Quality of Life:
Its Definition and Measurement

David Felce and Jonathan Perry

Welsh Centre for Learning Disabilities Applied Research Unit, University of Wales
College of Medicine

A model of quality of life is proposed that integrates objective and subjective indicators, a broad range of life domains, and individual values. It takes account of concerns that externally derived norms should not be applied without reference to individual differences. It also allows for objective comparisons to be made between the situations of particular groups and what is normative. Considerable agreement exists that quality of life is multidimensional. Coverage may be categorised within five dimensions: physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity. A research agenda is discussed as are the particular problems caused by difficulties in understanding and communicating.

Quality of life is an elusive concept approachable at varying levels of generality from the assessment of societal or community wellbeing to the specific evaluation of the situations of individuals or groups. Conceptualisation has reflected such variation. Broad social indicators have been used to chart the wellbeing of populations at the aggregate level (Flax, 1972; Liu, 1976; Schneider, 1976). Social and psychological indicators have been developed to reflect individual welfare (Bigelow, McFarland, & Olson, 1991; Bradburn, 1969; Campbell, Converse, & Rodgers, 1976; Heal &

Requests for reprints should be sent to David Felce, Meridian Court, North Road, Cardiff, CF4 3BL, Wales.

This research was conducted under a grant from the Welsh Office/Department of Health. The authors are grateful to Sharon Landesman-Ramey, Robert Cummins, Roy Brown, John Jacobson, and Jim Mansell for comments on an earlier draft.
Operational definitions of quality of life are diverse, with variability fuelled not only by use of societal or individualistic perspectives but also by the range of applicable theoretical models or academic orientations.

Many writing on the subject of quality of life have commented on this diversity. Liu (1976) stated that there were as many quality of life definitions as people, emphasising the axiom that individuals differ in what they find important. Baker and Intagliata (1982) point to there being as many definitions as the number of people studying the phenomenon, a comment that throws the spotlight on the lack of agreement between those attempting to operationalise the concept. In their view, writers had done little up to that point to achieve definitional consistency. A decade later, Cummins, McCabe, Gullone, & Romeo (in press) has echoed this position in observing that not 1 of over 80 quality of life scales identified has achieved a level of acceptance against which other scales can be validated.

Many of these scales, together with other measures of process and outcome, have been developed to evaluate fundamental changes in services that play a major role in the day-to-day lives of people in need of support, such as those with mental retardation, chronic psychiatric morbidity, physical disabilities, or infirmity due to old age. In the field of mental retardation alone, the last three decades have seen the introduction of major policy movements: deinstitutionalisation, investment in early intervention and ongoing family support, integration in schooling, and reform of adult day services. Although policy formulation has followed from our best efforts to pursue fundamental values in the light of knowledge or assumptions about human behaviour, and although evaluation has accompanied the process of change, the impact of these policies on quality of life cannot be wholly substantiated in the absence of an agreed assessment methodology.

The inadequacy of such a situation was recognised by Landesman (1986), who called for a concerted effort to explore the meaning of two concepts, quality of life and life satisfaction, and establish criteria to assess outcome in such terms. In response, a monograph on the subject (Schalock, 1990), together with a number of other relevant books, articles, and chapters have been published in the last 5 years (Borthwick-Duffy, 1992; Brown, 1988; Brown, Bayer, & MacFarlane, 1989; Goode, 1988; Parmenter, 1988). The Schalock (1990) monograph provides a starting point for reviewing the status of research in this field. However, as in many edited texts, synthesis was not achieved across the diverse contributions. The purposes of this article are, therefore, (a) to review the literature concerned with the definition of quality of life, (b) to identify common definitional themes, (c) to construct a model of quality of life based on common ground, and (d) to suggest research that needs to be done to move the field forward.
THE EVOLVING SCOPE OF EVALUATION:
TREATMENT OUTCOME TO QUALITY OF LIFE

The widening scope of evaluation in mental retardation is well illustrated by the evolution of research on residential services. Early research of alternatives to institutional care manifested a traditional treatment effectiveness approach, with effectiveness being equated with developmental gain (Tizard, 1964). Though moves to broaden the lens of evaluative effort were made almost immediately (King, Raynes, & Tizard, 1971), measurement of developmental progress has consistently featured in research on residential services up to the present (Aninger & Bolinsky, 1977; Felce, de Kock, Thomas, & Saxby, 1986; Hemming, Lavender, & Pill, 1981; Lowe, de Paiva, & Felce, 1993; Schroeder & Henes, 1978).

Emerson (1985) criticized the marked reliance researchers have placed on adaptive behaviour gain as an outcome measure and the limited attention given to other indicators, such as user satisfaction (Conroy & Bradley, 1985; Scheerenberger & Felsenthal, 1977), social relationships (de Kock, Saxby, Thomas, & Felce, 1988; Romer & Heller, 1983), or activity patterns (Mansell, Jenkins, Felce, & de Kock, 1984; Sackett & Landesman-Dwyer, 1977). Tizard had recognized that intelligence quotient data had not captured the changes in the quality of regime established in the Brooklands experiment (Tizard, 1964). His collaboration with King and Raynes in the analysis of staff–resident management practices (King et al., 1971) was important in conceptualising quality of care as an independent entity potentially related to but not definitionally the same as service or treatment outcome. Moreover, their attempt to encapsulate quality of regime was paralleled by other emerging environmental assessments reflecting developmental psychology (McLain, Silverstein, Hubbell, & Brownlee, 1977), social psychology (Moos, 1974), behavioural psychology (Risley & Cataldo, 1973), behavioural ecology (Sackett & Landesman-Dwyer, 1977), and normalization (Wolfensberger & Glenn, 1975).

In keeping with this broadening attention to the situations, social processes, activities, and outcomes experienced by people with disabilities, service agencies increasingly incorporated a range of target achievements within their mission statements (DHSS, 1971; Welsh Office, 1983). Maximising developmental growth was frequently cited, but so too were normal patterns of living, maintenance of family ties, development of social relationships, participation in community and civic life, exercise of personal choice, and other characteristics of a typical community lifestyle. Research responded to this emerging demand for multidimensional measurement. For example, several evaluations comparing community and institutional settings (Burchard, Hasazi, Gordon, & Yoe, 1991; Conroy & Bradley, 1985; Felce, 1989; Felce, Kushlick, & Smith, 1980; Lowe & de Paiva, 1991) have
addressed the majority of the following: environmental quality, staffing, staff turnover, staff performance, the use of professional services, developmental progress, resident activity patterns, family and friendship contact, community activities, and family and consumer satisfaction.

However, although evaluation practice has undoubtedly shifted to address issues of quality of life, a comprehensive assessment approach encapsulating its full complexities has not emerged. Although measures that reflect use of the community, social networks, the pursuit of constructive activities, and choice and variety in activity bear on and are important facets of quality of life, they do not constitute a full operationalisation of the concept. In his review, Emerson (1985) concluded that evaluation of personal satisfaction and psychological wellbeing had been seriously neglected and pointed to emerging models in other fields (Andrews & Withey, 1976; Baker & Intagliata, 1982; Campbell et al., 1976).

CONCEPTUAL MODELS OF QUALITY OF LIFE

Borthwick-Duffy (1992) has presented three perspectives on quality of life: (a) quality of life defined as the quality of one's life conditions, (b) quality of life defined as one's satisfaction with life conditions, and (c) quality of life defined as a combination of both life conditions and satisfaction. These and a fourth perspective are illustrated in Figure 1. The latter, which we will argue has advantages over the first three, similarly depicts quality of life as a combination of life conditions and satisfaction but emphasises the need to take account of personal values, aspirations, and expectations.

Landesman's appeal for definition of concepts (Landesman, 1986) suggested that there were two separate phenomena, quality of life and satisfaction with life. One possible model is that depicted in Figure 1a. Quality of life is the sum of a range of objectively measurable life conditions experienced by an individual. These may include physical health, personal circumstances (wealth, living conditions, etc.), social relationships, functional activities and pursuits, and wider societal and economic influences. Subjective response to such conditions is the domain of personal satisfaction with life. One interpretation of this model would follow from the argument that no citizen has the right to satisfaction with life but only the right to life and equality of opportunity. Life conditions may well affect personal satisfaction, but neither this potential relationship nor the subjective appraisal itself is germane to quality of life assessment. General indicators of quality of life may, therefore, be established by the assessment of a variety of life conditions across the population. The quality of life of a particular individual or subgroup would be located by comparing their position to the total population distribution.
Quality of Life defined in terms of Life Conditions

Quality of Life defined in terms of Satisfaction with life

Quality of Life defined as a combination of Life Conditions and Satisfaction

Quality of Life defined as a combination of Life Conditions and Satisfaction weighted by Scale of Importance

FIGURE 1. Conceptualisations of quality of life.

For somewhat different reasons, Edgerton (1990) has also equated quality of life with the conditions under which life is lived. He cautions against there being objective standards by which one can define a decent or reasonable quality of life. Satisfaction with life is described as a separate and ultimately more important criterion of individual welfare.
individual’s personal autonomy to maintain or change their quality of life is a paramount consideration. Such a position is also reflected in the model in Figure 1b.

The formulation in Figure 1a is at odds with the tradition of treating quality of life as the ultimate criterion by which to judge personal welfare. In defining quality of life in terms of life conditions without any subjective interpretation of how the individual perceives and reacts to such conditions, room is left to advance such subjective assessments as personal satisfaction with life as more important. From this perspective, the model in Figure 1b would appear preferable in defining quality of life as synonymous with personal satisfaction. Overall satisfaction with life may reflect satisfaction in a number of life domains: material comforts, health, work, recreation, learning, and creative expression (Flanagan, 1978); living situation, relations with family, social relations, leisure, work, finances, safety, health, and religion (Lehman, 1988); and, marriage, family life, friendships, standard of living, work, neighbourhood, city or town of residence, the state of the nation, housing, education, health, and the self (Campbell, 1981). It may be hypothesised that satisfaction is influenced by external and objectively quantifiable life conditions, and such a model has been tested (Allen, Bentler, & Gutek, 1985).

However, equating quality of life solely with personal satisfaction and treating the latter as a commentary on the acceptability of one’s life conditions is not to be accepted uncritically. Edgerton (1990) comments on the possible independence between life conditions or events and subjective reports of wellbeing. He cites his and others’ research (Costa, McCrae, & Zonderman, 1987; Keogh & Pullis, 1980; Lazarus & Lannier, 1979) to sustain the argument that reports of wellbeing owe more to internal dispositions than to external conditions. Significant life events may induce temporary changes in reports of wellbeing, but regression to a characteristic level will occur in time. Hence, the longitudinal pattern is relatively stable with the best predictor of current satisfaction being its past rating. If this argument is supported, reports of wellbeing may only be sensitive to gross and immediate changes in life conditions and not provide the subtle indicator of quality of life that may be assumed.

Further, the basis for reaching a judgement on satisfaction is comparative; it is impossible to divorce expressions of satisfaction from their context. Thus, a person may be satisfied with his or her wages until he or she discovers that a colleague of equivalent seniority, competence, and responsibilities at work earns significantly more. Such contextual factors may be specific, as in the preceding example, or general, as in the typical circumstances a person has experienced during his or her lifetime and seen experienced by peers. It is tempting to equate high satisfaction with maximised welfare as if it were the expression of preference under the conditions of
free choice, unconstrained opportunity, equality of expectation, and a standard comparative frame of reference. This is clearly not the case; satisfaction is a personal assessment, the frame of reference is personal and affected by experience and the judgement of what is possible and typical for a person in one's situation. Expectations and referents may be set low or high and may themselves change over the life course and in response to personal circumstance. In particular, expressions of satisfaction may adjust to rather than reflect circumstance. Quality of life defined as synonymous with personal satisfaction, without regard to widely different life conditions, is a less appealing formulation when reasonable independence and autonomy of action cannot be assumed.

Clearly, there are some members of society whose independence and autonomy is limited to a great or even atypical degree. Most people with mental retardation lack independence skills, a deficit that constrains their autonomy and frequently results in them inhabiting worlds of other people's construction. The autonomy to maintain or change life conditions in line with subjective appraisal that underpins the primacy of personal satisfaction in the argument advanced by Edgerton earlier may be missing. Moreover, if satisfaction is a measure of comparison, people whose circumstances and options to date may make them particularly prone to having low expectations may be the most likely to report satisfaction in situations that the majority would find intolerable. Edgerton, Bollinger, and Herr (1984), Close and Halpern (1988), and Flynn (1989) have shown that individuals remain philosophical or satisfied about the present and remarkably optimistic about the future, despite the adverse conditions under which they live (including poverty, poor housing, threats to health, threats to safety, victimisation, social isolation, experience of loss, failure to gain or retain employment). Holland (1990) found that expressions of satisfaction failed to differentiate among a range of living environments, from impoverished traditional hospital wards to typical community housing, settings that differed markedly on many objective characteristics. A definition of quality of life that ignores objective assessment of life conditions may, therefore, not provide an adequate safeguard for the best interests of vulnerable and disadvantaged people. Expressions of satisfaction may simply reflect the intractability of conditions commonly experienced by those with limited skills, autonomy, and attachment to the mainstream society and its economy.

Nevertheless, expressions of satisfaction remain expressions of satisfaction, a datum that most commentators agree lies somewhere near the heart of quality of life. Personal appraisals of wellbeing have a validity for which there is no substitute if one person's values are not to be imposed on another. Their accepted importance, tempered by some appreciation of the difficulties inherent in their interpretation, may account for the widespread view that the concept of quality of life must combine both objective and
subjective components (Brown et al., 1989), a view that produces a third formulation (Fig. 1c). Life domains may be assessed objectively by biological, material, social, behavioural, or psychological indicators. Subjective feelings about each area of life may also be reflected in reports of satisfaction and wellbeing. For example, Bigelow et al. (1991) view quality of life as an equation that balances the fulfilment of needs with the meeting of demands, and that involves the subjective assessment of wellbeing together with objective components, such as social functioning. Measures of quality of life in the field of mental retardation have also been constructed to take account of both objective and subjective facets (Schalock, Keith, & Hoffman, 1990). This formulation is sensitive to the individual's own view of his or her life circumstances, while maintaining an independent perspective on those circumstances.

Quality of life has also been defined "as the satisfaction of an individual's values, goals and needs through the actualisation of their abilities or lifestyle" (Emerson, 1985, p. 282). This definition is consistent with the conceptualisation that satisfaction and wellbeing stem from the degree of fit between an individual's perception of their objective situation and their needs or aspirations (Andrews & Withey, 1976; French, Rogers, & Cobb, 1974). The conceptual model put forward by Campbell et al. (1976) exemplifies this approach. Individuals judge their objective situation in each of various life domains according to standards of comparison based on aspirations, expectations, feelings of what would be just, reference group comparisons, personal needs, and personal values. Their resulting evaluation is their satisfaction with that domain. Domain satisfactions combine to produce a general sense of wellbeing. Intraindividual mediators between experience of life and satisfaction with life are also included in models addressing mental health or disability issues. Baker and Intagliata (1982) refer to need levels, beliefs, and attitudes as significant components of the bio-psycho system element of their model. Parmeinter (1988) lists beliefs, goals, values, and aspirations within the self element of his model.

Cummins (1992a) has suggested that quality of life should comprise both objective and subjective assessment and that the manner of combining subjective assessments across separate life domains to produce an overall appraisal should take account of the importance the individual places on the particular aspect being considered. Such a principle could also be applied to objective assessments: The significance attached to objective life conditions might also take account of the individual's scale of values. This formulation gives rise to a three-factor model in which personal values as well as life conditions and life satisfaction interact to determine quality of life (Fig. 1d). The significance of either the objective or subjective assessment of a particular life domain is interpretable only in relation to the importance the individual places on it. For example, size of income (the
objective measure) may contribute little to quality of life for a person whose values are nonmaterialist, although satisfaction with income (e.g., enough to meet personal needs) might still carry a high weight.

Capacity to put an individual weighting on how subjective and objective assessments are combined across life domains is a strength of this model. How to combine objective or subjective appraisals across issues of relevance is not specified in the model depicted in Figure 1c. Measures lacking a basis for ranking the importance that different individuals give to various aspects of their overall situation frequently combine them with equal weighting (Schalock et al., 1990). Alternatively, assumptions about the relative importance of different concerns may be used to generate a weighting structure (Wolfensberger & Glenn, 1975). In both cases, the method of combining items in the overall assessment can be criticized as arbitrary. The use of personal assessments of importance to weight the significance of objective and subjective indices also deals well with the concerns expressed by Edgerton (1990) that only individuals can decide the trade-off between competing aspects of their own personal welfare. Similarly, family goals are central to the model of family functioning put forward by Landesman, Jaccard, and Gunderson (1991). Moreover, as long as a similar model is applied to the assessment of quality of life among the general population, the position of individuals or groups can be judged by comparison to a total population distribution.

Indeed, judging whether a reasonable level of quality of life exists is a separate issue to its measurement. Life conditions and satisfaction with life will inevitably vary, and neither ideal conditions nor perfect satisfaction can be arranged for or achieved by every member of a society or societal subgroup. Aggregated data for a defined group of interest may be compared to those for the total population to establish whether aspects of quality of life are similarly distributed or narrowly clustered either in their favour or to their disadvantage. In other words, cultural norms and ranges may provide a standard of reference. A view that an acceptable quality of life had been achieved could require that both expressed satisfaction with various aspects of life and objective descriptors of those aspects were in keeping with, or at least not inferior to, the typical for the society as a whole. (This argument should not be mistaken as indicating that particular interested parties, such as family members, program professionals, or advocates, with or without disabilities, constitute a sufficient or more significant external reference group for making quality of life judgements.)

Agreement on Relevant Life Domains

Despite disagreement on the definition of quality of life, there is considerable overlap among researchers on relevant domains for assessment.
Fifteen key literature sources that describe conceptual models or operationalisations of quality of life have been reviewed (Fig. 2 footnote). The majority of aspects mentioned in these sources can be grouped under five domain headings (Fig. 2). The figures in parentheses in the following paragraph give the number of the 15 sources that include consideration of the aspect discussed, either in the precise terms adopted in Figure 2 (e.g., material wellbeing, interpersonal relationships) or via a synonym (e.g., standard of living, social relations).

Physical wellbeing is a main heading in the classification put forward by Blunden (1988) and subsumes health (8), fitness (3), and physical safety (4). Material wellbeing is again taken from Blunden (1988) and subsumes finance or income (9), quality of the living environment (12), and privacy, possessions, meals or food, transport, neighbourhood, security, and stability or tenure (variously 3–7). Social wellbeing includes two major dimensions. A strong concern for the quality and breadth of interpersonal relationships is reflected in the relationships a person has within their family or household life (9) and those with relatives in the extended family or with more general friends and acquaintances (14). Community activities (12) and the level of community acceptance or support (4) together reflect a similarly strong concern for community involvement. Development and activity is concerned with the possession and use of skills in relation to both self-determination — competence or independence (10) and choice or control (7) — and the pursuit of functional activities — work (10), leisure (10), housework (4), education (4), and productivity or contribution (5). Emotional wellbeing, affect or mood, satisfaction, or fulfilment was mentioned in 12 of the 15 sources with self-esteem, status/respect, and religious faith also being cited in between 2 and 6.

Although the categorization of domains in Figure 2 is based on a substantial overlap between sources, it is important to emphasize that the number and nature of quality of life domains depicted have not been empirically derived, but pragmatically specified by us, as a means of classifying the content encompassed by the literature. There seems to be considerable agreement that quality of life is a multidimensional concept, but, beyond that, the merits of particular formulations are not known.

An Overall Model of Quality of Life

Figure 3 brings together our categorisation of quality of life domain areas with the three-element model of quality of life discussed earlier and depicted in Figure 1d. Quality of life is defined as an overall general wellbeing that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal
FIGURE 2. Domains relevant to quality of life. Based on: Andrews & Withey (1976); Baker & Intagliata (1982); Bigelow et al. (1991); Blunden (1988); Borthwick-Duffy et al. (1992); Brown & Bayer (1992); Campbell et al. (1976); Cummins (1992a); Flanagan (1978); Franklin, Simmons, Solovitz, Clemens, & Miller (1986); Heal & Chadsey-Rusch (1985); O'Brien (1987); Parmenter (1988); Schalock et al. (1990); Stark and Goldsby (1990).
The three elements are shown in dynamic interaction with each other. Changes in some objective facet of life may change satisfaction or one’s personal values or both. Similarly, changes in values may change satisfaction and precipitate change in some objective circumstance. In the same way, a change in a sense of satisfaction may lead to reappraisal of values and lifestyle.

As well as affecting each other, the three elements are capable of changing independently as a result of external influences. Such external influ-
ences might include genetic, social, and material inheritance, age and maturation, developmental history, employment, peer influences and reference points, and other social, economic, and political variables. As the three elements that define quality of life are all open to external influence, assessment of all three is necessary to any measurement system purporting to capture quality of life. Knowledge of one set cannot predict another because the relationships between them may not remain constant.

A Research Agenda

Reaching a valid definition and measurable operationalisation of the quality of life construct is a central goal. A sustained research effort in three related areas is required before the field can establish the validity of such a multidimensional construct. These involve: (a) the refinement of a measurement technology for the assessment of objective aspects of wellbeing, personal development, and activity; (b) the refinement of a methodology for gaining subjective appraisals of a broad range of personal satisfaction concerns and of the importance an individual places on various lifestyle issues; and (c) research on how to establish whether individuals with conspicuous cognitive limitations and communication deficits consequent on their mental retardation have sufficient receptive and expressive language to discriminate what is being asked and to give answers that reflect their feelings accurately. Allied to this latter effort, for people with mental retardation who clearly cannot speak for themselves, is the need to investigate whether a valid representation of individual concerns and values can be given by anyone other than the subject, or whether only a restricted assessment of quality of life in terms of objective indicators is possible.

Refining objective indicators. Many measures relevant to the five domain areas exist. Borthwick-Duffy (1992) has suggested that multiple methods and informants should be used to determine what relationships exist among variables and whether they provide the basis for a meaningful and valid construct. Our own recent research has followed from a similar idea. Because existing evaluative research has largely restricted the number of measures used to a single approach per aspect evaluated, there is remarkably little information on agreement across different measurement methods. We are, therefore, currently engaged in a project that is using several alternative methods for measuring each of a number of quality aspects in staffed housing services (Perry & Felce, in press). Ratings are concerned with material and social wellbeing, personal development, and activity. Analysis of agreement and disagreement between ostensibly similar measures may help to refine measures and lead to general acceptance of the utility and properties of the resulting methods.
Establishing the social validity of a taxonomy based on the proposed five life domains is an equally important contribution to refining an agreed measurement technology. The adequacy of the scope of the items covered in Figure 2 needs to be examined by research that establishes which indicators of quality of life are frequently mentioned by the general public. The framework may also be checked against the particular concerns and opinions of those people with mental retardation able to speak for themselves. Again, relevant work has already been accomplished. For example, the Audit Commission and the Social Services Inspectorate Wales (in preparation) has identified 42 imperatives distilled from a variety of consultation exercises with users in Wales. These cover many of the life domain areas described earlier: issues of self-determination, choice, and control (11 items); access to community activities and a wider social life (6 items); opportunities for productivity, contribution, and recognition (9 items); and issues concerning social equity, civic rights, and respectful treatment, especially by staff (12 items). (The remaining four items referred to being given help and information.)

Assessment of satisfaction and personal priorities. Initially, focus for the measurement of satisfaction was derived from a relatively restricted assignment to gain the views of service users about changes to residential services (Scheerenberger & Felsenthal, 1977; Seltzer, 1981). More recently, scales have been developed to tap subjects' satisfaction with their lifestyles more generally. However, current examples still only cover a proportion of the domain issues highlighted in Figure 2. The Lifestyle Satisfaction Scale (Heal & Chadsey-Rusch, 1985) contains 29 yes-no items and addresses satisfaction with residence, living arrangements, neighbourhood, friends, the use of leisure time, and generic or professional services. The satisfaction section of the Quality of Life Questionnaire (Schalock et al., 1990) has 10 items rated on a three-point scale: an overall view on life, how much enjoyment respondents derive from it, how well off they are compared to others, whether most events or activities are rewarding or not, their satisfaction with their living arrangements, how well they are treated by neighbours, whether their education prepared them for what they are currently doing, the extent of their problems, whether they feel lonely, and whether they feel out of place in social situations. Subjective appraisal of such concerns as health, emotional wellbeing, material circumstances, productivity, contribution, and self-determination are relatively poorly represented.

Further research is also required on such methodological issues as questionnaire length, questioning style, and response format. Presumably for the purposes of keeping scales short, issues that are addressed in the examples mentioned here are done so by reference to one or at most a few items. However, brevity produces generality if the complexity of such major life
domains as homelife, social life, or work is not to be oversimplified. This makes greater demands on the language abilities of respondents, requiring them both to respond to abstract terms, such as the extent of their problems, and to collate experience relevant to the issue in question and distil a summary position. Such short scales appear, therefore, to ignore the advice of Wyngaarden (1981) to adopt a strategy of avoiding abstract questions. Although individuals may answer abstract questions, their answers may not carry a full understanding or appraisal of what is germane to the abstraction. It would be useful to conduct research in which the answers to a short list of general questions were compared to those answers individuals might make to a more detailed list of more specific and tangible concerns.

Scales also typically employ simple, structured answer formats to facilitate ease of response. Levine (1985) found that people with mild mental retardation had difficulty in responding to a four-point Likert scale; they tended to confuse the two intermediate responses. He therefore simplified the scale to one with only three points. Whereas simple yes-no or three-point structured answers may promote the ability of people with communication deficits to respond at all, there are disadvantages to such designs in that respondents may have a tendency to acquiesce (Sigelman, Budd, Spanhel, & Schoenrock, 1981) or to choose the last of a possible range of responses offered (Sigelman, Budd, Winer, Schoenrock, & Martin, 1982). Shaw and Budd (1982) have indicated that acquiescence may be related to cognitive disability, and this, linked with perceived social desirability, may produce inflated reporting of satisfaction. The use of pictures or simple drawings to denote responses does not reduce the acquiescence problem. Moreover, the adoption of simple response formats underlines the doubts expressed earlier about complex general or abstract questions. The two seem inconsistent with each other.

Qualitative interviewing approaches (Atkinson & Ward, 1987; Flynn, 1989), guided by topic lists but otherwise allowing an open-ended dialogue, have possible advantages in being less prescriptive of the manner of response and by avoiding providing "model" answers. Prescriptions for good interviewing practice in relation to people with mental retardation (Flynn, 1986) show much in common with guidelines for such qualitative research in general (Walker, 1985): emphasising clear, simple questions, patience, and sensitivity on the part of the interviewer; allowance of adequate time for the respondent to answer; and the desirability of checking the veracity of responses against other sources of data. Research is needed on how to construct quantitative assessments of satisfaction from information gained from qualitative interviewing, or at least, on how to take account of more detailed qualitative accounts alongside the use of quantitative scales. However, caution about the veracity of answers given in open-ended dialogue is also indicated by the research of Sigelman and her colleagues.
(Sigelman, Schoenrock et al., 1981). While recognising that closed questioning creates certain validity problems, they concluded that open-ended questions appear to reduce responsiveness and create validity problems of their own (see later). Moreover, methods for controlling interviewer bias or influence in qualitative interviewing are also required, particularly among people susceptible to acquiescence.

Holland's (1990) investigation of service user views confirmed the need to know more about the effects of interview format and style. Given a structured interview with a simple response format, her sample reported almost uniformly high satisfaction irrespective of issue addressed or the considerable differences in residential situation, from small house to large traditional facility. However, a more detailed follow-up of a subsample using qualitative interviewing over several meetings showed that residents could be dissatisfied about major aspects of their situations, such as not liking the other people with whom they lived. Such views were not necessarily expressed in the first interchange; concerns tended to emerge over successive interviews as the relationship between researcher and respondent was said to grow. A closer investigation of the interplay between elicited information and the nature of the relationship established between the interviewer and interviewee is required. In addition, whether and how specific instances of dissatisfaction are reflected in global assessments of satisfaction requires greater understanding.

Ascertaining individuals' personal values, that is, reaching a view of how important a particular issue is to a person within the wider scheme of things, may call for even greater cognitive abilities than the expression of satisfaction, because the former involves ranking of relative values and the latter merely the assignment of a value to a single issue. How difficult a task this is and the methodological development required are subjects for further investigation. Cummins (1992a) has constructed a scale that asks respondents not only to indicate their satisfaction in a number of life domains but also to rank the degree to which the life domain issue is important to them. He uses visual analogue Likert scales for both purposes and has embedded practical tests within the assessment protocol to check that the respondent's discriminative ability is on a par with the complexity of the scales used.

Ascertaining individuals' personal values, that is, reaching a view of how important a particular issue is to a person within the wider scheme of things, may call for even greater cognitive abilities than the expression of satisfaction, because the former involves ranking of relative values and the latter merely the assignment of a value to a single issue. How difficult a task this is and the methodological development required are subjects for further investigation. Cummins (1992a) has constructed a scale that asks respondents not only to indicate their satisfaction in a number of life domains but also to rank the degree to which the life domain issue is important to them. He uses visual analogue Likert scales for both purposes and has embedded practical tests within the assessment protocol to check that the respondent's discriminative ability is on a par with the complexity of the scales used.

**From whom is it possible to gain personal views?** There is a tremendous range in cognitive and communicative competency among people labelled as having mental retardation. At one end of the spectrum are people who have virtually no understanding of spoken or signed language and no means of expression. At the other are people who have language approaching that of people not so labelled. Much is known about the interaction between degree of mental retardation and the level of a person's language...
ability from research on receptive and expressive language and the development of adaptive behavior scale norms. What this research implies for the content and format of questioning will enable the field to determine what proportion of people can register what complexity of opinion under what conditions.

Detailed qualitative accounts have been obtained from people with mental retardation, most of whom were able enough to live largely independently (Edgerton et al., 1984; Flynn, 1989). Information is also available on respondents in quantitative studies. The abilities of participants in the study by Heal and Chadsey-Rusch (1985) were described in terms of intelligence quotients taken from people's files, one group ranging from 22 to 72 with a mean of 47 and the other from 47 to 97 with a mean of 64. These data are unsatisfactory, but, if taken at face value, they do illustrate the tendency for respondents in these studies to have moderate or mild mental retardation, or even intelligence outside the range for inclusion. Even so, acquiescence bias, which was deliberately accounted for within their study, was significantly above zero. It is not possible to see the extent to which acquiescence was attributable to those with moderate and severe disabilities within the sample.

The series of studies summarised in Sigelman, Schoenrock et al. (1981) addressed four questions: (a) to what extent can people with mental retardation respond to questions, regardless of truth or accuracy; (b) how consistent are such answers over time; (c) how valid and free of systematic bias are such answers; and (d) what types of question optimise responsiveness, reliability, and validity? Questions used a variety of yes-no, picture choice, either-or, verbal multiple choice, and open-ended formats. They found that some people with severe mental retardation and the great majority of people with profound mental retardation were unable to respond at all. The proportion of questions that children and adults with severe, moderate, or mild mental retardation answered were, respectively: 46.1% and 58.5%, 84.8% and 78.0%, and 90.9% and 73.5%. Unpredictability of responsiveness increased with severity of disability. However, higher rates of responding were obtained among children with severe mental retardation in a later study (78.7%) by using repetition to facilitate understanding and by restricting question types to those most likely to be answered (picture choice and yes-no formats).

Obtaining an answer is a necessary but not sufficient condition of sound interviewing. The Sigelman group's second and third questions (Sigelman, Schoenrock et al., 1981) related to consistency and validity of answers. They found that, for those who could respond, 85.2% of answers were consistent across similar repeated questions requiring yes-no responses, and 71.9% were consistent across repeated three- or four-answer multiple choice formats. Only 46.2% consistency was found for a four-choice picture format (smiling or frowning faces) to indicate how respondents felt
about aspects of residential life. Eight open-ended questions were also investigated. Roughly two-thirds responded to four factual questions about themselves (e.g., name, birthday) but achieved only 63.3%, 42.9%, 63.6%, and 61.9% consistency across repeated answers to each. The remaining four were factual but required descriptive answers (e.g., variety of social or leisure activities undertaken). Consistency was checked in terms of whether possible categories of activity were or were not mentioned in successive interviews. High consistency (83.9%) was found overall, but this was mainly attributable to possibilities not being mentioned. Consistency about what did occur was found to be much lower, for example, only 18.1% of respondents consistently mentioned an activity undertaken both times. The researchers concluded that open-ended questions calling for descriptive listing of activities or experiences yield little information, because many people with mental retardation are unable to respond at all, and those who do say very little.

Validity of answers was examined by comparing responses across alternatively worded questions designed to elicit similar information and by gaining reports from third parties, neither of which are completely satisfactory approaches to checking veracity. As previously noted, their research revealed that the tendency to acquiesce is a significant problem. Across a variety of questions, about half of the samples studied answered yes where the answer no was indicated either from the answer to an oppositely worded question or from known fact. Problems of acquiescence were found to be significantly inversely associated with intelligence, indicating that the majority of people with severe mental retardation will provide affirmative answers irrespective of question content. Agreement between respondents and care staff was found to be mixed, with some good agreement on yes-no questions about commonly occurring activities (e.g., watching television) but poor agreement on yes-no questions relating to less commonly performed activities or on questions using multiple-choice formats. Agreement was rare between respondent and staff answers to open-ended questions.

The findings noted here illustrate the difficulties that confront those wishing to gain valid and reliable information from people with mental retardation about complex issues. Research, whether qualitative or quantitative, must not only report results but also the checks incorporated within it to check for consistency and validity. Cummins (1992a) has constructed practical tests to ascertain whether respondents can make size or order discriminations that match the level of complexity of the Likert scales used. For example, for a five-point scale, he ascertains whether an individual can order five different sized blocks by length. Failure to do so would bring into question the person's response to a pictorial scale on the basis that the more concrete task is easier than one that involves symbolic interpretation. He then proceeds to test for use of an abstract scale against known preferences. This
seems a line of methodological rigour well worth further development. Cummins (1992b) reports preliminary indications from a study specifically addressing the level of intellectual functioning required to use his scale that the dividing line between those capable of responding from those not appears to be about the middle of the moderate level of mental retardation.

The lack of language ability among a substantial percentage of people with mental retardation means that it will not be possible to get accurate views from them on their satisfaction with life or on the importance they assign to various life domain issues. It may prove that other people can accurately reflect an individual's opinions and feelings, or it may be the case that quality of life assessment in such situations must be restricted to objectively measurable phenomena, interpreted via norms and ranges relating to the general population. In the absence of being able to gain information directly from the person with mental retardation, the perspectives of others have been taken, principally of the most immediate family or other carers (Schalock et al., 1990). However, the existing literature on how well third parties represent the views of individuals is not encouraging (Cummins, 1992a). On the assumption that some third parties might do so better than others, Cummins (1992a) has suggested that research could address the question of whether there are certain characteristics of third parties that might discriminate whether they were a good source of testimony. In relation to people with mental retardation who can speak for themselves reliably, such research could measure the personal characteristics of third parties and establish which predicted a good match between third party views and those of the individual themselves. Characteristics explored could include relationship to the person (e.g., relative, friend, service worker), role in relation to the person (e.g., carer, peer, advocate), gender (same, different), age (e.g., same age, 10 years different, 20 years different), length of association with the person (e.g., all individual's life through to recent meeting), frequency of current contact (e.g., frequent, moderate, occasional), and extent of current shared experience (e.g., with or without mental retardation, user of same services or not, similar activity pursuits or not).

CONCLUSION

In conclusion, a model of quality of life is proposed that integrates objective and subjective indicators, collectively reflecting a broad range of life domains, through an individual ranking of the relative importance of each domain. This model accommodates both concerns that objective data should not be interpreted without reference to personal autonomy and preferences and concerns that expressions of satisfaction are themselves relative to the individual's temperament and the circumstances and experiences that have shaped their frame of reference. Although in the proposed model
individuals may weight certain life conditions as less important than others, the objective assessment of those life conditions is still a part of the overall assessment and may be compared to those typically experienced. Considerable agreement among writers on this topic in the disability field exists on how to categorise life domains relevant to the conceptualisation of quality of life.

The conceptualisation offered is based on literature concerning the measurement of quality of life in the general population as well as for disability groups. Cummins (1992b) has argued that one of the characteristics of a good quality of life measure is that it will enable comparison between groups of people irrespective of their precise characteristics. In particular, measures of quality of life for people without disabilities should be equally applicable to people with disabilities, and vice versa, thus allowing comparison of the quality of life of people with disabilities to that of the general population. The five domains used in this article to categorise the content areas relevant to quality of life are all of a general nature, and this is desirable from the perspective of developing a quality of life measurement system with broad utility. However, it would be wise not to assume that such broad utility follows simply from the seeming general applicability of items to a wide range of people. Rather, the development of quality of life measures for people with disabilities should go hand in hand with and parallel measures of quality of life for the general population (see Cummins, 1992a, 1992c).

The development of a common approach to quality of life applicable across societal groups and to the total population is vital if information regarding one section of society is to be interpreted with confidence. Problems in inferring what alternative quality of life might be reasonable in the individual case are compounded by the fact that life conditions and satisfaction with life inevitably vary across individuals in all groups within society. However, aggregated data for a defined group of interest, compared to the statistical distribution for the population as a whole, can be used to reflect whether life conditions and satisfaction in various domains are typical of the general pattern or have a significantly different profile. Social policy may then respond to conspicuous inequality.

Finally, we have outlined some of the research steps that will contribute to the proposed multielement approach to the quality of life construct. Although we agree that continued conceptual and methodological development is important, we also recognise that such is the extent of social inequality, inferior opportunities, and disadvantaged circumstances experienced by people with mental retardation that existing research tools may very well adequately assess whether success accompanies our efforts to bring about beneficial change. Perhaps the most important implication of the current state of conceptualisation of quality of life is that it sets a broad
agenda. Research and service development targeted on a narrowly defined range of outcomes will inevitably fail to improve other issues of considerable significance in people's lives. The strength of that significance is a matter of individual weighting, a fact that directs researchers and service developers toward an even closer alliance with people with disabilities in order to respond to their interests, preferences, and concerns. However, cognitive and language limitations are real. A rational approach needs to be taken to the gaining of user views and, where this is not possible, to the investigation of the validity of third party opinions. The interpretation of objective data on quality of life against societal norms may provide a sound, if limited, approach in many cases.

REFERENCES


Quality of Life


