Quality of Life as an Outcome Measure

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Contents

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Learning Objectives

This chapter explains what is meant by quality of life, and it explores how quality of life can be used as an outcome measure. Readers will learn that quality of life is a social construct, subject to changing meanings over time and place, and thus, its corresponding measurement is subject to change. They will come to understand that there is no absolute method to measure quality of life and that different approaches to measuring quality of life as an outcome may be taken according to the purpose of applying the measure. Whatever method is used, it is best interpreted the results through the lens of the lived experience of individuals and families.

15.1 Introduction

It has sometimes been said that the ultimate outcome of everything we do in human services, including the overlapping fields of mental health and neurodevelopmental conditions, is to enhance a person's quality of life (QoL). In the broad context of human services, we have set for ourselves quality-related goals and ideals that set the direction for us to follow in providing support, and our fields are developing more and more strategies that help us move in that direction. Ideals such as human equality, full and meaningful participation, respectful inclusion, and full access to opportunities for all dominate the thinking of those of us providing supports and services today because we have increasing evidence that moving toward such goals will result in a greater degree of quality in our lives.

Intellectual disability (ID) and other neurological disability alone can make this challenging, and it is even more challenging when such disability co-occurs with mental health and behavioral problems. For individuals and families who experience such challenges, it is particularly important for services and supports to focus on QoL. They need skills, strategies, and supports as tools to help them along the path toward quality living, and it is for this reason that innumerable ways have been developed, and are continuing to be developed, to help individuals take their steps forward.

An important aspect of stepping forward toward quality living is assessing the impact of our supports and interventions by taking outcome measures. The concept *quality of life* has increasingly gained a central and essential place in person-centered outcome measurement of supports and interventions for people with neurodevelopmental disabilities. QoL has been especially applied to individualized planning, assessing the impact of interventions, and evaluating the effectiveness of services and policies offered by professionals and professional organizations. As QoL is a developing approach to individual and family life, further development is occurring and more will occur in the future. In this chapter, we attempt to provide an overview of what has been developed and usefully employed to date, and to identify areas where further refinements, including in outcome measurement, are needed.

15.2 Understanding Outcomes and Quality of Life as Outcome Measures

Outcomes are the longer-lasting results of what we accomplish in human services. QoL measures of individuals or groups of people with neurodevelopmental disability, when taken and compared at points over time, can record longer-lasting changes in people's lives or aspects of people's lives. As such, they can be used as valid indicators of the effectiveness of the practices, structures, and environments we have in place, and of the actions we have taken – or not taken – to support them.

Outcomes are ongoing and lasting changes that occur as a result of something. In human services, we strive to bring about ongoing and lasting *positive* changes in people's lives. We then assume that such changes improve their quality of life.

15.3 The Importance of Quality of Life as an Outcome Measure

People with neurodevelopmental disabilities are among those for whom assessment of life quality is of particular concern. Compared to those without disability, or with other types of disability, people with neurodevelopmental disabilities have lower rates of employment, tend to be socially isolated, and are generally afforded fewer opportunities for meaningful community participation. To deal with the many challenges of their varied conditions and the barriers to inclusion that exist in our society, they often need specific, and sometimes unique, skills, strategies, and supports to use as tools in moving forward. In the past, we have not always recognized the need for all people with neurodevelopmental disabilities to experience quality in their lives, and thus the goal of achieving QoL is a relatively new one and an especially important one.

Services and supports for people with neurodevelopmental disability have fostered numerous types of helpful policies and organizational structures (the physical buildings, the many types of professional supports, skill development through training and education, etc.). They have, at the same time, recognized that such people, as well as their families and supporters, sometimes have personal needs and characteristics that need to be taken into account and addressed when providing support. The uniqueness of individuals is also an important guide for us in developing QoL strategies, because a great deal of what adds quality to any one person's life involves aspects that are of particular value and importance to each individual. Thus, enhancing quality of life for people with neurodevelopmental disabilities can and should be addressed at the policy, organizational, and personal levels, and quality of life outcomes are probably much better if all three levels are aligned in intent as well as in practice [1–3]. The position taken in this chapter is that professional duty to enhance QoL outcomes for people with neurodevelopmental disability is best achieved when a comprehensive approach – involving an amalgam of practices at the policy, organizational, and individual and family levels – is taken, and when all work together toward the same purpose.

› People with neurodevelopmental disabilities are an important focus for quality of life, because our services and supports to date have not always resulted in them experiencing the "goodness" of life. Quality of life outcome measures can help us identify strategies to help remedy this.

15.4 Two Approaches to Quality of Life Measurement in Health

The concept QoL is, by necessity, a general construct that is widely understood to describe the "goodness" of life. When applied to individuals, the concept describes a balance of the degree of "goodness" in the various aspects of a person's life and in its various circumstances. Several definitions and descriptions of QoL are available that try to capture this balance. One well-known such definition is provided by the World Health Organization (WHO) [4]: "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p. 3).

The concept QoL overlaps somewhat with closely related concepts. *Standard of living* is sometimes used as a substitute for QoL, although high or low standard of living does not necessarily mean good or poor QoL, especially for individuals. *Happiness* is another term that is sometimes assumed to be synonymous with QoL, though, again, the two concepts differ because human beings characteristically create quality that relates to their own abilities, interests, and circumstances, and they often create happiness in circumstances that by other standards would not seem to be of high quality. Similarly, *life satisfaction* is not necessarily QoL, as humans often become satisfied in situations of low quality, especially when other needs are being met or when alternatives are not available.

When understanding QoL as a measure, then it is important to base measurement on the "goodness" of life as inherent to the concept, rather than on related concepts that may not fully capture quality.

Within the broad health field, two distinct ways of thinking about measurement using the QoL concept have emerged: generic or "whole-person" QoL and health-related QoL (HR-QoL). Generic QoL evaluates the perceptions of quality by people with respect to the full range of areas that have shown a qualitative value in human life – areas of life and values that are common to the human condition. The focus here is on the quality of a person's whole life as a social human being, regardless of the presence of particular pathologies, disabilities, or existential conditions. To date, the whole life of individuals has been measured by identifying life domains that are important across the human spectrum (e.g., positive social interaction), by identifying the most important indicators of those domains (e.g., friendships are an important indicator of social interaction), and determining specific ways to measure those indicators (e.g., number of close friends, time spent with friends, and ratings of satisfaction with friends might all measure friendships). Although this method of measuring QoL captures a great deal of the quality of most people's lives, it is not a full assessment. For example, time spent with friends may not be "quality" time or even highly enjoyable, and time spent on other activities that are not captured by the indicators of the domains may be much more important to the individual. Similarly, a person may be satisfied with her friends, but times spent with those friends may not be among the most enjoyable aspects of the person's life. On the whole, though, the generic measures that have been developed correlate highly with people's overall assessment of the quality of their lives [5].

HR-QoL is a more specific focus on QoL, relating to patients' or others' perceptions of their health status, and, more specifically, on physical and mental aspects of well-being and functioning (see the Quality of Life Instrument Database of the Mapi Research Trust for a list of available instruments; [6]). HR-QoL measures focus on either overall health and functioning or health and functioning as it relates to a specific disease or condition (e.g., cancer, arthritis, schizophrenia, depression, and many others). HR-QoL instruments typically try to measure both the degree to which symptoms are present and their effects on daily functioning. Thus, although these measures may not capture the broader range of life that generic QoL measures try to capture, they do expand upon the traditional medical approach (treating an identified problem) by considering the effects of identified diseases or conditions and treating them with various interventions [7]. As the use of HR-QoL measures is only a few decades old and is still developing, there is an international agreement that some caution should be exercised in interpreting their scores [8].

One aspect of both these approaches to QoL measurement that merits special attention is that the perception of individuals about their own lives may differ – sometimes quite considerably – from the perception of others [9]. The reason for this is that people with disabilities, like all humans, appear to have personal criteria for understanding the quality in their lives, as well as a tendency to cope with their particular life circumstances and find their "own" degree of life quality.

Over the past 30 years, these two approaches to QoL measurement have led to the development and application of numerous valid tools to measure the QoL of many groups of people, and there are ample QoL outcome measures available within the field of intellectual disabilities [10]. These have developed rapidly over the past few decades, and their use has resulted in a widely held view within the field of neurodevelopmental disabilities that QoL is a key outcome measure for the effectiveness of interventions and services.

Because individuals with disabilities include a wide range of persons, the nature of self-assessment or perception often requires diverse means of assessment. For example, if an individual is severely or profoundly disabled cognitively, or has major deficits in specific areas such as vision or hearing, specific and innovative assessment may be required.

For example, it may be beneficial to assess the individual in their most familiar environment, acclimatizing an individual to a new environment, or developing specific assessment tools to circumvent the disability such as painting and drawing as an interplay between the person with disability and the professional involved in assessment [11].

Tip

If we are most interested in the effects of a specific disability condition or a specific disease, we may choose to use one or more health-related quality of life tools to assess quality of life. However, if we are most interested in understanding people function in general, or in relation to their families or communities, we may choose to use a whole-person approach to assessing quality of life.

15.5 When to Use Shared and Unique Aspects of Human Life as Outcome Measures

Available QoL outcome measurement instruments for groups of people make use of measures that are assumed to be shared by all people and thus to indicate the QoL of all people. If the purpose of QoL outcome measurement is general in nature, such as evaluating the effectiveness of a larger service or policy or providing a "snapshot" of the QoL of a larger group of people, the shared aspects of life may provide sufficient valid information. Typically, these use perceptual measurement methods that combine subjective and objective approaches [12].However, if the purpose of QoL measurement is to provide a basis for individual planning or for evaluating individual interventions, a full assessment should include both shared and unique aspects of the individual's life. This section describes what unique and shared aspects of human life are, and it addresses their utility as outcome measures. The section that follows stresses the importance of relating both types of outcome measures to the lived experience of individuals and families.

15.5.1 Measuring Uniqueness that Enhances Quality of Life

Although all individuals share characteristics that are central to the human condition, they also have varied characteristics and interests that are very meaningful in their own lives, and thus add to their life quality but may mean little or nothing to other people. Personal uniqueness emerges from such factors as genetic makeup, personality, abilities, life experiences, culture, environmental conditions, and even chance (some of life's "quality" moments arise spontaneously and unexpectedly). These factors determine not only how a person's life is experienced, but also how it is interpreted across time and different conditions. Moreover, personal uniqueness is dynamic, changing over time with changing interests, age, and life conditions. Reinders explained that "…the concept of QoL is necessarily open- ended. There is on any account of the matter a dimension of incompleteness in assessments of QoL in the sense that we may discover things about ourselves that in due time will change our judgments. Precisely as a comprehensive concept, QoL must entail an element of the unknown future of our existence" ([13], p. 210). Thus, all of us, as human beings, develop and use over our lifetimes sets of unique interests, values, and capabilities that add to and intersect with those we share with others.

Sometimes, personal uniqueness takes on particularly strong positive meaning in our lives such that they become what Brown, Raphael, and Renwick [5] referred to as dominant and driving forces. When this is the case, they can add tremendously to an individual's QoL. There are innumerable examples, but some commonly recognized ones are enjoying a particular sport, developing a particular talent such as drawing, or spending time with a favored pet. For a very few people, such things can even take up a very large part of their lives and, if experienced in a highly positive way, form a very large part of the quality within their lives. Some examples include the musician who spends hours every day playing her instrument, an athlete who single-mindedly hones his physical skills, the spiritual follower whose life activities are strongly directed by a set of beliefs and values, a parent who is highly dedicated to the welfare of her children, the family that closely follows the customs of its cultural heritage, or the social activist who strives untiringly for social justice. Whatever their form, dominant and driving forces can add enormously to an individual's QoL in ways that are different from most other people.

Some aspects of QoL can also be negative for individuals. Such things as abuse, poverty, neglect, unsafe conditions, lack of access to food and water, war, and many others can become dominant and driving forces in an individual's life. When this occurs, either temporarily or in an ongoing way, the individual's QoL can be compromised, sometimes severely so.

The methods developed to date in QoL measurement enable us to capture personal uniqueness to some degree, but not fully. For example, an indicator of productivity may be variously interpreted by respondents as work in a paid job, a volunteer position, child-minding, or helping family with chores. What they do not do, except to the extent that there is an opportunity to provide comments or to identify additional factors that add to QoL, is ask specifically about unique personal interests and activities that provide (or detract from) QoL, especially if these are thought of as dominant and driving forces in the person's life. For this reason, when QoL as an outcome is applied to individuals, it is important to gather individually based information about unique interests, values, capabilities, and satisfaction with different areas of life and to assess their importance and value to each person's QoL. As no specific method has been set out in the QoL literature for doing this to date, standard professional assessment and counseling methods should be useful for this purpose.

> Individuals differ widely in the degree to which specific things affect their quality of life. But whether or not these factors are dominant or minor influences in their lives, they need to be taken into account. We do not have standardized methods for accomplishing this, so we have to rely on qualitative assessment methods to estimate outcomes.

15.5.2 Measuring the Quality of Shared Life Domains

Shared QoL refers to characteristics of individual life that are common to, or shared with, other people, such as sociability, productivity, or spirituality. In the field of neurodevelopmental disabilities, the measurement tools that have been validated are all based on these shared characteristics of human life. That is, they identify areas of life (referred to as domains) that groups of people identify as being important to the human condition and to almost every person. Although the various available measurement tools do not all feature the same life domains (see ◘ Table 15.1 for a comparison of four tools), there is considerable overlap among them (see [18] for a comprehensive list of available tools) and overall scores correlate quite highly (e.g., [19]). For individuals, well-researched and validated domains include physical, psychological, and spiritual well-being, personal development, social and community inclusion, and opportunities to achieve and be productive (e.g., [20]). Civic involvement and rights are also sometimes part of a measurement system for individuals and families, although it might be argued that these are determinants, rather than outcomes, of QoL. For families, well-researched QOL domains are family interaction, parenting, emotional well-being, personal development, physical well-being, financial well-being, community involvement, and disability-related supports [21, 22].

Shared QoL is relatively easy to assess, even in persons with severe cognitive impairment. The domains are most often not measured directly, but rather indirectly through

Table 15.1 Comparison of domains in four QoL tools

	WHOQOL-BREF and disabilities module [14]	**Personal well-being Index – intellectual disabilities [15, 16])**	**Quality of life questionnaire [17]**	**Quality of life instrument package [5]**
Number of QoL areas/domains	4 + disability module	7	8	9
Total number of items	39	8	40	54
List of QoL areas/domains	Physical Psychological Social relationships Personal environment + Disability	Standard of living Health Life achievement Personal relationships Personal safety Community-connectedness Future security Spirituality-religion (optional)	Physical Well-being Emotional Well-being Interpersonal relationships Material Well-being Personal development Self-determination Social inclusion Rights	Physical being Psychological being Spiritual being Physical belonging Social belonging Community belonging Practical becoming Leisure becoming Growth becoming

specially developed and validated indicators. These are typically measured on a 3–6 point Likert-type scale [23] for each of the tool's measurement indicators, sometimes for more than one measurement concept such as importance, satisfaction, opportunities, choice, attainment, initiative, and stability [24].

In scoring these dimensions, self-report by people with disabilities should be central, and any means should be mobilized to enable such people to express their own views. In all cases, information on the background of the person, descriptions of the person's current context and living/working environments, and the perceptions of close caregivers constitute additional sources of information that are potentially valuable to add to self-perceptions. Such assessment may even be used effectively with people with severe cognitive disabilities, as they express their inner states through consistent behavioral repertoires [25].

QoL scores are derived from measuring the indicators of life domains specified in the QoL tool. The resultant raw scores can be transformed into standard scores, then analyzed and reported as QOL area/domain scores, or aggregated into a total QOL Score [26]. Since these domains have been validated as aspects of human life that are important to all people with some leeway for cultural influence [27], scores from these tools are considered to be credible measures of shared QoL values.

Several tools that feature shared domains have been developed to assess individual QoL in persons with ID and low functioning-autism spectrum disorder (LF-ASD). Four well-known scales are described briefly below, and their main features are compared in ▪ Table 15.1.

A commonly used QoL measure for people with disabilities is the *WHOQOL-DIS*, developed by the World Health Organisation (WHO). The *WHOQOL-100* is a QoL measure of 100 items for the general population, and it has a brief form of 26 items (*WHOQOL-BREF*). The *WHOQOL-DIS* is the brief form with an additional 13-item section specifically addressing disability. The *WHOQOL-100* was designed with a hierarchical structure that includes overall QoL, six life domains, and then 24 facets within the domains with four specific items to measure each facet. The *WHOQOL-BREF* has a similar hierarchical organization, except that each facet is represented by a single item. The widespread international use of the *WHOQOL* provides for cross-cultural validity for QoL assessment across the adult lifespan and a range of physical, mental, and neurodevelopmental disabilities [28].

The *Personal Wellbeing Index* (*PWI*), developed by Robert Cummins and emerging from his previous *Comprehensive Quality of Life Scale* [16, 29] at Deakin University in Australia, has a useful ID version (*PWI-ID*). The seven domains and one optional domain, each represented by the same single item on the *PWI* (adult version) and the *PWI-ID,* are shown in ◘ Table 15.1. This scale was carefully constructed by a large cohort of international researchers, and takes a short amount of time to administer. Special features of the *PWI-ID* include a detailed set of pre-tests to help ensure the validity of responses, simplified wording of the *PWI* items, and, to promote comprehension, the possibility to use 2-, 3-, or 5-point rating scales in place of the 0–10 scale used in the *PWI* or to use a set of happy and sad faces [9]. The limited number of items on the *PWI-ID* suggests that its principal utility might be as a survey and program evaluation tool rather than a tool for individual assessment and support planning, but its robust psychometric properties ensure its overall credibility. Another consideration in using the *PWI-ID* is that it measures subjective wellbeing, a person's own perceptions of his or her life. The other tools in ◘ Table 15.1, as well as Deiner's well-regarded *Satisfaction with Life Scale* [30] and Heal's *Life Satisfaction Scale* [31] also use self-perception as an information source for measurement, although perhaps not quite as explicitly. But it might be kept in mind that these tools do not use objective observation of others as primary information sources for measurement.

One of the most internationally used QoL tools for ID populations evolved from the Schalock and Keith [32] *Quality of Life Questionnaire* (now known as *QOL-Q*), developed in the United States. The *QOL-Q*'s eight domains, as listed in ◘ Table 15.1, were expanded from the original four domains (satisfaction, competence/productivity, empowerment/independence, and social belonging) but, like the original, contain 40 items. The eight domains, listed in parentheses here, group within three main factors: (1) Independence (personal development and self-determination), (2) social participation (interpersonal relationships, social inclusion, and rights), and (3) well-being (emotional well-being, physical well-being, and material well-being). Like the original questionnaire, the *QOL-Q* has been extensively tested in a series of population and cross-cultural studies. Core indicators operationally define each QoL domain, and indicator items represent specific items that are used to measure the person's perception ("self-report") or an objective perspective based on the person's life experiences and circumstances ("direct observation"). The *QOL-Q* has been widely applied for a variety of purposes, especially in Schalock's far-reaching work in policy and organizational evaluation, and as such it is useful as a focus point for comparisons of QoL of populations across time and place.

A fourth QoL assessment tool is the *Quality of Life Instrument Package* (QoL-IP; I. [5]), developed in Canada. The QoL-IP features nine domains, organized into three macro-areas: being, belonging, and becoming (as listed in ◘ Table 15.1), each of which features three domains. QOL domain indicators are rated from three perspectives: the person being assessed, others who know that person well, and a trained assessor. Each indicator is assessed in four dimensions: (1) importance, (2) satisfaction, (3) opportunities that the person had/has to develop importance and to perceive satisfaction; and (4) choices that the person could/can make in the same areas. Importance and satisfaction interweave by mathematical formula to produce a basic QoL score, with satisfaction being weighted by importance. This idea had been put forward by a number of scholars in the 1990s, including Becker et al. [33], but was described by Bertelli et al. [34] this way: a thing that is highly important and gives high satisfaction has a considerable positive impact on a person's QoL, while a thing that does not interest a person or is not valued will never add satisfaction or quality to the person's life. Decision-making from choice and the availability of opportunities from which decisions can be made act as moderators to basic QoL scores.

Uses of QoL Scores Based on Shared Life Domains QoL scores based on shared life domains can be appropriately applied to evaluation for groups of people, for services, and for supports and policies that address the needs of large numbers of individuals. They can be used to keep track of progress made by policies and programs over time, where QoL is considered an excellent indicator of progress. In this way, they can be used to evaluate the effectiveness of an organization or system's services and supports over time [35, 36], and thus to assess organizational or system quality improvement [37, 38]. ▣ Table 15.2 provides an integrated approach to quality improvement based on the work of Baker et al. [39], Gomez et al. [40], Lee [41], Reinders and Schalock [42], Schalock and Verdugo [35], Schippers et al. [3], and van Loon et al. [43].

For individuals and families, QOL outcome measures of shared life domains can and should be used as one good source of data for individual and family assessment and developing person-centered and family-centered plans. An area of life that adds quality is one in which a domain is valued in the person's life, and the domain QOL score is high. These areas should be actively maintained, as they contribute quality to the person's life. An area of life that detracts from quality is one in which something is valued in the person's life, but it is scored low on achieving it or satisfaction with it. These areas require attention to eliminate the causes of the problems or to develop strategies to improve them. Individual indicators, too, can be used in a similar way.

▣ **Table 15.2** Quality improvement strategies

Focus	Examples
Individual	Determine QOL-related personal goals Assess individual support needs across QOL domains Use an outcomes focused planning format that aligns personal goals, support needs, and QOL outcome categories Use an ISP format that is user friendly and one developed and implemented by a support team composed of the service recipient, a family member or advocate, direct support staff, relevant professionals, and a supports coordinator Assess QOL domain indicators
Organization	Provide improved access to technology that allows for real time planning/reporting Provide training programs focusing on QOL and its multidimensionality Adjust job descriptions and hiring practices to reflect the QOL framework Evaluate staff as to whether necessary support is given (rather than activities were completed) Change to person-centered planning process Develop policies that promote the use of natural /community supports Base strategic planning efforts on QOL as the aligning construct
System	Develop and launch a web portal for service providers to share ideas that promote QOL for individuals served Train systems-level staff on the importance of QOL and its difference from goal attainment paradigms Provide workshops and conferences that promote a deeper understanding of the QOL concept and its application Conduct strategic planning with QOL as the aligning construct and the strategic driver for organization and system transformation Move toward using QOL outcomes as key performance indicators Fund pilot projects that focus on the key role of the QOL concept in agency change Modify contractual arrangements to reflect QOL assessment and continuous quality improvement

For example, if spending time with friends is a specific indicator of social well-being and this is important to the person, a low QOL rating for this indicator can strongly suggest action should be taken to improve the quantity and quality of time spent with friends.

QoL scores for individuals or families do need to be used judiciously. Often, other factors need to be considered alongside such scores for their use to be effective. For example, at the systems level, a relatively high score on QoL indicators may suggest that policy changes such as increases to income assistance and sustainable funding for communities are unnecessary when in fact such changes might significantly improve the "goodness" of the lives of individuals. At the personal level, a low outcome score might suggest a needed intervention, but that intervention may not be desired by the individual or helpful if it is implemented.

Continuing Work Needed in QoL Measurement Based on Shared Aspects of Life There is still work to be done in QoL measurement, and some examples are provided here:

- Most instruments set out QoL indicators under a number of logical domains, but it is not clear whether the domains identified to date accurately capture QoL as a whole, and the extent to which these domains make unique contributions to overall QoL. For example, the factor scores on importance did not fit clearly into the core domains proposed by current available tools to describe the set of cross-cultural factors that can impact personal well-being [34].
- We are not certain that QoL tools actually measure the whole concept, or whether they simply measure their domains [13].
- Our current tools do not show exactly how people experience QoL. We might assume, however, that people do not typically experience their QoL as divided among separate domains, but rather evaluate how their experiences within these various domains interact with one another and to their whole lives.
- The relationship between QoL measures and those of other closely related concepts, such as self-determination, personal development, and the possibility of choice, needs further exploration [44].
- The distinction between indicators of QoL and factors that cause QoL is not clear in the available literature [2].
- Work might be carried out to organize QoL indicator variables for life as a whole in a hierarchical way, a process that would help us to better define a minimum set of domains with equal variance [2].
- Work needs to be done around including people with disability more meaningfully in designing projects related to QoL measurement and application.
- In numerous countries of the world, there is a superficial understanding of the nature and causes of neurodevelopmental disabilities, autism spectrum disorder, and other disability conditions. Such limited understanding may influence the treatment of people with disabilities and, in turn, influence perceptions of individual and family QoL [45, 46].

Tip

Quality of life measures based on shared aspects of life may be more reliably assessed when more than one measurement tool is used.

Tip

Scores from quality of life indicators that are based on shared aspects of life provide a solid information base for assessing outcomes – the ongoing and lasting effects of a program or an intervention. This should be amended by considering unique aspects of life and the lived experience of individuals and families.

15.6 Relating QOL Measurement to the Lived Experience of Individuals and Families

The *lived experience* of individuals and families is a term used for the reality of people's lives, and understanding lived experience is considered to provide the most important understanding of people with neurodevelopmental disabilities and family life that includes disability [47]. It follows that, for individuals or families with disability, QOL outcome measures based on both unique and shared aspects of life need to be applied within the context of their lived experience.

Lived experience sometimes modifies, or even reverses, the strength of specific QoL outcome measures. For example, some aspects of life may score low on quality, but the person is not unhappy about that or does not necessarily want change. They may also be addressing some positive function that is "working" in the larger context of the person's lived experience. Conversely, some aspects of life may score high on quality, but they are not of particular interest or value to the person, change may be desired for other reasons, or they may contribute little to positive functions. Such considerations stress the importance of the lived experience context, and they suggest that it may not be fruitful to spend time and resources on some QoL improvement interventions suggested by the QoL scores alone.

But real life experience complicates the interpretation of QoL scores even more than this. Individuals and families have a variety of coping strategies that they may or may not use, to tolerate life adversities. Some stressful aspects of life may be tolerated even without such strategies when they are balanced by others that are enjoyable. Some unpleasant aspects of life are temporary and will go away on their own, so it is often a matter of coping temporarily then waiting them out. Some people enjoy a little challenge or chaos in their lives and others do not. There are many other factors relating to lived experience that may affect how QoL outcome measures can be applied effectively. The "art" of helping a person or a family enhance the quality of life involves exploring the various factors that need to be addressed within the context of their lived experience and to determine the most effective ways to address them.

> Since quality of life is experienced by people in the context of their lived experience, quality of life outcome measures need to be interpreted through this lens.

15.6.1 Individual Lived Experience

The unique and shared QoL measures that we might assume affect an individual's QoL are not always reflected in how an individual perceives his or her own life or lived experience. The early research on individual QoL, reported in the 1990s, strongly hinted that this might be the case – QoL scores from individuals with ID and those from trained assessors, support workers, and family members did not correlate well, suggesting a difference in perspective related to differences in lived experience (see [5], for example). The questions that emerged were: how do people with ID perceive their own lives and why do they perceive their lives in those ways?

The work of Cummins and colleagues in Australia provides an intriguing hypothesis. Based on extensive research and analysis, Cummins noted that almost all adults, including those with ID, no matter what their life circumstances may be, rate their own lives as positive but not perfect, typically between 70 and 80 on a scale of 0–100. From this base, Cummins developed his *theory of subjective well-being homeostasis*, meaning that human beings have a genetically generated tendency to look for happiness, satisfaction, and meaning in their lives despite the circumstances, and that their levels of happiness are quite stable across time and across geographic areas [48, 49]. Life satisfaction can go down in difficult times or it can go up in good times – and it fluctuates with temporary emotional highs and lows – but the tendency is to move back toward a stable point. A few years later, Cummins coined the term *set-point of happiness,* which is the point on the scale that ratings of life satisfaction tend to fluctuate around and to which mood returns under normal circumstances [50, 51]. What this suggests for QoL outcome measures is that people with neurodevelopmental disabilities, like all people, are highly likely to be subject to the homeostatic effect and rate their own lives around their set-points of happiness as their life circumstances change. Through extensive research from his *Australian Unity Wellbeing Index,* Cummins and colleagues also reported that three factors particularly influenced people's sense of well-being, which he called the "golden triangle of happiness": satisfaction with income, relationships, and life purpose [52]. These three factors, Cummins maintained, are especially strong in protecting us from ongoing negative mood and moving us homeostatically back to our set-points of happiness.

This hypothesis suggests an amendment to people perceiving their own lives within the context of their own lived experience. It suggests that people both with and without neurodevelopmental disabilities may have a genetically based tendency to return from both high and low emotional levels to their set-points of happiness, using both inherent and learned strategies, and, moreover, that this is a preferred process for humans. What this might mean for QoL is that a measure of quality or the "goodness" of life might best be described as the person's lived experience that has some enjoyable high emotional states, a few low emotional states, and very effective sets of skills both to recognize the effects of fluctuating emotional experiences and to return to the person's set-point in a timely way [53]. Those whose lives cannot be described this way might be thought to reflect lower QoL, especially where there is incapacity to return easily from negative experience to the set-point or incapacity to return at all and thus be mired in negative emotions and experiences.

Another interesting way to look at individual lived experience and QoL is by examining the "disability paradox" coined by Albrecht and Devlieger [54]. This refers to the fact that, when recording subjective well-being, it is often noted that QoL scores of people with intellectual or other disabilities do not differ significantly from those of the general population. This so-called paradox has been explained variously as a psychological mechanism of adaptation, coping, resilience, research methodological bias, or even poor conceptualization of persons with ID. But another explanation is that people with ID perceive their own lives through the lens of their own lived experience since this is the only lens they have, and their perception of their lives is of a higher quality than the perception of others. Simply put, life is experienced by all individuals through their unique sets of perceptions, and because of this subjective well-being may be an essential pathway to understanding "true" personal QoL.

An additional view of lived experience for people with ID is that personal perceptions may differ from other people's perceptions because those with neurodevelopmental disabilities view situations differently. As mentioned briefly in ► Sect. 15.3 above, this often results in non-significant correlations between ratings by people with ID and by proxies. For example, people with ID generally have clear views on what their choices are and what they want to do, while parents appear to respond to the barriers that they believe will inhibit the individual from attaining their wishes. It is therefore important to be aware of the different perspectives [55]. It is appropriate at this point to recognize that what are often referred to as subjective responses are in fact objective in the sense that they are heard and recorded. It is a fact that the statements were made by the two parties. The subjective component is the interpretations that are made of such data [1].

These perspectives on lived experience and QoL shed new light on scores derived from QoL tools. High or low scores (overall scores, domain scores, or indicator scores) may indicate seemingly clear courses of action that may sometimes need to be amended or abandoned when considered in the context of live experience. A challenge for disability professionals is that people with intellectual and other disabilities may not see themselves as needing support as much as others do, and they may not want the types of "improvements" that others assume will benefit them as a result of such support. Another issue that emerged from this is that QoL scores for individuals and families with disability would not be expected to be atypically low, and when they are, as Cummins [48] has pointed out, there is real reason for concern and assistance might well be needed.

Individuals with disabilities very often rate the quality of their own lives differently than others rate their lives. They are probably looking at their own lives through the lens of their abilities and their own lived experience. Moreover, people with disabilities, like all people, may have a natural tendency to "make good" of their particular life situations.

15.6.2 Family Lived Experience

The overriding issue in considering the lived experience of families is that, when parents and siblings find it difficult to deal with the challenges they face, it is not only the child with a disability who is further restricted, but also every member of the family. Families differ, sometimes quite markedly, in their willingness and ability to deal with disability, seek and implement solutions, work with those who can give support, manage their families, and cope with the ever-changing nature of family life. Thus, there is no "typical" or "normal" lived experience for families that have a member with a disability. Yet, like individuals, they have things in common, including set-points of happiness to which they have a tendency to return. Still, it is clear that certain disabilities and mental health problems, especially when difficult behavior is involved, have noticeable impact on the QoL of families (e.g., [56]).

Since the year 2000, family quality of life (FQOL) has been assessed in many countries of the world and in many languages using two main FQOL instruments: the *Family Quality of Life Survey, 2006* [57], and the *Beach Center Family Quality of Life Scale* [58]. These instruments produce FQOL outcome measures similar to those produced from individual QoL measurement. FQOL outcome measures are derived from indicators in identified family life domains such as parenting, family relationships, finances, support from services, support from others, leisure time, and others [7, 28].

Although the more complex family lived experience needs to be understood and taken into account when supporting families, the results from the many studies in FQOL around the world provide a basis for understanding where to begin. In a comparative analysis of 8 and 19 research studies, respectively, I. Brown [59, 60] noted that study respondents in every country rated satisfaction with supports and services as quite low, and as not nearly as important to their QoL as family relationships and values. Other analyses have reported that FQOL scores are lower when family members with ID have behavior disturbances [44], that health and financial challenges compromise QoL for many families, and that support from friends, relatives, and neighbors is low in every country studied [60]. Lack of respite means that many families are unable to take vacations or parents are unable to spend time together. A parent – usually the mother – frequently has to interrupt or stop a career to provide care for a child with a disability. Such results and the substantial general literature about families suggest that families face some major challenges, and that many of these challenges appear to cause exclusion for family members.

In many ways, this is sobering information for professionals supporting families that include a son or daughter with a neurodevelopmental disability. It tells us that much of the real quality in families' lived experience may be derived from things other than the things that those of us in the service industry are addressing. This poses a serious challenge to our services, because a great many families who have children with disabilities do need support, solving practical family and social issues as well as finding adequate intervention for mental health challenges. When additional challenges arise in the broader society (such as the COVID-19 pandemic that began in

2020), there is a considerable increase in family stresses that often result in mental health challenges. At times, FQOL measures may capture this, such as lower ratings of financial, social, or community involvement indicators, but their impact may not be fully reflected by outcome measures alone.

What steps, then, can we take to understand better families' actual lived experience, and to support the aspects of that experience that add to their measured QoL outcomes? Four key steps in this journey are briefly described below.

- *Base our efforts on practical principles embedded in the FQOL approach*. These principles have been described in detail by several authors and are expanded in R. Brown et al. [61]. General principles include, among others: dignity of disability, ethically based policy and practice, personal and professional values, duty of care, risk and safety, normalization, and exclusion/inclusion. Individual and group principles include: resilience, perception, self-image, empowerment, personal control, and intra- and inter-personal variability. Other principles are: holism, lifespan issues, opportunities and choices, and imaging the future [62]. Critical to all these principles is the perception of the individuals involved.
- *Focus on family functioning.* Family QoL research clearly shows that family relationships are very important to families in all countries yet, at times, having a member with an ID is associated with challenges in family functioning. Suggestions for professional services include developing education and support for families around effective parenting styles and family unity strategies. This education and support seems to be particularly effective when families are given opportunities to share information and expertise with each other in an organized peer support model [44]. The need to have opportunities to simply talk about issues that bother a person appears in the qualitative data from virtually all FQOL studies. Understanding and supporting the role of siblings in a family that includes a child with a disability may also be important in supporting the on-going QoL of the entire family [63]. These supports might include sibling support groups, and the meaningful inclusion of siblings in decision making and planning. Beyond siblings, it is important to understand the function of all family members, no matter how minor that might be.
- *Design family-centered supports.* As mentioned, a lack of satisfaction with service support appears as a challenge in all countries where FQOL research has been carried out [44]. Moreover, families have indicated high levels of stress related to interactions with formal disability-related staff and professionals [64]. Some common concerns that have been voiced are a lack of information about available services, difficulties in trust and communication with support providers, and a shortage of provider focus on family functioning and family relationships. An important practical suggestion for disability support workers is to develop supports based on family-centered approaches with the family controlling and contributing to their own support, rather than having plans and programs generated by providers. This approach emphasizes the rights and capabilities of families to direct and participate in their own social welfare experience and may result in more positive FQOL outcomes [65]. In addition, professionals who support families may see benefit from working in partnership with families on an equal basis [66]. Suggestions for providers wishing to build trustworthy, responsive family services include [67]:
  1. Focusing upon improved communication with families, such as sharing information and listening to feedback from families. To have available personnel to undertake such activity in the early stages of increased stress may have important implications for reducing complete breakdown later in the family's life.

2. Providing high levels of professional competence and ensuring disability professionals who are in contact with families are well-trained experts with relevant knowledge and experience. Professionals working with families should be trained in FQOL principles, be able to provide information about disability service and funding options, and be able to assist families in navigating the service landscape.
3. Providing an environment of respect, commitment, equality, and trust. Disability professionals may find a focus on building strong relationships with families beneficial for all involved.

- *Pursue inclusion of families in physical and social communities.* It has been noted that there is often a lack of support from informal sources such as friends, extended family, and neighbors [68, 69]. One way that providers might assist families in making and maintaining social connections and building social support is through family support groups. R. Brown et al. [70] recognized the need for such groups but noted that they need to include trustworthy, safe support for the child with disability and siblings so that family members can relax and have sufficient time to network with other family members. Faragher et al. [71] suggested that formal services may assist families in family support groups by suggesting ways to access the supports they need. For their parts, family members indicated that sharing meetings with others is highly supportive across the lifespan. The initial meetings need to be led by a skilled mediator, though family members will often run later meetings themselves.

Research has also suggested that service providers might become community connectors rather than simply caregivers, empowering families to make the social connections needed to find formal and informal supports [72]. These connections in the community might assist families in finding pathways to information and collective action for service and policy improvement. The enhancement of social connections can also enable the growth of relationships leading to the emotional and practical support that are so important for ensuring the health of the family ([69]; see [73] for further practical approaches).

Tip

Families that include a member with disability often have difficult lived experience. Quality of life outcome measures, especially for people with disabilities living with their families, need to include family quality of life outcome assessment – which needs to be interpreted through the families' lived experience.

15.7 Putting It All Together

Valid QoL outcome measures have been developed and reported for both individual and family QoL. These measures provide evaluation and assessment data for helping individuals and families move toward enhanced QoL, for improving the quality of disability-related services, and for policy and practice accountability. They also provide a strong basis upon which new or amended policy and practice models can be developed. A robust body of research on the QoL of individuals and of families is currently available in the published literature, a body of work that has established the utility of applying QOL outcome measures that are common to individuals and families. The work of Schalock and his numerous colleagues have steadily moved the application of QOL outcome measures to policy and practice forward over the past several years, and this is proving to be very helpful in shaping policies and services that focus on quality outputs and outcomes.

Although future work will offer advances, the considerable knowledge that has been generated to date on QoL as an outcome measure allows us to understand that there are various options for use with people who have neurodevelopmental disabilities or autism spectrum

Table 15.3 Options in using QoL as an outcome measure for people with ID or ASD

Issue	Options
Purpose of using QoL outcome measure	Individual planning Evaluating individual interventions Program planning Program evaluation Policy evaluation
Focus of QoL measurement	Shared QoL Personal QoL Family QoL
Content of QoL measurement tools	Domains/areas (objective assessment) Dimensions (personal appraisal) Indicators (individual objective assessment)
Person whose QoL is being measured	Person with ID (mild to profound) Person with ASD (any degree of support need)
Information source	Individual with ID/ASD Proxies (persons who know the individual well) External assessors
Understanding QoL data and scores	Overall, domain, and indicator scores Subjective and objective data Amendments based on lived experience of individuals and families

Expanded from Bertelli et al. [34]

disorder. Table 15.3 lists the options that have been described in this chapter as they pertain to: the purpose of using QoL as an outcome measure, the focus of the QoL measurement, the content of the measurement tools, the person whose QoL is being measured, the information source, and understanding the QoL data and scores. Together, these options illustrate that a variety of QoL outcome measures may be used in a variety of ways for a variety of purposes.

15.8 Moving Ahead

The development of QoL, both from a conceptual and from a measurement point of view, is not complete. The term *quality of life* itself is a social construct and, as such, its meaning changes over time. QoL conceptualization and outcome measurement will both have to adapt to such changes in meaning. Moreover, we cannot assume that we fully understand the complexity of QoL at the present time, despite its simple surface meaning illustrated by the question, "How good is your life for you?" [5]. But the various combinations of factors that combine to make up a "good" life or a "quality" life at any one time, for any one person or family, is a complexity that we have perhaps only begun to describe. Finally, the task of enhancing QoL for individuals and families by drawing together the outcomes of policy, practice, and people's lived experience – so that they work together toward a common goal – is one that is somewhat daunting but nevertheless an exciting challenge ahead.

We have come a long way since QoL first became a widely recognized concept in the late 1980s. It is now understood to be the overall goal of almost everything we do in the field of neurodevelopmental disability, and it is a commonly stated policy and practice goal in almost every country of the world. As the concept of QoL continues to evolve in the future, its outcome measures will also evolve and, as they do, they show real promise of being useful tools for moving toward our goals.

Key Points

- Quality of life is a social construct that is used to encompass the general notion of the "goodness" of life.
- Outcome measures are measures of ongoing and lasting changes. Quality of life as outcome measures use the scores derived from quality of life indicators

to assess ongoing and lasting changes to the "goodness" of people's lives.

- Two general approaches to attaining scores from quality of life indicators in the human services are: (1) a focus on specific conditions or diseases (health-related quality of life) and (2) a focus on the person's whole life in relation to the environment (whole-person quality of life).
- Numerous tools are available to measure health-related quality of life, and several valid tools have been developed to measure whole-person quality of life for people with intellectual and other neurodevelopmental disabilities.
- The available whole-person tools provide quality of life scores for domains of life that are deemed to be common to, and important to, almost all humans. These quality of life scores can be used as the primary assessment information in determining outcomes (ongoing and lasting changes).
- To make a final determination of outcomes, the primary assessment information obtained from the scores of quality of life tools needs to be amended by: (1) considering life factors that are unique and important to the individual and (2) interpreting the information through the lens of the lived experience of individuals with disabilities and families that have a member with disability.

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