Quality of Life Indicators for Individuals With Intellectual Disabilities: Extending Current Practice

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Abstract

Quality of life is a social construct that is measured by what are considered to be its most appropriate indicators. Quality of life measurement in intellectual disability reflects a variety of indicators, often grouped under life domains. Subjective and objective methods of measuring indicators each have strengths and drawbacks, but it is currently considered best to use both methods. Indicators of quality of life that are common to all people have been measured to date, although indicators that are unique to individuals are highly useful for enhancing individual development and for applying person-centered practice. Aggregate quality of life data from individuals may not always be the best source of information for evaluating policies and service practices. A case is made for supplementing quality of life frameworks or adopting other frameworks for these purposes, with the Capabilities Framework offered as an example. Further, an argument is made that a pragmatic approach might best be taken to policy and program evaluation, whereby the key criterion for using a conceptual framework and set of indicators is its usefulness in effecting positive change in people's lives.

Key Words: quality of life; quality of life indicators; quality of life measurement; capabilities framework

Improving the quality of people's lives has been one of the implicit goals of service provision in recent decades, and remains so today. It is also an explicit goal of numerous legislative bodies, service organizations, advocacy organizations, families, and individuals with intellectual disabilities. Moving from quality of life as an implicit or explicit goal to quality of life as a helpful concept and set of practical strategies to improve policy, practice, and life for individuals or groups of people has been a strong theme within the rich panoply of quality of life work in the field of intellectual disabilities.

This work has been considerably more challenging than might be expected. Quality of life, on the surface, appears to be a straightforward concept that has a general meaning, described for individuals by Woodill, Renwick, Brown, and Raphael (1994) as "how good is your life for you?" and more broadly by Bach and Rioux (1996) as the social well-being enjoyed by people, communities, and their society. But what is straightforward on the surface has proven to be complex underneath. Quality of life is a broad, multidisciplinary concept, referring to an array of "qualities"—positive and sometimes exquisite characteristics of human life—that, by their very nature, probably defy precise definition and may be perceived from a variety of perspectives (Lindström, 1994).

Underlying questions that have required exploration and clarification include such things as

- What constitutes a good, and an exquisite, life?
- Do people share views on what constitutes a good life?
- Are some aspects of life more important than others in determining quality of life?
- Are there aspects of life that can be said to universally contribute to, or detract from, life quality?
- To what degree should people's own perceptions determine how we consider their quality of life?
- How do social and cultural factors influence quality of life?
- What are the best ways to measure quality of life?

Such questions have been explored within several disciplines and from several theoretical and philosophical perspectives (see Schalock & Verdugo, 2002).
Quality of Life Indicators

The Need for Quality of Life Indicators
Complicating these explorations to a certain degree is that quality of life is a social construct—something that has been constructed within human minds that has meaning to those who understand and use it, but does not have objective reality. One cannot see quality of life, describe it physically, or measure it directly. Like other social constructs, judgment of quality of life must be inferred from the presence or absence of behavior, real objects, events, perceptions, and systems of organization. Something else has to indicate the state of quality of life and, collectively, the “something elses” make up what we refer to as quality of life indicators.

What Indicators Have Emerged?
Our challenge is to select those indicators that, when put together like pieces of a mosaic, most accurately create a picture that reflects what we understand to be the meaning of the social construct quality of life. In the early and mid-1990s, several major initiatives within the field of intellectual disabilities strove to identify sets of indicators that accurately reflect the meaning of quality of life (see Australian Centre on Quality of Life, 2012, for a catalogue of quality of life instruments developed; Cummins, 1997a). One approach was to ask questions about, and score, an array of indicators. The Lifestyle Satisfaction Scale (Heal, Harner, Novak Amado, & Chadsey-Rusch, 1992), for example, asked directly about such things as residence, friends, neighbors, daily life, community activities, and work. The Rehabilitation Questionnaire: A Personal Guide to the Individual’s Quality of Life (Brown & Bayer, 1992) is an in-depth exploration of a wide variety of aspects of a person’s life. Another approach that emerged—one that built on previous work (Lindstrom, 1994) and that has dominated the quality of life and intellectual disabilities literature since the mid-1990s—was, first, to identify life’s principal domains that contribute to quality of life and, second, to identify the most salient indicators of quality within each of those domains. Although this work was carried out within the field of intellectual disabilities, a consensus emerged that quality of life indicators for people with intellectual disabilities were essentially the same as those for all other people (Schalock et al., 2002a, but see Goode & Hogg, 1994, and Ouellette-Kuntz, 1990, for rationales that indicators for people with severe disabilities are unique in many respects).

A number of sets of domains and accompanying sets of indicators were developed in the 1990s. Three examples are provided here.

Quality of Life Questionnaire (Schalock, Keith, & Hoffman, 1990).
Four life domains with 10 indicators each = 40 indicators

Domains and Indicators
Satisfaction: Overall satisfaction, fun and enjoyment, how well off, rewards/disappointments, home and living arrangement, life problems, loneliness, feeling out of place, successful in life, being part of the family.

Competence and productivity: How well education and training prepared me, how I feel about my job or main daily activity, how good I am at my job, how people treat me on my job, skills and experience I have gained or am gaining on my job, learning new job skills to advance, receiving fair pay for work, receiving enough money to buy things I want, satisfaction with work benefits, how closely I am supervised on my job.

Empowerment and independence: How I decided to do my present job or main daily activity, who decides how I spend my money, how independent I am using health care facilities, how much control I have over doing everyday things, when friends visit my home, having a key to my home, having a pet if I wish, having a guardian or conservator, people living with me who maltreat me, overall freedom or restrictions in life.

Social belonging and community integration: Number of community clubs or organizations I belong to, how satisfied I am with these, worrying about what people expect of me, talking with neighbors, having friends over to visit, attending community recreational activities, having opportunities for dating and marriage, how neighbors treat me, overall worth or worthlessness of my life.

Quality of Life Instrument Package (Brown, Raphael, & Renwick, 1998).
Nine life domains with six indicators each = 54 indicators

Domains and Indicators
Physical being: Appearance, exercise and being fit, hygiene, nutrition, physical health, sex life.
Psychological being: Accepting the way I am, free of worry and stress, how I feel about myself, my mental health, my mood, thinking and acting independently.

Spiritual being: Celebrating special events in my life, feeling that life has meaning, having hope for the future, having religious or spiritual beliefs, helping others, own ideas of rights and wrong.

Physical belonging: Feeling safe where I live, have space for privacy, having my own personal things, residence I live in, neighborhood I live in, part of the country I live in.

Social belonging: Being close to people in my family, having a spouse or special person, having friends, speaking with acquaintances, socializing within small groups, thinking of myself as part of a larger social group (culture, citizen, etc.).

Community belonging: Going places in my community, attending special community events, access to education, access to meaningful work, access to professional services, having my own money to spend.

Practical becoming: Work around my home, helping other people do things, going places (errands, appointments, etc.), looking after myself, looking after other people and pets, working at a job or attending school.

Leisure becoming: Going to public entertainment, casual leisure activities, organized sports and recreation activities, hobbies, taking vacations and holidays, visiting and socializing for enjoyment.

Growth becoming: Coping with changes in life, improving physical skills, learning about new things, resolving conflicts with others, solving my problems, trying out new things.

Comprehensive Quality of Life Scale—Intellectual/Cognitive Disability, 5th ed. (Cummins, 1997b).

Seven life domains with three indicators each = 21 indicators

Domains and Indicators


Health: Illness requiring medical assistance, other disabilities or medical conditions, medications taken.

Productivity: Involvement in work, school, and/or child care, having something/nothing to do in spare time, time spent watching TV.

Intimacy: Having a close friend, someone to show caring when feeling sad or depressed, having someone to share special experiences.

Safety: Sleeping well, feeling safe, feeling worried or anxious during the day.

Place in community: Taking part in community leisure activities, belonging to clubs/groups/societies, being asked for help or advice by people outside the home.

Emotional well-being: Doing things you really want to do, wishing to stay in bed all day, wishes that cannot come true.

These three examples illustrate that there are obvious differences in the ways the important life domains were conceptualized and in the selection of indicators within each of the domains to show overall quality of life. On the other hand, quality of life measurement using the different scales has demonstrated that overall scores are fairly similar using subjective measures (Raphael, Brown, & Renwick, 1999), although this needs further exploration for objective measures (Hatton & Ager, 2002).

In an apparent consensus published in the intellectual disability literature in various places (e.g., Schalock, Gardner, & Bradley, 2007; Schalock & Verdugo, 2002), Schalock has identified eight life domains for considering quality of life. The eight domains, with their accompanying indicators (and descriptors) are:


Interpersonal relations: Interactions (social networks, social contacts), relationships (family, friends, peers), supports (emotional, physical, financial, feedback).

Material well-being: Financial status (income, benefits), employment (work status, work environment), housing (type of residence, ownership).

Personal development: Education (achievements, status), personal competence (cognitive, social, practical), performance (success, achievement, productivity).

Physical well-being: Health (functioning, symptoms, fitness, nutrition), activities of daily living (self-care skills, mobility), leisure (recreation, hobbies).

Self-determination: Autonomy or personal control (independence), goals and personal values (desires, expectations), choices (opportunities, options, preferences).

Social inclusion: Community integration and participation, community roles (contributor, volunteer), social supports (support network, services).
Rights: Human (respect, dignity, equality), legal (citizenship, access, due process).

How Indicators are Assessed

Scholars in quality of life and intellectual disability within the Quality of Life Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) undertook an international initiative that sought to clarify and extend quality of life knowledge through a series of discussions and debates, as well as to draw together its diverse ideas. The resulting quality of life consensus document (Schalock et al., 2002a; summarized by Schalock et al., 2002b), set out principles and descriptions to guide current and future work. The measurement section of this document contained five principles, each with several guidelines for assessing quality of life indicators. Together, these principles and guidelines provided, and continue to provide, a strong roadmap for the philosophy and values, as well as specific measurement methods, for assessing quality of life indicators for people with intellectual disabilities.

At the same time, quality of life measurement methods and issues have been discussed in considerable detail in the literature on quality of life and intellectual disability. In addition to specific measurement issues (e.g., Schalock, 1996), the need to align policy and practice values and realities with quality of life indicators has been addressed (Schalock & Verdugo, 2012). Two ongoing aspects of how indicators are assessed are perhaps particularly important in quality of life measurement: objective and subjective measurement of indicators, and, based on the examples of indicators described above, what indicators to measure.

Objective and Subjective Measurement of Indicators

One of the key principles to emerge in the Quality of Life Consensus Document, building on ideas previously put forward (e.g., Andrews, 1974) and extended by Cummins (1997a, 1997b)—regarding measurement of quality of life indicators, was that it is important to use both objective and subjective measures of quality of life indicators for a full understanding of an individual’s quality of life. The consensus debates specified the rationale for this (see Schalock et al., 2002a).

Objective measures (those able to be observed and independently verified) tend to satisfy reliability criteria, but they represent some problems for quality of life measurement if used alone. For example, spending at least one hour a week with at least two friends may be a good objective indicator that a person is socially active with friends, but such activity may vary among people in importance and quality. To one person, spending time with friends may be what Brown, Raphael, & Renwick (1997) referred to as a “dominant and driving force,” while another person may feel somewhat ambivalent about spending time in this way. The importance of objective measures to the individual, then, becomes a variable itself, and a number of researchers (e.g., Brown, Raphael, & Renwick, 1998; Cummins, 1997b) responded to this issue by measuring both importance and another measure, such as satisfaction or attainment, and using importance to weight the other scores.

Subjective measures, sometimes referred to as perceptual measures, have a credibility that emerges from the fact that they represent how an individual, and only the individual, perceives other people, things, issues, and situations. But subjective measures are also problematic if used alone, especially for people with intellectual disabilities (Hatton & Ager, 2002). Although such measures have the advantage of authenticity, inasmuch as they presumably represent the true perceptions of the person, they are impossible to verify. It is even difficult to conduct test–retest reliability, because quality of life perceptions are fluid, and what may seem pleasing or satisfactory one day may not seem that way the next day. Moreover, subjective measures may be compromised by a human tendency to see things in a similar way over time (Hatton & Ager, 2002), and by a tendency to make the best of things unless circumstances are dire (Cummins, 2001, 2003).

Given these strengths and drawbacks to both objective and subjective measures of quality of life, and since the two are different but equally important ways to measure quality of life, the current view is that it is probably best to use both. This and other measurement guidelines of the Quality of Life Consensus Document (Schalock et al., 2002a)—that a broad range of life domains be used, that a range of aspects within each domain be explored and described, and that measurement use either qualitative or quantitative methods or both—lead us to the current view that quality of
life need not be measured in a standard way, but rather is, and probably should be, measured in ways that are most suitable to the task at hand. This pragmatic approach is described more fully below.

**Aspects of Life to Measure**

Human beings have numerous characteristics in common. Our quality of life can be determined, in part, by indicators of the extent to which we experience success and fulfillment in those common areas of life. For example, humans are social beings for the most part, and a successful and fulfilling life is one that ranks high on indicators of frequent positive social interaction with others. Human beings also enjoy material security, emotional stability, safety, health, activity in the form of play and productivity, creative and learning endeavors, and other characteristics. Indicators of each of these aspects of life, common to all human beings, can be assessed in quality of life measurement.

Yet, quality of life is at the same time idiosyncratic (Brown & Brown, 2003). Individuals have characteristics and interests that are unique to them alone, characteristics and interests that sometimes differ fairly substantially from one person to another. In fact, one of the things we find most intriguing about others is their unique characteristics and interests, and we often purposely seek out others who are unlike ourselves to explore and be fascinated by how we are different. For humans, it would be a dull life if we were all the same and shared very similar characteristics and interests. Moreover, it is sometimes the unique characteristics and interests that are the best indicators of an individual’s quality of life. For example, a man who has been diagnosed with Asperger syndrome has a love of subways and subway maps, and has an incredibly extensive knowledge about the subway system in his city. He admits to spending large numbers of hours each week on this interest, and happily admits to the great pleasure it provides his life. Any accurate assessment of this man’s quality of life would have to include this specific interest as an indicator. This is done easily enough for individual assessments, but a measurement difficulty that has not been addressed to date is how to include indicators that are unique to the individual in quality of life measurement systems. Not only are they unique to the individual (and often mostly irrelevant to other people), but also they vary in importance in the life of the individual. Thus, although one measurement question is how we include such indicators in quality of life measurement systems, another such question is how to assess what weight or degree of importance should be given to each unique indicator.

**Drawing the Two Measurement Aspects Together**

In spite of these measurement difficulties, it is useful to think of assessing indicators of quality of life in terms of objective or subjective measurement methods, and indicators that are common to all humans or unique to individuals, for different purposes. As shown in Table 1, at the present time both objective and subjective measurement methods, and the advisability of using subjective data for these latter purposes, have been questioned because of current difficulties with establishing reliability and validity (e.g., Hatton & Ager, 2002). To date, no method has been advanced to incorporate aspects of life that are unique to individuals into program evaluation or policy evaluation, or into any available system for individual quality of life assessment, although it seems important to do so in the future.

Individual development, as well as program evaluation that is person-centered, can also use both objective and subjective indicators that are common to all people. However, they should also focus on aspects of life that are unique to individuals, both objectively and subjectively measured, because they directly influence personal support and growth goals. Aspects of life that are unique to individuals very often contribute greatly to and detract from an individual’s quality of life (Brown & Brown, 2003) and, as such, need to be strongly aligned with support. It has also been argued that they need to be strongly aligned to policy (Schippers, Zuna, & Brown, 2012), although methods for accomplishing this have not yet been developed.

**Additional Unanswered Challenges in Measuring Quality of Life Indicators**

Quality of life is an appealing concept that draws together the many and varied positive aspects of human life, but its very breadth and seeming lack of specificity has made for an emergence of questions for further exploration of how its indicators should be measured. Three such questions that appear to
be particularly important currently are briefly described here.

Whose voice should be heard when deciding on what constitutes the best quality of life indicators? The importance of hearing the voice of people with intellectual disabilities, a central tenet of the critical disability approach, has also been stressed in the quality of life literature (e.g., Brown & Brown, 2003; Goode, 1994; Woodill et al., 1994). This has been an implicit, and occasionally an explicit, rationale for subjective measurement of quality of life—the importance of hearing, recording, and acting on the perceptions of life experience of people with intellectual disabilities themselves. To date, no measures have been developed by, or even with, people with intellectual disabilities themselves, although some measures were tested and partially validated through consultations, and some data have been collected by trained peers (e.g., Alberta Human Services, 2013). Most quality of life measurement instruments, including the three whose domains and indicators are described above, not only allow for, but also emphasize, capturing the perceptions of people with intellectual disabilities whenever possible. The validity of scores from these measures has been identified in the literature many times as being at least potentially problematic (e.g., Hatton & Ager, 2002), because respondents with intellectual disability may not always understand the nature of the questions being posed, and because there appears to be a high level of acquiescence within this population.

To take these problems into account, but still represent the views of people with intellectual disabilities who constitute a population with diverse communication abilities and skills, some quality of life measures (e.g., Brown et al., 1998; Cummins, 1997b) also allow for the views of others who know the person with intellectual disability well to be recorded for the sake of comparison. Others’ perceptions can by no means be thought of as synonymous with those of people with intellectual disabilities since scores by proxies have generally not reliably reflected scores by people with intellectual disabilities themselves (e.g., Stancliffe, 1999). Still, they are thought to be important to take into consideration, especially for personal support and development, since those close to people with intellectual disabilities are often very influential in decisions made about their lives (Bertelli & Brown, 2006).

The overall issue here is how to hear the voice of people with intellectual disabilities, and especially those with severe intellectual disabilities who cannot communicate their quality of life ideas in ways that we can readily understand. Although Lyons (2005), Brown, Raphael, and Renwick (1997), and others have argued that this can be done quite effectively following training in using a variety of observation and sensitizing methods, major challenges remain and much more sophisticated ways

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Table 1

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<thead>
<tr>
<th>Uses</th>
<th>Measurement type</th>
<th>Type of indicators</th>
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<tr>
<td>Policy evaluation</td>
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<td>Subjective</td>
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<td>Program evaluation</td>
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<tr>
<td>Individual assessment</td>
<td>Objective</td>
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<td></td>
<td>Subjective</td>
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<tr>
<td>Individual development</td>
<td>Objective</td>
<td>Common to all people</td>
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<td></td>
<td>Subjective</td>
<td>Unique to individuals</td>
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<tr>
<td>Person-centered program evaluation</td>
<td>Objective</td>
<td>Common to all people</td>
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of allowing the voices of people with intellectual disabilities to be “heard” as valid by researchers need to be developed.

What are the best quality of life indicators for families? Researchers in quality of life and intellectual disabilities began to turn their attention to the question of family quality of life just before the turn of the millennium. Since that time, a book published on this topic (Turnbull, Brown, & Turnbull, 2004), numerous articles and, more recently, twin journal issues (Kober & Wang, 2011, 2012) illustrate a growing and robust interest from researchers in more than twenty countries around the world. Two major initiatives, at the Beach Center on Disability at the University of Kansas in the United States and the International Family Quality of Life Project, have each developed family quality of life domains and indicators, and collected and reported data from several countries (Samuel, Rillotta, & Brown, 2012). In general, these reports have especially noted the importance of family life, parenting, and health on family quality of life, and have identified social support from other people and, in some cases, somewhat surprisingly, support from services as contributing less positively (Brown, 2010). What is particularly noteworthy in these reports is the remarkable similarity in results from the studies in various countries, despite population, age, severity, cultural, service availability, and other differences.

Most data collected to date have captured the perspective of parents or caregivers only. Although it was recognized from the beginning that ways would need to be found to understand family quality of life from the perspective of all members of the family, and to measure family quality of life as a whole objectively (Turnbull et al., 2004), the parents’ and main caregivers’ perspectives alone have been measured as a starting point in an effort to expedite research in this area. The exception to these perspectives is the work developed by Moyson (2011), who studied populations of siblings with disabilities and, in doing so, developed domains and indicators reflecting that perspective.

In all of these three assessment methods, family quality of life indicators were developed through careful and sustained research, and thus represent a good place to begin the study of family quality of life. Yet, this is a relatively new area of study that has been developed by only a few scholars. The extent to which the currently available indicators are the best ones to measure the family quality of life concept is something that still needs to be examined in an ongoing way.

How can quality of life indicators for individuals and families inform policy and practice better? Most of the work in quality of life has focused on the measurement of individuals with intellectual disabilities and their families. The use of quality of life instruments in individual assessment and intervention—with a view to identifying and acting to enhance specific aspects of life in order to move toward an overall better life quality—has been relatively straightforward. For example, Butterworth, Steere, and Whitney-Thomas (1997) explored the close relationship between person-centered planning and quality of life, Schalock and Verdugo (2002) described a number of components of applying quality of life at the individual level, and Brown and Brown (2003) set out specific ways that a quality of life approach can directly use assessment and intervention to help improve individual people’s lives.

The application of individual quality of life data to policy and program evaluation, and to policy and program enhancement, has required considerably more conceptual development. Six chapters in Schalock’s 1997 book on the application of quality of life address conceptual and practical issues in using quality of life in organizational assessment and improvement, organizational change, and public policy. Principles and techniques for applying quality of life at the organizational and societal levels were described by Schalock and Verdugo (2002), and expanded upon by Schalock and colleagues in 2007. The carefully developed work by The Council on Quality and Leadership (2012) features 25 quality indicators that have been applied to assessing, accrediting, and transforming human service organizations.

Although considerable progress has been made, a problem in all this work is that policy principles and organizational goals ostensibly designed to improve quality of life do not always match well with one another (Turnbull, Beagle, & Stowe, 2001) and, further, that they do not match well with quality of life indicator measures at the individual level. Schalock and Verdugo (2012) have called for and described an initial method for improved alignment at the policy and services levels, and Schippers, Zuna, and Brown (2012) expanded this conceptualization by arguing that quality of life indicators at the policy, practice, and individual/family levels need to be aligned.
Alignment of quality of life indicators at these three levels can, however, be complicated by principles that are well known in the quality of life literature. Three are noted here. First, the homeostatic effect first described by Cummins (2003) recognizes that most people tend to make the best of things and tend to find ways to cope and feel satisfied, in spite of such things as their levels of support or the quality of existing social policies. To illustrate this, it has been noted that people who lived in institutions and people who lived in community settings both claimed to enjoy their social relationships and their daily activities equally (Brown et al., 1997), even though community living might reasonably be expected to be related to better quality of life than institutional living. This example suggests that some individual quality of life indicators are not very effective in evaluating broader policies, in this case community living.

Second, it has been recognized for almost 20 years that quality of life indicators can be realized in multiple ways (Brown et al., 1997). For example, “having friends” can mean having established satisfying relationships with one or two others or with many others, with others who live nearby or far away, with work colleagues or people who share specific recreational activities, or with people seen frequently or only occasionally. People in these various situations might all be equally happy with their friendships, but if they are equally unhappy it is almost impossible to set up policies and supports that will result in improvement for all. It is difficult to evaluate policy or practice when the indicators are being interpreted in multiple different ways.

Third, individuals’ perceptions of their own quality of life are often highly influenced by one aspect of life or by a few aspects of life (Brown & Brown, 2003). Particular interests in career choices or hobbies, or particular talents, affect how a person perceives his own life yet these are not usually specifically stressed in policies or services, which are geared to a wider variety of people. For this reason, indicators of the most important aspects of life to individuals may or may not even be addressed in policies and services. Looking at this another way, policies and services may influence one person’s quality of life strongly, but may influence another person’s quality of life very little. In the first case, using quality of life indicators at the individual level would be a good way to evaluate policy and practice, but in the second case it would be a poor way to do so.

Even if such issues can be resolved, the question remains whether quality of life indicators are the only, or even the best, way to inform policy and practice. This question is addressed more fully in the succeeding section.

**Extending Our Thinking About Evaluating Effectiveness of Policy and Practice**

As outlined above, quality of life frameworks have been enormously influential in guiding intellectual disability service evaluation policy and practice over the past 30 years (Buntinx & Schalock, 2010; Schalock, Borthwick-Duffy, Buntinx, Coulter, & Craig, 2010). At the same time, there are continuing fundamental questions in the quality of life field about how quality of life should be assessed, interpreted, and used as part of policy and service evaluation processes. Rather than focusing only on refining quality of life frameworks and measurements for evaluation purposes (see, for example, Schalock & Verdugo, 2012), an alternative argument is that quality of life frameworks, derived as they are from psychological theories attempting to account for human experience, may not be the only or the most suitable conceptual framework for understanding and evaluating the effectiveness of policies and practices concerning people with intellectual disabilities. For this reason, alternative ways of thinking might be helpful to complement, or even to predominate, this type of quality of life application. The capabilities framework is offered as one possibility.

**The Capabilities Framework**

An increasingly influential framework for documenting, understanding, and addressing inequalities in society is the capabilities framework (Nussbaum, 2011; Sen, 2001). The capabilities framework has arisen out of work on the economics of developing countries, with an original ambition to move beyond a country’s Gross Domestic Product (GDP) as an indicator of how “well” a country is developing. As many authors have pointed out (Nussbaum, 2011; Sen, 2001; Wilkinson & Pickett, 2009), a nation with higher or rapidly increasing GDP can also be a nation with huge levels of inequality that suppresses the rights of its citizens. This has led to the development of
composite indices of national progress or development that include multiple dimensions, such as the UN Human Development Index (with three dimensions: health, education, and living standards; United Nations Development Programme, 2013), and the Organization for Economic Cooperation and Development’s (OECD) Better Life Index (with 11 dimensions: housing, income, jobs, community, education, environment, civic engagement, health, life satisfaction, safety, and work-life balance; OECD, 2013).

The capabilities framework is not a psychological theory of human experience, but a framework for understanding what societies need to do to achieve social justice for their citizens, and to make visible the ways in which societies are failing to achieve social justice, in which areas, and for which of its citizens. In this sense, it has much in common with the social model familiar in disability studies, which identifies society’s failings as the source of disablement for people with impairments, historically leaving them excluded and oppressed (Shakespeare, 2010).

The capabilities framework has a number of characteristics that make it an encouraging approach for understanding the inequalities experienced by people with intellectual disabilities and prioritizing societal action to address these inequalities, as recognized by an increasing number of capabilities framework theorists (Burchardt, 2004; Nussbaum, 2009; Wolff, 2009, 2011). Nussbaum (2011) described the central focus of a capabilities approach:

The outline of the capabilities framework above suggests some fundamental differences between this framework and quality of life approaches in their application to people with intellectual disabilities.

First, there are fundamental differences between the two approaches in what should be measured. Capability theorists argue about the relative merits of attempting to measure substantial freedoms directly (Nussbaum, 2011) rather than the methodologically more straightforward task of measuring functionings as proxy indicators of substantial freedoms (Wolff, 2011; Wolff & De-Shalit, 2007). For example, whether it is better to measure people’s self-determination in terms of food choice and physical activity (measuring directly), or measuring people’s body mass index (measuring by proxy). However, they are agreed on the central importance of substantial freedoms, which are compatible with
and underpinned by notions of self-determination and human rights frameworks (Burchardt, 2008), where self-determination and human rights can be seen as another way of describing important domains of substantial freedoms.

While some objective indicators used in quality of life frameworks could be mapped on to functionings and, in a limited way, to substantial freedoms, their emphasis on assessing quality of life in hedonic and materialist terms (Buntinx & Schalock, 2010) is quite different and, particularly in the case of hedonic measures, insensitive to inequalities or changes in people’s circumstances. In addition, many quality of life frameworks treat self-determination and human rights as subdomains of quality of life (see Table 2) that are “tradeable” against other quality of life subdomains, rather than being the fundamental underpinning to the totality of a person’s life. However, it is important to note that other conceptualizations of quality of life (see Brown & Brown, 2003) do emphasize the centrality of choice and self-determination (e.g., Brown & Brown, 2009; Wehmeyer, 2007) more broadly.

Second, capability frameworks are concerned with social justice as it applies to each and every individual, rather than an approach that is only concerned with inequality at an aggregate level as quality of life models usually do when applied to evaluating the success or otherwise of programs and policies (Wolff & De-Shalit, 2007). Achieving population equality for people with intellectual disabilities would be inadequate if some people with intellectual disabilities were not meeting agreed minimum thresholds in terms of substantial freedoms or functionings. However, there is as yet no consensus about how minimum thresholds should be set (Wolff & De-Shalit, 2007). Of course, assessing inequalities between people with intellectual disabilities and the rest of the population is important for understanding the scale and nature of disadvantage experienced by people with intellectual disabilities, but according to the capability framework, eliminating inequalities is not necessarily the ultimate goal of social policy. Again, there is an obvious contrast to quality of life frameworks where creating aggregate quality of life scores across individuals within a population is an important tool for evaluation purposes, and issues of inequality or social justice are not an explicit part of the framework.

Third, capability frameworks are pluralist about value. In other words, every domain of combined capabilities is important in its own right, rather than being reducible to a single scale as occurs when quality of life models are used to evaluate programs or policies (Nussbaum, 2011). For example, both access to effective cancer screening services and healthy levels of physical activity are important for people with intellectual disabilities to experience, and achieving exceptional levels of physical activity would not absolve society of responsibility for accessible cancer screening services just because a pooled measure of “health” averaging across these domains might come out as satisfactory. In this sense, it is clearly in opposition to quality of life approaches to assessing the lives of people with intellectual disabilities for the purposes of service and policy evaluation (Buntinx & Schalock, 2010), which explicitly include the facility to combine domain scores into a single overall quality of life index score for an individual.

Table 2
The 10 “Valuable” Capabilities vs. Quality of Life Domains for People with Intellectual Disabilities

<table>
<thead>
<tr>
<th>The 10 “valuable” capabilities (Burchardt, 2008)</th>
<th>Quality of life domains for people with ID (e.g., Wang et al., 2010)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life, health, bodily integrity</td>
<td>Physical well-being</td>
</tr>
<tr>
<td>Individual, family, and social life</td>
<td>Emotional well-being</td>
</tr>
<tr>
<td>Legal security</td>
<td>Interpersonal relations</td>
</tr>
<tr>
<td>Adequate standard of living</td>
<td>Rights</td>
</tr>
<tr>
<td>Participation, influence, and voice</td>
<td>Material well-being</td>
</tr>
<tr>
<td>Identity, self-expression, and self-respect</td>
<td>Social inclusion</td>
</tr>
<tr>
<td>Education and learning</td>
<td>Self-determination</td>
</tr>
<tr>
<td>Productive and valued activities</td>
<td>Personal development</td>
</tr>
<tr>
<td></td>
<td>Performance</td>
</tr>
<tr>
<td></td>
<td>+ QoL Total</td>
</tr>
</tbody>
</table>
Applying a Capabilities Framework

A question for any conceptual framework is how it can be operationalized into a useful guide for evaluating social policy and practice, and some work has begun on this issue, although not specifically with people with intellectual disabilities.

A first step in the application of the capabilities framework is to determine which capabilities are the central ones for people with intellectual disabilities. Alternatives here include deriving “central capabilities” from a priori philosophical principles (Nussbaum, 2011), determining central capabilities democratically, and using hybrid approaches that start with a set of capabilities derived from human rights principles, then empirically developing these capabilities through processes of deliberative consultation (Burchardt, 2008).

Table 2 compares the eight core domains proposed for quality of life in people with intellectual disabilities (Schalock & Verdugo, 2002; Schalock et al., 2007; Wang, Schalock, Verdugo, & Jenaro, 2010) and the “valuable capabilities” developed partly empirically with members of the public in the UK (Burchardt, 2008). There is considerable consistency across these approaches, particularly at the level of subdomains, although there are also important points of difference. For example, rights and self-determination are treated as specific subdomains in the quality of life framework, whereas they are viewed as underpinning all aspects of substantial freedoms in the capabilities framework.

A second step is to determine what should be assessed within each of these central domains. Most quality of life approaches use subjective and objective indicators for each central domain (see Schalock et al., 2002b), resulting in some thorny methodological measurement problems (see above). Proposed operationalizations of the capabilities framework are more pragmatic, suggesting that within each central “valuable” capability, indicators should be sought in the aspects of autonomy (related to combined capabilities or substantial freedoms), treatment (relating to the social, political, and economic conditions influencing people’s capabilities), and functionings (Alkire et al., 2009). It should be noted that “treatment” in this framework is used in the broader sense of how people are treated, rather than denoting treatment as an intervention in a quasi-medical sense. Existing statistical and other indicators can be pragmatically mapped into such a framework, both to understand the position of people within society and identify priorities for social policy and practice, and also to identify where there are gaps in available indicators to prioritize the development of future indicators.

As an example of this, relevant indicators from the U.S. National Core Indicators Project (Human Services Research Institute, 2013) were mapped into the Productive and Valued Activities domain of the capabilities framework. This provisional mapping suggested the following NCI indicators under the three headings of Autonomy, Treatment, and Outcomes:

**Autonomy**
1. At day program or day activity
2. Working a paid job in the community but would like to work somewhere else
3. Chooses daily schedule
4. Chooses how to spend free time
5. Chose community job
6. Would like to have a paid job in the community

**Treatment**
1. Number of community jobs visited
2. Integrated employment a goal in service plan
3. Ever afraid at work or in day program/activity

**Outcomes**
1. Helps other people
2. Total number of months at current community job
3. Of those employed in community continuously employed during the year
4. Of those employed in the community receives benefits
5. Amount of community gross wages earned during two week period
6. Community hourly wage
7. Facility-based annual wage
8. Does volunteer work

As the above list shows, the NCI has many indicators mapping on to the different aspects of productive and valued activities (largely in terms of paid employment) that could be used to understand the scale and factors associated with the inequalities experienced by people with intellectual disabilities. For example, in terms of functioning, only 15% of the NCI sample were in a community paid job in 2010 and 2011, with rates much lower among people with severe (5%) or profound (1%) intellectual disabilities. In terms of autonomy, of those not in a community paid job, 48% of people with intellectual disabilities wanted a job, and even 30% of those in a community paid job would like to work somewhere else. Building up a comprehensive picture of autonomy, treatment, and functioning regarding productive and valued activities using NCI data would provide clear directions and priorities for social policy and practice.

These central features of capability frameworks provide a potentially coherent and useful way of
both understanding the inequalities experienced by people with intellectual disabilities and guiding public policy toward them. First, issues of human rights, self-determination, and social justice are fundamental to the framework. Second, it makes inequalities visible and forces us to be clear about what the goals of social policies and practices are, in terms of minimum standards of decency for everyone with intellectual disabilities. Third, it connects our expectations about a decent life for people with intellectual disabilities to our expectations about the lives of everyone else, including ourselves. Fourth, it is pragmatic in terms of what the indicators should be and how they can be measured. Finally, it is potentially easier to join up to government/policy paradigms about what they should be doing. This could be by sharpening up and operationalising commitments to human rights that seem to be a necessary but not sufficient condition for achieving social justice for people with intellectual disabilities, and also by placing existing national statistics within a capabilities framework to illustrate areas of relative inequity and gaps in the available data.

Pragmatic Approaches to Monitoring Quality of Life
Two recurring questions have run through the emergent literature on quality of life or well-being. What conceptual approach(es) provide the most useful organizing frameworks for defining quality of life or well-being? Which indicators provide the most useful measures of particular aspects of quality of life or well-being? In this section, we discuss these two issues as they relate to a particular pragmatic context: how to most appropriately monitor the impact of social policy on improving the quality of life or well-being of people with intellectual disabilities (and people with disabilities in general).

The discussion will be predicated on the assumption that the main aim of monitoring the impact of social policy is to influence future policy choices and direction. As such, the discussion will draw upon the ideas of utilization-focused evaluation (Patton, 2008, 2011), an approach to evaluation whose main emphasis lies in maximizing the impact of evaluation procedures and results on policy and practice.

Conceptual Frameworks
The central tenet of utilization-focused evaluation is the importance of tailoring evaluation processes to the specific needs of, and conceptual frameworks used by, the primary end users of any evaluative activity (in this case those politicians, administrators, and civil society organizations that may play an influential role in shaping future policy). Clearly, it would be a monumental task to identify the conceptual frameworks used by such disparate actors through an inductive process of stakeholder mapping in order to conceptualize the well-being of people with intellectual disabilities in any single jurisdiction. A pragmatic alternative is to identify clearly articulated frameworks that have already been developed by key primary end users (though not necessarily for this specific purpose), or frameworks that may have such a generic credibility that primary end users would be unlikely to argue against their value.

An example of the former is to apply existing generic frameworks for conceptualizing well-being to monitoring the well-being of people with intellectual disabilities. For example, a central component of current Australian government policy is to build “a stronger, fairer nation” in which “every Australian has the capability, opportunity, and resources to participate in the economy and their community” (Commonwealth of Australia, 2009). This has led to the development of a national Indicator Framework for Social Inclusion, containing 27 headline and 23 supplementary indicators, which is used to monitor national progress toward this policy objective (Australian Social Inclusion Board, 2010, 2012). Although quality of life and social inclusion are different concepts, social inclusion is sufficiently close to the capabilities approaches (see above) and the living standards approaches to conceptualizing quality of life to indicate a sufficient degree of common ground to warrant using this framework for monitoring the well-being of people with intellectual and/or developmental disabilities in Australia. Indeed, it has been used as a framework for monitoring the well-being of young adults with disabilities in Australia (Emerson, Honey, & Llewellyn, 2013; Llewellyn, Emerson, & Honey, 2013).

An example of the latter strategy is to use international human rights conventions as an organizing framework for monitoring well-being. The UN Convention on the Rights of the Child has increasingly been used for this purpose, by UNICEF and others, to monitor the well-being of children in high income countries (Bradshaw, Hoelscher, & Richardson, 2007; Martorano, Natali, de Neubourg,
Similarly, the UN Convention on the Rights of Persons with Disabilities (2006) could be used to provide an organizing framework for developing statistics to monitor the well-being of people with intellectual and/or developmental disabilities in countries that have ratified the convention. The large number (and collective population) of the world’s countries that have ratified the convention could mean that such an organizing framework could provide the basis for international comparisons of the well-being of people with intellectual and/or developmental disabilities. Such an approach has been adopted for making comparisons between selected low- and middle-income countries in the Asia-Pacific region regarding the well-being of children with intellectual and other disabilities (Llewellyn, Emerson, Madden, & Honey, 2012).

The point here is that choice of framework in the context of policy evaluation should not be considered an academic exercise, but be based on consideration of the likely value of competing frameworks in bringing about change in policy and practice and subsequently the quality of life of people with intellectual and/or developmental disabilities.

Indicators
Much has been written about the desirable characteristics of indicators of well-being (Australian Institute of Health and Welfare, 2005; Llewellyn & Leonard, 2010; Moore, 1997; United Nations Development Program, 2000). The Australian Institute of Health and Welfare, for example, proposed the following eight characteristics: (1) validity, (2) relevance, (3) applicability across groups, (4) reliability, (5) sensitivity, (6) robustness, (7) clarity and ease of understanding, and (8) availability or ease of collection.

Developing or adopting individual indicators that fulfill all eight criteria is a demanding task and it may be more appropriate to consider the extent to which indicator sets (rather than each individual indicator) fulfill these criteria. For example, measures based on subjective appraisal, especially more broadly based subjective appraisal such as global measures of subjective well-being, may be valid (as representations of internal states), relevant (in some jurisdictions), reliable, robust, easy to understand, and relatively simple to collect. They are also, however, inapplicable to some groups of people with more severe intellectual disabilities and are remarkably insensitive to the scale of change that could reasonably be expected of social policy. Indeed, it is the very insensitivity of global measures of subjective well-being to changing environmental circumstances that gave rise to set-point or homeostatic models of subjective well-being (Cummins, 2003). While the results of recent longitudinal research have suggested that global measures of subjective well-being may not be as insensitive to change as originally thought (Diener, Lucas, & Scollon, 2006; Headley, 2008; Lucas, 2007), their capacity to adapt to life’s changing circumstances has been amply documented (Diener & Biswas-Diener, 2008; Kahneman, Diener, & Schwarz, 1999). As such, their use as indicators in policy evaluation may be problematic.

To use indicators that may be insensitive to the scale of change that could reasonably be expected of social policy interventions could undermine the perceived value of progressive social policies (additional investment or change failing to improve subjective well-being), and inadvertently support regressive social policies (reducing the investment in or quality of supports not reducing subjective well-being). This may be particularly problematic when applied to people with intellectual disabilities, given their increased tendency to provide acquiescent responses to questions.

Take, for example, the results of the 2011–2012 Personal Social Services Adult Social Care Survey in England, a national survey that included responses from 10,800 people with intellectual disabilities (Information Centre for Health and Social Care, 2012). The survey included a general quality of life question: Thinking about all the different things in your life, good and bad, how would you say you feel about your life in general? Eighty-one percent of people with intellectual disabilities reported that their life was good, or so good it could not be any better. In comparison, only 53%–57% of participants from other client groups (e.g., people with physical disabilities, people with sensory impairments) reported that their quality of life was that good. Would it be appropriate to conclude from these data that social care services in England are doing an excellent job in supporting people with intellectual disabilities? What scope do these data leave for monitoring progress? What case do they make for addressing the violations of the human rights of people with intellectual disabilities in...
England (House of Lords and House of Commons Joint Committee on Human Rights, 2008)?

**Summary and Concluding Comments**

A great deal of work has been done to develop the conceptualization of the social construct, quality of life. Moreover, several methods have been developed to identify key life domains, quality of life indicators in each of those life domains, and ways to measure these indicators. An examination of whether objective or subjective measurement methods should be used has resulted in a consensus that it is best to use both. Quality of life indicators of aspects of life that are unique to individual people with intellectual disabilities are probably most useful for enhancing individual development and for applying person-centered support. Quality of life indicators of aspects of life that are common to all people are also useful for these purposes but, in addition, have been applied to both policy and service practice evaluation. A question that has emerged in the minds of some is whether or not aggregating individuals’ quality of life scores, even for those that measure indicators that are common to all people, is the most appropriate way to evaluation policy and service practice in the field of intellectual disabilities.

This question has been explored by examining the possibility of supplementing quality of life frameworks or adopting other frameworks for these purposes. Potential use of the Capabilities Framework is offered in an extended example to illustrate how another framework might be extremely useful. Finally, and supporting the preceding discussion, it has been argued that a pragmatic approach to evaluating policy and service practice might best be followed. The idea here is that better quality of life outcomes might best be supported by conceptual frameworks and sets of indicators that prove to be most active in effecting positive social policy change, and that prove to be most useful in bringing about positive changes in people’s lives.

**References**


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