family ADVOCACY

PO Box 502
Epping NSW 1710

305/16-18 Cambridge St
Epping NSW 2121

Phone: (02) 9869 0866
Facsimile: (02) 9869 0722

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Author: Parmenter, Trevor

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Abstract

Trevor Parmenter of the Unit for Rehabilitation Studies at Macquarie University fears that the term "quality of life", along with "normalisation" and "least restrictive alternative" to name just two others, has lost its essential meaning and become a superficial descriptive to suit professional and political purposes rather than helping people with disabilities achieve a better quality of life. Parmenter examines research into the theory of quality of life, the various theoretical models based on quality of life and whether quality of life can actually be validly assessed. While there are many problems which the article touches on, Parmenter is hopeful that the quality of life of people with disability will, in future, be viewed more from an individualised perspective than from a bureaucrat's predetermined notion. **Keyword: Individualisation**

Quality of Life of People with Developmental Disabilities

TREVOR R. PARMENTER

UNIT FOR REHABILITATION STUDIES
SCHOOL OF EDUCATION
MACQUARIE UNIVERSITY
NEW SOUTH WALES 2109, AUSTRALIA

I. INTRODUCTION

The study of quality of life of people with a developmental disability has its roots in the philosophical, economic, social, and political forces that have shaped the delivery of services to that group of citizens. This article, in providing a review of the various approaches that have been made in exploring the quality of life of people with developmental disabilities, analyzes the role these forces have played in the development of the concept. In particular, this article seeks to clarify whether, in Edgerton's (1990) terms, quality of life is "the challenge—or the shibboleth—of the 1990s," or are we replacing, in Goode's (1991) words, "the tyranny of normal" with the "tyranny of quality"?

The concept of "quality of life" is deeply personal although, along with other terms that have become catchwords in the field of disability, it is becoming bureaucratized to such an extent that it may be losing much of the richness of its meaning. To some it embraces the notion of liberating people with disabilities from oppressive restraints, both physical and psychological, that have limited their opportunities for active participation in a community. To others, it is an index to assist in the scrutiny of health and welfare budgets where value judgments are made regarding the relative quality or worth of one individual's life compared with another's (Richardson, 1991).

We are faced with the problem, possibly not restricted to the disability field, of having terms and concepts that have emerged as a result of philosophical debate losing their intrinsic meaning as we search to operationalize them and have them articulated into public policies. Sadly, quality of life may be following in the

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radition of "normalization," "self-determination," "independent living," community adjustment," and "least restrictive alternative," the essential meanings of which are being replaced by a superficiality of thinking that serves, in Goode's (1991) terms, "rhetorical, political and professional purposes, but does) not help people with disabilities achieve a better quality of life" (p. 5).

It has long been recognized that philosophical, economic, and social forces ave possibly had a much greater impact on policies that have affected the elivery of services to people with disabilities than has patient and detailed esearch (Baumeister, 1981; Emerson, 1985; Landesman & Butterfield, 1987; armenter, 1991). It is to the research community, however, that policy planners ook for tools that might measure the effectiveness of their policies. But without irst making a detailed examination of the premises on which the philosophies are rounded, researchers may find themselves trapped into a process that aids and bets the aims of the various pressure groups that abound in the welfare field.

This article examines the approaches that have been made to researching uality of life in areas not specifically related to developmental disabilities, to stablish the generic bases from which much of the current work in developmenal disabilities is proceeding. Next, an analysis is made of various theoretical nodels of quality of life that have been provided in the field of developmental isabilities, together with research that has emerged partly as a result of this nodel building. Related issues concerning the problems associated with meaurement and the more philosophical debate of whether quality of life can be alidly assessed are explored. Finally, predictions and recommendations are nade concerning the future conceptual and practical problems that must be ddressed for us to capture the essential meaning of quality of life as it relates to he lives of those with a developmental disability.

II. APPROACHES TO THE CONCEPTUALIZATION OF QUALITY OF LIFE

Although the history of the conceptualization of quality of life for people with levelopmental disabilities is relatively short (Schalock, 1990b), attempts in other lomains have a much longer background. For instance, Thorndike (1939) was ne of the first scientists to study the quality of life of American cities. In this radition social indicators, usually environmentally based, were used to provide n empirically based perspective of the collective quality of community life. The rea of gerontology also has a long tradition of exploring the well-being and life atisfaction of people who are elderly (Adams, 1941; Edwards & Klemmack, 973; Riley & Foner, 1968; Spreitzer & Snyder, 1974).

Other health-related areas that have been explored in terms of quality-of-life ssues include closed head injury (Klonoff, Snow, & Costa, 1986), mental illness (Dickey, Gudeman, Hillman, Donatelle, & Grimspoon, 1981; Lehman, 1983), intensive care (Ridley & Wallace, 1990), mobility (Hirst, 1989; Ramund & Stenssman, 1988), postcardiovascular therapies (Wegner, Mattson, & Furberg, 1984), chronic illnesses (Gill, 1984), health indices (Cadman & Goldsmith, 1986; Williams, 1979), and end-stage renal failure (Morris & Jones, 1989).

A relatively recent development by health economists is the use of cost utility analysis as a means of quantifying the relative benefits of medical procedures. With a cost-effectiveness analysis approach, medical outputs were equated with the number of lives or life-years saved. Thus, a redistribution of funds to projects with a low cost per life was seen as a means of increasing the total number of life-years that may be gained (Drummond, 1981). A major weakness of the cost-effective analysis approach was that it treated all life-years as having equal value no matter what the quality of life (Richardson, 1991). This has raised obvious ethical issues, especially in the treatment of neonates with severe abnormalities (Zaner, 1986).

Perceived weaknesses in the cost-effective analysis approach have led to the development of the concept of quality-of-life adjusted years (QALYs), (Williams, 1979, 1985). The essence of a QALY is that it assumes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life expectancy as less than 1. As Lee and Miller (1990) have pointed out, in essence, QALYs measure the cost effectiveness of specific medical interventions for decision making at a macro or micro level.

Not unexpectedly there is growing criticism of the QALY approach to health care (see Brahams, 1991; Carr-Hill, 1989; Harris, 1987; Loomes & McKenzie, 1989; Rowles, 1989). Loomes and McKenzies' view that support for QALY is based on its simplicity as a tool for resolving complex choices possibly sums up the opposition very well. Harris, too, took issue with the concept, arguing that QALYs fallaciously value time lived, instead of individual lives; they take an excessively narrow view of what quality of life might be and, finally, they are unjust.

Now, although much of the thrust of the work of health economists in this field may not directly impinge on our discussion of the quality of life of people with developmental disabilities, it possibly has a pervasive effect on the way decisions are made regarding resource allocation to devalued groups in society. Various approaches have been adopted in reviewing the concept and measurement of quality of life, one of the most comprehensive being that by Goode (1988a), who suggested a scheme containing seven major categories: social (community and individual), life domains, life events, psychological/psychosocial, overall quality of life, and outcome behaviors. Others (e.g., Brown, Bayer, & MacFarlane, 1989; Dossa, 1989) have classified studies into objective, subjective, and combined measures. A third approach, adapted by Schalock (1990b), has classified studies into either social science or disability categories. The former has been

subdivided into what are basically objective measures (social indicators) and subjective measures (psychological indicators). A third subdivision, described as goodness of fit/social policy, reflects the combined approach mentioned above.

From the disability perspective Schalock has been guided by U.S. legislative goals for people with disabilities, namely, independence, productivity, and community integration, goals not dissimilar to those advocated by Grimes (1985) in the Australian context. Although this issue will be raised later, it is interesting to note the effects legislative forces are having on the way quality of life of people with disabilities is being perceived in some countries. Bowles (1988a) has suggested that quality of life is metatheoretical by nature as it cannot be measured directly but must be assessed or measured indirectly through a series of "filters" or indicators.

A. Social Indicators

Objective measures of social indicators have been supported on the basis that they provide a scientific and systematic approach to the study of quality of life. Such measures, Lippman (1976) has suggested, provide a set of indicators that can be applied to community settings, both locally and cross-culturally; however, indicators such as income, marital status, race, and sex have demonstrated only a low to moderate relationship with self-assessments of well-being, life satisfaction, and life quality. On the other hand, Rodgers and Converse (1975) have argued that objective measures, being valid and reliable, are preferable to self-assessments as conditions can be better or worse irrespective of personal opinion. Schneider (1975), however, suggested that these should not be used independently of subjective measures. This view was supported by Lewis and Ryan (1986) who observed that there was little relationship between objective social indicators of the environment and subjective indicators of quality of life.

Ingelhart and Robier (1986), discussing their study of the relationship between objective and subjective indicators for the United States and eight West European countries, termed the weak relationship between objective living conditions and subjective well-being "the paradox of minimum intergroup variation." In a careful analysis of Ingelhart and Robier's findings, Bowles (1988a) cited the work of Zapf (1987), who pointed out that individuals are often under social pressure to suppress feelings of dissatisfaction and that expectations usually adjust to circumstances. In addition, those living under favorable conditions are more likely to be open to new value standards and are, therefore, more likely to express criticism and dissatisfaction. Schneider (1975) further criticized the prevalent tendency for objective measures to be overgeneralized to the extent that objective patterns are equated with differences in life experiences. For example, Campbell (1981) in comparing the well-being of groups found that only 20% of the difference could be attributed to objective measures.

B. Psychological Indicators

Within this classification one may include factors that reflect an individual's affective dimension, including how a person feels and experiences life. Here Rodgers and Converse (1975) have made a distinction between happiness (an affective component) and satisfaction (a cognitive component). Likewise, Zautra and Goodhart (1979) have pointed out that happiness is a short-term emotional state in contrast to satisfaction, which is more cognitively determined. Satisfaction with a particular state is evaluated in contrast to some external standard of comparison, related in relation to positive or negative effect.

More recently, Zautra and Reich (1983) have proposed a two-factor approach to life events and perceptions of life quality, from an analysis of the effects of positive and negative events on psychiatric distress. They concluded that (1) positive events produce positive affective states but not negative ones, and (2) negative events influence negative states but not positive ones.

A further psychological perspective is a person's perception of well-being. Here the pioneering work of Flanagan (1978, 1982) is relevant. Flanagan derived a list of 15 factors that define a person's quality of life from more than 6500 critical incidences collected from nearly 3000 people of various ages, races, backgrounds representing all of the United States. A wide variety of questions were used, for example:

> Think of the last time you did something very important to you or had an experience that was especially satisfying to you. What did you do or what happened that was so satisfying to you? Why did this experience seem so important or satisfying? (Flanagan, 1978, p. 138).

Flanagan subsequently grouped these 15 quality-of-life components into five general dimensions: physical and material well-being; relations with other people; social, community, and civic activities; personal development and fulfillment; and recreation.

An analysis of the responses for the 50- and 70-year-olds in the sample of their overall rating of the quality of life and his or her reports as to how well needs and wants were being met in each of the 15 areas revealed that the six areas showing the largest correlation coefficients with overall quality of life were material comforts, health, work, active recreation, learning, and creative experience.

It is important to note that large-scale studies such as these may obscure an individual's quality-of-life status. For instance, Flanagan suggested that "the effects on each individual's quality of life should be evaluated in terms of his or her personal values and needs rather than those that some central national authority believes all people have or should have" (p. 146). This observation is particularly relevant for countries such as Australia where legislative and bureaucratic forces are setting the national agenda in disability services (Parmenter, 1991).

As indicated above in the work of Zautra and Reich (1983) and Zautra (1983),

there are relationships between a person's perception of well-being and specific life events, such as moving house, death of a loved one, a new job, and divorce. The pioneering work of Holmes and Rahe (1967) tested the hypothesis that adverse events precede and contribute to the onset of illness. Later research extended this hypothesis to the field of mental health, principally neurosis and depression (Dohrenwend, 1973; Dohrenwend & Dohrenwend, 1978). Canadian (Atkinson, 1977) and Australian (Headey, Holmstrom, & Wearing, 1984) studies have also shown some statistically significant relationships between life events scores and changes in well-being.

A critical observation by Headey et al. (1984) was that the way people react to life events or the way they perceive life events are possibly as much influenced by their personalities, personal resources, and adaptive styles as the nature of the events themselves. There is, therefore, a need to examine the interactions between events and personal resources.

A criticism made of some approaches to the assessment of quality of life is that they do not examine it over time (Headey et al., 1984). Longitudinal studies of components of the past, the present, and the future need to be made to measure temporal changes in attitude (Hall, 1976). For instance, Dalkey, Lewis, and Snyder (1972) suggested that time can be broken down into a sequence of life events that can be categorized into properties or qualities (e.g., sociality, freedom, novelty) that can be scaled. Ratings in terms of behavioral adjustment as well as psychological growth can then be made of major events in a person's life.

C. Criticisms of Psychological Indicators

Although psychological indicators have a plausible prime facie case for giving valid assessments of a person's quality of life, Andrews (1974) has nevertheless drawn our attention to at least four criticisms of this approach. First, validity may be questioned as answers to surveys either vary over time or are biased. People may not have given much thought to their quality of life and, therefore, cannot answer questions about it. A second limitation may lie in the area of the interpretation of the subjective results. Comparisons across groups may not be possible as criteria may change over time. Third, a concern has been expressed about the completeness of the information, and finally there is the problem of utility. For instance, at a policy level the data, which are costly to obtain, may be ignored as the relationship between individual satisfaction and societal welfare is not yet clearly determined.

Zautra and Goodhart (1979) have also raised a number of validity problems that may weaken the use of these indicators. For example, scores may be inflated because a person's responses are skewed toward socially desirable factors. A second concern is that measures of feeling states may be simply indicating idiosyncratic ratings of satisfaction and happiness at a particular point in time. A

final caveat is that psychological indicators may not be a good reflection of the realities of external conditions; however, as will be discussed later, these reservations are a clear indication that quality of life is a multidimensional concept that may need a variety of indices to capture its intrinsic meaning.

D. Person–Environment Fit

The person–environment fit or goodness-of-fit proposed by Murrell and Norris (1983) defined quality of life as the criterion for establishing the goodness-of-fit between the person and his or her environment and, in one sense, represents a marriage between objective and subjective indicators of quality of life. Murrell and Norris proposed that the human unit (individual, family, community) may be exposed to stressors (negative life events such as divorce, retirement, illness) within the community that lead to trauma. The provision of resources, such as interpersonal resources and direct services, not only acts as a buffer and protection for the human unit, but may also provide opportunities for growth and advancement. As Schalock (1990a) has pointed out, a central assumption of this model is that the quality of life of a person is a function of the discrepancy between resources and stressors. Likewise, Brown, Bayer, and MacFarlane (1988) have defined quality of life "as the discrepancy between a person's achieved and their unmet needs and desires. The larger the gap between what people have and what they need and want, the poorer their quality of life" (pp. 111–112).

Schalock (1990b) has pointed out that the Murrell–Norris model "conceptualizes quality of life as both an outcome from human service programs (application of additional resources should improve a person's QOL) and the criterion for establishing the goodness-of-fit between a population and its environment. Thus, the better the fit, the higher a person's QOL" (p. 144). Schalock has therefore identified quality of life as an instrument of social policy, but will we ultimately see quality of life perceived in terms similar to the way Brown et al. (1989) have described normalization in Canada, as "a philosophy without an appropriate and functional technology" (p. 67)?

The person–environment fit approach is a striking reflection of the ecological approach that is increasingly shaping disability policies. In the field of rehabilitation, formerly dominated by medical and psychological models, there is a shift from an emphasis on the individual to a concern with the wider social system (Cottone, 1986). The interdependence of a person with his or her environment is now recognized in the disability field as reflected in the World Health Organization's classification of impairment, disability, and handicap (World Health Organization, 1980).

Schalock (1991) has also noted a "paradigmatic shift" in the disabilities field, reflected in the way people *with* disabilities are taking a more active role in

expressing their views about what they want out of life. He has suggested that the new-found paradigm is characterized by supports rather than programs, persons rather than places, person–environment matches, services in natural environments, consumer empowerment, real homes, and real jobs.

Within the rubrics of both ecological and symbolic-interactionist theories a number of studies have been conducted that assess a person's quality of life on the basis of his or her behavior in response to the environment or environments in which the behavior occurs. From an ecological perspective there has been a focus on the interactions that occur between individuals in the same settings in which they operate, highlighting the importance of relationships.

There is obviously an interaction between the affective, cognitive, and behavioral components of quality of life. For instance, Andrews and McKennell (1980) argued that actions (behaviors), feelings (affect), and values (cognitions) all interact to determine a person's level of perceived well-being or quality of life. To remedy what they perceived as a dearth of studies directed toward the behavior dimension, Evans, Burns, Robinson, and Garrett (1985) developed a Quality of Life Questionnaire that was designed to measure a person's behavior in response to a number of ecological domains that affected him or her, a position somewhat similar to the concept of person–environment fit.

The domains selected were general well-being, interpersonal relations, organizational activity, occupational activity, and leisure and recreational activity. Fifteen subdomains were identified and 12 items were developed for each to constitute the Quality of Life Questionnaire. Participants were 298 residents of London, Ontario. A principal-components factor analysis with varimax rotation of the intercorrelations among scales and correlation between each scale and the quality-of-life (QOL) score revealed five factors: (1) occupational/material well-being, (2) social well-being, (3) family well-being, (4) personal well-being, and (5) physical well-being.

With the exception of physical well-being, all factors had moderate loadings with the overall QOL score. A concurrent validation study indicated that there was a moderate correlation between life satisfaction ratings and QOL scale scores. Particular life satisfaction measures also had moderate correlations with the overall QOL score. On this evidence Evans et al. argued that there was support for the view expressed by several authors (Gutek, Allen, Taylor, Lau, & Majchrzak, 1983; Zautra & Reich, 1983) that functional or rewarding and enriching life experiences are necessary for an individual to report a high level of perceived life satisfaction or subjective well-being.

Another research strategy for the study of ecological aspects of quality of life was that of Milbrath (1982) who argued that studies of social ecology and studies of quality of life constituted a "natural marriage" between objective and subjective indicators. His research model allows quality of life to be analyzed for either an individual or a community. His basic premise is that there are interactive

effects between individual and community experiences of quality of life. His conceptualization of quality of life is a result of two major classes of variables: (1) values, goals, and aspirations; (2) life-styles. Milbrath defined quality of life as the "fulfillment of one's values, goals, aspirations, and needs" (p. 138).

In the context of the quality of life of people with disabilities, the work of both Evans et al. (1985) and Milbrath (1982) has much to offer. A model of quality of life should reflect the values, aspirations, self-perceptions, and other factors of the individual, but it also should accommodate functional behaviors in a range of life domains. There should also be opportunity for societal variables to be incorporated.

III. THEORETICAL MODELS OF QUALITY OF LIFE IN THE AREA OF DEVELOPMENTAL DISABILITY

The quest for an empirical definition of quality of life in the field of developmental disabilities undoubtedly received its greatest boost from the policies that have led to the deinstitutionalization of people with mental retardation and mental illness, along with their community integration at the school and work levels. Landesman and Butterfield (1987) pointed to the significant growth in interest in the scientific study of deinstitutionalization and community placement, reflected in articles published in journals such as the *American Journal of Mental Deficiency*, where there was a twofold increase in the proportion of articles concerning community placement in the decade 1975–1985. They also referred to the increasing number of volumes of original research on deinstitutionalization and community services such as those by Begab and Richardson (1975), Bruininks, Meyers, Sigford, and Lakin (1981), Edgerton (1984), and Landesman and Vietze (1987).

As Knoll (1990) has indicated, there has been an evolution in the development of outcome or program standard measures for services for people with developmental disabilities. The first evolutionary phase, suggested Knoll, was the era of institutional reform (roughly 1965–1975), when the minimal standards of care were established to protect individuals from harm. The next phase was the era of deinstitutionalization (1976–1986), when emphasis was placed on defining the characteristics of quality programs. In the current phase, the era of community membership, there is a concentration on community integration, quality of life, and development of individualized support systems.

From a scientific perspective efforts have been directed toward the measurement of objective program standards and quantifiable indices of quality. This approach has not been without its difficulties. As Emerson (1985) has cogently observed, evaluation of programs for people with developmental disabilities has produced equivocal results, either because of a lack of attention to the essential

social nature of research, or because of conceptual and methodological difficulties.

Too often it has been the superficial elements of community living that have been the focus of attention. Important as changes in the physical environment, residents' adaptive behavior, or provision of activities for daily living might be, there are more critical aspects that relate to outcomes such as client satisfaction, happiness, social and interpersonal relationships, activity patterns, degree of self-determination, socioeconomic factors, and access to community services. Complex as they might be to identify and measure, outcomes that reflect a person's interaction with his or her environment are more valid indices of the success or otherwise of community living programs (Bronfenbrenner, 1977; Landesman, 1986; Landesman-Dwyer, 1985; Landesman-Dwyer & Berkson, 1984). Researchers should therefore be guided by the multidimensional and codetermined nature of environments in their design of studies to seek a genuine picture of the degree of community integration of people with disabilities.

But, as Knoll (1990, p. 235) has pointed out, a significant factor must not be overlooked in our search for scientifically based outcome studies: "the definition of program standards and quality is a process that transcends empiricism. This process ultimately appeals to the fundamental values of a society." This view has also been supported by Emerson (1985) who suggested that the process of deinstitutionalization is basically "an ideologically committed social movement" that must be clearly understood when attempts are made to evaluate the success or failure of the process.

Addressing what quality of life actually means for people with developmental disabilities from an epistemological perspective may be of more value than pushing ahead too quickly with the development of indices that may manifest theoretical definitional, operational, and methodological problems (Goode, 1991). Contemporary social policies in many countries have been enshrined in legislation that underpins the way services to people with disabilities are funded and evaluated. There is therefore a need for research that questions the way those policies are being articulated in practice. This conforms with the conceptual role that research plays, in that it provides a framework of concepts, orientations, and generalizations that can inform policy, identify problems and potential solutions, and set the agenda for future policy formulations (Beyer & Trice, 1982). Unfortunately, as Emerson (1985) has noted, the major use of research is symbolic, that is, the nonfunctional use of data to justify predetermined positions. Hence, Goode's injunction concerning the "tyranny of quality" is timely.

The following section analyzes five models of quality of life, two of which have some psychometric support (Halpern, Close, & Nelson, 1986; Schalock, Keith, & Hoffman, 1990) and three that remain to be validated empirically (Brown et al., 1989; Goode, 1991; Parmenter, 1988).

Community adjustment is a construct that has been developed to encapsulate the outcomes of programs designed to enhance the participation of people with disabilities in the milieu of the general community. Halpern (1985) initially suggested the concept of community adjustment as being a preferred way of looking at the outcomes of transition programs for young people with disabilities in reaction to the "bridges" model of transition proposed by Will (1984). Will suggested that transition is defined as "an outcome-oriented process encompassing a broad array of services and experiences that lead to employment" (p. [illegible]). An alternative approach suggested by Halpern (1985) focused attention on broader dimensions of postschool life. Support for a multidimensional approach to postschool outcomes is found in the work of a number of authors (see Brown, Hughson, 1980; Close & Foss, 1988; Edgar, 1988; Mitchell, 1986; Parmenter, 1980, 186; Ward. Parmenter, Riches, & Hauritz, 1986; Whelan & Speake, 1981).

Working from essentially an empirical rather than a theoretical base, Halpern, Close, and Nelson (1986) developed an integrated model of community adjustment that included occupation, residential environment, social support, and personal satisfaction as four key dimensions of community living. To test the model, Halpern, Nave, Close, and Nelson (1986) developed a battery of tests that tapped three variables in each of the four dimensions. Under employment were included status, degree of community integration, and financial status; under residential were residential comfort, neighborhood quality, and access to resources; under social support were safety from minor and major abuse and social support; and under satisfaction were general satisfaction, self-satisfaction, and program satisfaction.

Measures for each of the 12 variables were field-trialled to test for internal consistency and reliability, as a part of a larger study that studied the community adjustment of adults with mental retardation who were residents of semi-independent living programs (SILPs) in California, Oregon, Washington, and Colorado. To test the model, data were gathered on the 12 variables from 257 residents (141 females, 116 males; age range from 18–59 years, $\bar{X}$ 28 years), the majority of whom were classified as mildly retarded. Using both exploratory and confirmatory factor analysis, Halpern et al. found strong support for the four-dimensional model. Inspection of Fig. 1 shows that the level of association between the four factors derived from the analysis using the LISREL program was, as predicted, quite low. There were, however, significant intercorrelations with the satisfaction factor that correlated .41 with the environment and .61 with social support/safety. Interestingly, as predicted, occupation was quite independent of the other factors. Of some significance was the fact that the proposed model was able to reproduce the original correlation matrix, with the average differe[illegible]

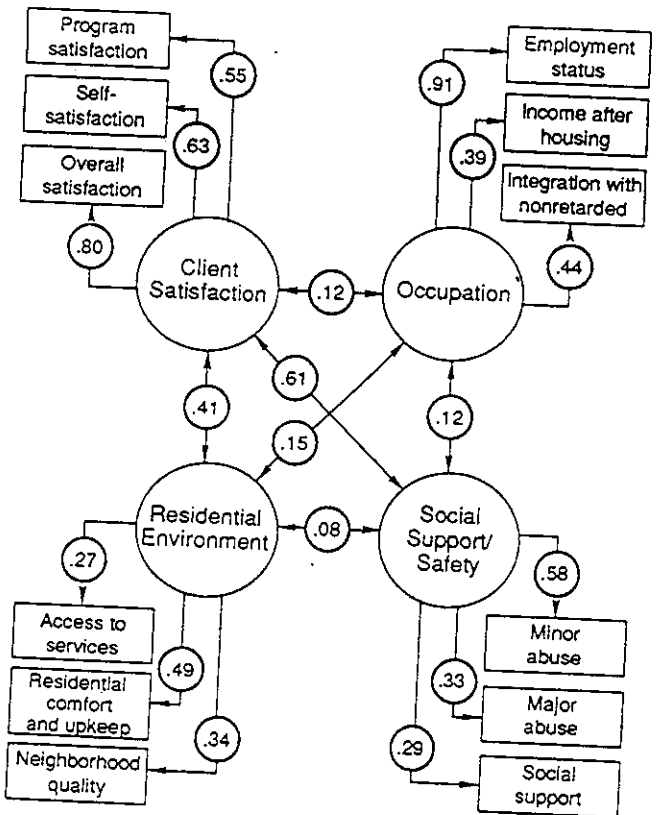

FIG. 1. A model of community adjustment. Reproduced, with permission, from Halpern, Nave, Close, and Nelson (1986).

between the true correlations and the reproduced values at a low value of .04. The goodness-of-fit index derived from the maximum likelihood technique was .97, providing additional support for the robustness of the model.

The Halpern, Nave, Close, and Nelson (1986) model of community adjustment makes a useful contribution to the analysis of quality of life of people with disabilities. It combines both objective and subjective variables and also incorporates aspects of a person's interaction with the environment. A limitation of the study, recognized by the authors, is that the number of variables within each dimension of the model is relatively small. Also, the location of community integration within the occupation dimension may not be appropriate across other disability areas; however, their premise that opportunities for community integra-

tion for people with intellectual disabilities are generally found in the vocational setting was supported by their data for the group studied. This is not altogether surprising considering that work often provides the context for other, more social activities for the population in general.

B. Conceptualization and Measurement of Quality of Life

In his presentation to the 115th Annual Convention of the American Association on Mental Retardation, Schalock (1991) proposed a multidimensional quality-of-life model (Fig. 2). A person's perceived quality of life, suggested Schalock, results from three aspects of life experiences: personal characteristics, objective life conditions, and the perceptions of significant persons about individuals with disabilities. These aspects may be reflected in the measured indicators of independence—productivity, community integration, and satisfaction—that Schalock has essentially drawn from U.S. legislation pertaining to people with disabilities.

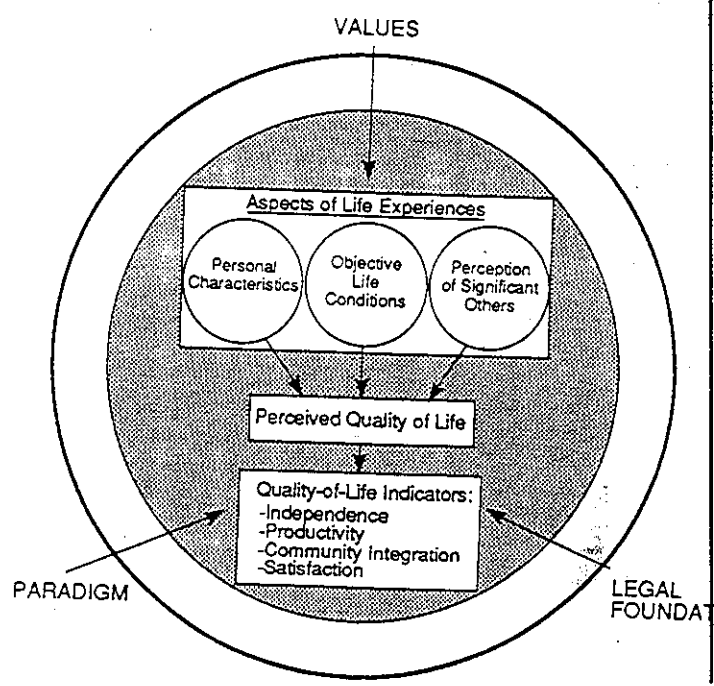

FIG. 2. Quality-of-life model. Reproduced, with permission, from Schalock (1991).

These aspects of life experiences are embedded with a number of cultural factors: values, legal foundations, and a paradigm shift in the way society is thinking about issues and solving problems related to people with disabilities. The concept of quality of life, suggested in this model, encompasses both aspects of the macrosystem that represents cultural trends and factors in a society (i.e., "the quality of American life") and aspects of the microsystem that relate to the individual, family, schools, or habilitation programs (i.e., "the quality of my life").

The inclusion of these cultural factors in Schalock's model is somewhat similar to the paradigm underpinning research that is being conducted into quality of life in Sweden. In Sweden there is a special law for children, young people, and adults with mental retardation that guarantees a life equal to the lives of others in the society. The basic objectives of the special law are integration and normalization, which ensure that people with mental retardation shall be given the possibility to live like every other citizen and with a mutual sense of community. Thus people with mental retardation in Sweden are by law entitled to a right of self-determination of their lives (Drugge, 1990).

Since 1985 Schalock and colleagues have developed, field-tested, revised, and standardized a 40-item *Quality of Life Questionnaire* (Schalock, Keith, & Hoffman, 1990) based on the model described above. The items in the scale cluster into four factors:

1. independence, reflected in the opportunity to exert control over one's environment and to make choices;
2. productivity, reflected in positive work outcomes, such as income or work that contributed to either a household or a community;
3. community integration, reflected in participation in the same patterns of life as nondisabled people, including social and interpersonal contacts;
4. satisfaction, reflected in the fulfillment of needs or wants and the happiness that goes with that fulfillment.

The scale items, encompassing both objective and subjective measures of well-being, can be administered directly in a structured interview format to people who are verbal. In the case of people who are nonverbal, two staff or significant others independently evaluate the person on each item and use the average score for each item (on a 3-point Likert-type scale). The standardization sample consisted of 552 people with mental retardation drawn from mental retardation/developmental disability programs across two regions of Nebraska and from the state of Colorado. The average age of the people in the sample was 37.8 years (47% female, 53% male). An indication of the level of severity of disability can be gauged from the fact that 45% of the sample had not had any formal schooling.

The cross-cultural utility of the scale has been supported by a study that revealed that its factor structure was consistent across data obtained from five countries (Australia, Federal Republic of Germany, Israel, Republic of China, and the United States). Also in each country's sample a consistent trend emerged, revealing that quality-of-life scores increased as the environments in which people lived became more normalized. Caution must be exercised, however, in drawing firm conclusions from this study as sample sizes were extremely small in three of the countries.

C. Quality of Life for Disabled Persons

As a vehicle for analyzing the data obtained from a study of 240 people with mental retardation in five community-based agencies situated across four provinces of Western Canada, Brown et al. (1989) developed a conceptual model of quality of life. The study employed a Client Quality of Life Questionnaire and a Sponsor Questionnaire. For the purposes of the study, Brown et al. defined quality of life as (1) the discrepancy between a person's achieved and unmet needs and desires and (2) the degree to which individuals increasingly control their environment. Their conceptual model of the measurement of quality of life (Fig. 3) consists of a combination of objective and subjective measures; the former include income, environment, health, and growth and mastery of skills,

FIG. 3. Conceptual model of the measurement of quality of life for disabled persons. Reproduced, with permission, from Brown, Bayer, and MacFarlane (1989).

TABLE I
QUALITY-OF-LIFE VARIABLES FOR DISABLED PEOPLE

Objective evaluation	Subjective evaluation
Skill attainment	Perceived growth and mastery
Physical environment	Safety and security
Level of physical and social integration	Social involvement and feelings of belonging
Training plans	Independence control
Actual support systems	Responsibility
Income	Self-esteem
Provisions	Expectation
Health	Perceived goal attainment
Philosophy of training agencies	Perceived supports
Attitudes of training staff	Satisfaction level
Attitudes of community	Perceived health (mental and physical)
	Normalcy of life
	Pace of life
	Family stability

and the latter, life satisfaction, psychological well-being, and the person's perception of skills and needs. Specific variables included under each of the objective and subjective components are provided in Table I.

Brown et al. have addressed the quality of environment at both the macro and micro level. At a macro level the political and economic climate and the societal attitudes toward people with disabilities are assessed. The existence of support systems, either formal or informal, is also seen as a crucial element in determining the quality of the environment. On a micro level elements such as safety features of one's neighborhood, workplace, and leisure activities, as well as the nurturing aspects of these environments, are considered. Other aspects of the environment that can be considered objectively are safety, health, and access. Obviously there may be a discrepancy between the way a person perceives these features and their objective presence or absence in the environment.

In their reporting of the data from the study Brown et al. have used the model to guide their discussion, but no attempt was made to draw together the various variables considered into a form of overall quality-of-life index. Rather, the perceptions of the consumers, their sponsors, and various service providers were used as a basis for a comprehensive set of recommendations concerning ways service provisions could be improved for Canadians with a developmental disability. In this respect they have responded well to Emerson's (1985) plea that evaluation research should address those issues that surround an individual's quality of life in specific environments, rather than focus solely on location and adaptive behavior repertoires.

D. A Process Model

Goode (1988a, 1991) has developed a model somewhat similar to that of Brown et al. (1989). He, too, has drawn on social research and policy in the field of disability, together with current philosophies concerning supports to these people including those that emphasize choices. The model (see Fig. 4) is described as a nonlinear, process model that is client centered. The circles and squares respectively suggest interactive relationships between the subjective and objective variables.

Central to this model is the premise that quality of life is specific to environments. For instance, Powers and Goode (1986) have argued that quality of life is basically the product of the relationships between people in each life setting. They have stressed that one's quality of life is markedly influenced by the quality of life experienced by the people with whom one interacts.

For example, Goode has suggested that it is imperative, when assessing the quality of life of people with disabilities in community residential settings, that the quality of life of the staff also be addressed.

The subjective elements of the model emphasize the relationships among perceived needs, capabilities, demands, and resources. Goode has stressed that

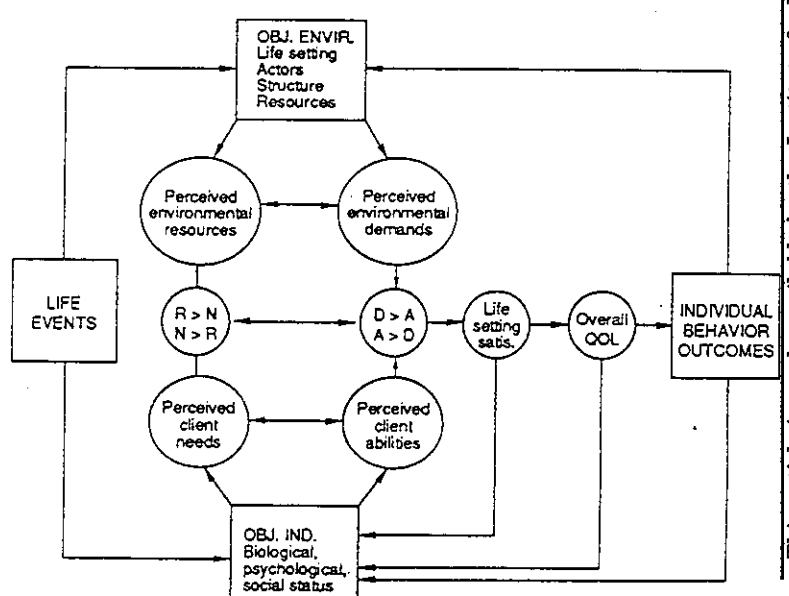

FIG. 4. A process model of quality of life (QOL). R, resources; N, needs; D, demands; A, abilities. Reproduced, with permission, from Goode (1988a, 1991).

the individual's overall assessment of quality of life is influenced if there is a misfit between environmental demands and personal capabilities and the person's perception of his or her personal needs and environmental and social resources.

Goode's framework has been heavily influenced by an ethnomethodological perspective of disability research, which is in the tradition of the "special constructionist" branch of sociology formulated at the University of California, Berkeley, in the early 1960s. Although not discrediting attempts to quantify the quality of life of people with disabilities, Goode, nevertheless, has perceived some inherent dangers in this activity. For instance, he has expressed concern that an index may produce a standard of quality that can be generalized across populations as a type of metric by which the effectiveness of programs may be judged, hence his term *tyranny of quality*. As quality of life is a deeply personal and individual construct, he has urged researchers to place more emphasis on observational methods, which may better portray the richness of the relationships a person forms with others in his or her environment, than on carefully validated and reliable scientific instruments, the content of which may not be sufficient reflection of an individual's subjective experience of life and their "actual" or "real" social identity.

Goode (1984) has made a plea that professionals (including researchers!) must get much closer to the people whom they are studying. For instance, he has claimed that we reify service activities by assuming that the objective data collected about the lives of developmentally disabled people truly reflect a person's "actual" self.

Goode's ethnomethodological approach to the study of the quality of life of people with developmental disabilities has been applied in a number of countries; an example from Finland is presented later.

E. A Symbolic-Interactionist Approach to Quality of Life

Much of the work that has been conducted in the development of quality-of-life models for people with a disability has failed to analyze the impact of disability per se. Although the general factors influencing a person's quality of life may be the same whether the person has a disability or not, the presence of a disability surely adds a significant dimension. The following analysis examines, from a symbolic-interactionist viewpoint, what it means to have a disability; this analysis forms a theoretical base for a proposed model of quality of life (Parmenter, 1988).

1. WHAT IS A DISABILITY?

Increasingly disability is being studied from sociological perspectives including structural–functional, conflict, phenomenological, interaction, and ecological. In the light of the almost total absence of sound theoretical bases for much of

the research in the disability field, examination of the concept of disability from a symbolic-interactionist viewpoint is proposed. Fundamental to this approach is the principle that human experiences are mediated by interpretation (Bogdan & Kugelmass, 1984). Another basic tenet is that the "self" arises and is maintained in a symbolic and interactive context. For instance, in addressing the question of exactly how a "self" comes into being, Stryker (1959) has suggested that we come to know what we are through others' response to us. In the context of the present discussion Bogdan and Kugelmass (1984) have pointed out that the word *disability* is not a symbol for a condition that is already there in advance. Paradoxically, disability is part of the mechanism whereby the condition is created.

Physical and/or psychological impairments set the parameters in which the definitions develop, but the way in which people determine their definitions depends on a variety of factors including personal and community attitudes toward people who appear different. Definitions and labels are influenced strongly by the degrees to which people have had the opportunity to interact at a personal level with people with disabling conditions.

2. DISABILITY AS DEVIANCE AND THE LABELING PERSPECTIVE

Goffman (1963) identified blindness, deafness, epilepsy, and physical disfigurement as examples of stigma. This list was expanded by Clinard (1974) to include mental retardation, cerebral palsy, and stuttering. Some may view the stigmatizing condition as being inherent in the individual, but Clinard (1974) maintained that the emphasis should be on the effects of the imputed impairment, through a process of labeling, on the individual. Schur (1971), for instance, pointed out that in examining deviant human behavior we are seeing the results of a *combination* of a personally discreditable departure from expectations and the development of certain stigmatizing reactions toward the individual. These reactions may serve to "isolate," "treat," "correct," or "punish" individuals who are engaged in such behaviors. Central to Schur's position is the notion that deviance is not a static entity; rather it is the dynamic outcome of the complex interactive processes ongoing in society.

For persons with a disability there is often a lack of congruence between their desired personal identity and their assigned social identity. Hurst (1984) has commented that stereotypes focus on generalities. This is supported by Scott's (1972) observation that society has ascribed to people with visual disabilities the attributes of "helplessness, dependency, melancholy, docility, gravity of inner thought, [and] aestheticism," all traits, he has suggested, "that commonsense views tell us to expect of the blind" (p. 4). The effects of this role-making process are such that the person with a disability will often not develop as an "authentic" person. Unfortunately people who have been assigned an identity or

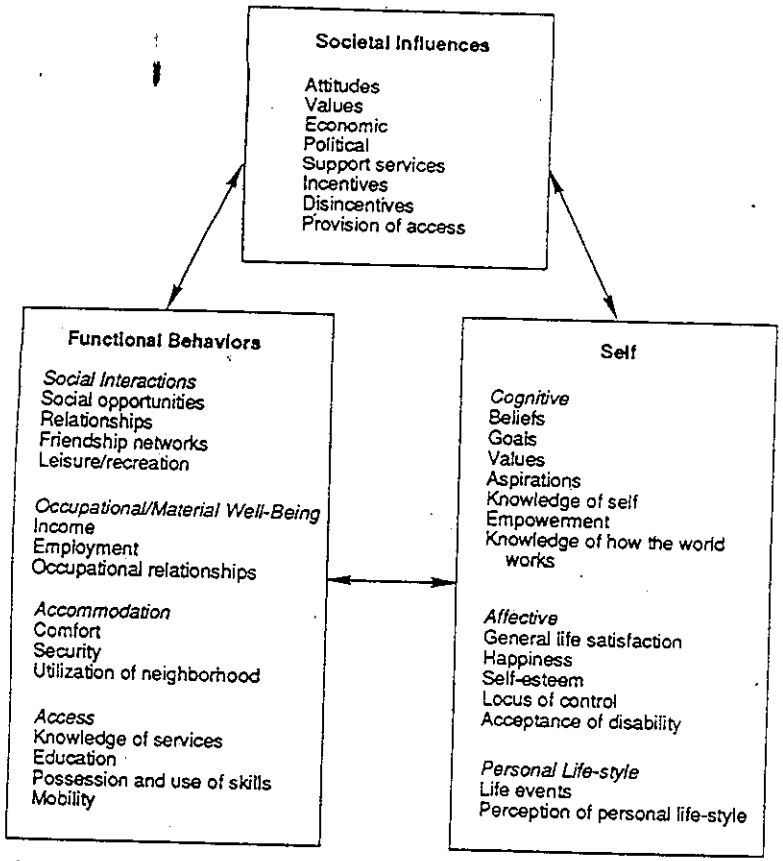

FIG. 5. A model of quality of life for people with disabilities. Reproduced, with permission, from Parmenter (1988).

the subcomponents that might constitute the basis for instrument development for subsequent testing of the model are described briefly. Figure 5 illustrates the components of the model.

1. *Self.* The subcomponents of self have been arbitrarily classified under cognitive and affective, given that they are highly interactive. A further moderating dimension, personal life-style, has also been included under self. Under the cognitive dimension are included beliefs, goals, values, aspirations, knowledge of self, knowledge of how the world works, and empowerment. The latter refers

to strategies such as risk taking and decision making, which may lead to greater levels of autonomy and self-determination. The facets of the affective dimension include general life satisfaction, happiness, self-esteem, locus of control, and acceptance of disability. It is anticipated that life events and perception of one's personal life-style would affect both the cognitive and affective dimensions.

2. *Functional behaviors.* These elements, which may be directly observed, have been grouped into four categories. The first, social interaction, includes social opportunities, relationships and friendship networks, leisure/recreational activities, and communications. The second, described as occupational/material well-being, incorporates income, employment, and occupational relationships. Under accommodation, the third subcomponent, are included comfort, security, and utilization of neighborhood resources. The fourth subcomponent, access, includes knowledge of and use of services, education, possession and use of skills, and mobility.

3. *Social influences.* As the individual with a disability comes to a view of his or her quality of life in the context of the environment in which he or she lives, it is essential that a model incorporate those societal factors that may influence the person's subjective well-being. Hence the following elements are suggested: community attitudes toward disability, community values, state of the economy, political support provisions, incentives, disincentives, and provision of access.

Within these three components the list of subcomponents is presently tentative but, from an examination of the research literature, together with the issues explored under the symbolic-interactionist rubic, and from the results of pilot studies, it would appear they represent important elements of a model.

It is proposed that each component interacts with the others. The development of self is largely influenced by both functional and societal factors. Functional behaviors are, in turn, affected by societal influences and the level of self-development. Societal influences possibly exert a strong moderating force on both of the other components; however, societal influences are also amenable to change, particularly if people with disabilities are assertive and demonstrate skillful control over their lives.

The strength of the model lies in its emphasis on how well the person with a disability perceives him- or herself within a community. What is paramount is how that person grows and develops as an autonomous individual, albeit in an interdependent societal framework, with an opportunity to achieve his or her hopes and aspirations.

The models described above are in part a reflection of some of the central themes in the study of quality of life outside the field of developmental disability. Described in the models, however, is a much stronger recognition of the need to involve the persons themselves in determining the major determinants of their quality of life. Furthermore, the environmental goodness-of-fit concept, which

role in society may ultimately fulfill the expectations others have of them, thus reinforcing in the eyes of others the validity of their assessments.

The closer the perceptions of self by the person with a disability come to those ascribed by society, the greater is the chance that secondary deviance or career disability will emerge as the major form of role adaptation. Burbach (1981), in distinguishing between primary and secondary deviance, has suggested that people with "primary" deviance do not see their "differentness" as defining them as a person, whereas people with "secondary" deviance see their "differentness" as the crucial defining element in their concept of self. In this respect career disability has been a major focus of attention of a number of writers in the field of rehabilitation (De Jong, 1981; Finkelstein, 1980; Stoddard, 1978). For instance, in his analysis of attitudes and disabled people Finkelstein (1980) has indicted professional groups as having contributed significantly to the social oppression of people with disabilities.

In summary, an examination of the processes of social definition or labeling, posited by Schur (1971), has revealed that the deviance attribute of disability is imposed by the social audience or, in the words of Becker (1983), "Social groups create deviance by making the rules whose infraction constitutes deviance" (p. 9). From a symbolic universe perspective, rules arise in society as a result of its need to maintain an orderly view of the world. The anomalous position of people with disabilities in this universe has led to the property of deviance being assigned to these individuals. There often follows a power struggle to determine whose rules should apply. As fragmented and uncoordinated groups of individuals, people with disabilities are relatively powerless in this conflict. In the area of interpersonal relations the lack of congruence between a personal and a socially assigned identity often prevents the person with a disability from developing as an "authentic" human being. This, in turn, has deleterious effects on the quality of interpersonal relations. A brief examination of organizational structures has demonstrated how, in Schur's (1971) terms, organizations produce deviance through their attempts to regulate and control those groups that are perceived as a threat to the natural order of things.

3. IMPLICATIONS OF LABELING FOR THE QUALITY-OF-LIFE QUESTION

In his illuminating analysis of the labeling issue Burbach (1981) suggested that it is superficial to ask whether we should or should not label anomalous individuals. He pointed out that labeling and categorizing people are the normal processes of apprehending and organizing our world. Of more importance is "how we label (people) and with what consequence" (Burbach, 1981, p. 376). Burbach's contention is that people with a disability are in a double-bind situation. In addressing the issue of what it means to be disabled they are confronted

by two messages. One comes from outside and proceeds from the social order. The other, however, comes from within and relates to what they know they can or cannot do. Thus, they have to deal with the negative aspects of their personal condition and at the same time cope with the negative effects of stigmatization and stereotyping. From a philosophical point of view there is a conflict between the existential nature of the person and the social nature of human experience.

In trying to establish a coherent meaning for life as well as creating and maintaining self-esteem, the conflict between the messages the person with a disability receives often presents insuperable problems. On the one hand, the person can live a cocoonlike existence built on socially unvalidated meanings or, on the other hand, he or she can conform to the patterns of behavior expected of him or her by society generally. Neither of these approaches leads to a satisfactory resolution to the issue of how these persons define their own meanings. Here, it is proposed, lies the nub of the quality-of-life issue. Quality of life represents the degree to which individuals have met their needs to create their own meanings so they can establish and sustain a viable self in the social world. The resolution proffered by Burbach draws on the basic principles of symbolic interactionism. That is, there is a need for consensuality whereby humans help each other unfold and establish contact and unity in their social existence.

Although not without its critics (e.g., Sharp & Green, 1975), symbolic interaction theory has usefully contributed to our understanding of aspects of the social situation of people with disabilities. Barton and Tomlinson (1984) have suggested that this approach has at least two strengths. First, it emphasizes the viewpoint of the participants in social interaction and, second, the perspective explores aspects of social life that have historically either been taken for granted or have been ignored. Other sociological approaches might emphasize economic considerations and the distribution of resources in the society (e.g., structuralist neo-Marxism) or use the traditional Marxist class conflict model to explore the imbalance of power between disabled and nondisabled groups in society. These theories may not be mutually exclusive, for in the context of quality of life it is suggested that the consciousness of self and social identity, status, and social role are obviously preconditions for political activism and social change.

4. A QUALITY-OF-LIFE MODEL

From a symbolic-interactionist/ecological theoretical perspective it would seem essential to include at least three components within a quality-of-life model for people with disabilities. The first would pertain to an individual's perception of self; the second to the individual's behavior in response to ecological domains that might affect him or her; and the third to responses the settings might make to the individual. Obviously the model would need to be able to accommodate the interactions that would occur among each of these components. In this section

sits comfortably with the view that disability is largely an environmentally determined phenomenon, is adding a much needed dimension to our understanding of what constitutes a life of quality for people with a developmental disability.

IV. RECENT EMPIRICAL STUDIES

This section reviews an internationally representative sample of studies that have sought to assess the effectiveness of program outcomes in the context of the quality of life of the individuals concerned. In a number of cases the theoretical models described above have formed a framework for the conduct of the study.

A. Canada

Brown et al. (1989) investigated quality-of-life outcomes for a sample of 240 intellectually disabled people across five agencies located in the four western provinces of Canada. As a prospective 3-year study, repeated measures related to vocational, social, educational, home living, and leisure/recreational aspects of learning and life-style. These indicators were drawn from the quality-of-life model developed by Brown and colleagues and described above.

The results Brown and colleagues found were fairly depressing. On both objective and subjective indicators the clients of the several programs did not show many significant gains over the 3-year period, although the extent of the variance within and between groups makes comparisons difficult to interpret. There was evidence that, although on the average the individuals improved in work skills, there was a lack of progress in social education skills. Despite the fact that many of the clients of the programs had high levels of skills in the vocational and home living areas, there was little evidence of movement into community-based work or living situations, even though there was policy emphasis on community-based work. The study found that in the area of objective indicators there was a high relationship between poor performance and the absence of specific training programs.

On subjective measures about half of the clients reported that they enjoyed living where they were and a majority stated they had friends, most of whom were selected from school, agency, or work. Analyses of changes in clients' perceptions over the study showed that for males significant improvements were reported in three categories: "being more happy now," "having improved work skills," and "having better co-worker relations." Females expressed gains in a larger number of categories: "reading," "laundry," "getting along with others," "leisure time activities," "making decisions," "being happy," "work skills," and "co-worker relations."

Three specifically subjective questions were asked of the clients: What do you

worry about? What would you like to change? Do you enjoy living where you are? Many of the clients' concerns related to their individual health and performance, to starting and maintaining relationships, and to items dealing with the family.

The most frequent response to the question What do you want to change? related to the clients' desire to change where they were living. The next most frequent response was a desire for an increase in leisure activities, followed closely by a request for change in employment and improvement in personal relationships. Other responses included a desire to earn more money, improve health, and have more or different friendships.

There was a high level of positive responses to the question Do you enjoy living where you are?, clearly outweighing the concerns and reservations. Brown et al. pointed out the idiosyncratic nature of the reasons given for preferences for a particular residence. For instance, one person liked where he lived because he had a fireplace in his room. This, suggested Brown et al., demonstrated how important individual variations in preferences were to the concept of quality of life, whether it be for disabled or nondisabled people. Other significant themes that demonstrated the importance of individuals meeting their own personal needs included freedom of choice, the need for family affection and contact, and the opportunity to use leisure time profitably.

As a result of their detailed analyses of the various indices measured, Brown et al. (1989) made 104 recommendations for program improvement, ranging from advice concerning the development of agency policy, administration, and staff training to the development of more individualized program planning for the clients.

Although the quality-of-life model developed by Brown and colleagues served as a general framework for their investigation, a weakness noted in their report was the absence of a detailed discussion of the results using the framework chosen. For instance, there was little discussion of the concept of quality of life being an interaction between the individual and his or her environment; nor was there a sufficient analysis of the discrepancy model of quality of life put forward earlier, that is, the discrepancy between a person's achieved and unmet needs and desires. Another aspect of the model that was touched on too briefly was the extent to which an individual increasingly controls aspects of his or her life regardless of the original baseline. One gains the impression that as such reports are directed primarily toward policy planners, there is a natural tendency on the part of researchers to highlight these more objective indices as they tend to fit more comfortably into funding criteria and legislative edicts. Although concepts such as freedom of choice, happiness, empowerment, and satisfaction are readily accepted as important variables, they do not seem to rate as highly as those variables for which "hard" data can be obtained.

B. New Zealand

A cross-sectional study examined the relationships between employment status, age, quality of life, and well-being for three cohorts of school leavers from classes for students with mild intellectual disabilities in Auckland, New Zealand (Tosswill, Tuck, & Wilton, 1991). The "early" cohort graduated through 1975–1979, the "middle" cohort through 1980–1984, and the "late" cohort through 1985–1989. There were 30 individuals in each cohort. Four published measures were used: Affectometer (Kamman & Flett, 1983), Quality of Life Questionnaire (Schalock et al., 1990), Self-Esteem Scale (Rosenburg, 1965) and General Health Questionnaire GHQ.12 (Goldberg, 1972).

The trend in employment status across the three cohorts indicated that, owing to recent high unemployment in the general population, only 23% of recent graduates were in competitive employment, compared with 43% of the early cohort and 47% of the middle cohort. Adults in competitive employment reported a better quality of life, higher self-esteem, higher levels of well-being, and fewer indicators of psychiatric illness than either adults in sheltered work or unemployed adults. The oldest adults experienced a better quality of life and fewer indicators of psychiatric illness than those who left school more recently, adding, suggested the researchers, some support to Edgerton's (1990) conclusion that adaptation tends to improve over time and to the suggestion of a number of authors that securing and holding a job are critical factors in determining a person's overall quality of life.

C. Finland

In 1989 the Finnish Association on Mental Retardation launched a research project entitled The Quality of Life and Mental Disability, the goal of which was to study the personal views and experiences of mentally disabled persons, to describe the quality of their life in terms of work, housing, and leisure. A significant factor influencing the overall methodology used in this project was the tradition of Finnish sociological research, which throughout the 1980s focused largely on welfare, the quality of life, and the actual way of life itself.

The Quality of Life project had three goals (Myhrman & Ohman, 1989):

1. To describe the quality of a mentally disabled person's life in Finland by studying the quality of life in different functional units, such as community residences, institutions, and sheltered work, and by analyzing the interdependence of the quality of life and the quality of services provided.
2. To identify the factors affecting the quality of a mentally disabled person's life by assessing the needs of a disabled individual, for example, in terms of social relations and activities, ego and self-image, and emotional life by assessing individual capacities and resources, and by assessing the environmental factors affecting an individual's life.
3. To develop methods for improving the quality of a mentally disabled person's life by supporting and developing a disabled individual's capacities and by improving the working methods of staff and other environmental factors.

The project is being conducted in three stages. The first stage, the development of a quality-of-life instrument, has followed procedures established by Goode (1988b). The method is based on group discussions including four to six mentally disabled persons, one to two parents, and one to two staff members. Each working group has eight 3-hour sessions. Over the 24 hours of discussion set topics are explored commencing with the question, What is a good life? Other sessions discuss topics such as important needs and ways to fulfill them in different settings.

Sessions were analyzed using the matrix method developed by Goode (1988b). This study used two matrices. The first was a need/goal matrix consisting of three dimensions. The first dimension included work, housing, and leisure time; the second concerned individual needs such as friendship, self-image, and security (based on a Scandinavian quality-of-life study: Kebbon, 1984); and the third consisted of different stages of integration. The second matrix analyzed resource implications, making it possible to analyze each need separately according to the resources needed to fulfill them in different stages of integration.

Work currently in progress is employing the QOL instrument developed out of the content analysis described above, in interviews with 1000 adults with mental retardation across Finland. The essential goal of the project is to test the capacity of the service system to satisfy the expressed needs of its clients.

D. Sweden

The County Council Vastmanland in Sweden is adopting an approach similar to that described in the Finnish project. Methods to measure the quality of services to people with mental retardation served by the County Council are being based on the people's own opinions and expressed needs (Drugge, 1990). Central to the philosophy underpinning this development is the concept that disability itself shall be regarded as a lack of ability of society to eliminate the consequences of the disability instead of the disability as perceived within the individual. This approach agrees well with the World Health Organization's (1980) definition of "handicap," which stresses the interaction between disability and environmental factors. It also parallels the thinking behind the American Association on Mental Retardation's 1991 draft definition of mental retardation that suggests that "the existence of disabilities in adaptive skills occurs

within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for support" (American Association on Mental Retardation, 1991, p. 1).

County Vastmanland has a population of 256,000 people, 1326 of whom have mental retardation. The Council is currently developing two projects that are designed to improve the quality of services and the quality of life of those with mental retardation. The first project involves the development of individual plans as a basis for planning the services that the person with mental retardation demands. An individual plan is established for each person with mental retardation by interviewing the person alone or together with an advocate (a parent or someone who knows the person well) in the case of a person with a severe disability. The subsequent plan is computerized so it can be conveniently updated. Objectives obtained are recorded so that the actual quality of performance may be assessed. These data are used to plan future service needs and estimated costs.

A second project under development assesses an individual's quality of life along several dimensions, including respect, commitment, accessibility, nearness, and security. The essential ingredient of quality of life is defined as "the worthiness the person experiences in his/her specific situation" (Drugge, 1990, p. 7). To develop a measurement instrument that would reflect consumer satisfaction or dissatisfaction, reference groups of people with a knowledge and experience in working with people with mental retardation and groups consisting of persons with mental retardation and their parents were formed. The latter groups especially helped to define the level of complexity of the questions and ways in which questions should be asked. For those with severe levels of retardation, rather than asking parents or staff to complete the questionnaire, it was recommended that observation techniques be used to establish valid responses.

A second Swedish study (Sonnander, 1990) appraised the quality of life of 217 individuals living in group homes in three representative Swedish counties. The instruments used in the study, which were based on the principle of normalization as enunciated by Nirje (1980), assessed quality of life along four dimensions: activity, relations, self-image, and mood (Naess, 1979). Thus, the personal experiences of the people studied were of paramount importance.

The results showed that in general a medium level of normalization had been reached in that all people in the group homes had access to twice as many activities and other services in their community as they used or from which they could benefit. With respect to quality of life, the scores obtained showed that the group as a whole had a rated quality of life around or below the mean on a 5-point scale. More than two-thirds of the interviewed people were assigned scores below the mean. Higher scores were attained by people in programs that almost approximated normal community life.

An interesting finding was that deficits in quality of life were ascribed to the

fact that the people were not participating socially in the community at large. Although they lived in the community physically they were on the fringe socially. The implication of this finding is that considerable attention needs to be paid to the development of interpersonal skills in addition to the usual emphasis on practical living skills. There is also a need to help these people develop informal social networks that do not depend on paid professionals.

E. United States

Thurlow, Bruininks, and Lange (1989) of the Institute on Community Integration at the University of Minnesota compared the postschool status of three groups of people with moderate to severe mental retardation who had been out of school for 7 to 10 years, 3 to 5 years, and 1 to 2 years. Comparisons of former students as a function of time out of school revealed few differences on employment-related variables or on other quality-of-life variables. Two instruments were used in the study: (1) the *Post-School Transition Study Survey Interview* (PTS) and (2) the *Inventory for Client and Agency Planning* (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986). Both instruments were administered by a trained interviewer to a respondent familiar with the subject.

The PTS, developed by a task force consisting of the research team, school personnel, and local site coordinators, elicited objective data in the following areas: employment, education, social participation, support payments, social adjustment and living skills, health/physical status, family/household characteristics, living arrangements, service and program information, citizenship status, and miscellaneous information.

The ICAP, a tool for managing information in areas for planning and evaluating services for people who are disabled, elicited information on diagnostic and health status, as well as normative scores for adaptive behavior and problem behaviors; information on service level, service history, current placements, and projected service needs; and data on support services and social and leisure activities. Thus, ICAP provides information that can be used to compare the adjustment of different groups to the adult world.

It is clear that both instruments basically provide inventories of objective indicators of quality of life; however, for the domains of work, day programs, and living arrangements questions were asked about the subject's level of satisfaction.

Despite the lack of significant differences between the three cohorts on the major variables (unlike in the New Zealand study reported above), there were significant correlations between measures of personal competence and composite outcome measures, suggesting that postschool outcomes are related to variables such as independence and adaptive behavior and, to some extent, to maladaptive behaviors.

A principal-components analysis of 21 variables from the PTS and ICAP produced an eight-factor solution, four identified areas of personal competence, and four community adjustment dimensions (Bruininks, McGrew, Thurlow, & Lewis, 1988). In the area of personal competence, the factors identified were personal independence, maladaptive behavior, physical mobility, and physical complications; for community adjustment, the factors were social-/recreation/leisure, social and service support, financial independence, and community independence/integration.

Thurlow et al. (1989) concluded that in assessing the community adjustment of former school students, major aspects to be considered are functional behaviors, personal competence, and social, economic, and community integration. More recent work by the researchers from the Institute on Community Integration (McGrew & Bruininks, 1991) has supported this conclusion.

F. United Kingdom

McGuire, Choon, and Akuffo (1991) assessed the quality of life of 19 elderly people with a developmental disability who had been living in two privately owned, government-approved group houses in London for between 1 and 2 years. Prior to living in community-based homes these people had resided in large residential institutions. The majority of residents were considered to have a moderate to severe level of intellectual disability.

Quality of life was assessed by a modified version of a life-style questionnaire devised by Raynes, Johnson, Sumpton, and Thorp (1987). The areas assessed included daily activities, involvement in domestic tasks, extent of community-based activities, and extent to which residents are responsible for, and can make decisions about, their own lives.

The results indicated that the involvement of residents in community-based activities was limited, although the authors suggested that the level was possibly as high as it could be for nondisabled, elderly people. In the area of decision making, it was observed that although choices were available (for example, choosing when to go to bed), many of the residents were unable to break away from the institutionalized routines by which they had lived for 50 or more years.

One gains the impression from the results of this study that there had been little effort by staff to establish community networks or to implement programs to teach decision-making skills to the residents, weaknesses also noted in the following Australian example.

G. Australia

Parmenter, Briggs, and Sullivan (1991) investigated the quality of life of 30 residents with severe developmental disabilities who had moved from a hospital

setting to seven community houses. With the three-component model of quality of life described above as a guide, a number of specific variables were assessed through a variety of data collection techniques. Variables explored included functional skills acquisition, amount of say the residents have in their lives, individual community-based activities, attitude change by staff and parents toward community living, and parents' perceptions of their changed roles.

Data were collected using interviews with residents (including those who had little verbal communication skills) and participant observation techniques. Staff and parents also completed the same interview schedules as those administered to the residents, to verify the results of the resident interviews.

When asked if they felt very happy, just OK, or unhappy, 19 residents indicated that they felt very happy, 10 felt happy, 1 felt just OK, and none felt unhappy. In terms of friendship, 21 residents were happy with the friends they had; 7 were not. The majority of their friends naturally came from their group home; 3 indicated the family home, 4 a staff member, and the remainder school friends.

When asked if they were happy with the move from the hospital, 27 indicated "yes" and 3 "no." Of the latter, two subsequently returned to hospital and the other expressed a desire to live at home with his parents.

In terms of functional skills the study revealed that little attention was being given by staff to the development of basic self-care skills and those skills necessary for the routines of daily living. This was attributable to staff shortages, high staff turnover, and lack of staff training.

Although residents reported being able to make choices in activities such as selection of menu, clothing, weekend activities, TV programs, time of going to bed and participation in group activities, from an analysis of the interviews and objective observation, it appeared that much more could be done to teach choice and decision-making skills and to provide opportunities where choices could be exercised.

In the area of societal influences the data on community access revealed fairly limited participation by individual residents in community activities. This was more a reflection of the inability or inaction of staff in setting up meaningful community networks, than reluctance by community organizations to accept these people.

The data assembled in this study support aspects of the quality-of-life model presented earlier. In practical terms, the data demonstrate that it is possible to address issues such as satisfaction, happiness, and decisionmaking in a population that has a severe level of disability. A trend toward increasing levels of empowerment of the residents was noted. A more detailed ethnographic study using longer-term participant observation techniques would possibly throw additional light on the possible changes in the development of a more positive identity by the residents.

V. METHODOLOGICAL ISSUES IN MEASURING THE QUALITY OF LIFE OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

Readers are referred to a comprehensive analysis of measurement issues by Heal and Sigelman (1990), a brief summary of which is presented here. Heal and Sigelman have suggested a methodological taxonomy for assessing quality of life. The first dimension is whether the measures are objective or subjective. The second relates to whether the measure is absolute or relative; that is, it can directly index a person's quality of life or it can compare it with a standard. Third, the quality of life can be directly reported by the subjects of the study or it can be assessed by someone else. Fourth, the index can be authored or generated by the researcher or by the subjects themselves.

Heal and Sigelman (1990) have explored a number of difficulties that may arise depending on the decisions implied by the taxonomy. For instance, as indicated earlier, various subjective measures of well-being do not correlate highly with objective indices of quality of life. In other words, they suggested, "method variance tends to dominate substantive variance in quality of life assessments" (p. 164). There are also difficulties, especially for people with mental retardation, in responding to relative measures that require a comparison of current with past or future quality of life. This problem was evident in the study by Parmenter et al. (1991) reported above. Many individuals had difficulty in responding to the question as to whether they felt happier in their new accommodation compared with their former hospital residence.

The use of respondents other than the disabled people themselves also raises questions of reliability, a danger noted in the first Swedish study. The use of independent participant observation techniques does help to mitigate the biases that may occur. An issue central to Goode's (1991) concern with psychometric approaches to the assessment of quality of life is the question of who generates the list of specific life circumstances to be evaluated. An area for future study would be an assessment of the potential differences between findings based on investigator-authored measures and those based on client-authored measures.

There is substantial literature on factors that affect responses in survey research, especially systematic response effects that are a function of the way questions are recorded and the way interviews are conducted. For people with developmental disabilities especially, the risk of acquiescent responding is very high. There is also the problem of socially desirable responding; that is, respondents will tend to present themselves in a favorable light. For instance, studies of quality of life in the general population have shown that people generally rate the quality of their lives above a neutral point, regardless of how "neutral" is anchored or described (Andrews & Withey, 1976; Diener, 1984). In a recent Australian study, Romeo and Cummins (1991) found that a significant number of

respondents to a quality-of-life questionnaire designed for people with intellectual disabilities were unable to use a 5-point Likert scale.

There is also quite a detailed literature concerning difficulties that may be experienced when interviewing people with mental retardation (see Sigelman et al., 1983; Heal & Chadsey-Rusch, 1985). Heal and Sigelman (1990) have suggested that multiple methodologies be employed to reduce these difficulties. For instance, they have urged that greater opportunities be given for people with developmental disabilities to speak for themselves, so they may tell us how they perceive their lives and ways in which they would like their lives to change. In terms of instrument development they have recommended either–or multiple-choice questions accompanied by pictures wherever feasible.

There is also a need to build into interview schedules checks for response bias that can be used later to adjust scores to remove the effects of their bias. Finally, information-gathering techniques other than client interviews may be used in place of interviews or to corroborate responses along the lines described by Parmenter et al. (1991).

VI. CONCLUSIONS

This article has reviewed attempts that have been made to conceptualize and assess quality of life of people, from the perspective of both the generic literature and those in the disability field. The term *quality of life* has on the surface a seductive simplicity, so much so that it almost seems improper to question its utility as an index of the effectiveness of policies and programs for people with developmental disabilities; however, a number of writers have urged caution in our quest to come up quickly with instruments that can measure the concept.

Indeed, Luckasson (1990) has gone so far as to suggest that the disability community should eschew the use of *quality of life* as an evaluation term, because of the inherent danger of it becoming a justification for the denial of rights to people with disabilities. There are examples of this happening, such as neonates who are born with severe disabilities and who are candidates for euthanasia because their potential for a "quality of life" is very doubtful. The use of an arbitrary metric of quality of life in the field of developmental disabilities could just as easily be applied when resources are being rationed as they are being applied in the general health area in some countries.

Luckasson's concerns are reinforced by Turnbull and Brunk (1990), who urge us not to overlook the fact that the question of quality of life for people with developmental disabilities is embedded in the larger perspective of what constitutes quality of life for the general population. And this raises the issue of what is "community"? Sadly, many informal mechanisms for facilitating the integration of people with developmental disabilities into the life of a community

become formalized into a government-sponsored "program" because some modest levels of funding are required. Just how we solve the problem of providing resources to informal networks that are the lifeblood of genuine communities, and at the same time maintain fiscal accountability, is a serious challenge for policy planners and governments.

Also, as Bowles (1988b) has cogently pointed out, disability is a phenomenon with roots in the social, political, and economic processes of our society, rather than in the clinical features of the individual. At this point in time, in particular, it is necessary, as Turnbull and Brunk have suggested, to emphasize the needs of these people for "informal support, friendships, intentional communities, and rights to association between people with and without disabilities" (1990, p. 205). There is an inherent danger that we have overbureaucratized the disability world, replete with its laws and armies of well-intentioned professionals, a point forcefully made by Blatt (1979) in his fine essay "Bureaucratizing Values."

In this context Fulcher (1989) has drawn a distinction between the forces of democratism and its opponent, professionalism. Democratism supports the notion that those affected by decisions should take a genuine part in debating the issues and making the decisions. Professionalism, on the other hand, is the view that the experts know best, and has been a major tactic in the historical struggle by professionals to gain control of an area of occupational life. This view parallels that of Turnbull and Brunk who fear that the overbureaucratization of services to people with developmental disabilities will lead to increasing isolation of the individual person from the nondisabled world, despite the multiplicity of individualized plans and other mandated mechanisms that are supposed to ensure quality programs. We have yet some distance to go in ensuring that people with developmental disabilities become OF communities rather than simply IN them.

A further worrying aspect is the ascendancy in industrialized countries of economic rationalism, which is leading to a marked reduction in distribution of resources to programs for people with disabilities generally. There appears to be a degree of sophistry in the assumption by governments that disability disappears once the individual has been "integrated" into the community.

Söder (1984) has wryly observed that "making the needs of the severely disabled invisible fills an economic function [that results in] strong political pressure for cuts in public sector expenditure" (p. 33). At least from a Swedish perspective Söder's main hypothesis is that "the optimistic and active ideology of the 1960s is changing as a result of economic difficulties into a pessimistic and passive one which is contributing to making the need the mentally retarded have of special resources disappear from sight" (p. 16). The strong suspicion that value systems are being misused by policy planners should make us vigilant concerning the possible ossification of the concept of quality of life.

On a more optimistic note, Mercer's (1991) prediction that by the year 2000 there will be a greater acceptance of the multiparadigmatic basis of the concept of

mental retardation will, it is hoped, lead to a greater appreciation of the need to approach the needs of this group from a more individual perspective. The recent developments in defining mental retardation in the context of support needs are a significant step in ensuring that the quality of life of people with developmental disabilities will be viewed more from their perspective, rather than from some bureaucrat's predetermined notion as to what constitutes "quality."

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