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Assessing the Quality of Life of Persons with Developmental Disabilities: Description of a New Model, Measuring Instruments, and Initial Findings

A conceptual model of quality of life and associated instrumentation for collecting data from persons with developmental disabilities are presented. The conceptual model assumes that the components of quality of life for persons with developmental disabilities are the same as for all persons. Additionally, in recognition of the complexity and importance of quality of life assessments, a multi-method, multi-source approach was developed. Results from a preliminary study provide evidence for the reliability and validity of the instrumentation associated with the model. The meaning of these preliminary results are examined and the issues raised by such assessments are discussed.

The Centre for Health Promotion at the University of Toronto has been developing a model and associated instrumentation for assessing the quality of life of persons with developmental disabilities. The program of research was in response to a perceived need to have quality of life assessments constitute part of an evaluation of a thrust towards community-based service provision to persons with developmental disabilities in the Canadian province of Ontario (Ministry of Community and Social Services, 1987). In Ontario, persons with developmental disabilities are those who possess an intellectual disability and whose adaptive behaviour is such that they require services. The purpose of this article is to describe the model of quality of life which resulted from this research, detail associated instrumentation, and provide initial results from a preliminary investigation of an application of the approach to a group of persons with developmental disabilities.

Background and Quality of Life Model

Since Landesman's (1986) call for an increased emphasis upon the quality of life of persons with developmental disabilities, a number of conceptualisations and measures have been developed (Brown, 1993; Cummins, Polzin,

& Theobald, 1990; Heal & Chadsey-Rusch, 1985; Parmenter, 1992, 1994; Schalock, 1993). Reflecting the increasing importance of quality of life, at least four recent volumes have been devoted to quality of life and disabilities issues (Brown, Bayer, & Brown, 1992; Goode, 1994; Romney, Brown, & Fry, 1994; Schalock, 1990). Nonetheless, our analysis indicated that any one of the available approaches, by itself, was not entirely satisfactory in providing a means of assessing the complexities involved in implementation and evaluation of a provincial thrust towards deinstitutionalisation and provision of quality community-based services.

More specifically, we felt it necessary to develop an approach which would separate quality of life from quality of personal care; make explicit our assumption that degree of disability and/or dependence is separate from quality of life; focus upon the abilities rather than disabilities of individuals; and emphasise the perspective of persons with developmental disabilities. Additionally, we felt it was necessary to carefully outline the assumptions underlying our approach towards quality of life and define the domains of life for which quality assessments would be made. Finally, we felt it necessary to develop a package of instruments which could capture the perspectives of the person with developmental disabilities, service providers, and that of an independent assessor. The last was necessary since we were concerned with being able to determine whether certain agreed upon standards associated with provision of government-funded services were being met.

Principles in model development

We developed our model paying careful attention to important current trends in developmental disabilities, while at the same time closely following a number of principles that we considered central to the concept of quality of life. First, we focused upon the abilities and competencies of persons with developmental disabilities rather than their limitations. Second, we carried out extensive consultative activities during each stage of the development of the model and instruments. Third, we saw individuals as potentially being the best judges of the quality of their own lives. Fourth, we believed that a variety of innovative means would be needed to collect information from individuals whose opinions had infrequently been elicited in the past. Finally, the warnings posted by other researchers (see Heal & Sigelman, 1990; Sigelman et al., 1981; Wyngaarden, 1981) on the difficulties of collecting meaningful data from persons with developmental disabilities reminded us of the need to provide clear evidence of the reliability and validity of our data. The influence of these five principles upon our work is presented in detail elsewhere (Raphael, Renwick, & Brown, 1993; Renwick, Brown, & Raphael, 1994; Woodill, Renwick, Brown, & Raphael, 1994).

Controversies and issues in assessing quality of life

We were also aware of some of the philosophical and practical arguments concerning the nature of reality and how these translate into the development of measures of quality of life (Raphael, in press). This is especially important for the study of persons with developmental disabilities since the strengths and

weaknesses of objective and subjective measures of quality of life become more pronounced when the life satisfaction and circumstances of individuals who may have lived their lives under somewhat limited and highly controlled situations are assessed (Raphael et al., 1993). These issues constantly came up as we met with service providers, parents, and policy-makers during the development process. Our solution to these issues was one of accepting the view that one's own reality is ultimately a personal construction based upon one's specific life circumstances. Similarly, any analysis of results of quality of life assessments were also seen as social constructions requiring shared consensus and agreement among the data users. As a result, we strive to make our assumptions explicit, recognise limitations of our approach, and remain open to viewpoints concerning our model and procedures. These and other issues concerning the assessment of quality of life of persons with developmental disabilities led to our emphasising multiple data types, multiple sources, and development of a bottom-line checklist concerning acceptable standards of living conditions. How these decisions became translated into instrumentation is detailed below.

Another important issue concerns our use of quantitative indices for assessing quality of life. We attempted to address the need for data which could be used in a variety of statistical analyses, be generalised from samples to populations, and be used to evaluate an important provincial social policy thrust. On the other hand, we did not want to force a complex, highly personal concept such as quality of life into an artificial, professionally determined, framework that could be used to maintain the marginal status of persons with developmental disabilities (Woodill, 1992; Woodill et al., 1994) or, in a worse-case scenario, be used to ration services. We attempted, therefore, to devise methods and measures which would allow individuals to tell their own stories, identify their own important life areas, and express personal satisfaction. We also tried to ground our instrumentation in the realities of persons' lives through ongoing and extensive consultation with a range of stakeholder groups including persons with developmental disabilities. One aspect of this was to establish a number of stakeholder advisory groups to assure positive applications of our model and instrumentation.

The conceptual model

The Centre for Health Promotion conceptual model is seen as applicable to all persons, with or without developmental disabilities. It was developed on the basis of an analysis of the literature on quality of life and qualitative data we collected in the context of focus groups and in-depth interviews with persons with and without developmental disabilities (Rootman et al., 1992a, 1992b). Following the preliminary development of the conceptual model, it was tested for relevance and refined by means of rigorous review by adults with and without physical and developmental disabilities, adolescents, and older adults living in the community (Raphael, Brown, Renwick, & Rootman, 1994). In each case, the applicability of these concepts was examined for relevancy for the population, instruments and methods were created, and collection of data

carried out. The model is multidimensional and, like Brown's (1993) approach, assumes that quality of life is holistic in nature.

Our definition of quality of life is: "The degree to which a person enjoys the important possibilities of his/her life" (Raphael et al., 1994). Possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors. Enjoyment has two components: The experience of satisfaction or the possession or achievement of some characteristic, as illustrated by the expression; "She enjoys good health." Three major life domains are identified: *Being*, *Belonging*, and *Becoming*. The conceptualisation of *Being*, *Belonging*, and *Becoming* as the domains of quality of life was developed from the insights of various writers (e.g., Bakan, 1964; Becker, 1971; Rogers, 1961; Sullivan, 1984). Woodill et al. (1994) present the philosophical background to the model.

The *Being* domain includes the basic aspects of "who one is" and has three sub-domains. *Physical Being* includes aspects of physical health, personal hygiene, nutrition, exercise, grooming, clothing, and general physical appearance. *Psychological Being* includes the person's psychological health and adjustment, cognitions, feelings, and evaluations concerning the self, and self-control. *Spiritual Being* reflects personal values, personal standards of conduct, and spiritual beliefs which may or may not be associated with formally organised religions.

Belonging includes the person's fit with his/her environments and also has three sub-domains. *Physical Belonging* is defined as the connections the person has with his/her physical environments such as home, workplace, neighbourhood, school and community. *Social Belonging* includes links with social environments and includes the sense of acceptance by intimate others, family, friends, co-workers, and neighbourhood and community. *Community Belonging* represents access to resources normally available to community members, such as adequate income, health and social services, employment, educational and recreational programs, and community events and activities.

Becoming refers to the purposeful activities carried out to achieve personal goals, hopes, and wishes. *Practical Becoming* describes the day-to-day, purposeful activities a person carries out such as domestic activities, paid work, school or volunteer activities, and seeing to health or social needs. *Leisure Becoming* includes leisure-time activities that promote relaxation and stress reduction. These include short duration activities such as card games, neighbourhood walks, or family visits, or longer duration activities such as vacations or holidays. *Growth Becoming* activities promote the improvement of knowledge and skills.

To describe the quality of life experienced by individuals, we consider the domains and sub-domains along four dimensions: *Importance* of the area of life as perceived by individuals; *Enjoyment* experienced; perceived *Control* in an area; and perceived *Opportunities* for change or enhancement. A *Basic Quality of Life Score* is determined by the interaction between *Importance* and *Enjoyment* scores. In this way, quality of life is adapted to the lives of all humans, at any time, and from their individual perspectives. This sensitivity to the specific life situations of individual people also presents a limitation,

namely that people may express high enjoyment of the important possibilities of their lives within an environment that is of poor quality. This may result from people being unaware that better quality is possible or from people being consciously aware that they have to suppress the importance of some possibilities because of their present circumstances. For example, people living in institutions may consider their quality of life to be good because they have had no opportunities to know other possibilities and have no power to effect change in any case. This suggests that quality of life, as we have determined it, needs to be broadened by including the quality of the environment in which the person lives.

To address this, we consider that a quality environment is one which (a) provides for basic needs to be met (food, shelter, safety, social contact), (b) provides for a range of opportunities within the individual's potential, and (c) provides for personal control and choice within that environment. Thus, people's perceptions concerning how much control they have over the important possibilities of their lives and the extent of their potential opportunities in the areas encompassed by *Being*, *Belonging*, and *Becoming* are important aspects of our conceptual model, that, along with basic care provides the environmental context for understanding the person's quality of life.

Implications for Calculation of Quality of Life Scores. Since our Basic Quality of Life Score results from the enjoyment of areas which are both important and possible for an individual, the importance rating provided by an individual for an area serves as a weight for the interpretation of their enjoyment scores. Very important aspects of a person's life can lead to the person having a very high quality of life score, if they are highly enjoyed, or to a very low quality of life score if they are very dissatisfied. On the other hand, unimportant aspects of an individual's life result in less extreme quality of life scores.

Instrumentation and Measurement

Assessment of quality of life of persons with developmental disabilities is a complex task and is especially important since many aspects of individuals' lives may be affected by policy or programming changes resulting from such assessments. In recognition of this, our approach calls for a number of measures to collect several types of data from a variety of sources. This multi-method, multi-source approach requires spending a full working day with each person, including 90 minutes with a significant other person who knows the person well.

Data collection from the person with developmental disabilities

Table 1 summarises the instruments used to assess quality of life.

Participant Interview. The interview provides a flexible format for gathering people's perceptions of what is important and enjoyed in their lives. Each of the nine sub-domains is broken down into six specific concepts with key questions and possible probes. Information provided is used by the interviewer to make ratings on how important this is to the individual, and how much enjoyment the individual experiences for this concept. These two ratings contribute to Basic Quality of Life Scores.

Table 1. Components of the QOL Instrument Package

Source	Measure	Brief Description of Measure
Person with DD	Participant Interview	Semi-structured interview examining importance given to and participant's enjoyment of 54 life domain concepts
	Self-Ratings	36 item self-report measure of Importance, Enjoyment, Control, and Opportunities
	Who Decides Questionnaire	16 item assessment of control over decision-making in life decisions and daily routines
Close Other	Other Questionnaire	216 item assessment of Importance, Enjoyment, Control, and Opportunities the participant experiences
	Who Decides Questionnaire	16 item assessment of control over participant decision-making in life decisions and daily routines
Assessor	Assessor Checklist	27 item checklist assessing quality of life in various domains

The assessor asks 54 key questions in a conversational manner—six for each of the nine areas of life—and may ask a number of follow-up questions or probes for clarification. The quality of life of each participant comes from his or her unique pattern of responses to the 54 key questions. To illustrate, for Physical Being the six concepts are: physical health, eating a balanced diet, physical mobility, hygiene and body care, personal appearance, and activity level and fitness. The key questions for the first two of the concepts are: Tell me about your health, how you feel? and What food do you usually eat?

Self-Ratings. These questions allow people with developmental disabilities to indicate directly their perceptions of their quality of life. Nine sets of four items (one set for each of the nine sub-domains of quality of life) inquire into the Importance, Enjoyment, Control, and Opportunities reported by the individual. Response formats for Importance and Enjoyment are along a five point continual scale, while the Control and Opportunities components have three categories. To illustrate, for the sub-domain of Physical Being the person with developmental disabilities responds to: Do you care what you look like? (Importance), Do you like the way you look? (Enjoyment), Who decides what clothes you wear? (Control), and If you wanted to, could you look different? (Opportunities).

Who Decides Questionnaire. Participants are asked who makes 16 decisions of daily living. Respondents indicate whether decisions are made by 'Me' if they usually decide by themselves; by 'Both' if they sometimes decide and

person, and from a trained assessor, provide important contextual information within which to interpret data from the person with disabilities. Differences in perceptions among the data sources are an important focus of our continuing work.

Reliability/Validity and Pilot Implementation Study

The purposes of this study were to assess the reliability and validity of the measures in the QOL Instrument Package, develop an implementation strategy for using the instrument, and provide preliminary quality of life data.

Recruiting and training assessors

Assessors with experience working in the field of developmental disabilities were sought through government and local service networks. Eight assessors—seven employed by government centres and one by a local service agency—were selected and successfully completed three days of training. During this time they became familiar with the conceptual framework for the study, learned procedures for collecting data as recorded in an Instrument Manual that accompanies the QOL Instrument Package (Rootman et al., 1993), and practised scoring through a series of simulated data collection situations. To avoid possible halo effects, none of the assessors interviewed any persons with developmental disabilities to whom they had or were currently providing services or who participated in any programs with which the assessor was involved.

Selecting participants and sites

Participants were selected with a view to including the range of persons with developmental disabilities in Ontario in four key areas: various regions of Ontario, both genders, various ages, and four living situations. The participants in this study met these criteria with the additional proviso that they could understand and respond to the demands of the Participant Interview and Self-Ratings Measures. These criteria are seen as describing approximately 85% of the population of persons with developmental disabilities in Ontario.

A stratified random selection procedure identified potential participants in four types of living situations: (a) large congregate care, (b) small congregate care, (c) supported independent living (SIL), and (d) family-based. Within each of these four groups, participants were selected from those receiving services from agencies and facilities within the general areas in which the assessors were employed. All participants were provided with a letter explaining the study and informed consent was obtained from all participants. Quality of life information was collected from 41 participants in five regions of Ontario: Western (15); Mid-Northern (6), Eastern (10), Southwestern (5), and Metropolitan Toronto (5). Sixteen (40%) were women and 25 (60%) were men—there are more men than women in the general developmental disability population—but, even so, women were slightly under-represented here. Participants ranged in age from 18 to 56 years. The average age was 37 years.

Results

We first provide mean Basic Quality of Life Scores (Basic QOL), Control Scores, and Opportunities Scores obtained from our sample. This is followed by evidence concerning reliability and validity of the instruments. Parametric statistical tests were used for all rating scales which yielded interval-level or quasi-interval data.

Means and standard deviations for Basic QOL scores

Mean scores and standard deviations for Basic QOL for four components of the QOL Instrument Package are presented in Table 2. The formula for creating Basic QOL Scores is as follows: $QOL = (Importance\ Score/3) \times (Enjoyment\ Score - 3)$. These enjoyment ratings are weighted by the importance ascribed to each sub-domain by the person with developmental disabilities. This algorithm produces a range of scores from -3.33 (very important areas with very low enjoyment) to +3.33 (very important areas with very high enjoyment), which is then converted to a scale of 0-5 for easier understanding. The absolute meaning of score levels is an area we are continuing to investigate. Based upon logical criteria, however, general interpretations for score ranges have been outlined. These interpretations are based on the assumption that, all things being equal, Basic QOL ratings that fall within the upper part of the rating scale are indicative of better quality of life, and ratings that fall within the lower part are indicative of poorer quality of life. The following interpretations have been outlined: Exemplary >3.62; Very Acceptable 2.87 to 3.61; Adequate 2.12 to 2.86; Problematic 1.37 to 2.11; and Very Problematic <1.37. Further validation work with larger samples will lead to clearer definition of score meanings. In the case of the Assessor Checklist, scores below 4 should be seen as problematic, since this measure focuses on minimal standards of functioning.

Table 2. Basic QOL Scores for Four Parts of the QOL Instrument Package ($n = 41$)

Instrument	QOL Components							
	Being		Belonging		Becoming		Total Score	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Participant Interview	3.18	.26	3.03	.50	2.90	.41	3.05	.38
Participant Self-Ratings	3.69	.84	3.74	.85	3.46	.86	3.64	.76
Other Person Questionnaire	3.26	.57	3.52	.62	3.21	.62	3.35	.53
Assessor Checklist	4.16	1.66	4.42	1.81	3.00	.70	3.86	1.14

Mean scores were in the Adequate and Very Acceptable categories. Individual scores however, did show range such that problem areas were identified for many individuals. Basic QOL Scores provided by the participants' Self-Ratings were consistently higher than scores obtained through the Participant Interview and Other Person Questionnaire. Becoming scores tended to be lower than those of the Being and Belonging areas across

instruments. For the Assessor Checklist, Belonging Scores were the highest and Becoming Scores the lowest. The relatively low score of 3.00 for Becoming—on a 0 to 5 scale where generally a score of at least 4 should be obtained to show that minimal expectations are being met—indicates that this sample scored lower than might be desired on activities related to the Practical, Leisure, and Growth Becoming areas of life.

Control and opportunities

Frequencies for decision-making on the Who Decides Questionnaire suggested that participants considered that they exercised control over their lives, but the scores from the other persons suggested otherwise (Table 3). It appeared that those with developmental disabilities perceived that they made most of the decisions that affect their daily lives, while the close others in their lives perceived that decisions were made by others much more frequently ($\chi^2 = 124.09$, $df = 2$, $p < .001$). A probable reason for this is that caregivers are very often competent at facilitating some degree of choice and control in daily activities. For example, a caregiver may make sure that a facility resident has time to get dressed before or after brushing her teeth, or eat all or part of her breakfast, but not offer total control on whether to get dressed, brush teeth, or eat breakfast. Table 4 provides scores related to Control and Opportunities. These scores support the view that people with developmental disabilities may have less control than they think.

Table 3. Control Source Identified in the Who Decides Questionnaire ($n = 41$)

Data Source	Response Option		
	Me	Both	Other
Person with DD	185	34	17
Other Person	67	67	94

Table 4. Control and Opportunities Scores for Four Parts of the QOL Instrument Package ($n = 41$)

Instrument	Control		Opportunities	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Participant Self-Ratings	3.22	1.04	4.09	.85
Other Person Questionnaire	3.11	.94	3.14	.88
Participant Who Decides?	3.46	.80	–	–
Other Person Who Decides?	2.91	.93	–	–

Reliability of the QOL instrument package

Table 5 outlines the methods of establishing reliability and the associated sample size for each instrument. As part of these analyses, we reviewed item-

total sub-domain relationships and identified items not contributing to domain and sub-domain scores.

Table 5. Methods for Assessing Reliability of the QOL Instrument Package

Source	Measure	Reliability Method	<i>N</i>
Person with DD	Participant Interview	Interjudge agreement	20
		Internal consistency	41
	Self-Ratings	Test-retest	15
		Internal consistency	41
	Who Decides Questionnaire	Test-retest	15
		Internal consistency	41
Other Person	Other Person Questionnaire	Test-retest	15
		Internal consistency	15
		Interjudge agreement	10
	Who Decides Questionnaire	Test-retest	15
		Internal consistency	41
Assessor	Assessor Checklist	Interjudge agreement	20
		Internal consistency	41

Participant Interview. Table 6 presents the results of the interjudge agreement analyses for the overall Importance, Enjoyment, and Basic QOL Scores for the three main domains. The reliability estimates for each sub-domain were of comparable magnitude. At this stage of our work, we were very satisfied with the level of agreement. The findings suggested that the training procedure may need to be lengthened and we are investigating means of raising the reliability of the Basic QOL scores for the Being domain.

Table 6. Interjudge Agreement for Interview Ratings of Persons with Developmental Disabilities ($n = 20$)

QOL Domain	Importance	Enjoyment	Basic QOL
Being	.86	.81	.65
Belonging	.76	.81	.78
Becoming	.92	.88	.85
Total	.91	.86	.88

Table 7 provides the results of the internal consistency analyses of the Participant Interview. Except for the Becoming Composite Enjoyment Scores, coefficients were acceptable ($> .60$). The three components which contributed to the overall Becoming Score appeared to be somewhat independent of each other. Factor analyses of larger data sets will provide further evidence of domain and sub-domain item structure.

Table 7. Internal Consistency for Interview Ratings of Persons with Developmental Disabilities ($n = 41$)

QOL Domain	Importance	Enjoyment	Basic QOL
Being	.86	.79	.84
Belonging	.85	.76	.77
Becoming	.89	.42	.70
Total	.94	.66	.62

Participant Self-Ratings. Reliability assessment of the Self-Ratings was undertaken through two procedures: Ascertaining the degree of absolute agreement in Self-Ratings for the Importance, Enjoyment, Control, and Opportunities Scores, and examining the correlations of scores obtained from two times of testing. Concerning test-retest agreement, 60.5% of the Self-Ratings were identical from test to retest and an additional 28.4% of ratings differed by only one level from test to retest. These results compare favourably with other reported findings with individuals with developmental disabilities (Heal & Sigelman, 1990; Sigelman et al., 1981).

Test-retest correlations (Table 8) indicated that the degree of association from test to retest was marginally acceptable for most Composite Scores, but somewhat problematic for domain scores. This finding may be due to the presence of a limited range of scores provided by individuals with developmental disabilities—assessors reported (see Table 2) that participants generally made high ratings. In response to these findings, we have developed a practice and training procedure to help persons with developmental disabilities feel more comfortable with this procedure. The sad reality is that for many of our participants, they had infrequently, if ever, been asked to indicate their satisfaction with specific aspects of their lives. We expect that with a wider range of persons with developmental disabilities, and with some pre-assessment training on the rating scales, the absolute magnitude of correlations will likely be higher. Internal consistency estimates (not tabled) indicated that the components of quality of life were reliably related to each other in individuals' self-reports. Based on data from 41 individuals, internal consistency estimates for each aspect were Importance .82; Enjoyment .86; Basic QOL .87; Control .76; and Opportunities .75.

Table 8. Test-Retest Coefficients of Self-Ratings of Persons with Developmental Disabilities ($n = 15$)

QOL Domain	Importance	Enjoyment	Basic QOL	Control	Opportunities
Being	.46	.20	.36	.50	.60
Belonging	.47	.48	.51	.54	.67
Becoming	.53	.82	.79	.59	.43
Total	.69	.56	.57	.63	.68

Who Decides Questionnaire. This instrument was completed on two occasions by the person with developmental disabilities and by a close other. Forty-one persons with developmental disabilities completed the questionnaire and internal consistency was .85 with an overall test-retest correlation of .64. The degree of absolute agreement in responses, using a 3-point scale, was a very acceptable 82%. Internal consistency for the Who Decides Questionnaire completed by persons who knew the person with developmental disabilities was .93. A sub-sample of 15 other close persons completed the questionnaire on two occasions. Here, the correlation coefficient was .98 and the degree of absolute agreement in responses was 93%. This is strong evidence of adequate reliability for this questionnaire.

Other Person Questionnaire. Reliability was first examined by comparing the scores of a sub-sample of 15 close others on two administrations. The reliability coefficients from this analysis (Table 9) were very satisfactory. The internal consistency of the Other Person Questionnaire was also very satisfactory (Table 10) with the possible exception of Importance in the Being area. The Other Person Questionnaire was also examined for degree of congruence between the scores of two caregivers who independently completed the items about the same person with developmental disabilities. The results of this analysis, presented in Table 11, indicate that two caregivers' ratings were similar in some areas, but not in others—especially in the Opportunities area. Our training will make clearer the definitions of opportunities as applied in differing settings.

Table 9. Test-Retest Coefficients of Other Person Ratings for Other Person Questionnaire ($n = 15$)

QOL Domain	Importance	Enjoyment	Basic QOL	Control	Opportunities
Being	.87	.84	.80	.91	.90
Belonging	.92	.87	.80	.88	.85
Becoming	.95	.87	.75	.94	.84
Total	.96	.89	.81	.91	.93

Table 10. Internal-Consistency Coefficients for Other Person Ratings ($n = 41$)

QOL Domain	Importance	Enjoyment	Basic QOL	Control	Opportunities
Being	.68	.91	.70	.93	.93
Belonging	.96	.88	.88	.97	.94
Becoming	.94	.88	.87	.96	.93
Total	.97	.96	.94	.93	.95

Table 11. Caregiver Agreement for Other Person Ratings for Other Person Questionnaire ($n = 10$)

QOL Domain	Importance	Enjoyment	Basic QOL	Control	Opportunities
Being	.72	.59	.65	.71	.27
Belonging	.88	.60	.55	.82	.17
Becoming	.91	.80	.72	.76	.01
Total	.77	.65	.55	.65	.23

Assessor checklist

Two assessors completed the questionnaire independently at the end of the assessment period for 20 individuals. The correlation coefficients for the Belonging (.87), Becoming (.81) and Total Composite Scores (.85) were high, and the Being Composite score (.67) was acceptable. Cronbach's alphas for the Assessor Checklist were: Being (.85), Belonging (.74), and Becoming (.68), and Total Composite Score (.83).

Summary of reliability analyses

Overall, the reliability analyses of the QOL Instrument Package were satisfactory. Most parts of the QOL Instrument Package met standards of acceptability for use of measurement instruments and many parts of it exceeded these standards. In cases where levels were marginal or low, training procedures have been revised and definitions made more explicit.

Assessing validity

We addressed validity by: (a) examining the relationships among the Basic QOL Scores from the three sources—participant, other person, and assessor (criterion validity); (b) correlating scores with Schalock's (Schalock, Keith, Hoffman, & Karan, 1989) Quality of Life Questionnaire (criterion and construct validity); and (c) examining differences among persons living within different settings (construct).

Correlation among Basic QOL Scores. The Participant Interview correlated moderately with the Other Person Questionnaire and the Assessor Checklist (Table 12) and provided evidence of criterion validity to the measurement approach. The less than perfect relationship is not problematic as these three parts of the QOL Instrument Package represent three separate perspectives. The Participant Self-Ratings correlated less well with the Assessor Checklist. This appeared to reflect the fact that the participants generally made very high ratings and showed a limited range in making their ratings, but also the fact that they rated aspects of their lives high even when standards of care were less than might be desired. A seemingly puzzling finding is the lack of correlation between the Other Person Questionnaire and the Assessor Checklist. This is less surprising, however, when we consider the primary function of each questionnaire. The Other Person Questionnaire represents other persons' perspectives of how important they think various aspects of life are to persons

with disabilities and the degree of enjoyment they think those persons experience with those aspects of life. The Assessor Checklist, on the other hand, is a measure of whether or not the lives and environments of the persons with disabilities reflect some commonly held expectations of functioning in each of the nine areas. It is quite possible that the others may assess importance and enjoyment using unique standards. Thus, it might be reasonable to expect that the scores for the two questionnaires would not necessarily be correlated. These findings reinforce the need to collect data from multiple sources, since each appears to represent a valid perception of the quality of life of persons with developmental disabilities.

Table 12. Correlation Among Basic QOL Scores from Instrument Package Measures ($n = 41$)

QOL Instrument	Participant Self-Ratings	Other Person Questionnaire	Assessor Checklist
Participant Interview	.38	.62	.56
Participant Self-Ratings	–	.37	.11
Other Person Questionnaire		–	-.02

Correlation of the QOL Instrument Package with the Schalock Measure.

Overall, Schalock Quality of Life score correlated strongly ($n = 41$) with the Participant Interview (.80) and the Participant Self-Ratings (.88), but not with the Other Person Questionnaire (.08) or the Assessor Checklist (.29). This is quite possibly a result of the data collection method. The Schalock Quality of Life Scale, like the Participant Interview and the Participant Self-Ratings, takes the perspective of the person with developmental disabilities and relies on self-report. It is not surprising that the Schalock score does not correlate highly with the perspectives of the other person and the assessors.

If the patterns seen for the correlations among the Quality of Life Instrument Package measures themselves and the Schalock Quality of Life Scale are reliable, it suggests that one portion of overall score variance is shared by the Schalock Quality of Life Scale, the Participant Interview and the Self-Ratings. An additional portion of variance, independent of the Schalock score, is detected and shared by the Other Person Questionnaire and the Participant Interview. The Assessor Checklist shows overlap with both the Participant and the Schalock scale. The small sample size in the present study precluded variance partitioning procedures, but such analyses with larger study groups will shed further light on the nature of these quality of life measurements and their interrelationships.

Differences Among Individuals Living in Different Situations. Participants lived in four types of residences: congregate care within one large ($n = 5$) and one medium-sized ($n = 5$) institution; congregate care within a group home in an urban or semi-urban setting ($n = 11$); supported independent living in small urban and town settings ($n = 10$); and family homes in small urban or town

settings ($n = 10$). Differences in group scores were examined through an analysis of variance followed by Neuman-Keuls multiple comparisons. Overall differences were found among the four living situations on the Overall Basic QOL Score for the Participant Interview ($F(3, 40) = 10.06, p < .001$), and the Other Person Questionnaire ($F(3, 40) = 15.42, p < .001$). Scores for the Control ($F(3, 40) = 6.53, p < .05$) and Opportunities sections of the Other Person Questionnaire ($F(3, 40) = 4.59, p < .05$) also differed among groups, as did the Control scores on the Who Decides Questionnaire when completed by the other person ($F(3, 40) = 5.26, p < .01$).

Neuman-Keuls tests revealed that in each case the supported independent living group scored higher than each of the other three groups for these measures ($p < .05$). (Mean scores are available from the authors.) That these differences were seen, on three different measures, with a small sample size was suggestive and provided evidence of discriminate validity of the indices. One interesting finding here was that there were no reliable differences among the four living groups for the Who Decides Questionnaire as completed by the participants. This adds to the finding, discussed earlier, that persons with developmental disabilities generally perceive that they exercise control in their lives, and in this case, across all four living arrangements.

The only difference between men and women was for the Other Person Questionnaire Basic QOL Scores ($F(1, 40) = 4.89, p < .05$), where females scored higher than males. Differences were not seen between those participants who were older or younger than 35 years. Overall, results of the validity analyses were satisfactory and support the recommendation that the QOL Instrument Package may be useful for collecting quality of life data. The differences among those living in differing settings were seen as especially important.

Conclusion

The goal of the Centre for Health Promotion Quality of Life Project is to develop a new and more thorough approach to assessing the quality of life of persons with developmental disabilities. A QOL Instrument Package containing a number of measures has been developed and a pilot instrumentation study has provided evidence concerning the psychometric properties of the measures. In addition to psychometric validation, the reactions of experienced service providers to the conceptual model and instrument package has been enthusiastic. Currently, an extensive survey and three year follow-up of over 500 persons with developmental disabilities is underway in Ontario, and the QOL Instrument Package is an important component of that study.

We continue to be aware of the need to ground our inquiry in the lives of persons with developmental disabilities. We maintain close contact with many stakeholder groups and constantly strive to assure that use of the approach will serve to help improve the lives of our study participants. Our work is being diffused into the service environment in Ontario through distribution of newsletters and updates, professional presentations, and meetings with stakeholder groups (Centre for Health Promotion, 1995; Raphael et al., 1993; Renwick et al., 1994). The extent to which we are meeting our goals of helping

to improve service quality and thereby enhance the quality of life of persons with developmental disabilities continues to be an important focus of our efforts.

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