phrase *quality of life* as a global evaluation of the life of the person with mental retardation" (p. 211). Her strong feelings are based on her view that measures of quality of life, no matter how sensitive to the perceptions of people with disabilities, and no matter how much they attempt to enhance human dignity and worth, will be seen as somehow "scientific" and used as a justification of denial of rights to people with disabilities.

IMPLICATIONS FOR THE PRACTITIONER

Philosophers and researchers cannot agree on the definition of quality of life for individuals or methodologies for studying it. This lack of agreement has little impact, however, on people with and without disabilities pursuing a better quality of life and conjecturing about how various factors will affect it. The pursuit of a quality life by people with disabilities is no less complex than the pursuit has been for all people throughout the ages. To better understand the influences of individual experience, culturally specific and common human values and needs that underlie subjective quality-of-life assessments of people with disabilities, practitioners must reflect on those same influences relative to their own quality of life values. Practitioners should avoid stereotypical assumptions about the experience and cultural values of others. Instead, practitioners should approach quality-of-life issues with an attitude of openness and respect for the values and needs of each individual with disabilities.

Although it may not be currently feasible, and perhaps never appropriate, for practitioners to use quality-of-life indexes and formulas to evaluate or measure the quality of life of people with disabilities, we must recognize that quality-of-life themes have had, and will continue to have, a significant impact on planning and evaluation

of services. These themes can serve as a context for planning and evaluating factors that influence quality services. Although there is a close relationship between quality of life for individuals with disabilities and quality services, they are not synonymous. Edgerton (1990) clarified the difference between quality services and the individual's quality of life:

We should continue every effort to ensure the mentally retarded have access to better housing, health care, recreational activities, dignified employment, and everything else an enlightened society can provide for its citizens. But we must never forget that all society should do is provide options; however well meaning, it should not impose standards. (p. 158)

Factors related to quality services may be addressed through promising and exemplary practices that reflect emerging models or theories of service provision shared and advocated for by consumer and professional groups. Many current "best practices" emphasize the importance of consumer participation, community presence, meaningful activity, social networks, recreational opportunities, new technologies, and choice for people with disabilities. It remains up to the practitioner to attend to different and emerging theories of practice and service delivery and to consider them carefully in the context of the quality-of-life needs and values of the person with disabilities.

Traditionally, factors considered in planning and evaluating services for people with disabilities have been rooted in only one of the three spheres suggested by the optimal theory framework (see Figure 1), that of individual values and needs. Even within this sphere, the needs considered in program planning have generally focused on the individual's experience of disability. Program outcomes emphasizing a narrow set of disability-related needs have typically been expressed in discipline-specific developmental or adaptive functioning objectives. For example, education services have addressed cognitive and academic objectives; vocational services have looked at whether people get and maintain work; and physical therapy services have been concerned with sensorimotor objectives. Such discipline-specific objectives may have led to fragmented services and interventions that have failed to attend to the individual's overall complex and interrelated quality-of-life values and needs. The illusory and subjective interpretation

of the quality-of-life context requires practitioners to consider the strengths and needs of individuals in a "holistic" manner. The optimal theory framework suggests that all individuals have unique and changing strengths and needs, both related and unrelated to their disability, which do not fall neatly into traditional discipline-specific service areas. Using quality-of-life themes as a context for quality service, practitioners must address how service outcomes for people with disabilities relate to a larger set of strengths and needs; to their human and civil rights; and to their full community participation as equal, dignified citizens. Outcomes of service must also recognize and respect the cultural differences of people with disabilities and attend to their needs for choice, control, and participation in program planning.

To affect the outcomes of program planning, quality-of-life themes should provide a context for the planning process itself. The following are examples of emerging practices in the planning process that reflect quality-of-life themes:

- The inclusion of people with disabilities and familiar others (e.g., families for young children and youth, friends for adults) as full partners in the planning process to address needs and to evaluate the effect of services.

- The articulation of discipline-free goals that attend to overall needs by people with disabilities, familiar others, and service providers.

- The use of ecological and discrepancy analysis to identify needed services and supports to maximize meaningful participation in the community.

Some promising approaches using quality-of-life themes as a context for program planning include the McGill Action Planning System (MAPS) (Forest & Lusthaus, 1987), Lifestyles Planning Process (O'Brien & Lyle, 1987), Personal Futures Planning (O'Brien, 1987), the family-centered approach to early intervention (Dunst, Trivette, & Deal, 1988), and Choosing Options and Accommodations for Children (COACH), (Giangreco, Cloninger, & Iverson, 1993).

The Lifestyles Planning Process (O'Brien & Lyle, 1987) and the Personal Futures Planning Approach (O'Brien, 1987) are planning processes used for adults with disabilities. These processes emphasize quality of life in home, work, and community settings. These processes

compare quality of life for the individual with disabilities with the quality of life of people without disabilities. In the planning process, the present quality of life of an individual is described by people who know the individual well in five areas: community presence, choice, competence, community participation, and respect. O'Brien (1987) pointed out that Personal Futures Planning, focused on quality-of-life issues, addresses three types of change: change in the individual, change in services that support the person, and change in community norms and opportunities.

The family-centered approach to early intervention for young children and their families uses the context of quality of life and participatory planning (Bailey, 1989; Dunst, Leet, & Trivette, 1988; Kaiser & Hammeter, 1987). One goal of this approach is to strengthen the family's capacity to build formal and informal networks of resources to meet their needs (Dunst, Johanson, Trivette, & Hamby, 1991). Dunst, Trivette, and Deal (1988) developed five scales for families to use to assess and evaluate their own family resources, strengths, supports, functioning style, and needs. The empowerment literature of early intervention indicates that families are best able to describe the outcomes of support and evaluate the benefit of those outcomes for their family and their young child with disabilities.

Educational planning tools that attend to quality-of-life themes for school-age children and youth with disabilities include the McGill Action Planning System (MAPS) (Forest & Lusthaus, 1987) and Choosing Options and Accommodations for Children (COACH) (Giangreco, Cloninger, & Iverson, 1993). Both processes stress collaborative teamwork strategies and creative problem-solving in designing individualized programs to be implemented in general education activities.

MAPS emphasizes the importance of developing relationships with others in the school community and includes peers, family members, and educators in the process of identifying priority needs and the supports necessary to enhance relationships (Vandercook & York, 1989). In the MAPS process, specific questions are asked to elicit a quality-of-life context or "the vision" for educational planning. These questions are: What is the individual's history? What is your dream for the individual? What is your nightmare? Who is the individual? What are the individual's strengths, gifts, and abilities? What are the individual's needs? and What would the

individual's ideal day at school look like and what must be done to make it happen?

Giangreco, Cloninger, Mueller, Yuan, and Ashworth (1991) identified five basic themes related to quality of life for students with significant disabilities from the perspective of their parents. The COACH planning process includes an interview protocol that elicits parents' and the student's perceptions regarding quality-of-life options they think are important in these same five areas: having a safe and stable home; accessing a variety of places and engaging in meaningful activities; having a social network of personally meaningful relationships; having personal choice and control that matches the person's age; and being safe and healthy. Family priorities for educational program goals and supports are then related to family-valued outcomes in these areas. The COACH Family Prioritization Interview is in the process of refinement to ensure that the quality-of-life domains explored with parents are socially validated by the literature, by families with different cultural perspectives, and by people with disabilities (Giangreco, Williams, Cloninger, & Fox, 1991).

Approaches such as MAPS and COACH show promise for planning a better "fit" between the supports provided through services and programs to people with disabilities and the quality-of-life themes they and familiar others determine to be important.

CONCLUSION

The literature indicates that there is no single definition of quality of life for people with or without disabilities. The model of optimal theory suggests that the subjective experience of quality of life is rooted in the overlap of basic human values and needs, culturally influenced values, and the experiences of individuals, which include the specific strengths and needs encountered by people with disabilities. Similarly, no single methodology exists for the study of quality-of-life issues. Researchers show general agreement, however, that, although there may be objective indicators correlated with quality-of-life perceptions, quality of life is essentially subjective in nature.

Gaining and using knowledge regarding quality of life for people with disabilities is not an easy, uncomplicated, or value-free endeavor. Such knowledge is best derived over time from people with disabilities and familiar others. We need to continually update this knowledge to re-

flect changes in needs and contexts. Services and programs for people with disabilities should attend to the "goodness-of-fit" between the quality-of-life themes identified as important for each person and the program-planning process, evaluation procedures, and outcomes of service. People with disabilities, familiar others, and service providers can work together to identify important quality-of-life themes that can serve as a context from which to plan and evaluate programs and services. Quality services developed in this context should provide options to individuals to pursue their own subjective quality of life and, at the same time, respect the individual's choice regarding the extent to which they access those options. Quality-of-life themes have played an important role in the development of promising professional practices, and these themes will continue to be important.

Continued research and debate on quality-of-life issues is needed to ensure they are appropriately incorporated into planning and evaluation of services for people with disabilities.

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ABOUT THE AUTHORS

RUTH E. DENNIS, Occupational Therapy Consultant and Lecturer; WES WILLIAMS (CEC VT Federation), Professor; MICHAEL F. GIANGRECO (CEC NY Federation), Research Assistant Professor; CHIGEE J. CLONINGER (CEC VT Federation), Research Associate Professor, Center for Developmental Disabilities UAP, Department of Special Education, University of Vermont, Burlington.