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ABSTRACT

The concept of quality of life (QOL) has become an important public policy and service delivery issue within the mental retardation/developmental disabilities field. QOL measurement focuses on a number of personal and environmental factors, including independence, productivity, living/residential environment, interpersonal and community relationships, and activity patterns. Three implications of this emphasis on QOL are discussed: cultural factors supporting the QOL concept; the conceptualization and measurement of QOL; and QOL enhancement practices. Cultural factors supporting QOL include values, legal concepts, and the way in which issues are addressed and problems solved. A QOL model is presented, proposing that a person's perceived QOL results from three aspects of life experiences (personal characteristics, objective life conditions, and perception of significant persons about individuals with disabilities) and is reflected in the measured indicators of independence, productivity, community integration, and satisfaction. Quality of life enhancement practices are then discussed, including fostering healthy environments, implementing QOL-oriented services, and fostering natural supports. (44 references) (JDD)

THE CONCEPT OF QUALITY OF LIFE IN THE LIVES OF PERSONS WITH MENTAL RETARDATION

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The concept of quality of life (QOL) has become an important public policy and service delivery issue within the mental retardation/developmental disabilities field. The importance of this "issue of the 1990's" (Schalock, 1990b) is at least twofold. First, for persons with mental retardation the current emphasis on QOL should result in program practices and habilitation services that enhance the individual's well-being and satisfaction. And second, the goal of an enhanced quality of life for persons with disabilities can become the basis for disability policy development, habilitation planning, service delivery, and program evaluation.

Interest in QOL and its measurement reflects a long tradition, beginning with the work of Thorndike (1939) and continuing with the seminal studies of the quality of American life by Campbell, Converse and Rogers (1976) and Andrews and

Whithey (1976). Within this tradition, attempts to measure a person's QOL have used one of two approaches: objective and subjective. The objective approach assesses external, objective social indicators such as standard of living, health, education, safety and neighborhood (Andrews & Whithey, 1976; Campbell et al., 1976). The subjective approach focuses on the person's perception and evaluation of one's life experiences, focusing on factors such as physical and material well-being, relations with other people, community activities, personal development, and recreation (Campbell, 1981; Flanagan, 1978, 1982).

Within the mental retardation/developmental disabilities field, QOL measurement has tended to focus on a number of personal and environmental factors including independence, productivity, living/residential environment, interpersonal and community relationships, and activity patterns. Examples of each of these are presented in Table 1.

Refer to Table 1

The measurement of QOL for persons with disabilities is still in its infancy (Schalock, 1990a). Despite this fact, plus concerns about the reliability and validity of QOL measures for persons with limited conceptual and verbal skills (Borthwick-Duffy, 1990; Goode, 1990; Halpern et al., 1986; Heal & Sigelman, 1990; Landesman, 1986), a number of factors reflecting a life of quality are beginning to emerge from the disability literature

Table 1

Quality of Life Measurement Areas Within The Mental Retardation/Developmental Disabilities Field

Focus Area	Factors Measured	Representative References
Independence	Decision Making Environmental Control	Schalock, Keith & Hoffman (1990)
Productivity	Employment Income Work Status	Halpern, Nave, Close & Wilson (1986) Kiernan & Knutson (1990) Schalock et al (1990)
Living/Residential Environment	Satisfaction Normalized Environment Neighborhood Quality Residential Alternatives	Heal & Chadsey-Rusch (1985) Bruinicks (1986) Halpern et al (1986) Borthwick-Duffy (1990; 1991) Rosen, Yoe, Dietzel & Simoneau (1989)
Interpersonal and Community Relationships	Social Support	Bruininks (1986) Halpern et al (1986) Intagliata, Crosby & Neider (1981)
	Social Interaction/Network	Bruininks (1986) Halpern et al (1986) Intagliata et al (1981;1980) Schalock et al (1990)
Activity Patterns	Community Activities	Bruininks (1986) Halpern et al (1986) Schalock et al (1990)

(Borthwick-Duffy, 1991; Cameto, 1990; Keith, 1990). Chief among these include environmental control and stability, decision making and choices, opportunities for personal growth and development, social and interpersonal relations, and satisfaction with one's living, work, and leisure/recreation environments.

The emphasis on quality of life and the work to date regarding this concept has direct implications for persons with mental retardation. The three major sections of this presentation discuss those implications as they relate to: (1) cultural factors supporting the QOL concept; (2) the conceptualization and measurement of quality of life; and (3) QOL enhancement practices.

Cultural Factors Supporting the QOL Concept

Social theorists talk alot about "macrosystems" that represent cultural trends and factors, and "microsystems" that reflect these trends and factors and relate to smaller units such as the individual, family, schools, or habilitation progams. These microsystems reflect the larger culture and embody that culture's values, laws and paradigm or way of thinking and organizing information. Quality of life is an interesting concept, since it encompasses both the macrosystem ("the quality of American life") and the microsystem ("the quality of my life"). This section of the presentation discusses three such cultural factors including values, laws, and paradigms.

Value Basis

Values represent principles or qualities that are intrinsi-

cally valuable or desirable. In a recent article, for example, Turnbull and Brunk (1990) argue for quality of life as value-driven policy, and that measures of QOL should be explicitly tied to values. In the article, the author also stress that there is a natural connection between the concerns for the quality of life of all Americans and the quality of life of Americans with disabilities.

> This connection is revealed in the new language that we, like the public philosophers, use. They share our vocabulary, language that is laden with such terms as quality of life, cooperation, fellowship, community as relationships, building community, fraternity ... and intentional associations. There is an underlying common measure of life for the public philosophers and for those of us in the disabilities field. (p.207).

Thus, liberty, equality and fraternity are overriding cultural values that both support and emphasize the concept of quality of life for persons with mental retardation. How these values are represented in the U.S. Consititution and have been encorporated into recent public laws are described in the following section.

Legal Foundations

Because all citizens of the United States enjoy the same basic human and legal rights, the types of choices and opportunities that determine the quality of life for a person without a disability apply equally to an individual who has a disabling condition. This premise is embodied in the United States Constitution and is also reflected in recent federal and state legislation aimed at either protecting persons with

disabilities against discrimination and other forms of unjust treatment, or establishing goals for persons with disabilities including the personal-referenced goals of enhanced independence, productivity and community integration (U.S. Department of Education, 1988).

In a recent article on the legal foundations of quality of life, we (Kaska, Keith, Schalock, & Powell, 1991) explored the legal bases for the factors used to determine the quality of life of persons with mental retardation or closely related conditions. A summary of the legal bases is found in Table 2. As can be

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Refer to Table 2

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seen, the Constitutional guarantees are based primarily on the 1st Amendment (freedom of association) and 14th Amendment (due process and equal protection clause).

Paradigm Shift

At its simplist level, a paradigm is a way of thinking, problem solving, or way of organizing information. Recently we have seen a "paradigmatic shift" in the disabilities field. Today, there are persons with disabilities who are expressing a new way of thinking about people with disabilities. They are beginning to develop personal future plans that include personal relationships, positive roles in the community, and increased control over their lives.

In the recent book The Structure of Scientific Revolutions,

Table 2

Quality of Life Measurement Areas Related to Constitutional Guarantees and Federal Statutory Law[a]

Constitutional Guarantees	Federal Statutory Law
Substantive Due Process	**Section 504 of the Rehabilitation Act of 1973**
Freedom from hurt or scare	Housing discrimination in federally funded programs
Training in home living	Denial of access to educational programming
Scheduling of appointments	**DD Assistance and Bill of Rights Act**
Access to living environment	Skill development programs
Interaction with neighbors, the community and living companions	**Fair Labor Standards Act**
	Employment
Procedural Due Process	Wages
Does not provide a substantive basis for QOL measurement; but once established (as per above), procedural due process comes into effect if there is a denial or reduction of service.	**The Education of the Handicapped Act**
	Skill development
	Educational programming
	Interaction opportunities
Freedom of Association	**Americans With Disabilities Act**
With whom one lives	Nondiscrimination in employment
With whom one associates	Barrier free environments
Activities participates in	
Right of Privacy	
Personal associations with others	
Control of individual space	
Equal Protection	
Equal treatment under the law (no invidious discrimination)	

[a] Adapted from Kaska, Keith, Schalock and Powell (1991).

Thomas Kuhn (1985) describes how the paradigm or approach we use to problem solving reflects both a culture's Zeitgeist ("mood of the time") and the techniques that hold promise for solving the issue at hand. And so it is with our current QOL-oriented service delivery system and its new-found paradigm characterized by:

- supports rather than programs
- persons rather than places
- person/environmental matches
- services in natural environments
- consumer empowerment
- real homes
- real jobs

To both the service delivery and program evaluation communities, this paradigmatic shift represents significant challenges. For service delivery, the primary challenge is to encorporate the above listed principles into service delivery practices; for program evaluation personnel, the challenge is to capture the desired outcomes from the new paradigm. Both of these challenges are described in subsequent sections.

In summary, quality of life is supported by a number of cultural factors including values, legal concepts, and the way we think about issues and solve problems. However, embedded in these cultural factors are also a number of other culturally-based reasons why studying and applying QOL concepts to persons with mental retardation are important. Chief among these

include the fact that the concept of quality of life:

- represents the true normalizing principle
- provides a yardstick or index in regard to how well and how much we are impacting the lives of persons with retardation
- contributes to a fuller understanding of the lives of persons with mental retardation
- reflects what we want for ourselves

The Conceptualization and Measurement of Quality of Life

A statement frequently heard in the area of QOL is that "we are data rich and theory poor." This section of the presentation addresses that issue by outlining our (Schalock, Keith & Hoffman, 1990) current model of QOL, which has and hopefully will continue to provide the theoretical basis for habilitation planning, service delivery, and program evaluation. In its broadest sense, the proposed QOL model proposes that a person's perceived QOL results from three aspects of life experiences including personal characteristics, objective life conditions and the perceptions of significant persons about individuals with disabilities, and is reflected in the measured indicators of independence, productivity, community integration and satisfaction. The model as outlined in Figure 1

Refer to Figure 1

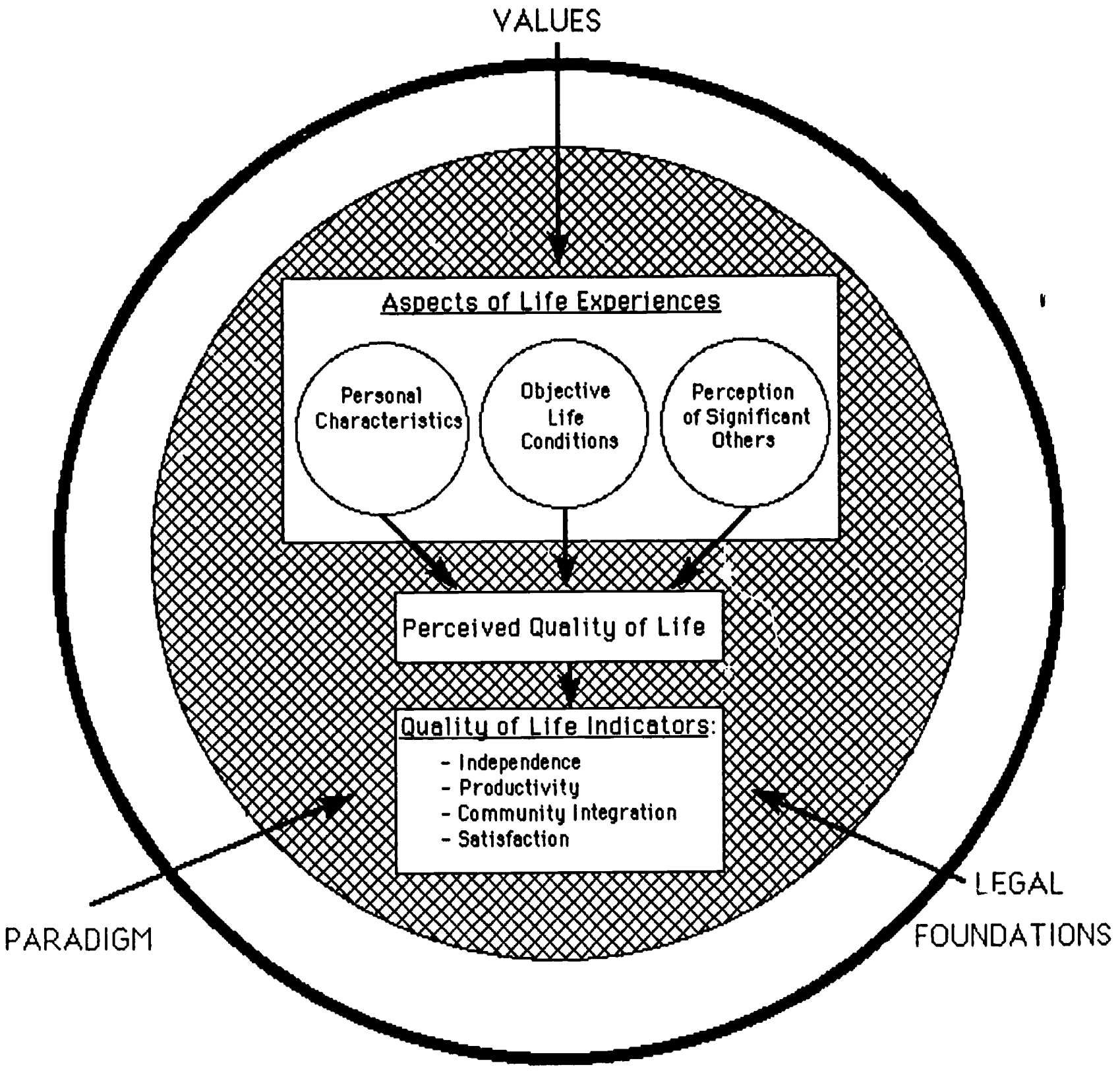

Figure 1. Quality of Life Model

(Schalock, 1991)

depicts the three cultural factors described in the previous section as major influence on the person's quality of life.

Aspects of Life Experiences

Three aspects of one's life experiences are proposed to impact significantly one's perceived quality of life. These include:

1. **Personal characteristics**. These are reflective of one's intellectual, physical, social, and emotional functioning (Anderson, Bush & Berry, 1988; Friedman, Furherg & DeMets, 1985). Examples of social functioning include feelings of support, family network, and friends network; physical functioning includes health status, well-being, symptoms/burden, and mobility; emotional functioning includes affect, mood, and sense of well-being; and cognitive functioning includes memory, visual-spatial, and hypothesis testing (Weiler, 1989).

2. **Objective life conditions**. Such conditions include marriage, family life, neighborhood, employment, housing. standard of living, amount of education, savings, and memberships in organizations (Campbell, 1981; Campbell, Converse & Rogers, 1976).

3. **Perceptions of significant others**. These perceptions are reflected in acceptance, encouragement, and opportunities provided by parents, peers, friends, and habilitation personnel (Goode, 1990; Schalock & Kiernan, 1990).

Perceived Quality of Life

QOL is necessarily subjective and cannot be inferred strictly from objective measures of conditions. In fact, there is general agreement that subjective and objective measures of QOL do not correlate highly, and that a valid QOL model requires the thorough study of both objective and subjective factors (Lehman, 1988; Milbrath, 1982). This points to the importance of having persons make a subjective evaluation of their life experiences that impact a person's personal beliefs about what is important and how the world works.

QOL Indicators

References was made earlier to the importance of the concept of quality of life and its measurement. In this regard, since 1985 we have developed, field tested, revised, standardized and used a 40-item **Quality of Life Questionnaire** (Schalock et al., 1990) that is based on the QOL model depicted in Figure 1. The Questionnaire can be considered a personal and social indicators scale that attempts to assess both objective and subjective measures of well-being. Specifically, the 1990 QOL Questionnaire measures the following four empirically derived QOL indicators that reflect desired outcomes from MR/DD-related habilitation services:

- **Independence:** as reflected in the opportunity to exert control over one's environment and make choices in one's life.

- **Productivity:** as reflected in income-producing work or work that contributes to a household or community.
- **Community Integration:** as reflected in participation in the same community activities as non-disabled persons, the use of the same community resources as non-disabled persons, and the development and experiencing of normalized social contacts and relations.
- **Satisfaction:** which is the fulfillment of a need or want, and the happiness or contentment that accompanies that fulfillment. Specifically, satisfaction relates to life in general, fun and enjoyment, personal experiences and feelings about one's general living/social situations.

Exemplary questions for each QOL indicator are presented in Table 3. Each of the 40 questions is scored using a 3-point

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Refer to Table 3

Likert scale. Directions for administration include:

> If the person is verbal, have him/her answer each of the following questions according to how he/she honestly feels. Help the person with any word(s) that is (are) not understood. If the person is nonverbal, have two staff independently evaluate the person on each item and use the average score of each item. Each of the four quality of life factors is scored separately. The score range is 10-30 per factor. A total score is obtained by simply adding the four factor scores.

Our recent research efforts have used the QOL model in Figure 1 and the 1990 QOL Questionnaire to identify a number

Table 3
Definition of QOL Factors and Examplary Questions

QOL Factor	Definition	Representative Examples
Independence	Reflected in the opportunity to exert control over one's environment, make decisions, and perceive choices.	22. Who decides how you spend your money? 24. How much control do you have over things you do every day, like going to bed, eating, and what you do for fun? 25. Do you have a key to your home?
Productivity[a]	Reflected in income-producing work or work that contributes to a household or community.	11. How well did your educational/training program prepare you for what you are doing now? 12. Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others? 13. How good do you feel you are at your job?
Community Integration	Reflected in participation in community activities, the use of community resources, and the development and experiencing of social contacts and relations.	37. Do you have friends over to visit your home? 38. What about opportunities for dating or marriage? 39. How do your neighbors treat you?
Satisfaction	Relates to life in general, fun and enjoyment, personal experiences, and feelings about one's general living/social situations.	2. How much fun and enjoyment do you get out of life? 5. How satisfied are you with your current home or living arrangement? 10. What about your family members? Do they make you feel: (a) an important part of the family; (b) sometimes a part of the family; or (c) like an outsider?

[a] If the person is unemployed, Questions 13-20 (which are job-related) are not asked. These items are scored as "1" in this case.

of significant correlates of the life experiences component of the proposed QOL model and the four QOL indicators. General results from these studies are summarized in Tables 4 and 5 and

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Refer to Tables 4 and 5

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described more fully in Schalock, Conroy, Feinstein and Lemanowicz (1991) and Schalock et al., (1989;1990). Generalizing from these studies, the significant factors identified to date that either enhance or impede one's measured quality of life include:

Factors That Facilitate		Factors That Impede
Adaptive Behavior	Social Presence	Negative Behaviors
Positive Health Status	Client Progress	Need for Medication
Income	Environmental Control	Setting Size
Integrative Activities	Positive Staff Attitudes	
Positive Physical Environment		

Quality of Life Enhancement Practices

The data summarized in Tables 4 and 5 indicate clearly the significant role that one's environment and habilitation services play on measured quality of life. If that is true, then there is a continued need to develop wholesome environments that will support a person's movement toward enhanced independence, productivity, community integration and satisfaction. To that end, three broad suggestions are discussed in this section including: (1) foster healthy

Table 4

Significant Correlates of the Life Experiences Component of the Proposed QOL Model[a]

	Significant Relationship[b]
Personal Characteristics	
Age	Negative (-)
Adaptive Behavioral Index	Positive (+)
Challenging Behavioral Index	-
Health Index	+
Need for Medication	-
Cognitive Level	+
Number of Disabilities	-
Objective Life Conditions	
Income	+
Integrative Activities	+
Physical Environment	+
Setting Size	-
Social Presence	+
Goodness-of-fit between Person and Environment	+
Employment Setting	+
Perceptions of Significant Others	
Perceived Client Progress	+
Environmental Control by Client	+
Staff Attitude: Job Satisfaction	+
Staff Attitude: Working with Person	+
Family Involvement	+

[a] Based on total scores as derived from the QOL Questionaire (Schalock et al., 1990).

[b] Based on significant ($p < .01$) Pearson Product Moment Correlations. Degrees of freedom varied from 264-1336. Total sample size across studies = 2660.

Table 5

Significant Correlates of QOL Indicators[a]

Indicators	Significant Correlates		
Independence	Adaptive Behavior (+)	Income (+)	Social Presence (+)
	Negative Behavior (-)	Integrated Activities (+)	Client Progress (+)
	Health (+)	Physical Environment (+)	Environment Control (+)
	Need of Medication (-)	Setting Size (-)	Staff Attitude (+)
Productivity	Age (-)	Income (+)	Client Progress (+)
	Adaptive Behavior (+)	Integrated Activities (+)	Evironment Control (+)
	Negative Behavior (-)	Physical Environment (+)	
	Health (+)	Employment Setting (+)	
	Need for Medication (-)	Social Presence (+)	
Community Integration	Adaptive Behavior (+)	Income (+)	Social Presence (+)
	Negative Behavior (-)	Integrative Activities (+)	Client Progress (+)
	Health (+)	Physical Environment (+)	Environment Control (+)
	Need for Medication (-)	Setting Size (-)	Staff Attitude (+)
Satisfaction	Adaptive Behavior (+)		
	Negative Behavior (-)	Integrative Activities (+)	
	Health (+)	Client Status (+)	
	Need for Medication (-)	Staff Attitude (+)	

[a] Data based on same references as listed in Table 4.

[b] $p < .01$ and greater (Pearson Product Moment Correlation)

environments; (2) implement QOL-oriented services; and (3) foster natural supports.

Foster Healthy Environments

There have been numerous recent demonstrations and reports concerning the significant role that environments can have in fostering positive behavioral growth and development (Edgerton, 1988; Fine, Tangeman & Woodward, 1990; Garber, 1988; Landesman & Ramey, 1989). The current situation is summarized well by Baumeister (1987) who states:

> ...given recent developments in the social-legal sphere together with a greatly enlarged scientific knowledge base, we can expect increasing pressure to fundamentally revise our conceptions of mental retardation. This will lead to new methods for valid diagnosis and classification. We can anticipate that classification systems will emerge with a much more balanced emphasis on both the individual and the demands and constraints of specific environments (pp. 799-800).

A major part of the reconceptualization that Baumeister refers to is the current focus on describing environmental characteristics that can either facilitate or hinder a person's growth, development, well-being, and satisfaction. More specifically, and as shown in Figure 2, wholesome environments

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Refer to Figure 2

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have three major characteristics including providing opportunities, fostering well being, and promoting stability (Schalock & Kiernan, 1990).

1. **Provide opportunities**. A basic truism is that, "you cannot benefit from an opportunity you've never had." And

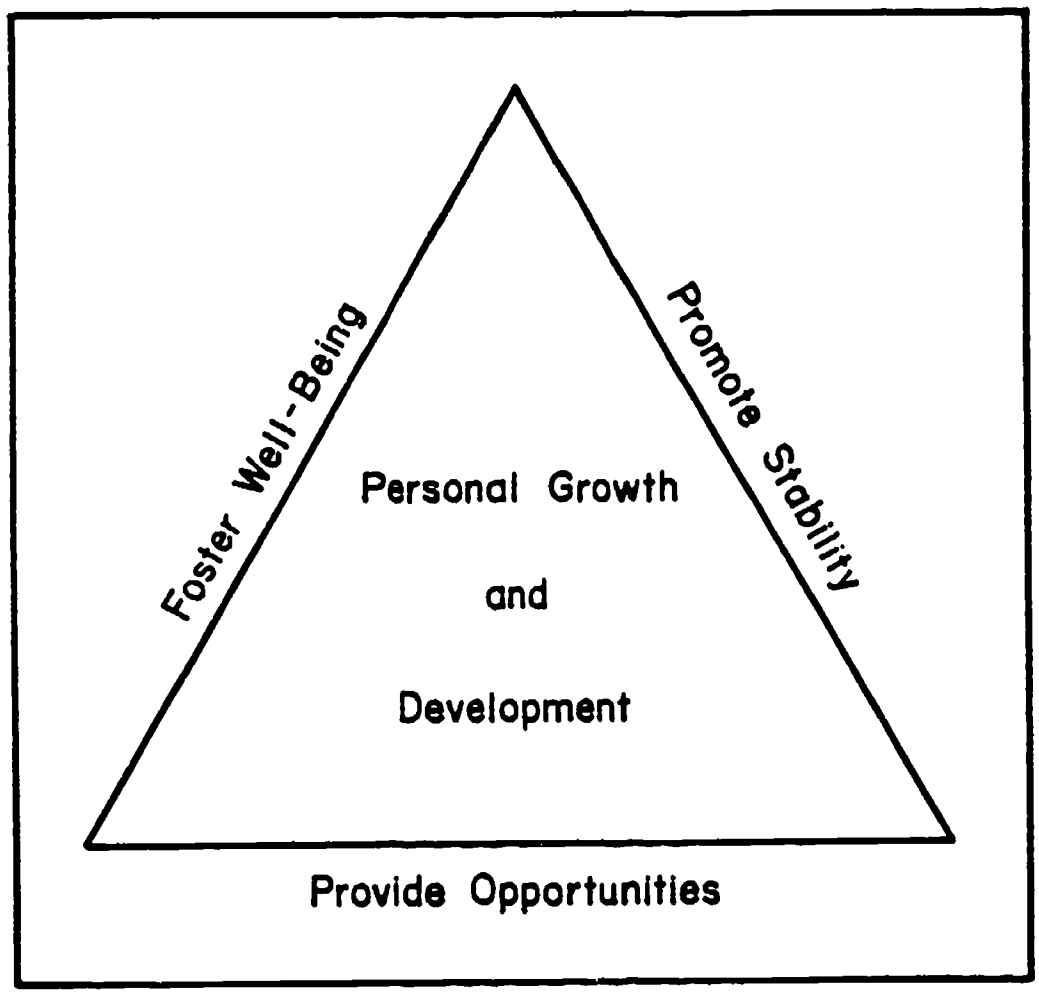

Figure 2. Qualities of Wholesome Environments.

providing opportunities to persons with mental retardation is one of our most important challenges and tasks. Providing education, living, work, and recreation-leisure opportunities in integrated settings create the opportunities that will allow the person to grow, develop, and experience an enhanced quality of life.

2. **Foster well-being.** Recently there has been considerable effort to identify factors within a person's environment that foster and enhance a person's well being. Four of these factors include (Blunden, 1988; Flanagan, 1978):

- **Physical**, including health and personal safety
- **Material**, including material comforts and financial security
- **Social**, including relations with other people, social, community and civic activities, and recreational activities within a wellness perspective
- **Cognitive**, including cognitive development, personal understanding and planning, work that is interesting, rewarding, and worthwhile, creativity and personal experience

3. **Promote stability.** One of the most important aspects of any environment is its quality of stability, with its associated aspects of predictability and continuity. The importance of such stability is supported by the demonstrated relationship between stability and enhanced learning, positive emotional affiliation and bonding, facilitative social support systems, and reduced stress.

Implement QOL-Oriented Services

The emphasis on enhanced quality of life for persons with disabilities will hopefully lead to improved services and outcomes in the 1990's, just as deinstitutionalization, normalization, and community adjustment have done in the last two decades. On the basis of the current literature, four key factors relate to a person's well-being and significantly influence one's quality of life. These four include physical, material, social, and cognitive well-being. The definition of each of these factors, along with suggestions regarding how service delivery programs can enhance a person's quality of life, are summarized in Table 6.

Refer to Table 6

Foster Natural Supports

There is currently considerable emphasis on the use of natural supports as an effective and efficient way to provide maximum habilitation services to persons with mental retardation (Nisbet & Hagner, 1988; Schalock & Kiernan, 1990). In this regard, it is important to conceptualize the different aspects of supports including types of resources, support functions and different levels of support.

1. **Support resources**. Supports can come from a number of resources including oneself, other persons, technology, and services. At the individual level, resources include skills, compentencies, choices, money, and information. Other persons

Table 6

Quality of Life Factors and QOL Oriented Program Practices[a]

Factor	Definition/examples	Suggestions to Maximize the QOL Factor
Physical	Health, fitness, nutrition	Safeguard the person's health, nutrition, and fitness Ensure adequate medical, dental, optical, physical therapy, and nutritional services
Material	Housing, possessions, income	Maximize the amount of disposable income that is under the person's control Safeguard and promote the physical quality of the home Promote quantity and quality of person's possessions
Social	Community presence	Promote access to community such as shops, leisure facilities, and places of education
	Relationships	Encourage a range of friends, family members, colleagues, and peers
	Choice	Allow choices over home, activities, possessions, and activities
	Competence	Develop basic abilities in communication, mobility, self-help, and social leisure skills
	Respect	Stress and allow for valued social roles and activities
Cognitive	Individual's life satisfaction	Encourage person, family, advocate's input Ask the person to evaluate personal satisfaction with the services received

[a] Adapted from Blunden (1988), O'Brien (1987), and Schalock and Kiernan (1990)

can also be resources and include family, friends, co-workers, co-habitants, and mentors. Technological resources include assistive devices, job/living accomodation techniques, and behavioral technology. Services are provided when natural supports are inadequate.

2. **Support functions** The focus of those resources, summarized above is typically on one or more of the following support functions:

- **Training** (developing adaptive skills)
- **Assisting** (with the performance of those skills)
- **Mentoring** (leading, guiding, and providing a role model)
- **Transporting** (within the community)
- **Networking** (accessing people and social support systems)
- **Accessing** and using technical devices

3. **Levels of support**. The levels of needed support vary across situations and life span. Four proposed levels include:

- **No support:** the person either performs the skill/activity on own, or procures the service on own
- **Minimum:** intermittent help or support in areas such as case management, transportation, home living, employment or self advocacy
- **Substantial/extensive:** involves regular (such as daily), ongoing supports and includes instruction, assistance (such as attendant care) and/or supervision within a designated adaptive skill area

- **Pervasive/consistent:** involves reliance on constant care or a 24-hour basis, including the maintenance of life support functions/systems.

It is important to point out that these support functions and different levels of support can vary both across adaptive skill areas and at different times and situations within a person's life. Additionally, supports should be used with outcomes clearly in mind. A model that shows the relationship between supports and desired outcomes is presented in Figure 3.

Refer to Figure 3

In conclusion, there are many persons with disabilities who are expressing a new way of thinking about people with disabilities. They are beginning to develop personal future plans that include personal relationships, positive roles in the community, and increased control over their lives. There are also those who believe that we have a "crisis in the community", and that we have created "islands of disability" rather than the promised opportunities of participation and integration (Smull, 1989). Never before has the concept of quality of life been a more important issue in the field of disabilities than it is today.

My strong belief is that the model and data presented today will not guarantee an increased quality of life for persons with disabilities, but rather a way to conceptualize quality of life

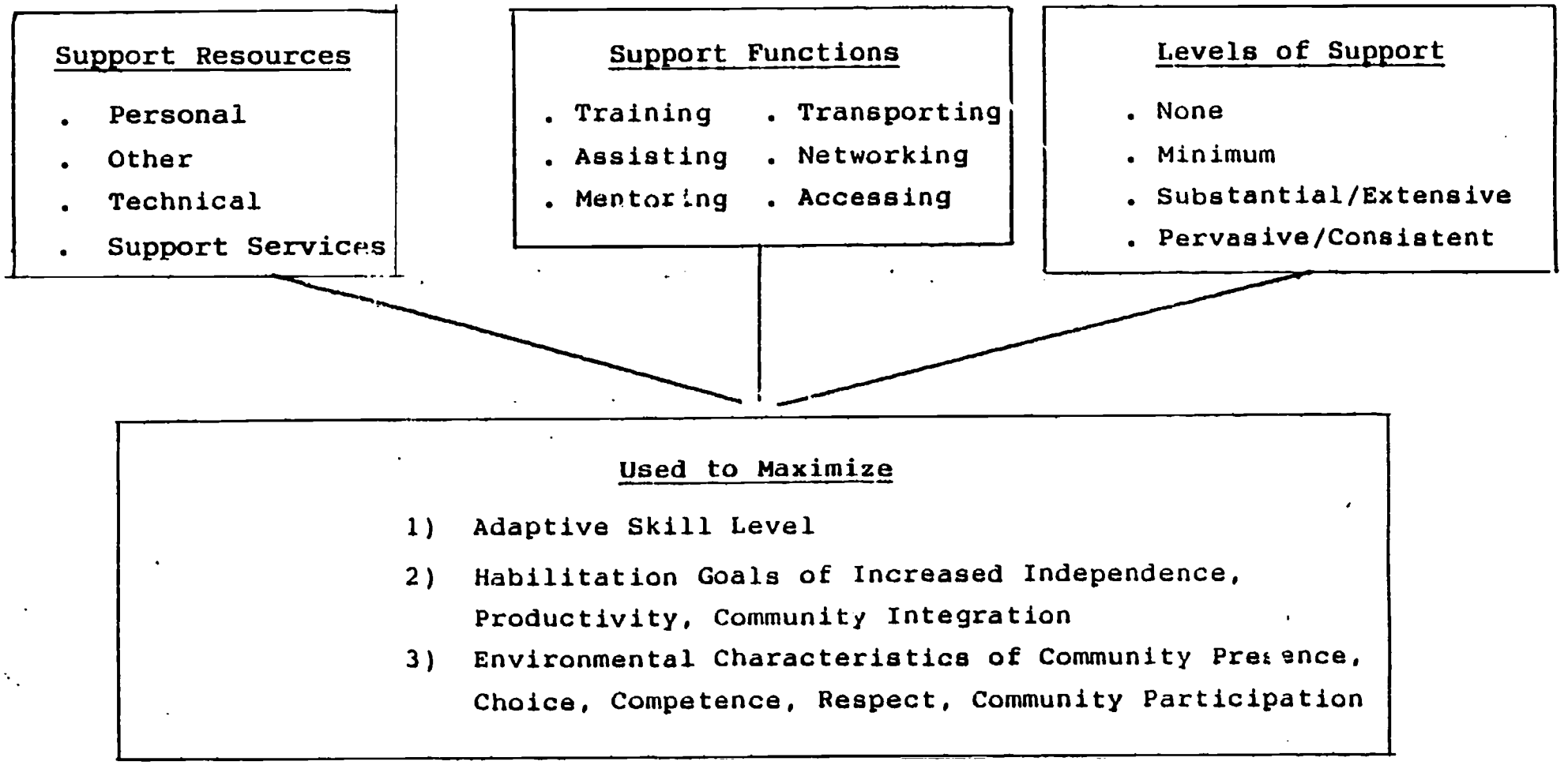

Figure 3. Supports-Outcome Model

as a method of asking questions to help evaluate the quality of life experience. In that sense, I hope that our work will be viewed as a tool to work more creatively at service design, delivery and evaluation.

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