

Conceptualization, Measurement, and Application of Quality of Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts

Robert L. Schalock, Ivan Brown, Roy Brown, Robert A. Cummins, David Felce, Leena Matikka, Kenneth D. Keith, and Trevor Parmenter

Abstract

In this article a number of issues involving the concept of quality of life as applied to persons with intellectual disabilities are summarized, and a number of agreed-upon principles regarding its conceptualization, measurement, and application are presented. We realize that the concepts and models presented in this article will vary potentially from country to country, and even from area to area within countries. The cross-cultural understanding of the concept of quality of life is in its infancy, and we hope that the discourses resulting from the material presented in this article will facilitate both cross-cultural understanding and collaborative work. The article reflects current thought about the conceptualization, measurement, and application of this increasingly important and widely used concept in the field of intellectual disabilities and sets the stage for its continuing development.

Historically, the interest in quality of life has come from three primary sources: (a) a shift in focus away from the belief that scientific, medical, and technological advances alone would result in improved life towards an understanding that personal, family, community, and societal well-being emerge from complex combinations of these advances plus values, perceptions, and environmental conditions; (b) the next logical step from the normalization movement that stressed community-based services to measuring the outcomes from the individual's life in the community; and (c) the rise of consumer empowerment with its civil rights movements and their emphasis on person-centered planning, personal outcomes, and self-determination.

Over the past 2 decades, the concept of quality of life has increasingly been applied to persons with intellectual disabilities. Quality of life has been adopted as a challenge to respond to in terms of theory and applied research regarding social policy, the design of program supports to individuals and groups, and service evaluation. Such interest is part of a wider view that quality of life is a relevant outcome for health and social policies and practices.

Reflective of this wider view is the extensive and significant work conducted over the last decade by the World Health Organization's Quality of Life (WHOQOL) Group on the concept of quality of life and its measurement (WHOQOL Group, 1995; World Health Organization, 1997; Skevington, Bradshaw, & Saxena, 1999). The work summarized in the present article is both parallel to—and quite consistent with—the work of the WHOQOL Group, especially in regard to their identification of the core quality of life domains (physical, psychological, level of independence, social relationships, environments, and spirituality/personal beliefs) and the need to incorporate both subjective and objective measures (WHOQOL, 1998).

The term *intellectual disability* is used in this article in accordance with terminology used by the International Association for the Scientific Study of Intellectual Disabilities. This term has a meaning that is very similar to that of terms used in other countries, especially *mental retardation*, *learning disabilities*, *developmental disabilities*, *cognitive disabilities*, and *mental handicap*. Intellectual disability is a condition that in practice affects people's ability to

make self-determined choices. Living a life that is judged as one of quality frequently requires support beyond that typically needed by others at a similar age and stage of life. Such support may include a variety of forms, such as specialist training, guidance, structured opportunities, or specially designed environmental or social arrangements. Providing these forms of support has been a major function of health and human service programs. In addition, the presence of disabilities is often associated with problems concerning participation in society, which means that people with intellectual disabilities are in danger of being excluded from many situations and opportunities that usually are available to other people. Quality of life discourses have, therefore, become central in developing environments that allow all people access to places and resources.

In reference to the meaning of the term *quality of life*, “quality” makes us think about the excellence associated with human values, such as happiness, success, wealth, health, and satisfaction, whereas, “of life” indicates that the concept concerns the very essence or essential aspects of human existence. This meaning explains why the concept of quality of life is impacting the field of intellectual disabilities and why throughout the world it is being used as a:

- *sensitizing notion* that gives us a sense of reference and guidance from the individual’s perspective, focusing on the person and the individual’s environment;
- *social construct* that is being used as an overriding principle to enhance an individual’s well-being and to collaborate for change at the societal level; and
- *unifying theme* that is providing a common language and a systematic framework to apply quality of life concepts and principles.

This article, which is based on an international consensus process, was developed jointly by the authors as members of the Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID). The consensus process involved three work teams (co-chaired by 2 or 3 of the authors) who over a 2-year period worked with their colleagues (see author acknowledgments at the end of this article) to develop each section of the consensus document: conceptualization, measurement, and application. This consensus process, which was accomplished through face-to-face work sessions in Australia and the

United States, E-mail chat rooms, and telephone conference calls, resulted in both the initial drafts of each section and the identification of a number of key published articles that are found in the *Suggested Readings* section. A combined work session held in conjunction with the 1999 AAMR annual meeting and individual editing submitted by E-mail (that was integrated into the manuscript by the first author) resulted in the final document, whose key aspects are summarized in this article.

The article includes three major sections that summarize the current understanding of the concept of quality of life and provides a guide for future work. The three sections are (a) the conceptualization of the concept of quality of life within the international intellectual disabilities field, (b) the measurement of quality of life, and (c) the application of the concept. The article concludes with a discussion of the implications of the concept of quality of life on public policy and disability reform.

Conceptualizing the Concept of Quality of Life in the Field of Intellectual Disabilities

Most conceptions of quality of life share these common features: general feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential. Quality of life might best be viewed as a sensitizing concept (rather than a definitive one) relevant to public policy determination; evaluation of services; and development of innovative local, national, and international programs. However, despite the wide-ranging implications of this conceptual view of quality of life, it remains a notion rooted in individual perceptions and values and capable of contributing to the identification of necessary supports and services. In fact, individual perceptions and values—the subjective views of the person—are recognized as a key facet of quality of life by virtually all contemporary researchers. This is not to say that objective measures (e.g., economic status) are not important, but the relationship between such measures and personal sense of well-being is modest.

The concept of quality of life has potential to allow a new perspective on intellectual disability and to be a positive influence on those who work in the field. It offers a new way of looking at issues of disability and is a useful paradigm that can contribute to identification, development, and evalua-

tion of supports, services, and policies for individuals with intellectual disabilities. To that end, in this first section of the article we discuss the concept of quality of life from two perspectives: core ideas and core principles. The importance of these two perspectives is evident in current efforts at measurement and application that are discussed in subsequent sections of the article.

Core Ideas

A number of core ideas have emerged in the international literature regarding the conceptualization of the quality of life concept. Chief among these are domains of well-being, inter- and intrapersonal variability, personal context, a life-span perspective, holism, values, choices and personal control, perception, self-image, and empowerment.

Domains of well-being. A number of domains of well-being have been identified in the international quality of life literature. Although the number varies slightly, 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 quality of life investigators suggest that the actual number of domains is perhaps less important than the recognition that any proposed structure must recognize the need for a multi-element framework, the realization that people know what is important to them, and that the essential characteristic of any set of domains is that they represent in aggregate the complete quality of life construct.

Inter- and intrapersonal variability. Variability means that the domains of well-being will apply to, or be experienced variously by, different individuals and cultural groups. Thus, quality of life differs for the individual over time and between individuals. Therefore, it follows that “a good quality of life” may mean different things to different people.

Personal context. People are best understood within the context of the environments that are important to them: where they live, work, and play. Environments should be viewed as changeable to accommodate the person’s interests, needs, and values. An essential idea is that people, places, and surroundings can promote and enhance a good life. In turn, an individual’s interests and values can emerge in part from the environment in which they live.

Life-span perspective. Quality of life involves a

life-span approach that requires individuals and services to conceptualize policy and practice in terms of the cumulative effects as the individual ages. It, thus, involves an anticipatory process and recognizes, for example, that the nature of primary school education for children with a disability influences later opportunities and development in secondary school, employment, and community life.

Holism. It is also generally accepted that a quality of life model should be holistic to the extent that, at any one time, different aspects or domains of the individual’s life may dramatically influence other aspects or domains. This theme makes it necessary to take into account likely effects and to employ participation, activity, and motivational aspects in one area to enhance development and satisfaction in other areas. This not only has measurement and intervention implications but requires a re-examination of service and policy development.

Values, choices, and personal control. Quality of life relates to choices by individuals and, wherever possible, personal control over their interests in activities, interventions, and environments. Quality of life is, thus, emancipatory and represents different value systems. The psychological acceptance of consumer choices has major implications for self-image, motivation, self-expression, and control as well as health in its broadest sense.

Perception. It is not a question of whether, in reality, one’s perceptions of these key quality of life themes are correct or incorrect, but that they are statements about what the individual perceives at any one moment in time. Such views may be stable (and often appear to be), although variation may be expected when intervention and change occur. Indeed, the greatest perceptual changes might be expected when intervention and rehabilitation are effective.

It is also necessary to take into account the suggestions, choices, and perceptions of parents, spouses, and service and support providers. However, it should be recognized that these may differ markedly and centrally from the perceptions of the individual. This multiperception aspect of quality of life provides a new challenge to the field of measurement because many people with intellectual disabilities have no or limited language. Thus, multiple perceptions are central to an understanding of one’s quality of life, and in many instances it may be necessary to identify personal choices using an individual’s nonverbal responses, particularly when language is limited.

Self-image. The aims of any quality of life program must be to enhance the individual's self-image and provide empowering environments that increase the individual's opportunities to control aspects of his or her life. These will be influenced by the individual's values.

Empowerment. The preceding eight core ideas reflect the need for individuals to have choices and personal control over their interests in activities, interventions, and environments—a form of personal empowerment that allows them to have control in life and service decisions and examination of sources of control in the environment. Quality of life is thus emancipatory, accepting individual choices and recognizing personal values. This calls for a recognition that such services will be required at different times, for different durations, and for different intensities. Such services will have aspects that show major control by the service user, and there will need to be a detailed examination of who, when, and how intervention takes place and who controls that environment.

Core Principles

The nine core quality of life ideas just described reflect the emerging framework for conceptualizing the concept of quality of life. They also give us a sense of reference and guidance from the individual's perspective and allow us to focus on the person's environment. In addition, a number of core quality of life conceptualization principles have emerged in the international quality of life literature that provide the framework for quality of life measurement and application. Chief among these are that quality of life:

1. Is composed of those same factors and relationships for people with intellectual disabilities that are important to those without disabilities;
2. is experienced when a person's needs and wants 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/she experiences;
4. is based on individual needs, choices, and control; and
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.

As the core ideas and principles reflect, the concept of quality of life has significant implications for the way we think about people with intellectual disabilities and our societal and personal approaches to them. They also influence how one approaches the measurement of quality of life.

Measuring Quality of Life

This second section of the article represents a consensus of international thought in the field of intellectual disability about quality of life measurement. *Measuring* quality of life, as the term is used in this article, refers to the function of measurement in its broad sense (i.e., includes objective and subjective measures, categorical data, description, and observation). This definition makes it clear that we are thinking beyond *just* quantitative measurement to include qualitative methods as well. Strictly speaking, some would argue that qualitative methods cannot be called measurement, but our view is that qualitative methods also typically lead to quantitative (although not always interval) differences. The term *assessment* is used in the application section of the article to describe how quality of life concepts and measures are used as both process and content for helping people to improve their lives. The primary purpose of this section is to provide an overall approach to measuring quality of life that will guide future work in our field by highlighting the enhancement of life as the central value in quality of life measurement; providing an overall approach to how quality of life is measured and setting out a number of principles and practices in its measurement.

The Utility and Ethics of Measurement of Quality of Life

Quality of life is important for all people and should be thought of in the same way for all people—with and without disabilities. Measuring quality of life is required to understand the degree to which people enjoy good quality of life. It is often measured for particular groups of people who are excluded from the mainstream. One such group is people with intellectual disabilities. This group has the right to enjoy the same high quality of life as do others. To ensure that they have a higher quality of life, we need to be able to determine whether

some areas of their lives are not very good and need enhancement in ways that are satisfying to them.

Measuring quality of life infers that we value quality within people's lives and that we want to maintain and enhance the things that already, or could, add worth to people's lives. It also infers that we want to take action to improve the things that currently detract from the quality of people's lives. This measurement should never support maintaining or encouraging low quality of life.

When assessing the quality of life of people with disabilities, we adopt the value that all people, with and without disabilities, share the human experience together and that every human being is entitled to live a good life within his or her environment. This central value is the principal criterion to be used for assessing the utility and ethics of measuring quality of life and reporting the results.

Overall Approach to Measuring Quality of Life

Measuring quality of life reflects the unique blend of two meanings of quality: that which is commonly understood by human beings throughout the world and that which has become valued by individuals as they live their lives within their unique environments. Typically, we measure the former by using indicators that can be reliably observed and appear to be universally held, such as material attainment, stability of human institutions, social connections, and life opportunities. Measuring quality of life, as it is understood and valued from the individual perspective, is usually carried out by identifying what specific things have come to be valued by individuals and by matching these to their perceptions of personal satisfaction or happiness. Sometimes, measurement of these two aspects of quality of life is referred to, respectively, as "objective" and "subjective" measurement. Both are necessary for a full measurement.

Core Principles for Measuring Quality of Life

1. Quality of life measures the degree to which people have meaningful life experiences that they value.
2. Quality of life measurement enables people to move toward a meaningful life they enjoy and value.
3. Quality of life measures the degree to which life's

domains contribute to a full and interconnected life.

4. Quality of life measurement is undertaken within the context of environments that are important to people: where they live, work, and play.
5. Quality of life measurement for individuals is based upon both common human experiences and unique, individual life experiences.

Guidelines for Measuring Quality of Life

For each of the five core principles, readers will find a number of consensus guidelines for measuring quality of life.

Principle 1: Quality of life measures the degree to which people have meaningful life experiences that they value.

Guidelines

1. The measurement framework is based on well-established theory of broad life concepts.
 - The theoretical framework is comprehensive and multidisciplinary.
2. It is recognized that the meaning of life experiences that are positively valued varies across time and among cultures.
3. The measurement framework provides a clear way to demonstrate the positive values of life.
 - Assessment methods provide categories or terminology that describe how life is valued.
 - Measurement describes quality of life clearly, using terminology that illustrates the degree to which life experiences are positively valued.
4. Quantitative measurement of quality of life represents placement on a continuum between the "best" and the "worst."
 - Measurement uses clear categories that have an ordinal relationship or terminology that can be clearly related to a best–worst continuum.
 - Measurement scales show life at its "best" at one end of the scale and its "worst" at the other end.

Principle 2: Quality of life measurement enables people to move toward a meaningful life they enjoy and value.

Guidelines

1. Measurement focuses on key aspects of life that can be improved, such as:
 - the degree to which basic needs are met,

- the degree of material and social attainment,
 - choices and opportunities available and acted upon, and
 - the degree to which environments enable people to improve.
2. Measurement is carried out for a clear, practical purpose that supports people moving toward better lives.
 - It sets out a clear purpose related to improved policy, service, or individual support.
 - It helps identify unmet needs and suggests ways to remediate those unmet needs.
 - It helps determine those aspects of a person's life that are of very good quality for him or her so that quality can continue to be supported, fostered, and maintained for these aspects of life.
 - It is used as baseline and outcome data in evaluation of service delivery or interventions with a view to enhancing the quality of people's lives.
 - It may differ according to the purpose for which it is being carried out (e.g., education, service, housing, employment).
 3. Measurement is described within a framework that is potentially positive, neutral, and negative—suggesting that it is possible to move toward the very positive.
 - Measurement scales clearly show positive, neutral, and negative ratings/scores.
 - Measurement methods describe categories or use terminology that is positive, neutral, and negative.
 4. Measurement is interpreted within the context of an overall lifespan approach.
 - It is interpreted within the age range of those being measured.
 - It is interpreted with a view to supporting people in moving smoothly from one life stage to another.

Principle 3: Quality of life measures the degree to which life's domains contribute to a full and interconnected life.

Guidelines

1. Measurement uses a broad range of life domains, which are widely accepted as key indicators of the fullness and interconnectedness of life.
 - Domains are validated by a consensus of a wide range of people.

- Domains are relevant for all people being measured.
 - Domains encompass a substantial but discrete portion of the quality of life construct.
 - The main domains are the same for people with and those without disabilities. Some domains (e.g., services to people with disabilities) vary according to the special needs of the group (e.g., people with behavior or emotional problems).
2. Quantitative measurement uses key indicators of the fullness and interconnectedness of life within specific domains.
 - There is consensual validation that key indicators adequately reflect the life domain.
 - Key indicators may vary for people at various stages of life.
 - Key indicators may vary for people within specific cultural environments.
 - Key indicators may vary for people with special needs.
 3. Qualitative measurement procedures are used to explore and describe a range of aspects within each domain.

Principle 4: Quality of life measurement is undertaken within the context of environments that are important to individuals with intellectual disabilities: where they live, work, and play.

Guidelines

1. *Proxy measurement* (measurement by another person for an individual with intellectual disabilities) is not valid as an indication of a person's own perception of his or her life.
 - Those who measure quality of life from the perspective of people who are not able to speak for themselves should use methods such as observation and participant observation that are most applicable to such people.
 - Measurement of one person's quality of life from another person's perspective might be useful in some instances, such as when people are not able to speak for themselves and others make life decisions on their behalf, but such measurement should be clearly identified as another person's perspective.
2. Measurement takes an ecological approach, viewing the individual in interaction with his or her living environments.
 - Interpretation is carried out within the context of the individual's environment.

Principle 5: Quality of life measurement for individuals is based upon both common human experiences and unique, individual life experiences.

Guidelines

1. Both objective and subjective (perceptual) measurements are used.
 - Either qualitative or quantitative methods or both are used.
 - For objective measurement, quantitative instrumentation that reports frequencies and quantities of observable indicators are employed. Degrees of expressed satisfaction with aspects of life or other kinds of subjective evaluations or descriptions about people's lives are employed for subjective/perceptual measurement.
 - Subjective measurement has both cognitive and affective components.
2. Measurement allows for weighting of domains and key indicators, according to individual or group significance or value. Where it is not possible to do this, quality of life measures need to be interpreted in light of significance or value to the individual.
3. Measurement allows for weighing to reflect individual or group cultural life experiences.
4. In most cases, domain scores and descriptions are more useful and expressive than are the total scores or descriptions aggregated from separate domain data.

Applying the Concept of Quality of Life

At its core, the concept of quality of life makes us think differently about people with intellectual disabilities and how we might bring about change at both the individual and societal level to enhance their well-being and reduce their exclusion from the mainstream of society. To that end, the application of the concept of quality of life to persons with intellectual disabilities is based on five principles:

1. The primary purpose for applying the concept of quality of life is to enhance an individual's well-being.
2. Quality of life needs to be applied in light of the individual's cultural and ethnic heritage.
3. The aims of any quality of life-oriented program should be to collaborate for change at the personal, program, community, and national levels.
4. Quality of life applications should enhance the

degree of personal control and individual opportunity exerted by the individual in relation to their activities, interventions, and environments.

5. Quality of life should 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.

Social System Actions

These five application principles suggest a number of actions regarding social systems. As shown in Figure 1, these actions occur in reference to the core quality of life domains discussed earlier and within the context of four levels of any social system: people, programs, communities, and nations.

People pursuing a life of quality. Individuals with intellectual disabilities are already applying the concept of quality of life. Specifically, throughout the world we are seeing (a) strong self-advocacy movements directed at increasing opportunities to participate in the mainstream of life, associated with increased inclusion, equity, and choices; (b) provision of increased individual supports within regular environments; and (c) participation of people with intellectual disabilities in major activities, such as decision-making, person-centered planning, and participatory action research.

Programs implementing enhancement techniques. Once the core domains of quality of life are understood and their correlates assessed, it is possible for service and support providers to implement a number of program-based quality enhancement techniques, such as the following that are related to eight core domains listed in Figure 1:

- *emotional well-being:* safety, stable and predictable environments, positive feedback
- *interpersonal relations:* affiliations, affection, intimacy, friendships, interactions
- *material well-being:* ownership, possessions, employment
- *personal development:* education and habilitation, purposive activities, assistive technology
- *physical well-being:* health care, mobility, wellness, nutrition
- *self-determination:* choices, personal control, decisions, personal goals
- *social inclusion:* natural supports, integrated environments, participation

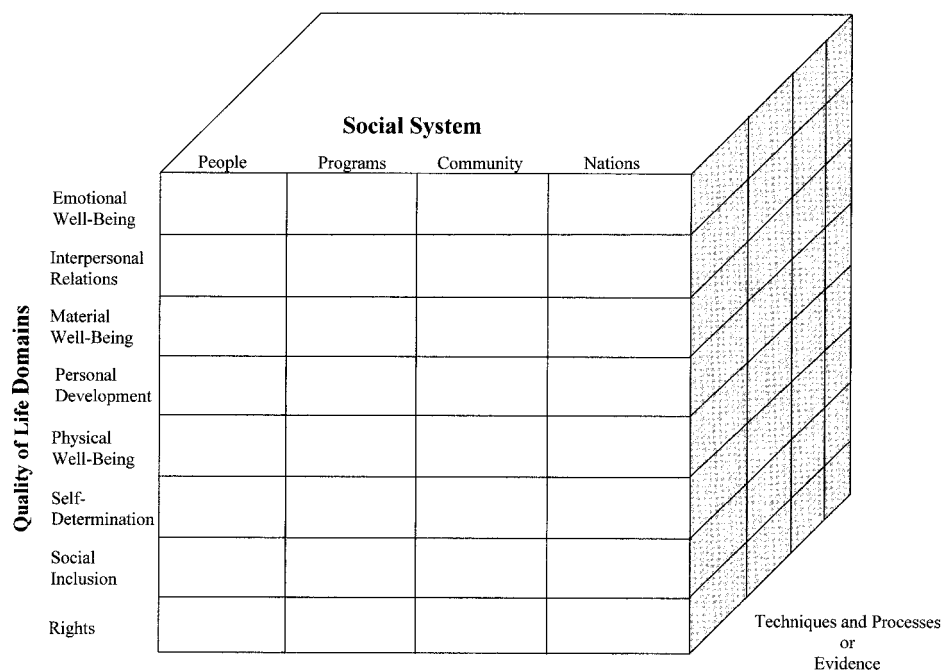


Figure 1 Quality of life application model.

- *rights*: privacy, ownership, due process, barrier free environments

Communities implementing quality enhancement techniques. The application of the concept of quality of life within communities requires implementing quality enhancement techniques that are focused on environmental factors related to a life of quality. The application of these techniques rests on the demonstration that (a) an enhanced quality of life is the result of a good match between a person's wants and needs and their fulfillment and that reducing the discrepancy between a person and his or her environment increases the individual's assessed quality of life; (b) it is possible to assess the match between people and environments; and (c) that the higher the imbalance, the greater the person's support needs. Environmentally based enhancement techniques involve designing environments that are user friendly and reduce the mismatch between individuals and their environmental requirements. Examples include opportunity for involvement (e.g., food preparation); easy access to the outdoor environment; modifications to stairs, water taps, door knobs; safety (e.g., handrails, safety glass, non-slip walking surfaces); convenience (e.g., orientation aids, such as color coding or universal pictographs); accessibility to home and community; sen-

sory stimulation (windows, less formal furniture); prosthetics (personal computers, specialized assistive devices, and high technological environments); opportunity for choice and control (e.g., lights, temperature, privacy, and personal space).

Nations adopting the quality of life concept. There are currently over 40 world-wide treaties, or conventions, of human rights that address people with disabilities. Examples include the 1971 United Nations Declaration on the Rights of Mentally Retarded Persons, the 1975 United Nations Declaration on the Rights of Disabled Persons, and the 1976 International Covenant on Civil and Political Rights. This 1976 Covenant resulted in the 1982 World Programme of Action Concerning Disabled Persons, which contains a declaration of principles, policy options, and plans to enhance disability prevention, rehabilitation, and equalization of opportunities of individuals with disabilities to further their full and effective participation at all levels of society.

The second half of this decade has witnessed a major initiative by the International Community to increase the legal status and situation of citizens with disabilities. Reflective of this initiative, the United Nations General Assembly adopted in 1993 the United Nations Standard Rules on the Equal-

ization of Opportunities for Disabled Persons (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, policy making and planning, coordination of work, personnel training, and monitoring and evaluation. Significantly, the 14 “outcome standards” relate to the previously referenced eight core quality of life domains.

Enhancing a person’s well-being is facilitated by an understanding of those factors just discussed: the core quality of life concepts and domains, a number of quality of life-related principles, and actions at the level of people, programs, communities, and nations; but true and long-lasting change will not occur unless there is collaboration for such change at the societal level and information as well as evidence that the enhancement has occurred. These two core actions are described next.

Core Actions

There are two core actions that go across the four levels of social systems shown in Figure 1: collaboration for change at the societal level and provision of information and evidence.

Collaboration for change at the societal level. Collaboration requires a model that integrates the quality of life concepts, principles, and actions discussed in the previous section with the multiple societal systems within which people live. The quality of life application model outlined in Figure 1 includes two major components to this collaboration: (a) implementation techniques and processes and (b) evidence. Techniques and processes include what needs to be done to ensure that the core quality of life principles are applied across the core quality of life domains and each level of the societal system. These techniques generally include interventions, advocacy, and reducing barriers. Evidence involves demonstrating that the techniques and processes employed have actually changed or impacted the individual’s well-being and changed behaviors at the societal level. Evidence measures can include personal appraisal (e.g., satisfaction), functional assessment data (e.g., adaptive behavior level and role status), and social indicators (e.g., economic status, health and safety indicators, life expectancy, educational levels).

Three aspects of the model outlined in Figure 1 are key to these core actions. First, the techniques and processes that focus on the eight core quality

of life domains and the four societal levels provide information about what to do to enhance an individual’s well-being. Thus, in reference to emotional well-being, service providers can ask, “What can we do to ensure that the person’s needs are met, that opportunities are provided to enhance the individual’s emotional well-being, and that obvious barriers to one’s emotional well-being are addressed and reduced?” Second, core quality of life core ideas are then used as *judgment criteria* to ensure that the techniques and processes reflect the quality of life themes of holism, the individual’s life span, choices, personal control, and empowerment; are of value to the person; and reflect individual variability. Thus, the model should be used to guide service provision and decision-making as we collaborate for change at the societal level. It is within this context that the third aspect of the model becomes critical: it provides a *common language* around which public laws can be envisioned, policies and procedures developed, and evidence gathering activities organized.

At the aggregate population level, objective indicators for a defined group of interests may be compared to total population norms and ranges to establish the social equity of a group’s circumstances. The distribution of a lifestyle characteristic, such as index of health, income, or activity level, will be influenced by many factors, among them personal values and choices. The distribution, therefore, contains variance attributable to differences between individuals and the self-determination they exercise. Applied to people with intellectual disabilities, comparison of the distribution of a salient aspect of quality of life among a representative large sample of people with intellectual disabilities against the total population distribution will reveal differences not attributable to the personal choices people make. Thus, the low representation of people with intellectual disabilities in the workforce and their relative state of poverty may occasion social policy initiatives to develop techniques and processes that broaden the opportunity of paid work at levels of remuneration at or above the minimum wage. Similarly, the lower level of age-peer friendships in the social networks of people with intellectual disabilities compared to the norm may result in effort and resources being directed towards developing techniques and processes resulting in the formation of enduring friendships.

Provision of information and evidence. The second core action requires the provision of informa-

tion and evidence that both the person's well-being has been enhanced and collaboration for change has occurred. Measurement of quality of life was discussed in the second section of this document. Such measurement can be used to garner evidence on quality of life outcomes at the individual and societal levels. Measures relate to personal appraisal (e.g., level of satisfaction), functional assessment (e.g., adaptive behavior level), lifestyle indicators or measures of social role (e.g., level of activity, social affiliation), and social indicators (e.g., educational, financial, health, or social status).

Public Policy and Disability Reform

It is our strong feeling that the quality of life concept has moved beyond a theoretical construct and is quickly emerging as an instrument or tool to guide and produce change in public policy and disability reform. We anticipate that this change will occur among consumers and advocates, educators and practitioners, program administrators, policy makers, and researchers and evaluators. Potential roles and necessary changes for each are discussed below.

Consumers and advocates. These individuals are in the best position to suggest the components of quality services and outcomes that impact positively their sense of personal well-being. Change efforts should focus on self-efficacy, internal locus of control and self-determination, empowerment so that individuals can define and achieve their own goals, and self-advocacy.

Educators and practitioners. These individuals are in a prime position to affect attitudes towards people with intellectual disabilities. Change efforts should focus on person-centered planning, personal development (empowerment and self-determination), user-friendly and person-first language, and prosthetics and technology.

Program administrators. These individuals are in a prime position to advocate for change at the program and societal levels and to collaborate for change. Change efforts should focus on dimensions of quality services (reliability, responsiveness, empathy, extensiveness, appropriateness), program-based quality enhancement techniques, collaboration, and evaluation of outcomes that reflect both person-referenced valued outcomes and organization effectiveness and efficiency outcomes.

Policy makers. These individuals need to be

sensitive to the fact that all people want a life of quality. Change efforts should focus on listening to consumers and advocates, incorporating key quality of life concepts and principles into public policy, funding research and demonstration projects to develop cultural-sensitive quality of life models and data sets, and evaluating the effects and impacts of quality of life-oriented policies and procedures.

Researchers and evaluators. These individuals are in an excellent position to further the quality of life movement by fostering quality of life as a "discovery science" that (a) gives access to human variability, (b) refashions how we view people, (c) provides a vehicle for improving the human condition, and (d) encourages the gathering of evidence demonstrating that quality of life principles and procedures can improve the human condition. Change efforts should focus on providing the scientific basis for what could become a "discovery science," fostering the use of a holistic approach to quality of life research, incorporating the use of participatory action research into all research and evaluation activities, and conducting cross-cultural research into the *etic* (i.e., universal) and *emic* (i.e., culture bound) properties of the concept of quality of life.

Conclusion

In conclusion, it is important to point out that the concept of quality of life is still emerging in the field of intellectual disabilities and that currently there is considerable debate about its conceptualization, measurement, and application. In addition, there are a number of contextual issues around which this debate is occurring. Three of these issues concern economic rationalism and the allocation of resources to people with intellectual disabilities; the disability reform movement, including the rapid emergence of the self-advocacy movement; and which outcomes best provide evidence that services and supports provided to people with intellectual disabilities have indeed enhanced personal well-being.

These three contextual variables and discourses (economic rationalism, the disability reform movement, and evidence outcomes) will not only affect the conceptualization, measurement, and application of the concept of quality of life to people with intellectual disabilities, but they also emphasize the need to be sensitive to the measurement and application principles discussed in this article.

The last 2 decades have seen considerable pro-

gress in understanding the significant role and impact that the concept of quality of life has played in the lives of individuals with intellectual disabilities and the systems that interact with those lives. Indeed, the concept of quality of life has extended beyond the person and has now influenced an entire service delivery system because of its power as a sensitizing notion, social construct, and unifying theme. At its core, the concept of quality of life gives us a sense of reference and guidance from the individual's perspective, an overriding principle to enhance an individual's well-being and collaborate for change at the societal level, and a common language and systematic framework to guide our current and future endeavors. It is our consensus that future work in this field needs to move in the following four directions: (a) the development of public policy based on quality of life concepts; (b) the implementation of societal practices that reflect quality of life principles; (c) the provision of supports to people with intellectual disabilities based on quality of life principles; and (d) the evaluation and monitoring of social policies, societal practices, and programmatic supports based on quality of life principles.

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Authors:

The authors are members of the Special Interest Research Group on Quality of Life of the International Association for the Scientific Study of Intellectual Disabilities. **Robert L. Schalock, PhD**, Professor Emeritus, Hastings College, currently can be reached at PO Box 285, Chewelah, Washington 99109-0285 (E-mail: rschalock@plix.com). **Ivan Brown, PhD**, Director, Quality of Life Research, 100 College St., Suite 511, Toronto, Ontario, Canada M5G 1L5 (E-mail: ivan.brown@utoronto.ca). **Roy Brown, PhD**, Professor, School of Special Ed-

ucation and Disability Studies, The Flinders University, GPO Box 2100, Adelaide 5001 Australia (E-mail: roy.brown@flinders.edu.au). **Robert Cummins, PhD**, Professor, School of Psychology, Deakin University, 211 Burwood Highway, Victoria 3125, Australia (E-mail: robert.cummins@deakin.edu.au). **David Felce, PhD**, Professor, College of Medicine, University of Wales, Meidan Court, Nord Rd., Cardiff CF4 3BL, United Kingdom (E-mail: Felce@cf.ac.uk). **Leena Matikka, PhD**, Director of Research, Finnish Association on Mental Retardation, Viljatie 4A, 00700 Helsinki, Finland (E-mail: matikka@helsinki.fi). **Kenneth D. Keith, PhD**, Chair, Department of Psychology, University of San Diego, 5998 Alcalá Park, San Diego, CA 92110-2492 (E-mail: Kkeith@acusd.edu). **Trevor Parmenter, PhD**, Director, Centre for Developmental Disability Studies, PO Box 6, Ryde 2112, Australia (E-mail: trevorp@medusyd.edu.au).