

QUALITY CONTROL AND QUALITY ASSURANCE IN THE HUMAN
SERVICES FIELD: OPERATIONALIZING A MANAGEMENT MODEL

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Dedication

This project is dedicated to individuals everywhere who have never experienced an adequate quality of life in their existence on this planet. It is dedicated to those who develop a notion that life can be better and decide to take action to improve themselves in a positive and constructive fashion. It should not be surprising that while the choice is always there; timing, circumstances, fate, the degree to which others are willing to help create opportunities of quality, and hard work are also necessary to help make the majority of our achievements both realistic and possible.

This project is also dedicated to my father (Harold K. Gossett) whose humble and obscure life as been described and dignified by such writers as John Steinbeck and James Agee. I trust that my own children (as they grow older) will learn from their experiences in life not to judge others more harshly than they judge themselves. My hope is that they will be able to ask Pirsig's oft quoted statement "What's the betterness?" in all that they do. And as they go "round and round spinning their mental wheels," at some point, my faith is based on the premise that they will find their own traction.

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"Qualityyou know what it is, yet you don't know what it is. But that's self-contradictory. But some things are better than others, that is, they have more quality. But when you try to say what quality is, apart from the things that have it, it all goes poof! There's nothing to talk about. But if you can't say what quality is, how do you know that it even exists? If no one knows what it is, then for all practical purposes it doesn't exist at all. But for all practical purposes, it really does exist. What else are grades based on? Why else would people pay fortunes for some things and throw others in the trash pile? Obviously some things are better than others.....but what's "betterness"?.... So round and round you go, spinning mental wheels and nowhere finding any place to get traction. What the hell is quality? What is it?"

Robert Pirsig (1974), p.
178.

"God, I don't want to have any more enthusiasm for big programs full of social planning for big masses of people that leave individual quality out. These can be left alone for awhile. There's a place for them but they've got to be built on a foundation of quality within the individuals involved."

Robert Pirsig (1974), p.
352.

CHAPTER 1

INTRODUCTION TO THE PROBLEM

Quality control and quality assurance in the human services field is rapidly moving toward a focus on clients and their service experiences. At the same time, quality is emerging as a central theme in the administration of human service programs (Fox and Lubarsky, 1988). This emphasis reflects consumer concerns regarding service quality and parallel attempts by government bodies to reimburse human service programs for quality of care and quality of life.

Unfortunately, this pervasive concern for quality has not come packaged with definitions and measures which can be easily applied by human service providers. At present, each provider must struggle with requirements for quality without a clear understanding of what is demanded. This uncertainty fosters an organizational environment in which quality issues are frequently discussed but rarely acted upon. Bradley (1984) has indicated that to a large extent quality assurance activities have been put into place more to satisfy documentation requirements than to contribute to the development of service quality.

This research project was an effort to address the various mandates to establish adequate quality control and quality assurance mechanisms (Landesman, 1986). It also represented a serious desire to help organize the disorderly

material of the quality control literature into a conceptual structure that gives it coherence and meaning. In addition, methodologies were to be developed that are not linked to a sanctioning process but encourage quality enhancement through improved performance based on a sound measurement foundation.

An Overview of Quality Control

In order to improve quality control functions, a detailed model needs to be developed which identifies the key elements of quality of care and quality of life and their functional relationship in the quality control process. Regulatory approaches in the human services field have focused too often on the familiar tripartite aspects of the service delivery system: inputs, processes, and outputs with a major emphasis on standards compliance activities. As a result, human service providers often associate the concept of standards set by regulatory agencies with quality. From this perspective, quality is compliance with standards (Crosby, 1979). Thus Intermediate Care Facilities for persons who are mentally retarded (ICF/MR's) must comply with eight conditions of participation and 53 Standards (Federal Register, Vol.53, No.107, June 3,1988). Skilled

nursing care facilities (SNF's) must comply with 18 conditions of participation and with 90 standards. In addition, providers must comply with local and state requirements as to licensure and certification standards. The result is a view of quality characterized by innumerable dimensions and piecemeal definitions and a management structure where correction is problematic (Kane, 1987).

Defining the terms quality, quality of care, and quality of life is not an easy task. Some professionals believe quality is used with reference to so many aspects of the service delivery system such as access, availability, appropriateness, and cost effectiveness that it becomes impossible to arrive at a definition that is acceptable as well as useful (Coulton, 1982). Debates on this issue are predictably time-consuming and inconclusive. According to Crosby (1979, p.13) "The problem of quality management is not what people don't know about it. The problem is what they think they know."

The shortcomings of a compliance perspective on quality have led to many attempts to arrive at a more workable definition. Quality has been defined as consistently meeting the expectations of consumers (Anderson, 1987). While this approach has received a great deal of attention in the private sector, Kane and Kane (1988) have pointed out that consumer satisfaction in the human services field by itself may be an inadequate indicator of quality. A client

could easily lack the knowledge to evaluate technical aspects of care; could feel intimidated in expressing an opinion, or could become habituated to lowered expectations.

Brook and Williams (1975) viewed quality of care as an interaction between technical care (the adequacy of the diagnostic and therapeutic process) and the art of care (milieu, manner, and the behavior of the provider in delivering care to the clients). ICF/MR regulations refer to this interaction between technical care and the art of care as active treatment. It becomes an important issue to provider agencies because facilities may claim reimbursement only for the cost of care of clients classified for the ICF/MR level of care who are receiving active treatment. The problem with this definition is that active treatment is reported on in a negative fashion measured by deficiencies. This negative emphasis creates additional problems for institutional settings because they are affected by the environments in which they operate (Hasenfield, 1983). When an environment is negative and hostile, it is difficult for any organization to be excellent.

In addition to the objective impact of care (or quality of care), there are subjective evaluations by the clients of the service experience (Spalding, 1985). These are, in effect, judgments as to the quality of life as it is experienced by clients in a particular service organization (Osberg, et.al., 1987). By enhancing the level of positive

evaluations (quality of life), providers can maximize the functional gains of clients (Ward, 1984).

Quality of life has been defined as the goodness-of-fit between the quality of the life experience as subjectively evaluated and as objectively determined by assessing external conditions (Zautra and Goodhart, 1979). A recent Quality of Life Questionnaire developed by Keith, Shalock, and Hoffman (1986) has focused on environmental control (the degree to which one has control over his/her daily schedule, meal planning, grocery shopping, home decorations, appointments, and income); social interaction (as reflected in activities involving neighbors, co-habitants and friends); and community utilization (as reflected in recreational, educational, and other activities participated in by the person). These same authors have indicated that quality of life concerns will provide the impetus for improved services just as deinstitutionalization, normalization, and community adjustment were the major issues of the 1970s and 1980s. Efforts to measure quality of life to a large extent have not been properly designed for lower functioning clients and the relationship between quality of care and quality of life has never been clearly defined.

Deciding what to measure has also been a difficult task in determining the quality of services. Wray (1985) has repeatedly pointed out that in establishing an appropriate

quality assurance framework, there has been an over-emphasis upon input standards in regulating providers of services. Wray believed that outcome standards should be used as the foundation for selecting or eliminating certain input or process standards to help simplify the regulatory system.

At the same time, there has been little unanimity among top level managers as to the outcome criteria to be selected and used in monitoring residential facilities (Mayer and Rosenblatt, 1974; Polak, 1970; Smith and Metzner, 1970; Strauss, et. al., 1964; and Wessen, 1958). These differing perceptions about quality have been primarily attributed to the proposition that professionals will most likely develop divergent views as to what outcomes are important in evaluating the success or failure of a program. Wilder and Rosenblatt (1976) have demonstrated, however, that individuals from differing professional backgrounds can develop common viewpoints about quality assurance measures by working closely together on an on-going basis. Much of the controversy has centered around whether professionals can agree on the definitions of adequate care and whether such definitions are valid. Some have argued that professionally determined definitions are inherently biased toward a particular view of quality of care or quality of life that may not be consistent with the views of consumers (Leismer, 1984).

Professionals have also used the term quality assurance

in a broad fashion without substantial agreement regarding its boundaries. Coulton (1982) pointed out numerous internal (concurrent reviews, profile analysis, peer reviews, program audits, record reviews, utilization reviews and other evaluation studies) and external reviews (licensure, certification, and accreditation surveys) are what professionals refer to when they talk about quality assurance efforts. These internal and external quality assurance efforts typically identify a set of discrete indicators of program effectiveness, conduct needs assessments for each individual indicator, and develop a set of separate interventions designed to raise each indicator to some desired level that, it is believed, will produce improvements in program quality. The underlying assumption is that a set of independent variables (the indicators of quality effectiveness) affect the dependent variables (client outcomes). The emphasis has been on their separate effects.

There are difficulties with this approach. Haselkorn (1978, p.330) describes this situation succinctly:

There remains a number of thorny problems which will not be resolved simply with a deluge of forms, statistical tabulations, or postures of professional self criticism. What we are witnessing in the name of accountability, is often pseudo-accountability. This situation is especially evident in bureaucratic auditing and reporting, in the evaluation of records which may not reflect the quality of performance, in the empty compliance that may sacrifice service in order to give the appearance of accountability.

Although lip-service is generally paid to the importance of accountability, change-strategies focus on separate interventions for separate deficiencies and have not looked closely at the dynamic nature of the service delivery system itself. In spite of the efforts to develop relevant input-output models that assess the relative importance of different variables in influencing client outcomes, improvement strategies tend to assign equal importance to each intervention.

Finally, the lack of a clear theory about how indicators of program quality affect client outcomes makes it difficult to determine what the desired level of an indicator should be. This theoretical uncertainty also impedes understanding the importance of feedback relationships among client outcomes and future client and staff behaviors and the nature of system constraints that may severely limit the impact of a given policy. Nowhere do we find a systematic discussion of the dynamics of quality control.

If quality control is to take place, data as to inputs, processes, and outputs must be used in connection with the critical feedback loops needed to change organizational conditions and/or service delivery practices throughout the human services. This awesome responsibility requires not only the commitment of all staff who work in a human services agency; it also requires- beyond the rhetoric of

exhortations in praise of quality- a careful delineation of reasonable goals, measurement methods, review strategies, and constructive ways to ensure that corrective action is taken in a timely fashion. A quality control model is needed where the primary goal of the service delivery system is to improve quality of care and quality of life rather than the ease of bureaucracy.

A General Model of Quality Control

The relationships between quality of care/quality of life and client functioning are at the center of human service quality control systems. A functional view of quality as depicted in Figure 1 shows how client functioning is the result of the impact of quality of care and quality of life on clients.

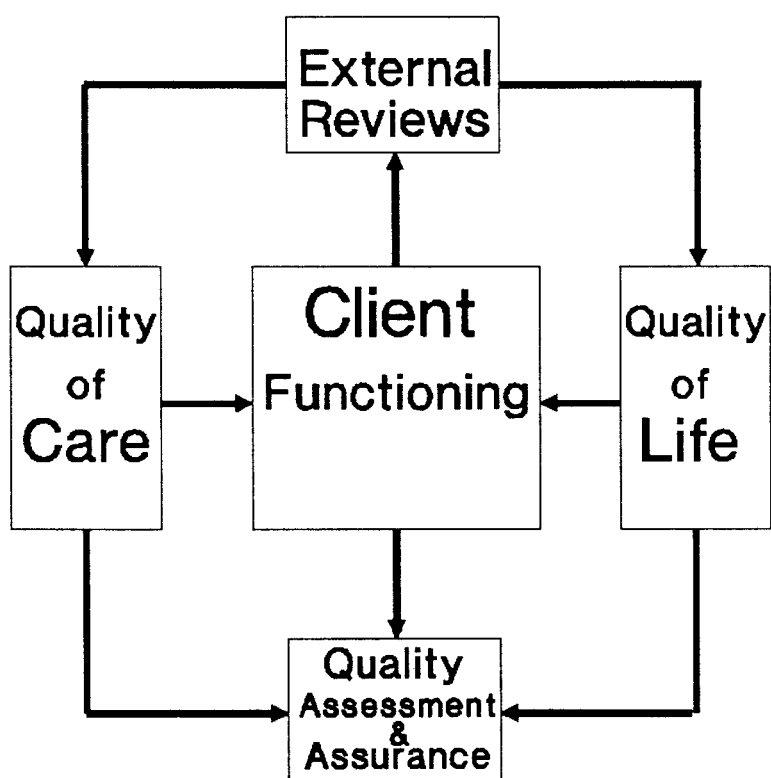
Figure 1 **A Functional
View of Quality**



By expanding upon this model, we can see in Figure 2 how information concerning functioning is used by consumers and managers to alter both quality of care as well as quality of life.

Figure 2

Quality Control Model Basic Structure

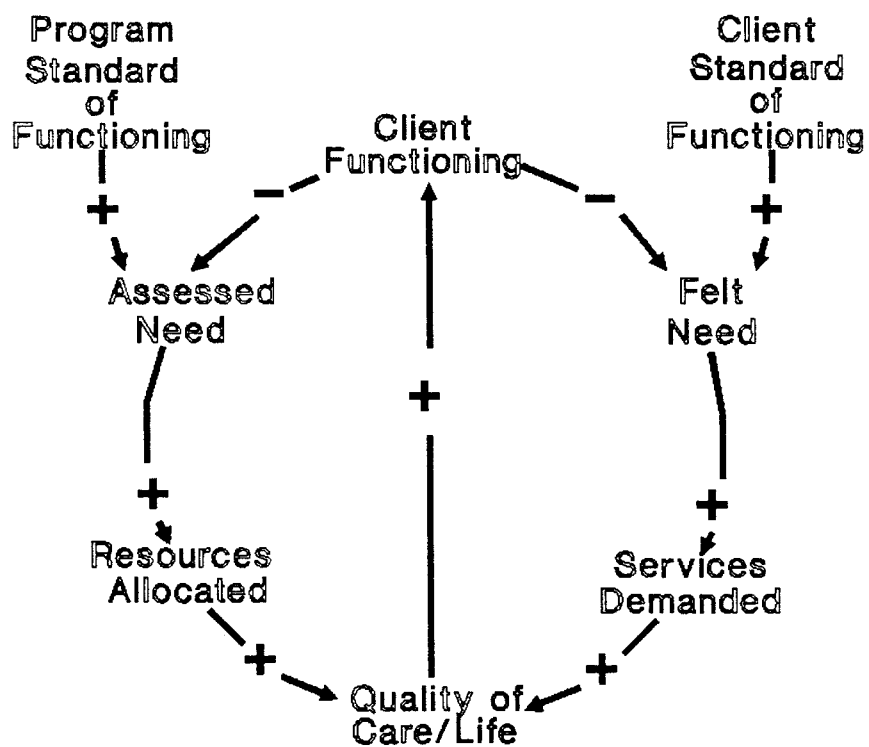


Implicit in this scheme is the notion of standards of functioning which are held by consumers and managers. These are used by way of comparison to determine whether observed client functioning is acceptable. Discrepancies between expected and actual client functioning should lead to adjustments in the quality of care and the quality of life so that functioning might be brought into line with expectations (Levin and Roberts, 1976).

These relationships are based on an assumption that the control structure is a negative feedback system in that the current measure of client functioning is subtracted from the standard of functioning and action is taken in proportion to the results of the subtraction (Roberts, 1981). According to Levin and Roberts (1976), any human services program would be classified as a negative feedback system governed by its operation to satisfy client need. The greater the need, the greater the demand; the greater the demand, the greater the program activity, and the greater the services rendered, the less the client need. The dynamics of the basic quality control network are depicted in Figure 3. The (+) sign indicates a direct relationship between the variables and a (-) sign indicates an inverse relationship between the variables (e.g. as client functioning goes down, needs increase).

Figure 3

Basic Quality Control Network^{*}



+ = Direct Relationship

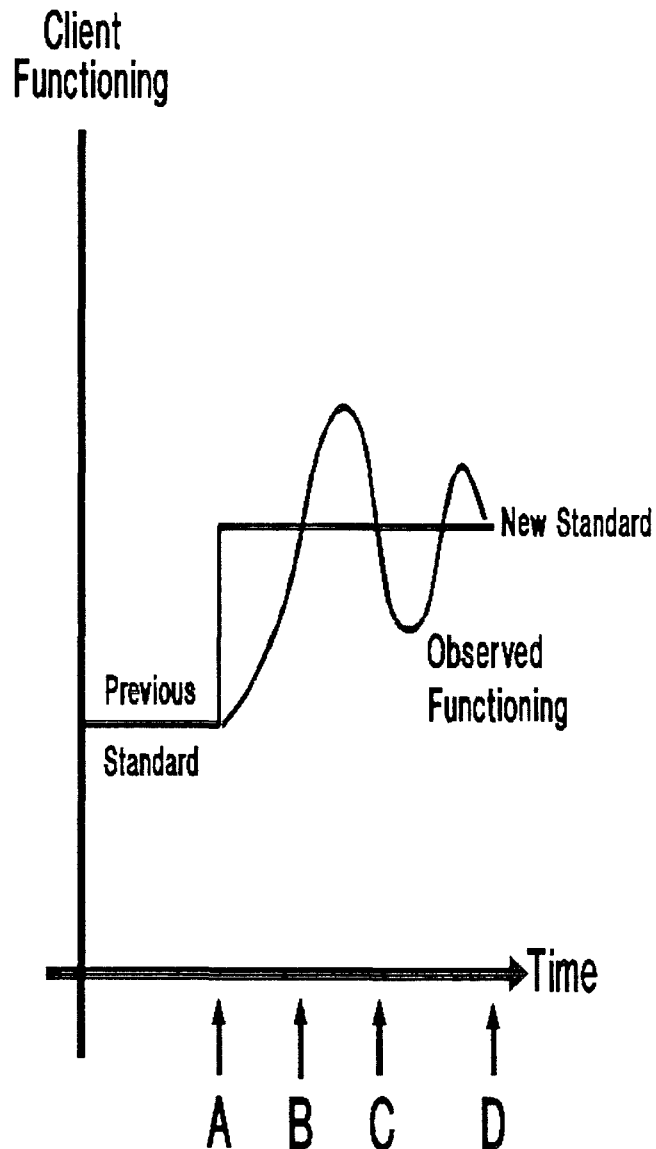
• Adapted from Levin & Roberts (1976)

- = Inverse Relationship

A human services program answers needs with services that reduce these needs, and consequently lessens the demand for services. Assessed need will generally require resources to be allocated to address those needs. Increased service demands for an individual client in a human services program will quite frequently increase the quantity of services delivered. As quality of care and quality of life increases, client functioning should improve (reducing client need as depicted by the inverse relationship in Figure 3).

Programs go into business, ultimately, to go out of business. Where gaps exist between performance and standards, need for service is generated and the system will shift from a steady state to a transient condition only when one or more of these gaps exist. The basic Levin and Roberts theory as it relates to quality control and quality assurance is that the goal of this system, and of all negative feedback systems, is to eliminate the discrepancies, to re-establish a steady state. If the system were initially under control (as indicated by the previous standard) and a new (higher) level of client functioning were set as a goal (A), changes would be expected in observed client functioning similar to those shown by the dynamics of quality goal attainment in Figure 4.

Figure 4 **The Dynamics**
of
Quality Goal Attainment*



• Adapted from Ammentorp & Oelschlager (1985)

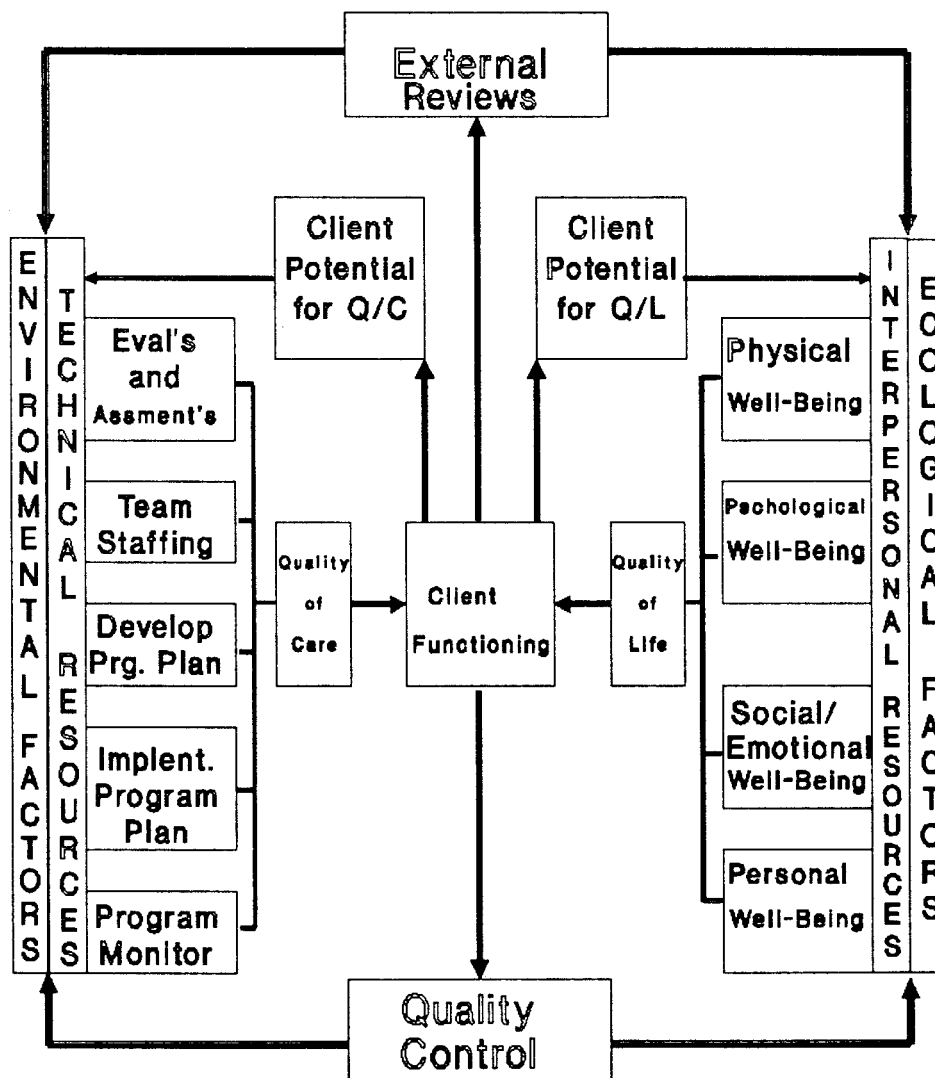
If the quality control system were working perfectly, we would see client functioning rise to the newly set goal (B). However, delays are inherent in this process. Functional discrepancies will lead to corrections in quality of care and quality of life. The result is a cyclic response like that shown by the observed functioning line in Figure 4 (Ammentorp and Oelschlager, 1985). The result is a high degree of variability in management emphasis on quality. In the early stages of a push for quality managers and consumers apply considerable pressure on the organization to improve both aspects of quality of care and quality of life. As client functioning meets and exceeds expectations, operations are allowed to decline in performance. When the decline becomes obvious in the functional shortcomings of clients (C) through existing consumer and manager feedback mechanisms, a new push (D) is initiated.

Cycles of this type are inevitable when there are only very general understandings of the quality-functioning relationship. In those cases, it requires very large-scale "pushes" in order to have any impact on client performance. If cycles and their associated waste of scarce resources are to be avoided, there must be a clearer understanding of those organizational variables which can be managed to improve quality of care and quality of life. To accomplish this, each concept must be factored into dimensions which express

its relationship to programs and client functioning. In Figure 5, the writer has identified these factors and the causal relationships whereby information can be used for quality control.

Figure 5

Quality Control Model



The best way to deal with the complexity of Figure 5 is to work from the inside out, that is, to examine how quality control decisions impact client functioning. This can be done in the form of a set of general propositions as follows:

- (1) Client functioning defines the individual's potential for both quality of care and quality of life;
- (2) Quality of care and quality of life have positive effects on client functioning;
- (3) Quality of care can be defined as a five-factor measure of services provided to the client;
 - A. Evaluations and Assessments
 - B. Team Staffing
 - C. Development of the Program Plan
 - D. Program Implementation
 - E. Program Monitoring
- (4) Quality of life can be defined as a four-factor measure of client experience;
 - A. Physical Well-being
 - B. Psychological Well-Being
 - C. Social/Emotional Well-Being
 - D. Personal Well-Being
- (5) The organization's capacity to deliver quality care and quality living experiences to the client is determined by its use of technical and interpersonal resources;
- (6) Quality Control is exercised by allocating technical and interpersonal resources to those activities which alter the components of quality of care and quality of life;
- (7) Environmental and ecological factors can also have an impact on client functioning and on quality of care and quality of life but are generally less responsive to management control than the other variables in this model;

- (8) Client functioning measures are inversely related to outcome monitoring and directly related to consumer satisfaction.
- (9) Quality is proportionate to the attainment of achievable improvements in client functioning.

Quality control procedures have typically been seen as a set of external activities which are expensive and limited by the capacities of external surveyors. As a result, assessment is often infrequent, inconsistent, and produces reactive rather than proactive responses (Kane and Kane, 1988). Quality control is not synonymous with quality assurance. Although, it is typically linked to a sanctioning process; it can still encourage quality enhancement through improved performance based on the use of information feedback in management decision making.

Quality assurance is an internal process whereby the expertise of the service provider is used to set standards and to evaluate performance. In recognition of these concepts, it is not surprising that accreditation agencies require facilities to:

- (1) develop their own standards of performance based on state-of-the-art knowledge;
- (2) measure their own performance through such mechanisms as peer review, self-imposed audits and credentialing requirements;
- (3) and govern their own performance through other mechanisms such as clinical privileging and professional staff membership requirements.

The implication is that professional providers must be responsible for the quality of their own work. Donabedian (1988) points out that a knowledge of quality is indispensable to rational management. However, the key to making use of this model in a human service organization is measurement. As providers are able to measure client functioning in relation to the factors associated with quality of care and quality of life, they can develop management systems to track program performance. These systems will, in turn, help managers identify which factors are most likely to impact quality and client functioning in their organization.

Up to this time, three measurements (client functioning, quality of care, and quality of life) have not been addressed in a synchronous fashion. Of the three, client functioning has received the greatest amount of attention. Mayeda, Pelzer, and Van Zuylen (1978) have reported on 134 instruments designed to establish performance measures of skill and adaptive competencies for persons with mental retardation and developmental disabilities. The A.A.M.D. Adaptive Behavior Scale (Nihira, Foster, Shellhaas and Leland, 1974), the Minnesota Developmental Programming System (Weatherman and Bock, 1976), and the Vineland Adaptive Behavior Scales (Sparrow, Balla, and Cicchetti, 1984) have been used widely throughout the country as comprehensive measures of client's behavioral

competency and behavioral repertoire in both residential and school settings. The recent development of the Inventory for Client and Agency Planning (ICAP) that measures adaptive and maladaptive behavior for program planning and evaluation purposes has been well received by service providers because of its strong psychometric properties that make it possible to assess persons whose eligibility for specialized services might otherwise be difficult to document (Bruininks, Hill, Weatherman, and Woodcock, 1986).

As client functioning takes center stage in the implementation of quality control and quality assurance systems, it will begin to exert a profound influence on the day-to-day actions of managers and staff. For example, the increased focus of both policy makers and providers on client functioning has resulted in what can be described as a case mix orientation to service delivery. What this means is that the condition of the client is measured against pre-defined functional standards and program success is referenced to changes brought about in the cases served by a given provider. This development is evident in the use of Diagnosis Related Groups (DRG's) in medicine (Cretin and Worthman, 1986); Resource Utilization Groups (RUG's) in long-term care (Fries and Cooney, 1983); Disability Groups (DG's) in mental health (Lewin, 1988); and Educational Disability Groups in education (Ammentorp and Weatherman, 1988). In each case, the performance of the provider

organization is measured against expected changes in client functioning. Eyman, Demaine, and Lei (1978) evaluated changes in client functioning over a three-year period with six PASS (Program Analysis of Service Systems, Wolfensberger and Glenn; 1975) environmental scores. Their results showed a number of PASS scores were significantly associated with positive changes in adaptive behavior for specified types of behavior. This is one of the few studies which have attempted to link the characteristics of organization and management with measures of client functioning.

Only two studies have been done to evaluate the relationship between client functioning and quality of life (Schalock and Keith, 1986; and Schalock and Lilley, 1986). Both studies report a statistically significant negative correlation between need level and quality of life. The higher one's level of need, the lower the measured quality of life. However, in another study, Schalock and Harper (1982) report significantly larger gains in client functioning in less restrictive (higher quality) environments.

Statement of the Problem

The components of quality identified in Figure 5 suggests that the backbone of an effective quality assurance model consists of feedback relationships involving the

identification of discrepancies in both quality of care and quality of life that can lead to action through outcome monitoring and consumer satisfaction. Since quality of care measures have been at the center of quality assurance and quality control efforts in the human services field, there is little problem in operationalizing this aspect of the model. However, the same cannot be said for quality of life. Despite the visibility given to quality of life in recent legislative initiatives (eg. the Omnibus Budget Reconciliation Act 87), there is little consensus as to how it can be measured and controlled by either regulatory agencies or human service providers.

The pressures for quality control and quality assurance found in long-term care, acute care, mental health, education, and the field of mental retardation all argue that quality is foremost among the measures of program effectiveness. By tying quality control with potential funding sanctions in the recent Look Behind initiatives, the Health Care Finance Administration has exerted tremendous pressure on the majority of human service providers. The result is a substantial unmet need to define quality of life in a clear, helpful fashion as a programmatic concept. There are also a shortage of operational definitions which can facilitate compliance with legislation and response to consumer demands.

The research reported here represented an attempt to

operationalize the concept of quality of life as it is experienced by clients who are mentally retarded and/or developmentally disabled. Thus, the research is directed at development and testing of an instrument for measuring quality of life. To this end, the research involved:

- (1) Identifying the constructs associated with the concept quality of life;
- (2) Preparation of scales which can be used to measure levels of the above constructs;
- (3) Conducting tests of candidate scales in order to:
 - a) Assess scale reliability;
 - b) Begin the process of validation of proposed quality of life constructs; and
 - c) Link measures with independent measures of quality of life based on consumer input.

These studies were based on the assumption that a quality of life concept exists and is shared among clients of MR/DD services. Further, it was assumed that the concept is made up of a set of latent constructs which are shared by both clients, parents, and service providers. Finally, it was assumed that statements (items) can be written and scales developed that bear a systematic relationship to the latent constructs. While these statements are plausible, they are also impossible to support because they represent latent, hypothetical concepts (Wiley, 1967). As a result, the measures growing out of this research can only be generalized to the specific individuals with mental retardation involved in this study. Only by subjecting the

resulting measures to further testing with other populations, can one gain confidence in their validity.

This research began to operationalize a general model of human service quality management through the development of an audit instrument designed to measure quality of life. By identifying factors associated with quality of life, it becomes possible to create a management environment where quality control in the human services field has a measurement foundation. In this way, the approach identified in this research activity will provide managers with a reference point for resource allocation and management decisions.

Definition of Terms

- (1) Quality: Refers to the achievement of excellence in services as measured by changes in client functioning measures.
- (2) Quality of care: Refers to the interaction between technical care (the adequacy of the diagnostic and therapeutic process and the art of care (the milieu, manner, and the behavior of the staff in delivering care to the client). The term is used interchangeably with active treatment.
- (3) Quality of life: Refers to the goodness-of-fit between the quality of life experiences as subjectively experienced by the client and as objectively determined by assessing external conditions.
- (4) Quality control: Refers to a set of internal/external procedures, tests, inspections, analyses, and audits linked together in a rational manner in order to accomplish some set of organizational quality objectives designed to ensure compliance with rules, regulations, or standards.
- (5) Quality assurance: Refers to the ongoing process of promoting excellence in the provision of services.
- (6) Quality enhancement: Refers to the achievement of successively higher standards in the quality and quantity of service delivery.
- (7) Standards: Refers to any set of benchmarks which can be used to evaluate services. These include rules, regulations, licensure requirements, Medicaid Standards, and Accreditation requirements. Standards can be viewed as inputs, processes, or outcomes.
- (8) Input standards: Refers to the raw materials from which a service is produced. These can be human or material resources.
- (9) Process standards: Refers to the actual performance of staff interacting and/or delivering services to clients according to accepted notions of good practice.

- (10) Outcome standards: Refers to changes in client functioning measures, consumer satisfaction measures, and changes in critical incidents as a result of service delivery.
- (11) Client functioning: Refers to the overall developmental level of each client including physiological/psychological well-being.
- (12) Consumer satisfaction: Refers to the increasing demand by advocates, relatives, guardians, elected officials, and the interested public for higher quality services.
- (13) Critical incidents: Refers, for example, to injuries, accidents, deaths, etc., that can impact adversely on both quality of care and quality of life.
- (14) Outcome monitoring: Refers to the systematic monitoring on a regular basis of expected and unexpected outcomes of service delivery.
- (15) Discrepancies: Refers to a gap between service expectations as identified by programmatic standards and the actual delivery of services. Discrepancies can be quantified as the number of deficiencies in an ICF/MR Survey conducted by the Department of Health.
- (16) Adjustments: Refers to corrective actions taken by an agency or program component within an agency to ameliorate and/or eliminate deficiencies or other identified problems.

Summary and Overview of Last Chapters

This study has been organized into five chapters for presentation. Chapter 1 has provided the introduction to the problem, overview on quality control, statement of the problem, purpose of the research, and definition of terms. A general model of quality control was introduced as a useful way to organize the development of a theoretical model describing the components of quality.

Chapter 2 provides the relevant literature review to support the development of a quality of life audit instrument that can be used to operationalize a proactive quality assurance feedback system.

Chapter 3 addresses the research design of the study and the sampling procedures to develop the audit instrument.

Chapter 4 deals with the analysis of the data collected from the F-sort, cluster analysis, importance study, item analysis, and factor analysis. The importance study collected data from clients, parents, and staff on the relative importance of the quality of life indicators. Nonparametric measures were used to determine if there were any meaningful differences among these groups.

The final chapter summarizes the study, presents major findings, discusses important policy implications of the findings, and suggests areas for future research and development.

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter presents a review of the literature related to the factors associated with quality of life. The review is organized under the following major headings:

- 1) Historical perspective on quality of life:
- 2) Quality of life as a multidimensional concept;
- 3) Ecological/environmental factors and quality of life;
- 4) Attempts to measure quality of life.

Historical Perspectives on Quality of Life

Formulations about quality of life have antecedents that date back to early philosophy. We can understand some of the historical, normative underpinnings by looking at the writings of Aristotle, Kant, and John Dewey. Aristotle's viewpoints represent the culture and thought of Greece in ancient times; while Kant represents the thinking of northern Europe during the Enlightenment; and Dewey, of course, is representative of the American twentieth century. These three individuals were chosen to help establish some breadth of representation in time and to demonstrate some of the differing notions as to the definitions and components of the quality of life concept.

Henderson (1947) has argued that the great philosophers have been interested in an attempt not only to understand the universe and man's place in it; but also, on the basis of that study, to formulate a conception of the kind of life that would best meet man's needs in the acquisition and transmission of excellences of body, mind, and character. Consequently, philosophers have been concerned not only with what is but also with what ought to be (Wingo, 1974). This has been an area of interest for human beings because such excellences (which are necessary to achieve a "quality of life") are neither innate nor automatically acquired in the course of natural experiences. The cultivation of excellences, however, is only part of the human problem because more is needed for the life and well-being of an individual than the mere possession of certain abilities and traits. Needed also, as Aristotle pointed out, are adequate natural endowment, favorable physical conditions, and a not too brief span of life (Ross, 1959).

Aristotle's Philosophy on Living Well- Eudaimonia

The Greeks may have been among the first to think philosophically about quality of life as they thought about the aims of education. The aim of education, or **paideia** was the transmission and acquisition of something they described as **arete**, which can also be viewed as the transmission and acquisition of **excellences** (Frankena, 1965). Arete referred

to all the qualities, dispositions, and excellences which they came to regard as desirable.

Aristotle did not believe that one's goal in life was simply to know what excellence is. He indicated in his discussion on Ethics in Book X that it was more important for man to endeavor to acquire excellences and then to act accordingly (Aristotle, Chapter 9, 1179b). The good that comes out of this is happiness or living well (**eudaimonia**). Living well (**eudaimonia**), according to Aristotle, would be considered synonymous with the modern use of the term **quality of life**. However, it would not be viewed as pleasure, enjoyment, or contentment; and it certainly would not be perceived as living it up. Aristotle would say that something is good if it is desired or aimed at for its own sake (excellent intellectual activity) while other things are sought for the sake of themselves. He would say that something (morally excellent activity) was good if it occurred in moderation and a person found the mid-point between whatever extremes confronted them. This is why he believed that happiness (living well or **eudaimonia**) was the ultimate goal of all human striving. Once it was achieved, it would satisfy completely and nothing more would be sought after. It would be a life one would find pleasant and be contented with if it were achieved; but the happiness would come from the kind of life or activity that is desirable, not from the enjoyment that may accompany it.

Kant's Philosophy on the "Summum Bonum"

While Aristotle ranked the intellectual excellences as the highest, Immanuel Kant's eighteenth century viewpoint placed its emphasis on moral excellences. Morality seemed to be Kant's favorite subject. He believed that education must see to the moralization of man in acquiring the skills needed for all sorts of ends; including the disposition to choose only good ends (Churton, 1960).

Kant sharply rejected in his writings the celebrated principle of Aristotle which located virtue in the mean between two vices. Kant argued that virtue was not a matter of the degree to which one follows certain maxims, it was also a matter of the maxims one possessed in the first place (Gregor, 1964).

Self-mastery was Kant's answer as to the first step towards the formation of a good character capable of controlling one's own desires and inclinations. To achieve this level of maturity, each person needed to be grounded with the essential knowledge and information to cultivate their own moral disposition.

The combination of moral perfection, natural perfection, and happiness is what Kant called the **summum bonum** or the highest good. From his perspective, it alone would be regarded as the whole end of man and creation. The achievement of the summum bonum would represent the highest quality of life (**humanity**- the end and destiny of man).

The development of the best in each person is an idea which allows us to formulate and cherish ideals that creates an interest in the hierarchical concept of quality of life measures and differences in quality of life outcomes. As a result of Kant's efforts, this subject does not have to be approached by anyone in an opprobrious manner.

Dewey's Philosophy on the "Good Life"

Just as Kant's world was not Aristotle's, Dewey's world was tremendously different because of the industrial revolution, theory of evolution, use of the scientific method, and theories about social democracy. In opposition to Aristotle and Kant, Dewey insisted that excellences could not be divided into two separate types. Instead, he said that any question about what kind of a self one is to be is a moral question; so therefore, all dispositions are moral since they enter into the being of the self. Thus, he rejected Aristotle's distinction between moral and intellectual excellences and Kant's distinction between moral and natural perfection. All education was moral as he defined it "as the continuous reconstruction of experience or as the enrichment of the content or meaning of experiences" (Dewey, 1960, p.16).

Even though Dewey wrote a great deal about education over a period of 65 years, it is very difficult to find any systematic account of the dispositions to be formed in looking at a higher quality of life. If one looks at his philosophy

as a whole, however, there are many dispositions advocated by Aristotle or Kant that would have to be quickly abandoned.

These would include any attitudes or beliefs that were dependent on a rationalistic theory of knowledge or supernatural explanations based on a belief in God or immortality of the soul. These attitudes and beliefs were incompatible with Dewey's position on the nature of the scientific method which required that all of the premises about the nature of man/world which are used in determining what dispositions are to be fostered or how they are to be fostered must be empirically testable.

As a result, Dewey was actually against the fostering of many dispositions advocated as excellences by other philosophers who were also interested in improvements in quality of life. However, if there is anything that Dewey is noted for, it is that persons should acquire the dispositions called for by democracy as both a form of government and as a way of living with others. Thoughtfulness and aesthetic tastes are two separate dispositions that Dewey felt were important parts of the education of man in a democratic society.

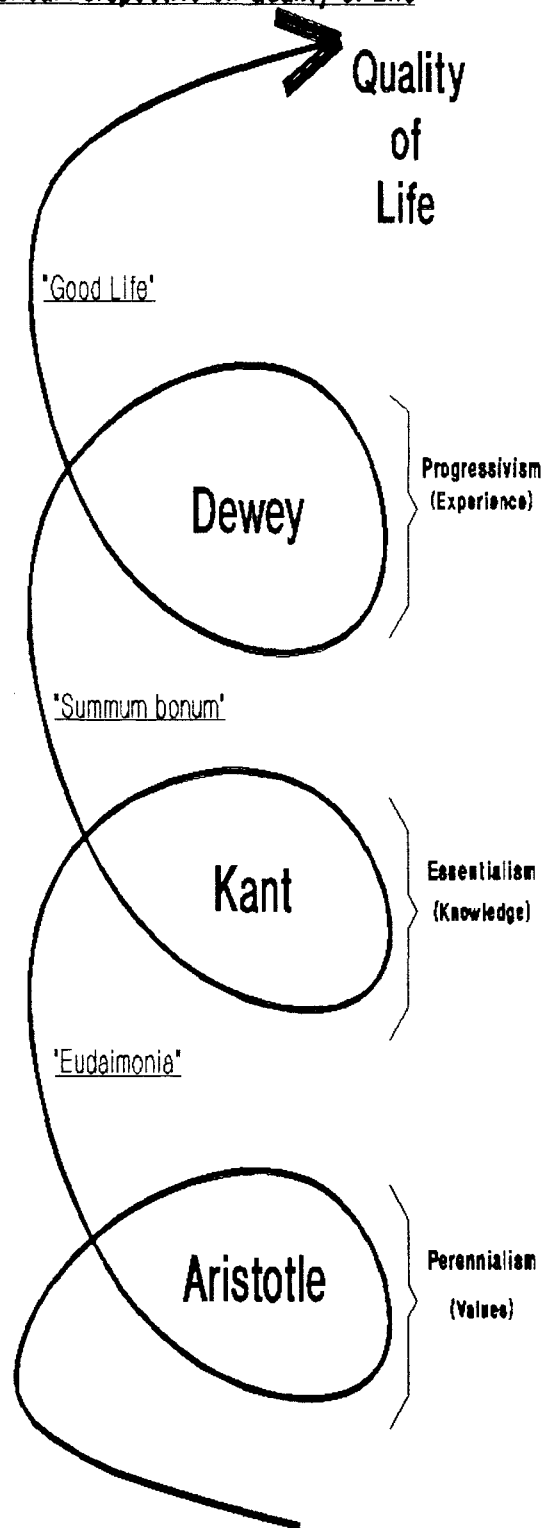
The good life according to Dewey would be a harmonious whole consisting of good experiences or values. These experiences or values are achieved through intelligent action, that are approved after reflection in the light of full knowledge of their conditions and consequences, and are

enjoyed as being so achieved and so approved. Such enjoyments were referred to by Dewey as the **consummatory experiences** and represent a higher level of quality of life experiences.

It is important to note the good life rejects hedonism, the view that pleasure is the end or the good. Dewey felt the hedonists were wrong in identifying happiness or well-being with pleasure. Happiness was seen as the satisfaction of the whole self while pleasure was perceived as the satisfaction of a single and independent appetite dependent upon external pleasures. Excellence of body meant satisfaction of one's whole self from a highly stable standpoint.

This discussion on a historical perspective of quality of life may be summarized by looking at the characteristics and features of Figure 6.

Figure 6: Historical Perspective on Quality of Life



Quality of Life as a Multidimensional Concept

The conceptual exploration of quality of life is as Donabedian (1980) put it "an exasperating complex subject". Given the state of affairs of the day, the definitions may be almost anything anyone wishes them to be; although they ordinarily reflect the values and norms associated with the well-being of individuals rather than the value of life of the larger society of which they are a part (Cohen, 1983). The literature suggests that quality of life is not a unitary concept (Diener, 1984 and Gilmartin et al., 1979). Instead, it is made up of components which, when added together, make up the quality construct as seen by professionals and clients. As each component is discussed, a more detailed submodel is presented of causal linkages between the variables. Although it is not possible to prove that variation in one phenomenon causes simultaneous or later variation in another phenomenon, the causal models are used heuristically to force explicit statements about how the concepts are assumed to affect one another in order to produce the relationships that are theorized. It is generally accepted that models that cannot closely reproduce the observed data, or that require theoretically or empirically unreasonable parameters to do so, are surely not accurate representations of how the world actually works. The literature suggests that the following factors are central to the quality of life construct.

Physical Well-Being

Maddox and Douglass (1973) have stated that physical well-being is probably a necessary part of the foundation upon which more subjective dimensions of life quality rest. Ironically, despite the importance of health to quality of life, there is no simple or straightforward way to define or measure health. Health, itself, is a multidimensional concept, with different dimensions suitable to different research questions. Sullivan (1966, p.6) indicates that health is more than just the absence of disease, it is also "physical and emotional well-being."

Four major approaches have been used to define and measure physical health: A. subjective health ratings, B. symptom or illness inventories, C. measures of physical functional status, and D. multidimensional measures of functional status.

A. Subjective health ratings attempt to measure an individual's perception and evaluation of his or her overall health status. Maddox and Douglass (1973) provide an excellent overview of the uses and correlates of subjective health ratings. They believe very strongly that self ratings of health have utility as a measure of health because of the demonstrated significant relationship with the ratings of physicians. Other subjective health ratings reported on in the literature include Suchman, Phillips, and Streib (1958), Shanas (1962), Tissue (1972), and two Duke University longitudinal studies to assess age changes (1978).

The appropriate usage of subjective health ratings, however, is still an unanswered question because it is not clear to some researchers exactly what they measure. George and Bearon in their book Quality of Life in Older Persons (1980) believed that subjective health ratings are best used as a control variable in studies where the investigator wishes to eliminate the confounding effects of health and at the same time, use an inexpensive and convenient method to determine where more extensive medical followup is needed. Such ratings would not be useful for measuring the distribution or incidence of illness or the degree of illness limitation or disability.

B. Symptom or illness inventories rely upon respondents self-reports of ailments. Subjects are asked to report whether or not they suffer from this list of items. For example, the Health Index developed by Rosencranz and Pihlblad (1970) asks respondents to examine a list of 40 illnesses or medical conditions and report which ones they currently have. Subjects are also asked to report specific health problems experienced in the past four weeks and any complications resulting from these recent health problems. In addition, type of illness and length of illness are weighted in the calculation of index scores as important illness indicators.

Illness inventories have been found to be relatively inexpensive and convenient to administer. However, the

reliable reporting of specific illnesses has been found to depend to some degree upon the diagnostic experience of the person. In order to accurately report an illness, a respondent should ideally have been examined by an appropriate health care professional, have been told the diagnosis in detail, and have understood and remembered the diagnosis. Unfortunately, it is impossible to insure that persons with mental retardation and developmental disabilities would fulfill this criteria.

C. Measures of physical functional status relate directly to the ability to perform social roles, while measures of general health can basically ignore this component. In developing the Functional Status Index, Reynolds, Rushing, and Miles (1974) clearly distinguished functional status from general health. These authors believe that measures of physical functional status are probably more sensitive to change as potential measures of quality of life than subjective health ratings or illness inventories by themselves.

Subjects are asked to report activity limitations, difficulties in mobility and self-care, and whether or not they have the ability to perform expected social roles at home, at school, or in a work setting. Measures of functional status are designed to measure the effects of disease through behavioral aspects of functional status rather than the existence of disease. Functional status has been considered

the component of health that is probably most sensitive to change and hence; the one factor best suited as an indirect measure of quality of life (Reynolds, Rushing, and Miles, 1974 and Sullivan, 1966).

D. Multidimensional measures of functional status include not only the assessment of physical functional status; they are more comprehensive. They typically include such factors as mental health status, quality of interpersonal relationships, and social and economic resources. The OARS Multidimensional Functional Assessment Questionnaire developed at Duke University (1978) consists of 72 questions designed to measure current functional status in five dimensions: social resources, economic resources, physical health, mental health, and capacity for self-care and activities of daily living. Each dimension yields a functional status score that has been well documented in terms of reliability, validity, and sensitivity to change.

Physical well-being was also identified by Flanagan (1978) as a quality of life component through an inductive process of gradual refinement of 6,500 critical incidents reported from 3,000 persons of various ages, races, and backgrounds representing all regions of the United States. He felt that freedom from sickness, possessing physical and mental fitness; avoiding health hazards and the effective treatment of health problems served as a foundation for a good quality of life.

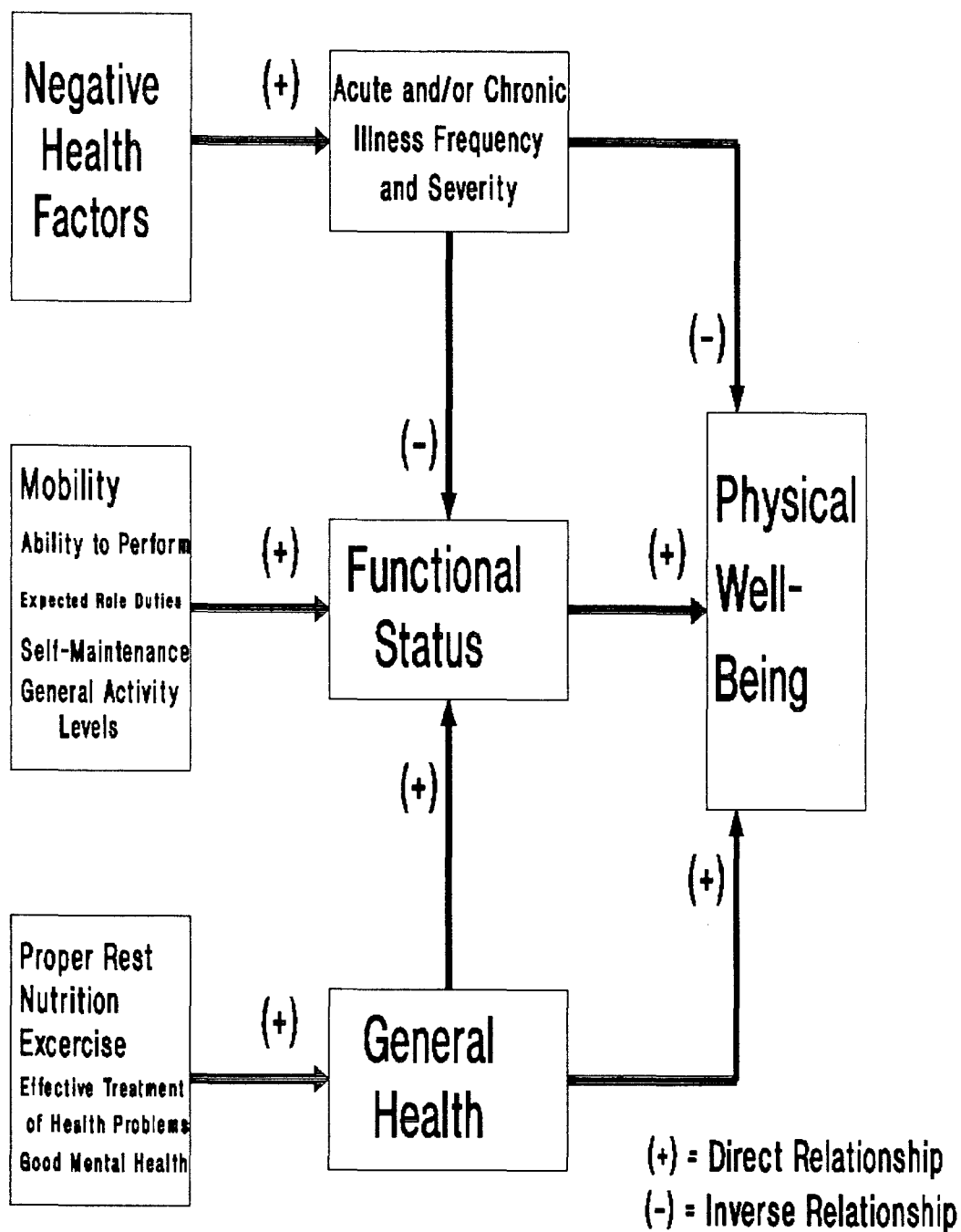
Stokols, Shumaker, and Martinez (1983) would agree with

the importance of this factor. They found a lower quality of life associated with a higher prevalence of health problems and increased personal mobility rates (frequency of lifetime moves). Reker and Wong (1984) also identified physical well-being as a separate factor in the development of their Perceived Well-Being Scale. Subsequent administration of this scale to 238 subjects confirmed the meaningfulness and internal consistency of this particular factor.

Pearlman and Uhlmann (1988) have completed what is perhaps the most extensive work on the relationship between physical well-being and quality of life. They interviewed 126 elderly outpatients with five common chronic diseases (arthritis, ischemic heart disease, chronic pulmonary disease, diabetes mellitus, and cancer) to ascertain what comprises quality of life. To their surprise, Pearlman and Uhlmann found that in general, elderly patients with chronic diseases considered their quality of life to be good enough in that they had no major complaints. This finding was in contrast to their physicians who rated their patients quality of life as being significantly worse. General health demonstrated the most consistent correlation with global quality of life assessments as reported by the elderly patients in this study.

These findings suggest to the writer that physical well-being is a multidimensional construct and it is embedded in a causal structure like that depicted in Figure 7.

Figure 7: Schematic Sub-Model of Causal Linkages Related to Physical Well-Being



In this model, functional status is one component of general health. It includes such factors as mobility, the ability to perform expected role duties at home or in the work environment, self-maintenance, and a general, overall energy level. It is placed between general health and the frequency and severity of illness because it emphasizes the effects of disease rather than the existence of disease. The model suggests an inverse relationship between illness frequency and severity and functional status. As functional status is decreased by an increase in the frequency or severity of an illness, perceptions of physical well-being should also be affected in a negative fashion. However, since functional status is directly related to physical well-being, its presence even in the face of illness helps to explain how chronic patients in the Pearlman and Uhlmann (1988) study could rate their quality of life good enough that they did not have any major complaints in contrast with their physician ratings.

Psychological Well-Being

Psychological well-being refers to an assessment on a cognitive level that life conditions and aspirations are closely matched (Andrews, 1981; Mason and Faulkenberry, 1978; and Michalos, 1983). When this is the case, there is congruence between what people have and what they aspire to be or what they want out of life. If there is a gap or discrepancy between these variables, psychological well-being

will suffer in a negative fashion. George (1979, p.210) defined psychological well-being as "essentially a cognitive assessment of one's progress toward desired goals."

A number of research studies support this theory for persons whose choices have been limited in their ability to function independently (Beck, 1982; Langer and Avorn, 1985; Langer and Rodin, 1976; Seligman, 1975; and Schulz and Brenner, 1977). In addition, Spalding (1985) found that persons in nursing homes experienced greater frustration when they did not have the choice of a physician and when they lost the ability to make decisions over small details in their everyday lives. It was apparent that a lack of choices only accentuated the gap or discrepancy in the lives of these persons and created psychological discomfort as opposed to well-being.

This particular area of inquiry can be traced back to the work of Marie Jahoda, Current Concepts of Positive Mental Health (1958). The book contains self-reports of individuals detailing accounts of their happiness, life satisfaction, and psychological well-being. Having options and choices as an aspect of increasing independence and exercising freedom was consistently portrayed as a characteristic of positive mental health.

It is also important to note that Abbey and Andrews (1986) report that in a stepwise regression analysis, the predictors related to psychological well-being consistently explained the

greatest variance (54%) in life quality regarding the self.

Other factors that have been linked in both positive and negative ways to psychological well-being include the effects of depression, anxiety, and stress; perceptions about internal versus external control over one's life; the adequacy of social supports; and the role performance plays on well-being. These factors will be considered separately.

A. Depression, anxiety, and stress have been found to be linked together in a direct fashion (Beck, 1976). It is widely accepted that depression and anxiety are common reactions to stress. At the same time, an extensive research literature documents the negative impact that stress typically has on psychological well-being (Caplan, 1983; Holmes and Rahe, 1967; Pearlin, Menaghan, Lieberman, and Mullan, 1981; and Selye, 1980).

The impact of life events such as the death of loved one or relocation trauma will create stress (Braddock and Heller, 1985; Dohrenwend and Dohrenwend, 1978; Vinokur and Selzer, 1975; and Williams, Ware and Donald, 1981). Long-term conflicts at work or within family systems will also create stressful situations that will affect psychological well-being (Conroy and Latib, 1982; French, Caplan, and Harrison, 1982; and House, McMichael, Wells, Kaplan, and Landerman, 1979).

Research findings have also shown that persons under stress are more susceptible to illness (Caplan, Cobb, French, Harrison, and Pinneau, 1980). In a recent study, Abbey and

Andrews (1988) identified role ambiguity, negative life events, and social conflict as factors directly related to stress and negatively related to life quality.

B. Internal versus external control is a factor that Keith, Shalock, and Hoffman (1986) included in their Quality of Life instrument. It is a topic that has been identified as being important to quality of life research. Abbey and Andrews (1988); Abbey, Dunkel-Schetter, and Brickman (1983); Abramson, Seligman, and Teasdale (1978); Johnson and Sarason (1978); and Wortman (1976) hypothesized that perceptions of internal control were positively associated with well-being while perceptions of control by others would relate negatively to life quality.

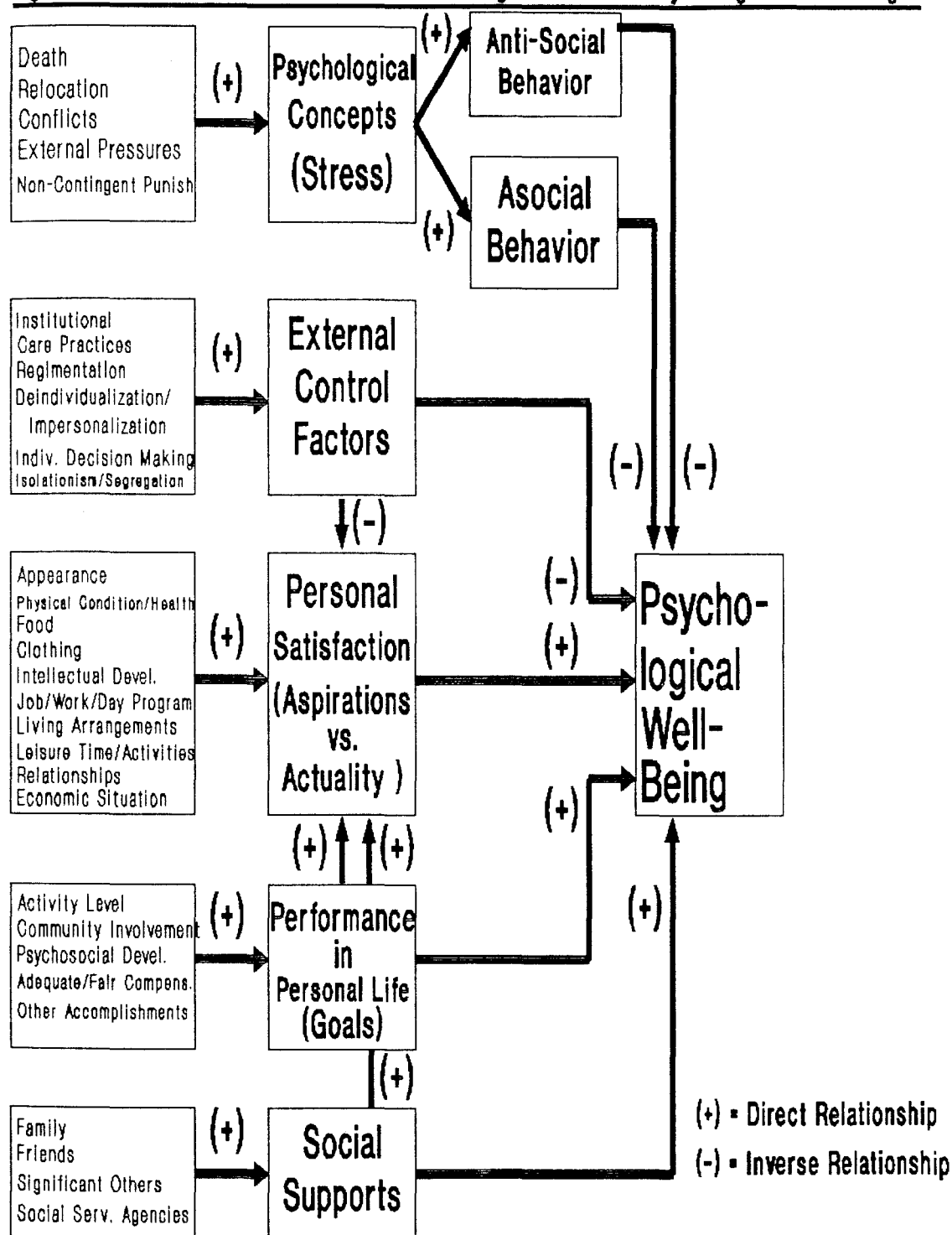
Schalock and Hill (1986) included a section on individual decision making in their approach to assessing the status of community life. Shipe (1971) identified having a sense of control over one's individual destiny (locus of control) as being highly correlated with achievement and personal and social adjustment among mildly retarded persons who appeared to be managing successfully in community settings.

C. Social Supports refer to the extent to which individuals perceive positive regard, feelings, affection, encouragement, and validation from family, friends, and significant persons in their lives. An extensive literature demonstrates the beneficial effects of social support on well-being (Abbey, 1983; Cobb, 1979; Kahn and Antonucci, 1980; and

Sarason, Levine, Basham, and Sarason, 1983; and Veroff, Kulka, and Douvan, 1981). Social supports have also been related to decreased depression and anxiety and improved life quality in previous research (Abbey, Abramis, and Caplan, 1985).

D. Performance relates to an individual's perceptions about how successfully they are fulfilling either role demands or their own expectations. While this factor has typically been viewed as an outcome measure, it was examined in relation to personal life demands by Pearlin and Schooler (1978) and in work settings by Katz and Kahn (1978). Several researchers have hypothesized that stress, perceptions of control, and social supports will affect performance (Abbey, 1983; Conway, Abbey, and French, 1983; and French, Caplan, and Harrison, 1982). They suggest that individuals who feel their performance is inadequate are likely to feel incompetent and will experience a diminished sense of well-being. T h e s e findings are consistent with Andrews and Withey (1976) who suggest that there are separate factors that have positive and negative affects on well-being. These factors have been taken into consideration in the conceptual submodel depicted in Figure 8 on psychological well-being.

Figure 8: Schematic Sub-Model of Causal Linkages Related to Psychological Well-Being



Although there have been numerous attempts to impose order on the nature of self-reported psychological well-being, most of these have focused on only a limited aspect of the components reviewed in this section. This model hypothesizes that stress and external control are inversely related to a cognitive sense of psychological well-being. As stress and external control increase, well-being and personal satisfaction (self-regard) would decrease because the "gap" or discrepancy between actuality and aspirations would be increased creating psychological distress. On the other hand, as choices, options, performance, and supports increase, then personal satisfaction (self-regard) and psychological well-being would increase.

Social/Emotional Well-Being

Social/emotional well-being has been found to be tied very closely with satisfactory personal/social relationships and to concepts related to self-esteem (Flanagan, 1978). This concept refers to a basic sense of security on an affective level as well as a feeling that one is connected to others (Coopersmith, 1967; Rosenberg, 1965; and Wells and Marwell, 1976). Having a high social/emotional well-being for oneself would be viewed as a healthy component of personality, associated with interpersonal success and mastery. It is viewed as a subjective dimension of quality of life (Epstein, 1973).

Relationships are also important to social/emotional well-being. Relationships refer to personal and social involvements with other persons (spouses, children, friends, family), integration within residential communities, and involvements with other citizens in society at large. Moos (1974) identified relationship dimensions as one of the three broad categories (along with personal development and change dimensions) that emerged from his studies of eight different kinds of environments.

Relationship dimensions identify the nature and intensity of personal relationships within the environment. They assess the extent to which individuals are involved in the environment and the extent to which they support and help each other. The relevant subscales identified by Moos include involvement, affiliation, staff support, peer cohesion, and spontaneity.

Since the essential core of mental retardation is social incompetency, Evans (1977) has argued that this social inadequacy can only be overcome by instruction in the understanding and proper expression of anger, in working on the nature and management of personal relationships, and learning how to cope effectively with leisure time.

In an effort to evaluate the importance of interpersonal relationships and social competency in new environments, Birenbaum (1979) followed a cohort of 63 mentally retarded adults for almost 4 years from the time they were placed

into community residential programs from institutional settings. His aim was to determine whether changes in self-image, interpersonal relationships, work experience, use of leisure time, personal decision-making, and social competency would occur as a result of living in a new environment. Results of four different interviews indicated that clients maintaining involvement with sheltered workshops were more likely to have established personal relationships with their own peers. However, they were less likely to be active participants in community leisure activities and they were more restricted in personal decision-making in their own homes.

Since this study raised a number of questions about the social behavior of retarded adults in community settings, Landesman-Dwyer, Berkson, and Romer (1979) published their research findings on the social behavior of 208 mentally retarded residents in 18 group home settings. One of their surprising findings was intense, social relationships could occur as likely in large as in small homes. It was also significant that even profoundly retarded persons were capable of engaging in social behavior, affiliation, and friendship.

In the following year, Williams (1980) published an anthropological study of 31 persons who had been formerly classified as mentally retarded living independently in the community. He found that for most of these individuals their social and personal adjustment to the community could at best

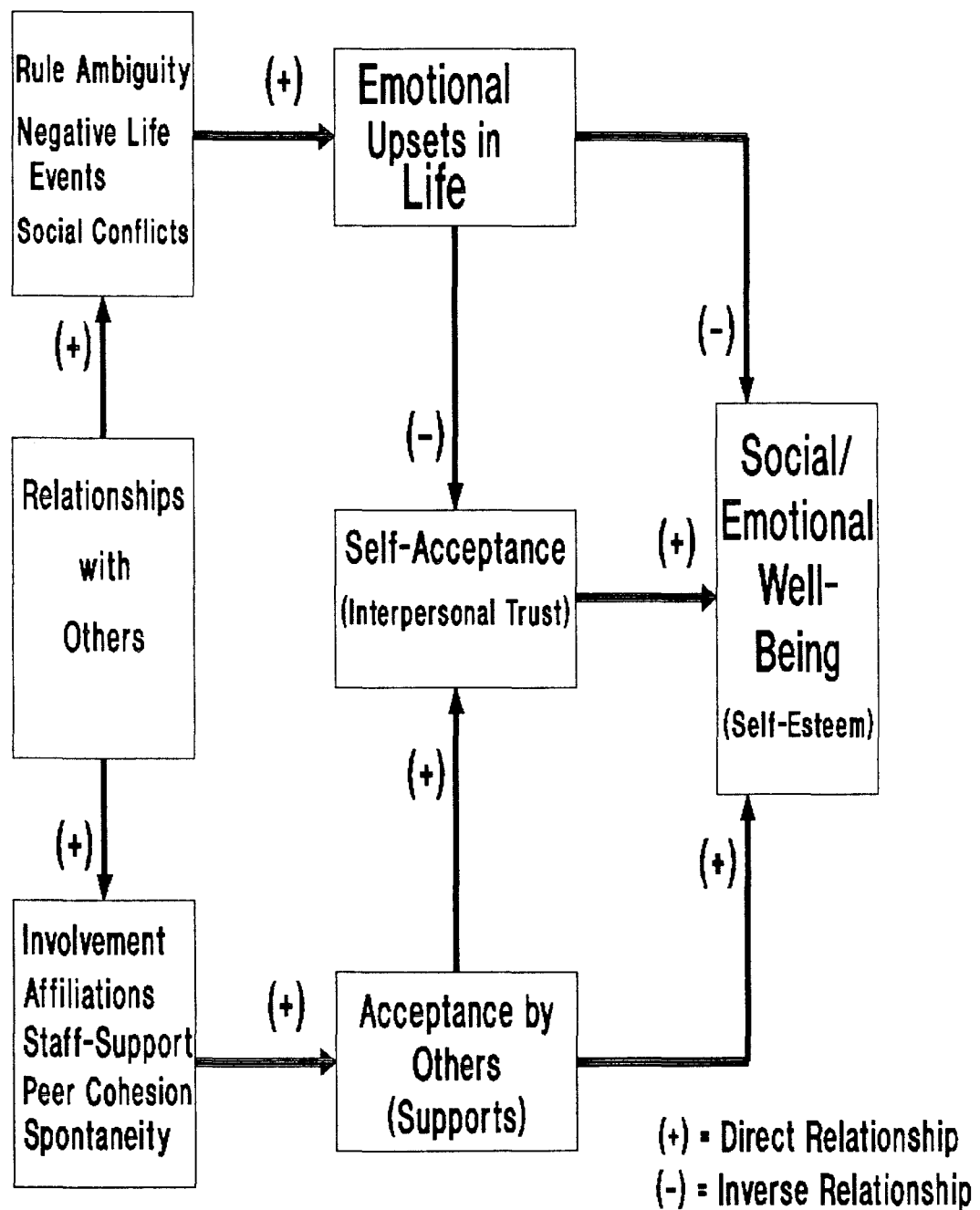
be considered only marginal, with their most severe adjustment difficulties existing in the area of interpersonal relationships.

Earlier research findings by Griffin (1969) suggests that interpersonal trust is the key to increased interaction between aged persons and their immediate social environment. Environments that allow for rigid structuring of staff and client roles seem to limit the interpersonal exchanges on a human scale that promote trust. Consequently, it is not surprising that Dudley and Hillery (1977) found that typical institutional management created environments that promoted alienation, limited personal freedom, and created social and emotional deprivation for a large number of unfortunate persons.

This is consistent with Anderson's recent work (1987) where he found that the most conspicuous factor between excellent and ordinary nursing homes was the relationships between staff and clients. Positive interactions between staff and clients (even persons who were troubled, anxious, or disturbed) resulted in increased satisfaction and improved adjustment to reality.

These research findings have been taken into consideration in the schematic submodel of causal linkages related to social/emotional well-being in Figure 9.

Figure 9: Schematic Sub-Model of Causal Linkages Related to Social/Emotional Well-Being



This schematic submodel of social/emotional well-being refers to the affective responses on the part of a person to their own level of self-acceptance, acceptance/support from others or to emotional upsets in life. In this regard, affect refers to an emotional, "from-the-gut" reaction in contrast to the intellectual, "from-the-head" response discussed under psychological well-being. It is a component tied closely to the fundamental building blocks of all attitudes. It is also consistent with the distinction between affect and cognition in life quality research that has been explored by Andrews and McKennell (1980).

This model indicates a direct relationship (+) between relationships and either positive outcomes (involvements, affiliations, peer cohesion, spontaneity, and supports) and/or negative outcomes (role ambiguity, negative life events, and social conflicts which result in emotional upsets). Relationships in life will result in both types of outcomes.

As upsets increase, self-acceptance and interpersonal trust is affected in a negative way and social/emotional well-being would suffer. These effects, however, can be offset or mitigated through acceptance from others and the addition of social supports. These factors are directly related (+) to social/emotional well-being. This hypothesis is consistent with the work of Wells and Marwell (1976) and Wylie (1979).

Personal Well-Being

Personal well-being has often been taken as a global measure of quality of life (Cleary and McNeil, 1988). Lemon, Bengston, and Peterson (1972, p.513) defined the concept as "the degree to which one is presently content with his general life situation." Personal well-being or self-regard is important to consider as a separate and independent factor because of the limitations of other objective and subjective measures associated with quality of life phenomenon. For example, knowledge about physical, psychological, and social/emotional well-being may not fully explain the global quality of a person's life without knowledge of the circumstance in which a person lives. These circumstances involve where someone lives, their job satisfaction, their health, their friends, their relationships with others, how they spend their spare time, educational satisfaction, and their satisfaction with financial security (Campbell, 1981; Michalos, 1986; and Walton, 1973).

Since occupations play such an important role in orienting individual attitudes and actions throughout life, it is not surprising that job satisfaction has been linked with personal well-being and life satisfaction (Andrews and Withey, 1976; Campbell, Converse, and Rodgers, 1976; Dailey, 1979; Michalos, 1980; Morgan, 1980; Rice, Hunt, and Near, 1980; Rose, 1980; Vredenburg and Sheridan, 1979; White, 1981; and Wimperis and Farr, 1979).

A number of factors have been found to be positively associated with job satisfaction in a direct fashion. These factors include job enrichment (Caldwell and O'Reilly, 1982; and Cherrington and England, 1980); worker participation in decision-making (Greenberg, 1980; Hatfield and Huseman, 1982; and Schuler, 1980); perceptions of personal development through work (Bergmann, 1981); the ability to set one's own work goals (Ivancevich and McMahon, 1982 and Lee and Schuler, 1982); and the use of flexitime (Coltrin and Baraendse, 1981; Orpen, 1981; and Pierce and Newstrom, 1980).

Those factors having an inverse relationship with job satisfaction include role ambiguity, role conflicts, and job turnover (Abdel-Halim, 1981; Bedeian and Armenakis, 1981; Price and Mueller, 1981; and Spencer and Steers (1981).

Since education and learning has been considered to be a determinant of life quality, it has also been looked at in relation to personal satisfaction (Andrews and Whithey, 1976; Baker and Intagliata, 1982; and Heal and Chadney-Rusch, 1985). In a recent publication, Brockett (1987) investigated the relationship between personal well-being and the extent to which one possesses attitudes and skills associated with self-direction in learning. His results suggest that self-directed learning and personal well-being may be linked together in relation to independence. Individuals who are able to take charge and remain in control of their lives are in a stronger

position to meet personal needs as they arise than those who view themselves as more dependent upon others. An important aspect of his research is that this might suggest that quality of life for many persons as they get older may be associated with a positive attitude about learning.

Satisfaction with financial security has been found to have the greatest impact on satisfaction with life as a whole. Michalos (1983) argues that for every standard deviation of increase in satisfaction, personal satisfaction with life as a whole increases 23 percent of one standard deviation. Financial security is closely linked with income.

However, income is only one part of an individual's financial picture. Assets (e.g., personal property, consumer durables, bank deposits, stocks and bonds, etc.,) and liabilities (e.g., loans, obligations to creditors, etc.,) constitute another important part. A well-rounded picture of the economic situation of any person requires consideration of both income and net worth (i.e., assets minus liabilities). This calculation needs to be made very carefully because it may be very impractical to convert some assets into disposable income and dollar values cannot capture the subjective significance that financial resources have for some people. Such feelings might preclude some people from converting assets into cash even to meet pressing needs.

While traditional methods present difficulties in the relevant application of measurements in the areas of

occupations, education, and income, it becomes more important to develop measures which examine the degree to which basic needs are taken care of and addressed rather than measures which tap the more intangible gratifications of relative social standing.

In this regard, one needs again to focus upon the subjective perceptions of the persons being studied. The emphasis is on understanding how people feel about themselves in terms of where they live, where they work, and how they are treated by others around them. Neugarten (1974) viewed personal well-being as the extent to which the person:

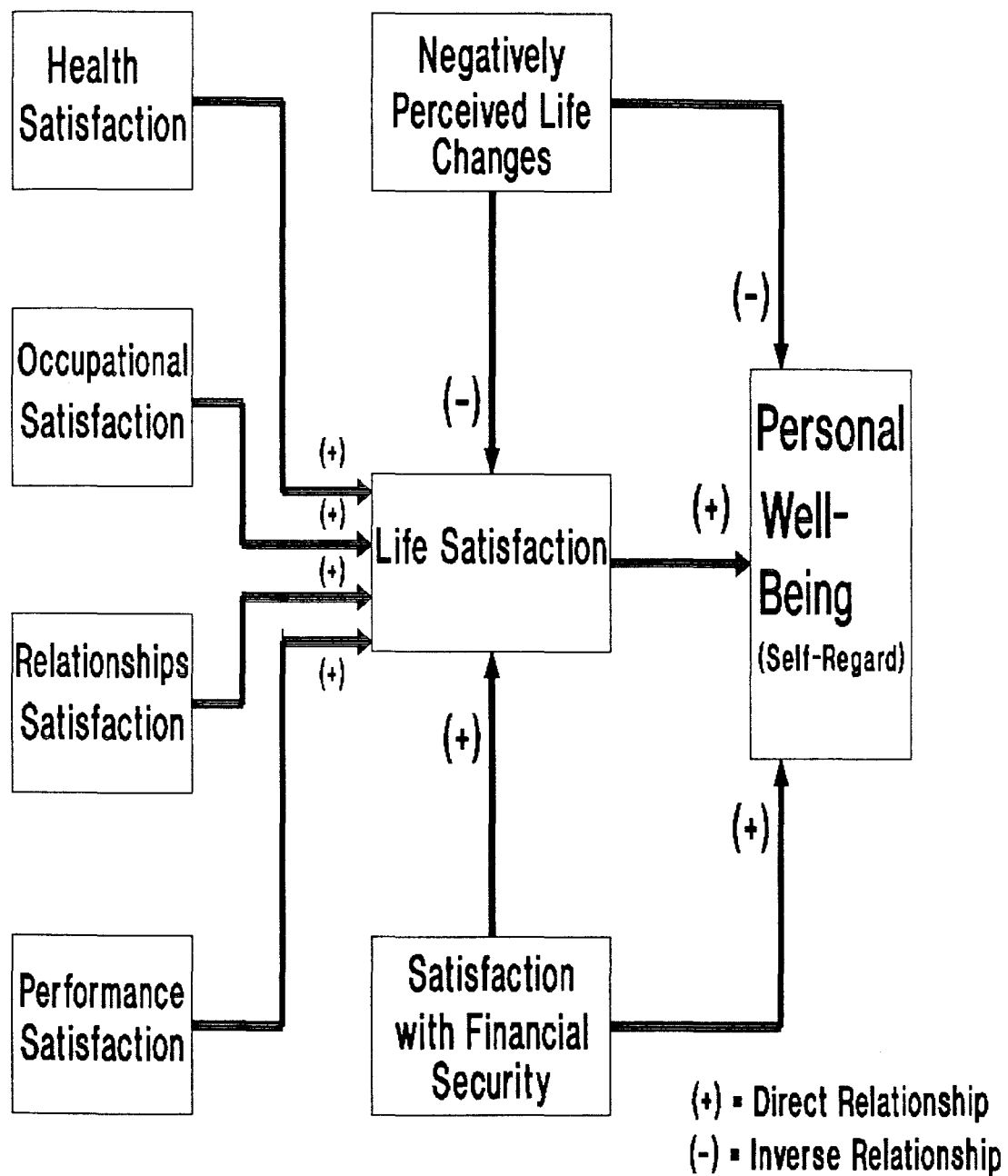
- 1) Takes pleasure from whatever round of activities that constitute his everyday life;
- 2) Regards his life as meaningful and accepts responsibility for what his life has been;
- 3) Holds a positive self-image and regards himself as a worthwhile person;
- 4) Feels he has succeeded in achieving his major life goals;
- 5) Maintains optimistic attitudes and moods.

While it has been demonstrated that individuals can reliably report their satisfactions, there are some limitations to using personal well-being as a measure of quality of life by itself (Kane, 1987). For example, residents of long-term care facilities cannot be expected to know whether their health care is technically adequate or whether any negative functional outcomes could have been prevented.

If a client is satisfied with their experience in a program, we can assume that the other interpersonal factors are probably treated appropriately by the provider. In making this statement, we assume that the quality of care has also made a contribution to well-being and satisfaction. However, the technical factors which determine quality of care are also mediated by care givers. Thus, interpersonal factors are likely to modify the client's perception of care which is why Abramowitz (1987) has argued that personal well-being depends heavily upon the personal warmth exhibited by direct care staff.

A schematic sub-model of causal linkages related to Personal Well-Being is depicted in Figure 10.

Figure 10: Schematic Sub-Model of Causal Linkages Related to Personal Well-Being



All of the major linkages with the exception of negatively perceived life changes have direct (+) relationships with personal well-being. As they increase (health satisfaction, occupational satisfaction, relationship satisfaction, performance satisfaction, and satisfaction with financial security), life satisfaction increases in a corresponding fashion.

The sub-model shows the inverse (-) relationship between negatively perceived life changes related to numerous possibilities (e.g., role ambiguity, role conflict, job turnover, death of a loved one, stress, illness, loss of financial security or increased external control, etc.,) and life satisfaction. As these variables increase, life satisfaction would be diminished and has been shown to decrease (Cresswell, Corre, and Zautra, 1981). As this happens, personal well-being or self-regard would also be affected in a negative fashion.

From the literature review, job satisfaction is linked directly (+) with worker participation in decision-making, perceptions of personal development, the setting of one's own work goals, and the utilization of flex time arrangements and inversely related to role conflicts, role ambiguity, and job turnover.

Ecological/Environmental Factors and Quality of Life

In the right hand side of Figure 5, Ecology was shown as interacting with interpersonal resources to affect quality of life. Moos and Insel (1974, p.180) have defined ecology "as a more complete view of man interacting with both his physical and social environment." Since behavior is a joint function of both the person and the environment, these factors will have a bearing on quality of life. Insel and Moos (1974, p.180) identified six major methods by which characteristics of environments have been related to indexes of human functioning. These are:

1. Ecological dimensions-geographical and meteorological variables (This view of the environment suggests that society has been shaped by climate, topography, and other geographical features of inhabited regions) and architectural variables (physical design constraints which limit or even define the range of activities in which man can be involved);

2. Behavior settings- These are conceptualized as ecological units which have both an environmental and a behavioral component (Barker, 1968);

3. Organizational structure- This view of the environment suggests that behavior is influenced by structural dimensions such as size, staffing ratios, span of control, and salary levels;

4. Personal and behavioral characteristics of the milieu

inhabitants- This view implies that the character of an environment depends on the nature of its members, such as age, sex, socioeconomic status, abilities, physique, and other background data;

5. Psychosocial characteristics and organizational climates- This approach encompasses both psychological and social dimensions in a framework of a person-milieu interaction; and

6. Variables relevant to the functional or reinforcement analyses of environments- This view suggests that people vary their behavior from one setting to another as a function of the reinforcement consequences for particular behaviors.

Moos believes that these six categories are nonexclusive, overlapping, and mutually interrelated. They cannot be ignored because each has been conceptualized and shown to have an important impact on individual and group behavior. Ecological and environmental factors provide a background in which interpersonal and technical skills and resources function. These factors cannot always be directly controlled, but can be shaped over time by changes in the use of technical and interpersonal variables.

Attempts to Measure Quality of Life

As in all research endeavors, the data and/or research results are only as good as the instruments used to collect the information. Investigators must have confidence in the instruments used in order to have confidence in the results generated by their research projects.

While it is clear that throughout history, people have written about the good life, it is also apparent that social scientists have failed to provide consistent and concise definitions of quality of life. This is primarily because definitions for quality of life are largely a matter of personal or group preferences which people value.

However, during the past 15 years, Abbey and Andrews (1986) believe that substantial progress has been made in finding effective ways to measure quality of life concepts. For example, national level studies have been completed by several researchers: Allardt (1976) (Scandinavian countries), Andrews and Withey (1976) (United States), Headey (1981) (Australia), Shin, Kim, and Lee (1982) (South Korea), Mukherjee (1983) (India), and Thornton, Chang, and Sun (1986) (Taiwan).

One of the surprising findings to emerge from this initial research work was the modest correlation between standard demographic variables (e.g., age, sex, race, education, income, marital status, and stage in the family life cycle)

to most self assessments of quality of life. Most of the national studies show that even when several such factors are used together in a multivariate analysis they explain less than 15 percent of the variation in assessments of life quality as a whole. As a result, demographic and social classification factors do not show strong potential for explaining much variation in perceived well-being. This lack of association between demographic variables and quality of life measures according to Moum (1983) has created a problem that has intrigued almost every quality of life researcher. Other factors will have to be identified.

For the most part, social scientists have used two primary categories of variables to define quality of life. These categories include both objective conditions of life as well as subjective experiences of life (Campbell, Converse, and Rodgers; 1976). Of these categories of variables, the subjective assessment of life quality has been considered the most crucial assessment that individuals can report. For example, Maddox and Wiley (1976, p.15) report that the subjective assessment of life satisfaction has been the "oldest and most persistently investigated issue in the social scientific study of aging."

The vast majority of all attempts to measure quality of life have relied on the self-reports of subjects in an interview situation or in response to a self-administered questionnaire. In his book on the Research of Quality of

Life, Andrews (1986) indicated that other measurement approaches have utilized archival records (e.g., medical charts) and the observation of behavior in natural settings.

Self-report measures have been determined to be essential to investigators on quality of life because of the need to obtain subjective assessments about the experience of life as well as objective information about life conditions. These measures have been used in both basic as well as applied research because they are easy to administer and require little interpretation by the investigator.

Although self-report measures may take a variety of forms, scales are generally preferred because they contain a larger number of items and are suitable for mathematical calculations using both summed and weighted scores. Single item measures of global quality of life have been considered least preferable because researchers have been skeptical that one question can effectively tap a given phenomenon and because it is difficult to assess the adequacy of a single item instrument. This is probably why Campbell and Fiske (1959) suggested that the optimal measurement strategy is to measure the same phenomenon using different approaches.

As a way of getting at this problem, Moum (1983) in the book Quality of Life: Problems of Assessment and Measurement constructed a six-item, additive Quality of Life Index from the work of Gurin, Veroff, and Feld (1960), Bradburn (1969), and Monge (1973). These items showed a very high reliability

(alpha = .85) and a .88 (Pearson's r) with the 27 item Quality of Life Scale. He believes that the six items would be very useful as a dependent measure in a global quality of life assessment.

Perhaps the most significant work in the measurement of quality of life in recent years has occurred in the field of indicators. This is important because without good indicators of the core concept itself, progress would be difficult on both a theoretical as well as an applied level.

If the investigator chooses the particular items to include in the quality of life assessment, comparability across subjects is maximized while the salience of the items to the subject's frame of reference is unknown. However, they would have a tendency to vary widely. In the case of measures where subjects provide their own definitions and frame of reference, the opposite of this would be true. There is no apparent method of maximizing both comparability across subjects and salience to all who complete the assessment at the same time. The choice between an investigator-determined set of variables versus those variables defined by the subjects can only be determined by the research question under consideration.

Different approaches to operationalizing a person's quality of life are highlighted in Table 1 in relation to dimensions of quality of life looked by various researchers. As can be clearly seen, 22 out of 44 (50%) research approaches

have concentrated on a single global measure (life satisfaction). None of these has evaluated all four dimensions simultaneously in the assessment of quality of life.

From an extensive review of this literature, it appears that four independent components have the potential to assist us in the measurement of quality of life. These components are physical well-being; psychological well-being; social/emotional well-being; and personal well-being.

The need for relevant and appropriate quality of life measurement tools has been articulated by experts in the field. Walker's 1988 Presidential Address for the American Association of Mental Retardation stressed the need to define what this concept means and to exercise great caution in the formulation of that definition. Harshman (1979) indicated that a model was also needed in assessing quality which had the following characteristics:

- (1) The model should include considerations for all aspects of a program.
- (2) The model should be an integral part of an educational feedback system, not separated from them.
- (3) The model should identify the nature, intensity, and importance of the relationships between variables within the environment.
- (4) The model should be flexible enough to fit the needs of a variety of programs.
- (5) The model should identify its inputs, processes, and outcomes.

Table 1: Different Approaches to Operationalizing
A Person's Quality of Life

Authors (in alphabetical order)

Abbey and Andrews (1986)	2,3,4
Andrews and Withey (1976)	4
Baker and Intagliata (1982)	4
Berger	3,4
Bradburn (1969)	3
Brown et.al., (1984)	4
Campbell et.al., (1976)	4
Cantril (1965)	2
Coopersmith (1967)	3
Duncan (1961)	4
Fitts (1965)	3
Flanagan (1978)	2
George and Bearon (1980)	1,3,4
Golden, Teresi, and Gurland (1984)	1
Gurin, Veroff, and Feld (1960)	3
Heal and Chadney-Rusch (1985)	4
Hollingshead and Redlich (1958)	4
Keith, Shalock, and Hoffman (1986)	2,3,4
Kutner, Fanshel, Togo and Langner (1956)	4
Lawton (1972)	4
Langner (1962)	2
Leighton et al., (1969)	2
Lehman, Possidente, and Hawker (1986)	4
Maddox and Douglass (1973)	1
Meer and Baker (1966)	1,2
Monge (1973)	3
Moum (1983)	2,3,4
Neugarten, Havighurst, and Tobin (1961)	4
Osberg, McGinnis, DeJong, and Seward (1987)	4
Osgood and Suci (1955)	3
Pearlman and Uhlmann (1988)	4
Pfeiffer (1975)	1
Plutchik, et. al., (1970)	1,2
Reker and Wong (1984)	1
Reynolds, Rushing, and Miles (1974)	1
Rosenberg (1965)	3
Rosencranz and Pihlblad (1970)	1
Schalock and Hill (1986)	4
Spalding (1985)	4
Suchman, Phillips, and Streib (1958)	1
Shanas (1962)	1
Tissue (1972)	1
Walton (1973)	4
Wood, Wylie, and Sheaffer (1969)	4

1= Physical Well-Being; 2= Psychological Well-Being
3= Social/Emotional Well-Being; 4= Personal Well-being

A model which seeks to advance our knowledge about quality of life appears in Figure 5. The model provides us with a way to think of the components of quality of life. The model considers quality of life as a four-factor measure of client experience. Quality of care is viewed as a five-factor measure of services provided to the client. Both quality of care and quality of life can have a positive impact on client functioning. Client functioning is at the heart of the relationship between quality of care and quality of life. Quality, itself, is proportionate to the attainment of achievable improvements in client functioning. This model was used to organize data in this study.

The study and assessment of environments is also important because of its relationship to individual functioning. The climate of an environment will affect not only the delivery of care but will also influence the social atmosphere related to personal satisfaction, mood, self-esteem, and the potential for improved quality of life.

Ammentorp, Gossett, and Morgan (1988) refer to these variables as Ecological Factors in identifying the components of quality. Environmental factors refer to the objective physical characteristics of environments (e.g., temperatures, rainfall, humidity, air pollution, noise levels, and physical arrangements or constraints of architectural buildings and structures). It has been suggested by these same authors that these variables interacting with technical resources can also

influence quality of life.

Until quality of life is more clearly defined and measurement tools are developed to aid and assist in the monitoring of quality, there is no clear way for a program to establish that it offers satisfactory quality of life services and no clear method for managing human service programs to insure quality.

Chapter 3

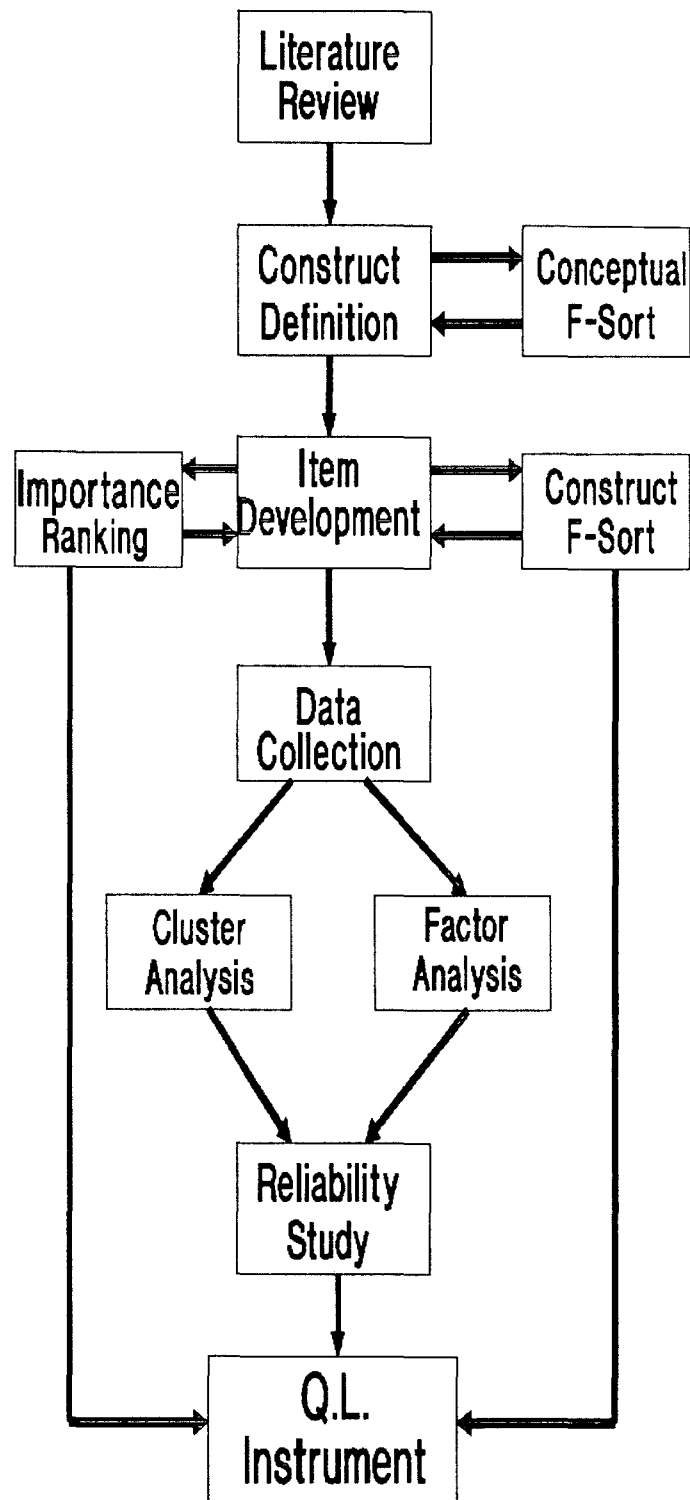
METHODOLOGY AND PROCEDURES

This chapter presents a design to develop a Quality of Life Instrument as referred to in Chapter 2 (see Figure 11). It includes a discussion of the following methods:

- (1) Review of the quality of life literature to generate an Item Pool;
- (2) Construct Definition-subscale development
 - a) F-Sort Procedures;
 - b) Cluster Analysis;
- (3) The determination of the importance of quality of life items:
 - a) Likert-style ratings of clients, parents, and staff;
 - b) Coefficient of Concordance
- (4) The administration of the quality of life instrument:
 - a) Sample description;
 - b) Factor Analysis;
- (5) Issues of reliability and validity;
- (6) Identification of Item Master list selection.

This study was intended to be an exploration into the components to be considered in measuring quality of life for human service programs serving persons with mental retardation in the United States. The study had the primary aim of developing an instrument which would be more programmatically useful as a measure of quality of life than existing instruments.

Figure 11: Research Scheme



Data for the study were collected in four phases to identify the indicators of quality of life. The four phases are:

- A. The generation of an item pool occurred in the first phase.
- B. The second phase consisted of organizing the item pool to assess whether there exists an underlying, meaningful structure.
- C. The third phase involved selecting items from the item pool that had high importance rankings across clients, parents, and staff.
- D. The fourth phase involved the administration of the instrument to collect data so that scales measuring the specific quality of life constructs could be identified and evaluated.

Identified below is a detailed description of each of the four phases of scale construction and the statistical procedures involved.

Phase One: Generating an Item Pool

Quality of life candidate items were initially selected based on a psychometric-rational approach suggested by Jackson (1971). This approach involves reviewing the relevant literature on quality of life and utilizing expert judgment as a way of identifying a set of variables that best represents the quality construct. The use of this methodology has produced indicator scales with high validity generalization in a wide variety of contexts (Golden, Teresi, and Gurland; 1984).

Ideally, variables should be chosen within the context of an explicitly stated theory that is used to support the classification. In practice, the actual choice of these variables is extremely important if one wants to create objective groupings of data in the hope that a structure will emerge. The use of this approach should rely heavily on existing instrumentation designed to measure quality of life and literature references that identify variables associated with the construct.

The use of this approach should assist the research effort in reducing the difficulty of assessing the relevance of variables to the construct of quality of life. It should also help improve the content validity of the instrument through utilization of prior research.

Items for the Quality of Life Scale were identified by the researcher that related to the four sub-models described in Figures 7, 8, 9, and 10 as potential measures of quality of life. In addition, the 28 items from Keith, Shalock, and Hoffman's (1986) Quality of Life Instrument were included since inter-item correlations, reliability coefficients, and extracted statistics from an initial factor analysis were available. These reviews resulted in a pool of approximately 44 candidate items. An additional 26 items were written to measure physical well-being. The resultant content items were prepared in card form for use in the second phase of data collection.

Phase Two: Organizing the Item Pool

In Phase Two of data collection, two panels of qualified mental retardation professionals from the Department of Human Services in the State of Minnesota and from the Lake County Board of Mental Retardation in Lake County, Ohio were asked to sort the 70 items using the F-Sort procedure (Wiley, 1967).

F-Sort

The F-Sort is a data collection technique for observing and recording categorical judgments resulting when subjects perform a series of sorting manipulations on a given set of items. The F-Sort is a free sorting technique in which the end result is a set of categories defined by each sorter with no restrictions on the order or the size of the categories. This sort is based on an assumption that the knowledge elements of an area of study and their relationships exist in the minds and writings of experts. The use of the F-Sort technique allows the information to be arranged or dimensioned according to the underlying structure of these knowledge elements. Consequently, the method is both structure-seeking as well as structure-imposing on data where that structure may not be readily apparent by visual inspection.

Each panel member was free to place an item anywhere among the distribution (so that each subset of items measured the same thing in an effort to control the contextual significance of each item). Each staff member could form as

many subsets as he/she desired. The grouping of these data by the F-Sort served as input to a cluster analysis.

Cluster Analysis

A cluster analytical technique was used to evaluate the results of the F-Sort procedure. The cluster analysis looked at how the items naturally grouped together. The operational definition of grouping was the frequency with which sorters paired the quality of life items.

Cluster analysis is designed to create homogeneous groups of cases or entities called clusters. It is a generic name for a wide variety of heuristic procedures (hierarchical agglomerative, hierarchical divisive, iterative partitioning, density search, factor analytic, clumping, and graph theoretic) that can be used to create a classification (Aldenderfer and Blashfield, 1984). Despite the apparent simplicity of "lumping together" things that are perceived as similar, the concept of similarity and the procedures used to measure and validate the findings are far from simple.

Tversky (1977) has stated that the quantitative estimation of similarity has been dominated by the concept of metrics. From this viewpoint, similarity is perceived as the metric distances between the observed similarities and dissimilarities of the points in coordinate space.

Aldenderfer and Blashfield (1984) have pointed out that despite differences in goals, data types, and methods used, five basic steps characterize all cluster analysis studies:

- (1) Selection of a sample to be clustered;
- (2) Definition of a set of variables on which to measure the entities in the sample;
- (3) Computation of the similarities among the entities utilizing Spearman's Rank Order correlation;
- (4) Use of a cluster analysis method to create groups of similar entities;
- (5) Validation of the resulting cluster solution.

To create a similarity matrix, Step 4 of the above procedure involved determining the number of times each possible pair appears together relative to the number of raters (Wiley, 1967). Hierarchical agglomerative methods (single linkage, complete linkage, average linkage, and Ward's method) have been dominant in the frequency of their applied use.

A single linkage method was chosen for this particular research activity in part because of its ease of use. Single linkage begins the clustering process by entering all items associated with each cluster and then searching for the two most similar entities in the matrix. New candidates for cluster membership can be joined to an existing group on the basis of the highest level of similarity of any member of the existing group. Only a single link is required between any two groups for them to merge, which has a tendency to produce

long, chained clusters.

The single linkage method does not require an understanding of matrix algebra or an extensive background in multivariate statistics. It is based on a simple rule of how to search a similarity matrix and when to combine cases through the use of special algorithms to produce non-overlapping clusters. Each of these clusters is "nested" as a member of a larger, more inclusive cluster at a higher level of similarity. The results of this clustering activity will be expressed in the form of a dendrogram (tree diagram).

The dendrogram is a graphical display of the hierarchical structure which describes the general pattern of the relationships between the items in the matrix and those items clustered by the linkage rule. The validity of the clustering activity will be confirmed or disaffirmed by the results of a factor analysis when the instrument is field tested.

Phase Three: Refinement of the Item Pool

To assess whether the 70 items in the Quality of Life item pool had relevance to individuals with mental retardation, 27 clients, 21 parents, and 22 staff members were asked to rank the importance of the items using a Likert-style rating. All clients, parents, and staff members were either enrolled or involved with the Lake County Board of Mental Retardation located in Northeastern Ohio.

Likert Ratings of Clients, Parents, and Staff

Likert-style scales have been defined as any scale that adds together the response scores of its constituent items (McIver and Carmines, 1981). Likert scaling, therefore, involves giving a group of subjects a set of items and asking them to respond to each statement in terms of their own degree of agreement or disagreement. Using the Likert method, the researcher wrote positive and negative statements; and respondents were asked to respond to each item by means of a four-point scale ranging from "Very Important" to "Somewhat Important" to "Not Very Important" to "Not Important At All." The items were weighted from 1 to 4 and a total score obtained. The specific responses to the items are combined so that individuals with the most favorable attitudes will have the highest scores. The importance rankings across the three groups of clients, parents, and staff can be determined by using Kendall's Coefficient of Concordance.

Coefficient of Concordance

Churchill (1983) has referred to the coefficient of concordance as a method for determining the degree of agreement for ranking the importance of items. Since there are 3 (k) sets of rankings, Kendall's coefficient of concordance W can be employed to examine the association among the k variables.

Since the coefficient of concordance W is a function of the variance in the sums of the ranks, it is calculated in the following way:

Kendall's Coefficient of Concordance

- 1) First, the sum of the ranks for each of the items was determined by adding across the groups of raters for each of the seventy items;
- 2) Second, the sum of the squared deviations between the sum of the ranks for each item and the mean for the sum of ranks is calculated;
- 3) Finally, the calculation of Kendall's coefficient of concordance is then computed in the analysis of the rankings.

The significance of the coefficient of concordance can be assessed by using a Chi-Square test. The null hypothesis is that there is no agreement among the rankings while the alternative hypothesis is that there is some agreement. For an assumed alpha equals .05, the critical value for Chi-Square with $n-1 = 69$ degrees of freedom would be 90.53. If the calculated Chi-Square exceeds the critical value, the null hypothesis would be rejected. The limits of W are zero with no agreement and one with perfect agreement among the ranks.

Phase Four: Administration of the Quality of Life Instrument

The results from the F-Sort and cluster analysis suggested the presence of four distinct components in the measurement of quality of life. When the item selection process was completed, each of the 70 items was assigned, on the basis of face validity, to one of the four components of quality of life (i.e., physical well-being, psychological well-being, social/emotional well-being, and personal well-being) identified in the theoretical construct. Since there were 70 items identified across these separate components, there is a good possibility of redundancy among these items. In the interest of parsimony and efficiency, it became necessary to complete both a factor analysis as well as an item analysis on these data sets.

To accomplish this objective, the instrument was to be field tested on a population of 70 adult clients with mental retardation during the last phase of data collection. These clients were selected to obtain a representative sample from a community population of approximately 250 persons living in licensed residential facilities by the Ohio Department of Mental Retardation and Developmental Disabilities in Lake County, Ohio. The 70 clients live along a continuum of services from more restrictive settings (30 beds in two different ICF/MR facilities) to less restrictive settings (40 beds in foster family homes, group homes, and semi-independent living arrangements).

Factor Analysis

According to Kerlinger (1973) factor analysis can help a researcher discover and identify the unities or dimensions behind complex measures. The construct validity of the Quality of Life Instrument was to be examined through the use of a factor analytic procedure involving the varimax rotation. Two criteria were used in order to determine the number of factors:

- 1) The eigenvalue (eg. the total amount of variance accounted for by a factor or the amount of explained variance due to a factor) of each factor should be at least one (1.00);
- 2) The loading of one variable or more should be greater than or equal to 0.4 and items whose communalities are smaller than 0.3 will be removed from the instrument.

In the research reported here, factor analysis was used to identify significant quality of life dimensions in the population under study. It was to be used to minimize the number of variables for further research while maximizing the amount of information about quality of life in the analysis. Gorsuch (1983) has indicated that factor analysis can also be used to search data for possible qualitative and quantitative distinctions which may lead to new constructs and hypotheses for future theory and research. Since the quality of life data have been hypothesized to have certain qualitative and quantitative distinctions, factor analysis will be used to test this theory.

Issues of Reliability

Reliability is a standard criterion used to assess the adequacy of measuring instruments. It has been defined as the degree to which a measuring instrument is free of random error--the less the amount of random error, the greater the reliability and accuracy of the instrument (Bohrnstedt, 1969).

Since reliability is the degree of accuracy between a person's observed, fallible score and a true score (i.e., the ideal value of a person's quality of life score), one would expect that a person's quality of life assessment score would be similar even under slightly altered conditions utilizing different raters. However, it is impossible to know the true score for any individual since it could vary for many reasons (e.g. trait instability, sampling error, administrator error, random error within the test, and scoring error). The true score must be estimated from an obtained score and the error of measurement of the assessment instrument (Stanley and Hopkins, 1972).

The reliability of the Quality of Life Scale was to be determined using the coefficient alpha formula (Cronbach, 1951) for internal consistency reliability. This procedure is a derivation of the Kuder-Richardson Formula 20 similar to Hoyt's procedure. If the values of the reliability of the subscales are all uniformly high, this finding would indicate that the instrument consistently measures what it purports to measure (Beggs and Lewis, 1975). Reliability coefficients of

.80 or above are generally considered adequate for internal consistency purposes (Newcomer and Hammill, 1982).

In addition to internal consistency, it is also important to determine how much error may occur in a score due to the person(s) who did the scoring or rating. Test-retest is generally investigated to determine the degree to which test scores remain consistent from one rating to another over a relatively short period of time. A Pearson Product Moment Correlation Coefficient can be used to determine a substantial degree of test-retest reliability.

Inter-rater reliability also needs to be considered in order to determine the reliability of an instrument in providing consistent results when rated by more than one rater. Pearson Product Moment Correlation Coefficients can again be used to determine the degree of inter-rater reliability.

Both test-retest and inter-rater reliability studies were to be evaluated with a revised quality of life instrument once internal consistency of the instrument is established.

Measures of Validity

Since the degree of validity is the single most important aspect of any assessment instrument, it is critically important to know if the Quality of Life Instrument measures what it purports to measure (Beggs and Lewis, 1975). The latest Standards for Educational and Psychological Tests and

Manuals (American Psychological Association, 1974) identifies three types of validity:

- 1) Content validity;
- 2) Criterion-related validity;
- 3) Construct validity.

While these aspects of validity can be discussed independently, they are interrelated operationally and logically. The identification of factors in the dimensioning of quality of life requires attention to all three aspects of validity.

Content validity refers to the extent to which an assessment instrument appears to measure what it purports to measure (Nunnally, 1970). Content validity is typically determined by an inspection of all the items in an assessment instrument. Each item should be judged as to its ability to represent the specified category or domain. The content validity in the construction of an assessment instrument can be increased through the use of expert judgment in the selection of the items to begin with in establishing the initial item pool (Tinsley and Weiss, 1975).

Salvia and Ysseldyke (1981) have indicated that there are three facets with regard to content validity.

- 1) the appropriateness of the types of items included in a scale;
- 2) the completeness of the item sample; and
- 3) the way in which items assess the content.

To assure the integrity of the content validity, the researcher initially created an item pool based on a theoretical model of the components of quality of life from the relevant literature on this subject. Expert judgment was utilized from a group of qualified mental retardation professionals to organize the items into meaningful subscales. To assure the appropriateness of the items included in the subscales, a cluster analysis was conducted to identify the underlying dimensions of the data base. To further assure validation of the item pool for the scale, the researcher obtained importance rankings from clients, parents, and staff to refine the scale. Recommendations for eliminating inappropriate items, modifying or re-wording items which could be stated in a clearer or more useful manner, and adding items that might assist in the measurement of quality of life were also solicited from respondents. The content validity of the scales was hopefully assured as a result of the meticulous literature review and relevant input from clients, parents, and staff who supplied the information necessary for the creation of the candidate items of the quality of life scales.

Criterion-related validity pertains to the empirical technique of studying the relationship between the scores as predictors and some other independent, external measure as criterion. In order to measure criterion-related validity, it is necessary that an independent external measure of quality of life addresses the same constructs of well-being

as identified in the subscales. Unfortunately, external criterion measures of these same constructs do not exist and therefore, were outside the scope of this particular study. However, as the results of this research study are expanded, the use of "known groups" will be selected to help establish the discriminating power of the instrument.

Construct validity refers to the degree one can infer certain constructs from the actual assessment scores (Anastasi, 1981). It is central to the measurement of any abstract theoretical concept. The three aspects of construct validity to be investigated include:

- a) diagnostic validity,
- b) subscale inter-relationships, and
- c) item validity.

In order to measure diagnostic validity, the Quality of Life Instrument was administered to 70 adult clients with mental retardation. These clients comprised a representative sample served by a county mental retardation program. Quality of life was defined as a four-factor measure of client experience (physical well-being, psychological well-being, social/emotional well-being, and personal well-being). The researcher was to assess the diagnostic validity of the instrument by the extent to which these dimensions were confirmed by the factor analyses in an empirical fashion.

The interpretability of the factor analysis will either support or not support this contention. It would be assumed that the subscales of the instrument would show inter-correlations similar to those predicted by the theoretical model. To the degree that this is so, one would have additional support for construct validity of the theoretical model.

Item validity for the Quality of Life Instrument refers to the discriminating powers of the items on the scale. The individual item ratings should correlate within an acceptable range (.36 to .60) to add unique variance to the scale. Items that are either too highly correlated with one another or items that are not correlated at all should be removed from the scale. Spearman rank correlations will be used as the measure to determine the discriminating power of the items with the subscale scores.

Identification of a Final Item Master List

To create a final item master list, the researcher reviewed all items against the following criteria so that each item could be used effectively in the measurement of quality of life.

- (1) It had to be meaningful to the care giver and care recipient;
- (2) It had to be supported by the professional literature of the field;

- (3) It had to allow for valid representations of client behavior, conditions, and feelings;
- (4) It had to be responsive to changes in the technical and/or interpersonal aspects of care;
- (5) It had to have appropriate properties of:
 - a) Reliability,
 - b) Validity,

These criteria were chosen to establish a set of yard sticks which could be relied upon to make good judgments about eliminating any items which were deemed inappropriate for an adequate representation of quality of life. The researcher intended to use these criteria along with feedback from clients, parents, and staff to edit the identified measures (see Appendix D-3). McCarney, Leigh, and Cornbleet (1983) used a similar procedure in developing items for the Behavior Evaluation Scale.

Chapter 4

Results

This chapter presents the findings of the study. Included are the results of the four phases of data collection. Tables 2 through 12 report the findings.

Phase I: Generating an Item Pool

Generation of the data base for the study occurred in the first phase of data collection. The initial data search occurred in April, 1988 at the Cambridge Community College in Cambridge, Minnesota using the Project for Automated Library Systems (PALS). A term search on quality assurance generated 150 references (see Appendix A-1). Relevant articles were reviewed by the researcher.

A more extensive literature search was conducted in November, 1988 utilizing Knowledge Index (Subsystem of DIALOG Information Services, Inc.). A term search was completed reviewing Dissertation Abstracts, Psychological Abstracts, and Sociological Abstracts. Over 1,000 United States and International periodicals were searched from 1974 to the present using the terms quality of life, physical well-being, psychological well-being, independent functioning, choices, relationships, social/emotional well-being, self-esteem, self-regard, life satisfaction, personal well-being, and personal satisfaction. These terms were chosen because of their

consistency with the quality of life model identified in Chapters One and Two.

44 articles were identified with the development of specific instruments related to these concepts. The researcher reviewed the relevant aspects of this literature and sorted the instruments into categories that corresponded to the quality of life dimensions. The results were highlighted in Table 1 (p.68). The researcher developed a listing of items that corresponded to the theoretical submodels in Figures 7, 8, 9, and 10. This activity generated an initial item pool of 44 candidate items (see Appendix A-2). The resultant content items were prepared in card form for use in the second phase of data collection.

Phase II: Organizing the Item Pool

A panel of 6 qualified mental retardation professionals (see Appendix B-1) from the Lake County Board of Mental Retardation were asked to sort the items into meaningful categories so that each subset of items measured the same thing using a data collection technique called the F-Sort as described by Wiley (1967). Each staff person could form as many subsets as they desired. This data was coded and served as input to a similarity matrix. The resulting matrix was analyzed using a cluster analysis procedure.

The University of Minnesota's Cluster Analysis Package developed for the CDC Cyber Systems was used to identify the

underlying factors. A data reduction procedure was used to reduce the possibility of sorter error (Vanatta, 1987). A bias of 3 was chosen. If at least 3 out of the 6 raters could not agree on a specific relationship of a given term with another term, the relationship was thrown out of the accumulator matrix.

The cluster analysis procedure utilized clustering algorithms to analyze the accumulative matrices data into a multi-level hierarchical structure or dendrogram. The results of this clustering method produced 3 nonoverlapping clusters at the highest level of similarity (see Appendix B-2). The results were also used to identify aspects of quality of life which were not addressed in the initial item pool. An additional 26 items were added to create an initial listing of 70 items (see Appendix B-3).

A panel of 6 qualified mental retardation professionals from the Department of Human Services in the State of Minnesota was asked to sort the complete listing of all 70 items using the F-Sort method (see Appendix B-4). However, a more stringent criterion (bias of 5) was chosen to reduce the possibility of disassociated relationships and a blurring of the categories. 5 out of the 6 raters had to agree on a specific relationship of one term with another or the relationship was thrown out of the accumulator matrix. The results are shown in Table 2.

TABLE 2 Dendrogram Identifying Four Factors



4 factors emerged from this analysis. Each factor was named from the sorted items loading on it.

A. Health factor. The items loaded were:

1. Did you get enough sleep at night?
2. Do you get tired during the day?
3. If you feel hungry, do you get enough to eat?
6. Do you have any pain or problems when you use the bathroom?
7. Do you get headaches?
8. Do you get stomach aches or other pains?
9. Do you get ear aches?
10. Do you feel physically comfortable?
11. Do you generally feel healthy?
12. Do you get colds?
13. Do you get enough to drink?
14. Do your feet hurt?
15. Do your teeth or dentures hurt?
16. Do you feel anxious or scared?
17. Do you feel tense or upset?
18. Do you feel sad or unhappy?
19. Do your eyes bother you?
20. Do you have a pet at home?
28. Who makes your doctor/dentist appointments?
30. How do you get to work?
44. How do people in the community treat you?
45. How often do you talk with people in the community?
46. Do you have any friends?
48. Do you get a chance to make friends where you work?
49. Do the people you work for think your job is important?
61. How do you feel about your job?
62. How do you feel about visits from your family?
68. Is your home too hot or cold for you?

The 29 items accounted for 41% of the total.

B. Decision making/Independence factor. The items loaded were:

4. Do you exercise during your free time and/or on weekends?
21. How often do you decide when to go to bed and get up?
22. Do you decide who you will eat with?

- 23. Do you decide what you will eat?
- 24. Do you go shopping for your groceries?
- 25. Can you select the decorations in your room?
- 26. Who choose your doctor/dentist?
- 27. When you need medicine, who gives it to you?
- 29. Do you use public transportation?
- 31. Do you have enough money to buy the things you need?
- 32. Can you lock your house or room?
- 33. Are you locked out of places you would like to go in your home/facility?
- 34. Do you have a chance to decide what you want to do?
- 35. Do you decide how you want to spend your money?
- 36. How often do you do things like shopping and movies?
- 37. Do you have a chance to practice your religious beliefs?
- 41. Do you choose what you wear each day?
- 42. How often do you decide on the work you will do?
- 70. Do you feel a sense of belonging here?

The 19 items in this factor accounted for 27% of the total.

C. Relationship factor. The items loaded were:

- 38. Are you free to go out with friends when you want to?
- 39. Can you call or write family and friends when you want to?
- 50. Do friends come to visit you?
- 51. How often do the people you live with annoy you?
- 53. Can friends come to visit you when they want to?
- 54. How often have you been visited by your family?
- 55. Do you have friends on the staff?
- 56. How do staff members treat you?
- 57. How often do you hear staff members talking about other clients?
- 58. How many of the staff members seem happy to have you around.
- 59. How do you feel about this community?
- 63. How do you feel about the staff here?
- 64. How do you feel about others who live here?

The 13 items in this factor accounted for 19% of the total.

D. Personal Satisfaction factor. The items loaded were:

- 40. Can you be alone here when you want to?
- 43. How many people share your room?
- 52. Are you frightened by the people you live with?
- 60. Do you like the food you eat at home?
- 65. How do you feel about your room?
- 66. Are you satisfied that you have enough clothes?
- 67. Would you like to live somewhere else?
- 69. Are you able to do most of the things you like to do?

The 8 items in this factor accounted for 11% of the total.

The empirical validation of these 4 factors (health, decision-making/independence, relationships, and personal satisfaction) are subject to confirmation as client data becomes available in Phase IV of this research project.

The percent of the total number of items accounted for by each of the 4 factors were:

- A. Health factor (41%)
- B. Decision-making/independence (27%)
- C. Relationships (19%)
- D. Personal Satisfaction (11%)

Phase III: Refinement of the Item Pool

The third phase of data collection was designed to assess the importance of the 70 items as quality of life concepts. A Likert scale was developed for this purpose (see Appendix C-1). The use of a Likert scale is a common approach employed for respondents to assign an absolute score to values or desiderata of any kind (Moum, 1983).

Using the Likert method, the writer wrote positive and negative statements about the items to avoid problems with response bias. Respondents were asked to respond to each item by means of a four-point scale ranging from "Very Important" to "Somewhat Important" to "Not Very Important" to "Not Important At All." The items were weighted with scales from 4 to 1 points respectively. The specific responses to the items were summed.

27 clients diagnosed as mentally retarded, 21 parents, and 22 staff volunteered to serve as respondents in ranking the importance of the 70 items during the months of November and December, 1988. All clients, parents, and staff members were either enrolled, involved with the program, or employed by the Lake County Board of Mental Retardation located in Northeastern Ohio.

The data from the importance rankings can be viewed in their entirety (see Appendix C-2). Table 3 shows the 3 (k) sets of rankings and the use of Kendall's Coefficient of Concordance to determine the association among the variables.

The significance of the coefficient of concordance ($W = .583651$) can be assessed by using a Chi-Square test since it assumes a Chi-Square distribution. For an assumed alpha equals .05, the critical value for Chi-Square with $n - 1 = 69$ degrees of freedom would be 90.53. Since the calculated Chi-Square (120.8157) exceeds this value, we can reject the null hypothesis that there is no agreement among these rankings.

TABLE 3 Data From Importance Rankings

						Data from Importance Rankings (continued)					
ITEM #	STAFF	CLIENT	PARENT			ITEM	STAFF	CLIENT	PARENT		
RANK	RANK	RANK	RANK	R	SQDEV	RANK	RANK	RANK	RANK	SQDEV	MEAN R
1	36	29	7	72	1190.25	48	35	23	40	98	72.25
2	55	64	50	169	3906.25	49	40	25	49	114	56.25
3	26	9	25	60	2162.25	50	11	7	18	36	4970.25
4	64	63	17	144	1406.25	51	44	61	54	159	2756.25
5	27	37	12	76	930.25	52	1	69	43	113	42.25
6	33	67	11	111	20.25	53	28	43	14	85	462.25
7	54	60	15	129	506.25	54	18	47	4	69	1406.25
8	52	45	19	116	90.25	55	50	13	30	93	182.25
9	47	62	27	136	870.25	56	2	1	1	4	10506.25
10	34	35	29	98	72.25	57	14	51	42	107	0.25
11	32	21	37	90	272.25	58	9	15	5	29	6006.25
12	63	8	55	126	380.25	59	60	17	58	135	812.25
13	7	10	9	26	6480.25	60	48	19	13	80	702.25
14	56	66	44	166	3540.25	61	38	2	28	68	1482.25
15	41	68	24	133	702.25	62	19	54	3	76	930.25
16	25	6	23	54	2756.25	63	8	4	2	14	8556.25
17	30	33	21	84	506.25	64	17	44	26	87	380.25
18	29	41	16	86	420.25	65	31	14	22	67	1560.25
19	37	53	46	136	870.25	66	58	22	34	114	56.25
20	70	70	70	210	10712.25	67	22	40	51	113	42.25
21	59	56	68	183	5852.25	68	53	58	32	143	1332.25
22	45	46	66	157	2550.25	69	13	11	38	62	1980.25
23	46	42	59	147	1640.25	70	3	26	6	35	5112.25
24	67	49	69	185	6162.65						
25	21	38	67	126	380.25						
26	68	20	63	151	1980.25						
27	61	55	45	161	2970.25						
28	66	31	48	145	1482.25						
29	69	50	64	180	5852.25						
30	62	36	52	150	1892.25						
31	23	12	56	91	240.25						
32	39	59	61	159	2756.25						
33	57	65	65	187	6480.25						
34	5	5	36	46	3660.25						
35	15	3	47	65	1722.25						
36	16	34	35	85	462.25						
37	20	52	62	134	756.25						
38	12	32	41	85	462.25						
39	6	24	39	69	1406.25						
40	4	18	10	32	5550.25						
41	49	16	57	122	240.25						
42	65	27	60	152	2070.25						
43	51	57	31	139	1056.25						
44	43	30	20	93	182.25						
45	42	48	53	143	1332.25						
46	10	28	8	46	3360.25						
47	24	39	33	96	110.25						

The over-all agreement across clients, parents, and staff exhibited significant agreement in rank orders at the .001 level. This means that this result had a likelihood of occurring by chance less than one time out of a thousand.

In addition, Kendall rank correlations were calculated (see Table 4) between groupings of clients to parents (.16), clients to staff (.26), and staff to parents (.36). While these correlations were significant at the .05 level, these results indicate only a low to moderate relationship in the rankings by these three subject groups.

Three items (13, 56, and 63) were included in the top ten rankings for all three groups. These items address: (13) "If you feel thirsty, do you get enough to drink?", (56) "How do staff members treat you?", and (63) "How do you feel about the staff here?" It is also clear that there is a greater degree of agreement between staff and parents than with either staff-clients or parents-clients. In fact, seven items (13, 40, 46, 56, 58, 63, and 70) appear on both staff and parent lists. One can conclude from the importance study that there is some similarity between the rankings of clients, parents, and staff as to the importance of the seventy items as quality of life measures.

TABLE 4 Kendall Rank Correlations

	SRANK	CRANK	PRANK
SRANK	1.000	.2629	.3648
	(70)	(70)	(70)
	1.0000	.0013	.0000
RANK	.2626	1.0000	.1677
	(70)	(70)	(70)
	.0013	1.0000	.0401
PRANK	.3648	.1677	1.0000
	(70)	(70)	(70)
	.0000	.0401	1.0000

Phase IV: Administration of the Quality of Life Instrument

Having completed the item selection process, the instrument was field tested during the month of January, 1989 on a population of 70 adult clients diagnosed as mentally retarded during the last phase of data collection. The 70 clients were selected as a representative sample of the adult population served by the Lake County Board of Mental Retardation. Demographic characteristics of the clients in the sample are compared with the same characteristics of the adult population served by the agency in Table 5.

Raters during this phase of data collection were qualified mental retardation professionals. Each rater was asked to interview clients by asking the respondents to answer a listing of questions according to how he/she honestly felt about each item (see Appendix D-1). For example, the question concerning "Do you get enough sleep at night?" could be answered in one of three ways (most of the time, some of the time, or rarely).

If a person was non-verbal, two staff members were required to evaluate that person on each item; and the average score was used. Scores could range from a low of 70 to a high score of 210. If an item did not apply, an N/A was assigned and the score was adjusted accordingly.

Table 5 Demographic Characteristics of Clients in Pilot Study

CHARACTERISTICS	PERCENTAGE OF THE SAMPLE	PERCENTAGE OF OF THE COUNTY
SEX		
Male	61.4% (43)	57%
Female	38.6% (27)	43%
AGE		
22-35	44.3% (31)	47%
36-50	38.6% (27)	34%
50 and over	17.1% (12)	19%
FUNCTIONING LEVEL		
Profound	14.3% (10)	12.7%
Severe	21.4% (15)	28.5%
Moderate	41.4% (29)	36.2%
Mild	22.9% (16)	22.6%
CURRENT LIVING ENVIRONMENT		
Semi-independent living	38.6% (27)	46.7%
Purchase of service Group Home	24.3% (17)	10.7%
Intermediate Care Facility/MR	37.1% (26)	42.6%

Factor Analysis

A principal components analysis of these ratings was completed utilizing the University of Minnesota's Statistical Package for the Social Sciences (SPSS) version 9.1. A principal components analysis is frequently chosen as the preferred method for examining the structure of a given domain as represented by the sample of variables to identify basic conceptual dimensions (Gorsuch, 1983). This is because it represents the greatest proportion of the variance of the variables in the fewest possible dimensions. Of the various factor solutions (2 to 8) generated by the computer, the principal components analysis yielded a 4 factor solution with eigenvalues larger than one.

These 4 factors, their eigenvalues, and percentage of variance were as follows:

	Eigenvalues	Percentage of Variance
Factor 1	11.7776	46.6%
Factor 2	7.33478	29.0%
Factor 3	3.32419	13.1%
Factor 4	2.84659	11.3%

These scores show that the instrument has a very dominant first factor and probably has three or four common factors that best describe the underlying structure of this data.

Table 6 lists the items that had their largest loadings on one of the first four factors. The items are listed in the order of the size of their factor loadings with the largest first. The 18 items loading on the first factor are measures of decision-making/independence. The second factor is defined by 13 items related to health or physical well-being. The third factor is also defined by 13 items related to friendships or social and emotional well-being. The fourth factor is defined by 7 items related to personal well-being or personal satisfaction. Appendix D-2 identifies an Item Master List showing both a four-factor and a three-factor interpretation.

The initial extraction statistics, including eigenvalues, percentage of variance and cumulative percentage of variance, are included in Appendix D-3. The majority of the variance (79.5%) is accounted for by the first twenty items.

The rotated factor matrix is presented in Table 7. The actual items composing each factor have already been identified.

TABLE 6 Items Composing the Four Quality of Life Factor Scores and factor Loadings

Factor 1	Factor 2
23. Do you decide what you will eat? <u>.8686</u>	16. Do you feel anxious or scared? <u>.6569</u>
25. Can you select the decorations in your room? <u>.8387</u>	17. Do you feel tense or upset? <u>.6422</u>
24. Do you go shopping for your groceries? <u>.8357</u>	9. Do you get ear aches? <u>.5321</u>
27. When you need medicine, who gives it to you? <u>.8295</u>	7. Do you get headaches? <u>.5147</u>
32. Can you lock your house or room? <u>.7889</u>	11. Do you generally feel healthy? <u>.5047</u>
35. Do you decide how to spend your money? <u>.6893</u>	70. Do you feel sense of belonging here? <u>.4929</u>
28. Who makes your doctor/dentist appointments? <u>.6825</u>	66. Are you satisfied that you have enough clothes? <u>.4897</u>
43. How many people share your room? <u>.6801</u>	1. Do you get enough sleep at night? <u>.4735</u>
22. Do you decide who you eat with? <u>.6792</u>	5. Do you use the bathroom when you need to? <u>.4565</u>
21. How often do you decide when to go to bed and get up? <u>.6477</u>	4. Do you exercise during your free time and/or on weekends? <u>.4378</u>
41. Do you choose what you wear each day? <u>.6036</u>	69. Are you able to do most of the things you like to do? <u>.4363</u>
36. How often do you go out to do things like shopping and movies? <u>.5927</u>	2. Do you get tired during the day? <u>.4272</u>
51. How often do the people you live with annoy you? <u>.5873</u>	19. Do your eyes bother you? <u>.4172</u>
45. How often do you talk with people in the community? <u>.5866</u>	
33. Are you locked out of places you would like to go in your home/facility? <u>.5795</u>	
29. Do you use public transportation when you need to go somewhere? <u>.5729</u>	
34. Do you have a chance to decide what you want to do? <u>.5094</u>	
50. Do friends come to visit you? <u>.4041</u>	106

TABLE 6 Items Composing the Four Quality of Life Factor Scores (continued)

FACTOR 3	FACTOR 4
49. Do the people you work for think your job is important? <u>.6597</u>	67. Would you like to live some- place else? <u>.6377</u>
55. Do you have friends on the staff? <u>.5902</u>	3. If you feel hungry, do you get enough to eat? <u>.4652</u>
47. Do you get a chance to make friends where you work? <u>.5882</u>	20. Do you have a pet at home? <u>.4553</u>
63. How do you feel about the staff? <u>.5283</u>	60. How do you like the food you get at home? <u>.4218</u>
39. Can you call or write family and friends when you want to? <u>.4959</u>	40. Can you be alone here when you want to? <u>.4011</u>
48. Do you get a chance to make friends where you work? <u>.4854</u>	68. Is your home too hot or too cold for you? <u>.4049</u>
58. How many of the staff members are happy to have you around? <u>.4549</u>	52. Are you frightened by the people you live with? <u>.3967</u>
38. Are you free to go out with friends when you want to? <u>.4457</u>	
54. How often have you been visited by your family? <u>.4301</u>	
14. Do you feel hurt? <u>.4263</u>	
64. How do you feel about others who live here? <u>.4245</u>	
56. How do staff members treat you? <u>.4159</u>	
61. How do you feel about your job? <u>.4061</u>	

TABLE 7 Rotated Factor Matrix

VARIABLE	FACTOR 1	FACTOR 2	FACTOR 3	FACTOR 4
QL1	-.14679	.47350	.18940	.10885
QL2	.07251	.42721	-.01305	-.08333
QL3	-.01675	.12362	.09171	.46515
QL4	.08738	.43775	.02997	-.04978
QL5	.38436	.45649	-.04123	-.17676
QL6	.08967	.30473	.33418	.22197
QL7	-.02664	.51465	.10642	.16767
1L8	.02034	.36149	.12851	-.02031
QL9	.05159	.53206	.02697	.10450
QL10	-.09498	.22666	-.09096	.23932
QL11	.07429	.50473	.05318	.16207
QL12	-.12336	.39424	.01764	-.08884
QL13	.02432	.01685	.19241	.34222
QL14	-.18825	.25964	.42635	.34236
QL15	.18016	.03872	.11406	.39669
QL16	.19483	.65692	.00135	.08530
QL17	.02730	.64220	.33632	.01544
QL18	.10565	.25092	.31077	-.19336
QL19	-.12102	.41720	-.12176	.34678
QL20	-.09675	-.00471	.12170	.45529
QL21	.64769	.22431	.04740	-.01320
QL22	.67918	.35019	.16079	-.14859
QL23	.86864	-.02236	.10242	-.01924
QL24	.83574	-.11803	-.04206	.01376
QL25	.83874	-.03452	-.00749	.06070
QL26	.37389	-.08081	.03462	-.09542
QL27	.82950	-.06596	-.05835	.06082
QL28	.68251	-.27587	-.05195	-.03070
QL29	.57298	.02250	-.11940	.06728
QL30	.39052	.04492	-.27185	.02038
QL31	.14010	.04759	.38457	.08055
QL32	.78892	.03912	.02273	.02347
QL33	.57953	.17699	.05484	.40676
QL34	.50938	.25082	.02614	.26140
QL35	.68934	.28740	.09654	-.10364
QL36	.59271	.26888	.15437	-.11654
QL37	.29095	.24514	.15823	.24274
QL38	.33572	-.14972	.44572	.29995
QL39	.24505	.03625	.49592	.36188
QL40	.21426	-.09070	.11902	.40107
QL41	.60362	.31676	.08826	-.26852
QL42	.39440	-.08782	.35521	-.07036
QL43	.68006	-.03515	-.01153	.00699
QL44	.18154	.36383	.36999	-.19014
QL45	.58656	.19714	.35031	-.22220
QL46	.35570	.18110	.34918	-.30478
QL47	-.13541	-.03130	.58823	.05454

TABLE 7 Rotated Factor Matrix (continued)

VARIABLE	FACTOR 1	FACTOR 2	FACTOR 3	FACTOR 4
QL48	-.05462	-.06214	.48538	.03282
QL49	.06356	.08700	.65966	.21013
QL50	.40406	.08218	.26234	-.21065
QL51	.58727	-.04216	-.06268	.27194
QL52	.02729	-.23444	.15425	-.39585
QL53	-.02486	.09421	.22018	.10782
QL54	-.03227	.01866	.43010	-.24436
QL55	.06760	.07690	.59020	.01445
QL56	-.02589	.20174	.41590	.34528
QL57	.36012	-.09557	.04682	.19104
QL58	.10934	.41247	.45495	.12559
QL59	.32496	.40037	.36858	.09689
QL60	.00590	.32429	.36023	.42178
QL61	-.22081	.15705	.40613	.29301
QL62	-.12678	.09349	.19570	.06259
QL63	.11552	.24597	.52832	.22750
QL64	.18517	.37238	.42449	-.08838
QL65	.28408	.32056	.27808	.21150
QL66	-.23684	.48974	.12746	.25525
QL67	.10008	-.05137	.08919	.63775
QL68	.25476	-.02432	-.06923	-.40493
QL69	.37350	.43625	.31526	.18040
QL70	-.05266	.49285	.43050	.21171
	FACTOR 1	FACTOR 2	FACTOR 3	FACTOR 4
FACTOR 1	.82083	.40238	.38275	.13356
FACTOR 2	-.56216	.53133	.52115	.36064
FACTOR 3	.08894	-.59667	.16419	.78046
FACTOR 4	-.04806	-.44695	.74494	-.49294

Item Analysis

The item analysis of the 70 items comprising the Quality of Life Instrument consisted of three parts:

- (1) An analysis of the response distribution of the items;
- (2) The pairwise correlation of the items within a subscale;
- (3) The use of the coefficient alpha formula to calculate internal consistency reliability.

The first analysis indicates whether variation exists in the responses to the items. If little variation exists, the items cannot differentiate among individuals. The second part of the analysis indicates how each item relates to every other item within a specific subscale. These data will be used in selecting those items that best fit each scale. The use of the coefficient alpha will determine the degree of scale homogeneity (i.e. whether the items in the scale are measuring the same thing and measuring it well).

Table 8 shows the means, standard deviations, and communality for each of the 70 items. The means vary from a low score of 1.23 to a high score of 2.89. The standard deviations vary from a low score of .38 to a high score of .97. The communality (i.e., the proportion of each item's variance that can be accounted for by the common factors) also varies from a low score of .06703 to a high score of .76590.

The results of the item by item analysis within each of the four subscales can be found in Table 9 through Table 12.

TABLE 8 MEANS/STANDARD DEVEATIONS/COMMUNITY

VARIABLE	MEAN	STANDARD DEV.	COMMUNALITY
QL1	2.6000	.6151	.29347
QL2	2.0933	.6813	.19488
QL3	2.7600	.5157	.24034
QL4	1.8400	.7718	.20263
QL5	2.8933	.4215	.38906
QL6	2.8133	.4253	.26185
QL7	2.2133	.7031	.30501
QL8	2.2667	.6644	.14802
QL9	2.5867	.5717	.29740
QL10	2.6667	.6224	.12595
QL11	2.7333	.5534	.28937
QL12	2.2133	.5994	.17885
QL13	2.8933	.3881	.15501
QL14	2.6267	.6733	.40184
QL15	2.6667	.5285	.20433
QL16	2.3600	.6072	.47678
QL17	2.2800	.6273	.52652
QL18	2.2800	.5342	.20809
QL19	2.7733	.5087	.32378
QL20	1.4667	.6644	.23148
QL21	2.4267	.7384	.47223
QL22	2.3867	.7866	.63185
QL23	1.9733	.9001	.76590
QL24	1.8000	.8542	.71435
QL25	2.0400	.9648	.70841
QL26	1.3467	.7258	.15663
QL27	1.8133	.8806	.69953
QL28	1.3333	.5774	.54556
QL29	1.3333	.6003	.34759
QL30	1.2267	.4814	.22884
QL31	2.6933	.6570	.17628
QL32	2.2133	.9767	.62498
QL33	2.7687	.4124	.53564
QL34	2.6000	.5199	.39139
QL35	2.4400	.7021	.57786
QL36	2.0133	.6677	.46101
QL37	2.4933	.6852	.22870
QL38	2.6533	.6039	.42375
QL39	2.8400	.4040	.43825
QL40	2.6800	.5492	.22916
QL41	2.6533	.6876	.54460
QL42	2.1067	.7273	.29439
QL43	2.3733	.5876	.46390
QL44	2.3467	.5573	.33837
QL45	2.1333	.8275	.55500
QL46	2.3733	.5876	.37414

TABLE 8 Means/Standard Deveations/Community (Continued)

VARIABLE	MEAN	STANDARD DEV.	COMMUNALITY
QL47	2.5200	.6009	.36830
QL48	2.6267	.5641	.24352
QL49	2.6667	.5534	.49091
QL50	1.8000	.7352	.28321
QL51	1.9333	.7769	.42454
QL52	2.2000	.8853	.23620
QL53	2.8667	.4137	.06960
1			
QL54	1.9333	.7769	.24609
QL55	2.4267	.5495	.35903
QL56	2.6000	.5452	.33356
QL57	2.5333	.6003	.17751
QL58	2.4933	.6233	.40484
QL59	2.5333	.5534	.41113
QL60	2.7200	.4810	.41286
QL61	2.6000	.5927	.32422
QL62	2.6400	.5363	.06703
QL63	2.6267	.5396	.40472
QL64	2.3200	.5964	.36096
QL65	2.7200	.5342	.30552
QL66	2.6933	.5446	.37734
QL67	2.5600	.6826	.42733
QL68	1.4533	.6215	.23425
QL69	2.6267	.5396	.46174
QL70	2.7333	.5285	.47583

TABLE 9 Correlation Matrix for Factor I (Decision making/Independance)

	QL21	QL22	QL23	QL24	QL25	QL27	QL28	QL29
QL21	1.00000							
QL22	.27297	1.00000						
QL23	.56636	.62556	1.00000					
QL24	.52274	.45853	.78389	1.00000				
QL25	.44995	.49574	.8104	.73129	1.00000			
QL27	.51900	.49578	.81201	.72214	.77237	1.00000		
QL28	.32755	.30748	.58945	.68500	.53373	.62904	1.00000	
QL29	.43698	.29572	.39184	.47434	.39666	.50274	.45489	1.00000
QL32	.56540	.59478	.71371	.71592	.67921	.61256	.42339	.43025
QL33	.39169	.42433	.45773	.45262	.49721	.33537	.24593	.29111
QL34	.48580	.41638	.38122	.39558	.43647	.33650	.27014	.25981
QL35	.62349	.69098	.59619	.50920	.53225	.48432	.40004	.28856
QL36	.37206	.47894	.54031	.45492	.60755	.50994	.26877	.32593
QL41	.58804	.65094	.50892	.43252	.40823	.44962	.29302	.28374
QL43	.43773	.56061	.65792	.52771	.64079	.63273	.34525	.33205
QL45	.34798	.54258	.53104	.42060	.50105	.40552	.33001	.31740
QL50	.20910	.29910	.37984	.40881	.43056	.37987	.28652	.21433
QL51	.28581	.33021	.48056	.40723	.50841	.51486	.41173	.36702

TABLE 9 Correlation Matrix Factor I (continued)

QL32	QL33	QL34	QL35	QL36	QL41	QL43	QL45	QL50	QL51
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1.00000

.51711 1.00000

.38325 .54204 1.00000

.57070 .56188 .45167 1.00000

.49295 .30493 .28810 .50621 1.00000

.55431 .35518 .21170 .68410 .48118 1.00000

.54225 .38888 .27429 .44812 .50386 .42502 1.00000

.53286 .32207 .31414 .45590 .48595 .48611 .34096 1.00000

.26724 .08022 .21213 .35603 .47351 .26197 .30031 .42205 1.00000

.42861 .54546 .40149 .32701 .36646 .23441 .49931 .28728 .02366 1.00000

TABLE 10 Correlation Matrix for Factor II (Physical Well-Being)

	QL1	QL2	QL4	QL5	QL7	QL9
QL 1	1.00000					
QL 2	.38051	1.00000				
QL 4	.20494	.20869	1.00000			
QL 5	.09382	.27044	.23761	1.00000		
QL 7	.35618	.35281	.03885	.16901	1.00000	
QL 9	.40732	.30856	.15436	.09496	.35678	1.00000
QL 11	.23817	.13858	.21513	.45571	.21761	.28757
QL 16	.31841	.34237	.26877	.36329	.35578	.39553
QL 17	.36422	.28584	.31707	.26781	.38357	.32707
QL 19	.22458	.10087	.21617	.01177	.28816	.09170
QL 66	.35499	.15103	.20319	-.02669	.31432	.28184
QL 69	.11400	.09606	.17911	.41670	.17713	.19391
QL 70	.24942	.03253	.22530	.05258	.26426	.30117

TABLE 10 Correlation Matrix for Factor II (Continued)

QL11	QL16	QL17	QL19	QL66	QL69	QL70
1.00000						
.28955	1.00000					
.21797	.58329	1.00000				
.26241	.22403	.28629	1.00000			
.30787	.33839	.33386	.42864	1.00000		
.47663	.37452	.39283	.17987	.34091	1.00000	
.30802	.471699	.55438	.17427	.55720	.54655	1.00000

TABLE 11 Correlation Matrix for Factor III
(Friendships/Social/Emotional Well Being)

	QL47	QL48	QL49	QL54	QL55
QL 47	1.00000				
QL 48	.54060	1.00000			
QL 49	.32507	.37514	1.00000		
QL 54	.24894	.00411	.19904	1.00000	
QL 55	.50582	.30283	.42951	.38404	1.00000
QL 56	.18973	.16696	.40303	-.06380	.26158
QL 58	.27999	.18501	.28729	.09674	.36351
QL 38	.24280	.24966	.25607	.15169	.80524
QL 39	.23600	.20871	.36260	.09471	.25076
QL 61	.21246	.39607	.41193	.11738	.11616
QL 63	.23172	.11306	.43741	.26217	.27100
QL 64	.13273	.07873	.32753	.25082	.31997

TABLE 11 Correlation Matrix for Factor III (Continued)

QL56	QL58	QL38	QL39	QL61
1.00000				
.34993	1.00000			
.27087	.20920	1.00000		
.38032	.31768	.65576	1.00000	
.29268	.17557	.06040	.18056	1.00000
.49605	.51485	.30246	.28017	.45630
.23272	.36937	.16209	.10319	.17584

TABLE 12 Correlation Matrix for Factor IV (Personal Satisfaction)

	QL60	QL67	QL68	QL3	QL20	QL33	QL40
QL60	1.00000						
QL67	.23708	1.00000					
QL68	.38332	.22424	1.00000				
QL3	.21574	.42535	.16190	1.00000			
QL20	.07611	.36948	.19198	.29185	1.00000		
QL33	.23979	.28609	.03936	.20078	.12165	1.00000	
QL40	.06548	.26819	.24228	.05916	.22961	.29115	1.00000

The item-by-item correlations show how the items correlate with one another. The items with correlations between .30 to .60 should add unique variance to the scale. Items that are either too highly correlated with one another or not correlated at all should be removed from the scale. These data were displayed in Tables 9 through 12 to allow for a clear presentation of the relationships between items.

The internal consistency (an estimate of reliability) of the Quality of Life Instrument was determined using the coefficient alpha formula. The values of the reliability of the subscales were all uniformly high (.94, .83, and .80) with the exception of the fourth factor (personal satisfaction-.66). The latter score is somewhat low due to the small number of items (n=7) that composed the scale since length of items is the primary way to make a test more reliable (Nunnally, 1967). Newcomer and Hammill (1982) reported that reliability coefficients of .80 or above are considered adequate for a scale used with individual clients.

Nunnally's (1967) formula allows calculation of the number of items needed to reach a desired level of reliability (.80).

$$K = \frac{r_{kk}(1-r_{11})}{r_{11}(1-r_{kk})} \quad \text{where} \quad \begin{array}{l} r_{kk} = \text{desired reliability} \\ r_{11} = \text{reliability of existing test} \\ k = \text{number of times test would have to be lengthened to obtain reliability of } r_{kk} \end{array}$$

Using this formula, the Quality of Life Instrument would require an additional 7 items in personal satisfaction to reach the desired level of internal consistency.

An overall summary of performance for each of the subscales is presented in Table 13.

TABLE 13
Summary of Performance in the Quality of Life Instrument

	FACTOR ONE CHOICES/ INDEPENDENCE	FACTOR TWO HEALTH/PHYS. WELL BEING	FACTOR THREE FRIENDSHIP/ SOC. EMOTION.	FACTOR FOUR PERSONAL SATISFACTION
MEAN	38.05	32.43	30.31	17.52
MAX.	54	39	36	21
STD. DEV.	9.35	4.41	3.95	2.29
COEF. ALPHA	.94	.83	.81	.66
Percentage Variance	46.7%	29.0%	13.1%	11.3%
Eigen- values	11.78	7.34	3.32	2.85

In confirmation of the cluster analysis, four factors emerged with eigenvalues greater than 1.00.

Chapter 5 will summarize the study and make recommendations based on the analysis of the data.

Chapter 5
SUMMARY, DISCUSSION, and
RECOMMENDATIONS

The purpose of this chapter is to present a summary of the findings, state conclusions, and present recommendations. The study was organized to identify the theoretical constructs associated with the concept "quality of life" for a selected sample of persons with mental retardation. The quality of life constructs would be used to develop and to test an instrument for measuring quality of life. The study would attempt to answer the following questions:

1. What are the clusters and/or factors to be considered in the measurement of quality of life for adult persons with mental retardation?
2. Can clients, parents, and professional staff show agreement as to the importance of potential measures of quality of life candidate items?
3. Can Quality of Life subscales be developed with sufficient reliability (coefficient alpha's higher than .80)?

A review of the literature suggested four major components (physical, psychological, social-emotional, and personal well-being) in the measurement of quality of life. These areas will be briefly summarized.

A. Physical well-being is perceived as a necessary foundation upon which the more subjective dimensions of life quality depend. It includes an individual's perception and evaluation of their overall health status and self-reports of ailments or health problems.

Since physical well-being is more than just the absence of disease, measures of physical functional status also need to be looked at in relation to the performance of social roles, limitations in activities and self-care, and difficulties in mobility. Measures of physical functional status are designed to measure the effects of disease or illness rather than the existence of specific health care problems. Stokols, Shumaker, and Martinez (1983) found a lower quality of life associated with a higher prevalence of health problems and diminished physical well-being. General health has also demonstrated the most consistent correlation with global quality of life in a number of studies (Abbey and Andrews, 1983 and Pearlman and Uhlmann, 1988).

B. Psychological well-being refers to an assessment on a cognitive level that life conditions and aspirations are closely matched. According the "gap or discrepancy" theory developed by Campbell et., al., (1976), psychological well-being will suffer if there is a gap between what a person has and what they want or what they aspire to be. As described by George (1979), it is essentially a cognitive assessment of one's progress towards desired goals in life. Psychological

well-being also seems to be affected by the choices available to individuals in their living and working environments. As choices are limited, the degree of outside control will be increased and psychological well-being will suffer. Spalding (1985) found that persons in nursing homes experienced greater frustration when they did not have the choice of a physician and when they lost the ability to make decisions over the small details in their everyday lives.

Just as illnesses and disease will have an inverse relation to physical well-being (ie. if they increase, physical well-being will suffer), an increase in outside stressors and external control agents will also have an inverse relationship to psychological well-being. As they increase, psychological well-being would be diminished. Social supports and performance successes have been found to improve psychological well-being. Abbey and Andrews (1976) found that psychological well-being consistently explained the greatest variance (54%) in life quality regarding the self.

C. Social/emotional well-being refers to a basic sense of security on an affective (emotional) level as well as a feeling that one is connected to others throughout relationships. It has been viewed as a subjective dimension of quality of life (Epstein, 1973). Moos identified a relationships dimension as one of three broad categories that emerged from his studies of 8 different kinds of environments.

Griffin (1969) identifies interpersonal trust as the key to social/emotional well-being. He argues that environments that promote a rigid structuring of staff and client roles will limit the interpersonal exchanges on a human scale that promote trust. The literature seems to suggest that attempts to measure social/emotional well-being have typically been designed as measures of self-esteem.

D. Personal well-being is generally viewed as the degree to which one is presently content with their general life situation. It has often been taken as a global measure of life satisfaction and has frequently been discussed as self-regard. It is closely linked with health, occupation, relationships, performance, and financial security satisfactions.

This fourth dimension to the assessment of quality of life seems appropriate, since knowledge about a person's physical well-being, psychological well-being, and social/emotional well-being may not fully explain the global quality of a person's life without a more indepth knowledge of the circumstances in which a person lives and the meanings attached to such circumstances. This dimension also allows us to take into consideration in a more complete fashion, the immediate impact of outside variables that may affect a person's quality of life (eg. collapse of the stock market, world hostilities, rise in world oil prices, etc.). The research suggests that satisfaction with financial security

has been found to have the greatest impact on satisfaction with life as a whole.

Based on a review of the relevant literature, a model which seeks to advance our knowledge about quality of life was developed (see page 16 in Chapter One). The model provides us with a way to think about the components of quality of life. Quality of life is defined as a four factor measure of client experience. Schematic sub-models were developed for each of these four factors.

Summary of the Study

Data for the study were collected in four phases, employing a different subject pool in each phase.

Generation of the item pool occurred in the first phase. Two different data searches utilizing the Project for Automated Library Systems and DIALOG Information Services, Inc., produced over 150 references related to quality assurance and quality of life. 44 articles were identified that related to specific quality of life measurements. The researcher developed an initial listing of 70 items as possible candidate measures for a quality of life instrument. These items were prepared in card form for use in the second phase of data collection.

Two different panels (a group of 6 qualified mental retardation professionals from the Lake County Board of Mental Retardation in Northeastern Ohio and a group of 6

professionals with similar qualifications from the Department of Human Services in the State of Minnesota) were asked to sort the seventy items into meaningful categories using an F-Sort technique as described by Wiley (1967).

The University of Minnesota's Cluster Analysis Package was used to identify the underlying factors. A more stringent criterion (bias of 5) was chosen for the complete analysis of all seventy items by the group of professionals from the State of Minnesota. The results of the Cluster Analysis are displayed in a dendrogram on page 94 in Chapter Four.

The third phase of data collection involved refinement of the item pool. A total of twenty seven (27) clients, twenty one (21) parents, and twenty two (22) staff members were asked to participate in ranking the importance of the items using a Likert-style rating instrument. All clients, parents, and staff members were either enrolled or involved with the Lake County Board of Mental Retardation located in Northeastern Ohio. Respondents were asked to respond to each item by means of a four-point scale ranging from "very important" to "somewhat important" to "not very important" to "not important at all." The extent of agreement across the three groups would be determined by using Kendall's Coefficient of Concordance. In addition, feedback from clients, parents, and staff as to the importance of the items would also be used in organizing the quality of life instrument.

The last phase of data collection consisted of field testing the Quality of Life Instrument on a population of 70 adult clients with mental retardation. All raters were qualified mental retardation professionals. Each rater was asked to interview clients by asking the respondent to answer a listing of questions according to how they actually felt about each item. If an item did not apply, an NA was assigned and that person's score was adjusted accordingly. Data from the 70 ratings were coded and subjected to a factor analysis to identify the unities or dimensions behind the measures.

Findings of the Study

Data for the study were collected in each of the four phases of data collection. In Phase One, 150 references to quality assurance and quality of life were identified. 44 articles were identified with the development of specific instruments related to the measurement of quality of life. An initial item pool of 70 items were developed to serve as input to a similarity matrix. This matrix was analyzed using a cluster analysis procedure with a bias of 5 as a stringent criterion.

4 factors emerged from the cluster analysis. The largest factor was identified as a health factor. It accounted for 41% percent of the items. A decision-making/independence factor accounted for 27% percent of the items. The third factor was identified as relationships. It accounted for

19% percent of the items. The last factor was personal satisfaction. It accounted for 11% percent of the items. A third subject pool of 27 clients diagnosed as mentally retarded, 21 parents, and 22 staff members were surveyed. Each group was asked to rank the items according to their importance.

Results of these rankings were analyzed using Kendall's Coefficient of Concordance to determine the degree of association among these variables. The significance of the Coefficient of Concordance was assessed by a using a Chi-Square test since this data assumes a Chi-Square distribution. For an assumed alpha equals .05, the critical value for Chi-Square with $n - 1 = 69$ degrees of freedom would be 90.53. The calculated Chi-Square was 120.8157. Since it exceeded the alpha level, we were able to reject the null hypothesis that there was no agreement among these rankings. The overall agreement across clients, parents, and staff exhibited agreement in rank orders at the .001 level. This result had a likelihood of occurring by chance less than one time out of a thousand. We were able to conclude that the rankings had some similarity in importance across the samples. This input was also used in the identification of the items for the Final Item Master List.

In addition, Kendall rank correlations were also calculated between groupings of clients to parents (.16), clients to staff (.26), and staff to parents (.36). While

these correlations were significant at the .05 level, their practical value remains questionable because the results indicate only a low to moderate relationship in the rankings by these three subject groups.

Having completed the item selection process, the Quality of Life Instrument was field tested and the data was subjected to a factor analysis using the University of Minnesota's Statistical Package for the Social Sciences (SPSS) version 9.1. The principal components analysis resulted in four factors with eigenvalues larger than 1.00.

	Suggested Name	Eigenvalues
Factor 1	Decision-making/ind.	11.77768
Factor 2	Health-related items	7.33478
Factor 3	Relationships	3.32419
Factor 4	Personal Satisfaction	2.84659

The results of the principal components analysis were consistent with the results of the cluster analysis. Both the cluster analysis and the factor analysis lend support to the theoretical structure of the quality of life model. The researcher conducted an analysis of the items that loaded in each of the four factors and their relationship to the items in the schematic submodels. The interpretability of this data supports the diagnostic validity of the Instrument.

The reliability of the Quality of Life Subscales was determined using the coefficient alpha formula (Cronbach, 1951) for internal consistency reliability. The reliability for each of the Quality of Life subscales were as follows:

Subscale	Reliability
Choices/Independent functioning	.9367
Health/physical well-being	.82592
Friendships/Relationships	.80387
Personal Satisfaction	.66413

The values of three out of four factors (each corresponding to a subscale of the instrument) were all uniformly high which indicates that the subscales are internally consistent. The relatively low coefficient alpha for the personal satisfaction scale is not judged to be due to an invalid construct. The researcher believes that the reliability value is simply related to the small number of items in this scale.

Item validity was also looked at to determine the discriminating powers of the items in the scale. The individual item ratings correlated well with their subscale ratings which indicated that the internal cohesiveness of the subscale as a measure of quality of life was substantiated.

Limitations and Discussion

On the basis of the data obtained, the following conclusions were reached within the restrictions of the study.

The study was limited to a select county program serving adult clients in licensed, residential beds. The study did not address persons with mental retardation living in state-operated programs or individuals who still reside with their

natural families. The study did not address school age children in residential settings. The study was limited to adult clients living in licensed beds since the county program has legal requirements to monitor both quality of care and quality of life. The size of the pilot study was limited because of time constraints in developing an acceptable quality of life instrument prior to March 15, 1989. In actuality, the study should have been conducted with approximately 350 clients or five times the number of items in the instrument.

Since quality of life is only vaguely defined as a concept, the representativeness of the items in the subscales was not guaranteed. However, internal consistency reliability was assured for three out of four factors in the instrument. Criterion related validity was not assured.

The findings of this study indicate that the components to be considered in the measurement of quality of life may be identified. The factors identified fit the model proposed in Chapters One and Two in a close fashion. As a result of the pilot study, a four-factor instrument which measures quality of life was developed with significant factor loadings and internal consistency reliability. Since the sample size was limited, however, we can have confidence in their validity only by subjecting the resulting measures to further testing with other populations of persons with mental retardation. Other studies to obtain normative data for the population

including specific norms for "low to medium and high to normal" functioning groups needs to be completed.

The findings from the importance study suggest that there is some similarity between the rankings of clients, parents, and staff as to the importance of items to be used in quality of life ratings. This finding is in contrast to Mayer and Rosenblatt (1974), Polak (1970), Smith and Metzner (1970), Strauss, et. al., (1964), and Wessen (1958) who have indicated that lack of agreement and divergent views in the mental health field is more likely the norm when it comes to selecting criteria for program successes or program failures. The possible reason that the current data disagrees with previous findings is the greater involvement that parents have with staff and clients in the field of mental retardation. The goals are more apparent and are communicated on a regular basis through habilitation team meetings where clients, parents, and staff have the opportunity to interact with each other. The process of developing the instrument did address Leismer's concern (1984) that consumer input was not taken into consideration in the definition of quality of life in the first place.

The item ranking the highest from a client perspective for a quality of life measure was "How do staff members treat you?" The item ranking the highest from a parent perspective was "How do you feel about the staff here?" The staff rated "Are you frightened by the people you live with?" as the top

measure. All three questions clearly deal with relationships. It is also consistent that staff rated this same question (Number 56: "How do staff members treat you?"), as their second highest ranked item and parents ranked it third on their listing. These findings are consistent with this research model of quality of life being a measure of client experience where relationships are important for social/emotional well-being.

It is also interesting that all three groupings (clients, parents, and staff) identified question Number 20. as having the least importance in the measurement of quality of life ("Do you have a pet at home?"). Anderson's quality of life research (1987) in nursing homes found higher quality of life ratings for clients who had pets in their residential settings. Feedback from clients, parents, and staff, however, suggested that this item was listed as having the least importance because of its incorrect wording. All three groups were more concerned about whether pets were allowed. A person's quality of life score should not be penalized because they have made a choice not to have a pet in the first place. A comparision of item wording and suggested changes for Schalock, Keith, Hoffman, and Karan's (1989) Quality of Life Instrument is reviewed in Appendix D-4.

Only one item (Number 13: "If you feel thirsty, do you get enough to drink?") did not load after it was identified by all three groups as having importance in the measurement

of quality of life. This item had the highest mean score (2.89) and the lowest standard deviation (.3881). This finding suggests that in the current sample, there was inadequate item variance on this issue (i.e. all clients were found to have ready access to liquids) despite its importance to physical well being.

This research has several practical implications for policy makers. The rankings of the quality of life items in terms of their importance allows decision makers to establish priorities as to how they intend to measure and manage quality of life in their human service organizations. By openly asking for subjective evaluations by the clients about their service experiences in the development of their plan of care, the provider can make judgments as to the quality of life as it is experienced in his or her particular agency. Ward (1984) believes that providers can maximize the functional gains of clients as a result of this input. The identification of items deemed important in the measurement of quality of life also helps to make assumptions explicit. To ask questions of importance to clients, parents, and staff and to act on those judgments are important values for a sound model of quality control. The identification of the items of importance extends the program's information base for decision-making. Identification of the importance of physical well-being, psychological well-being, social/emotional well-being, and personal well-being to the overall concept of

quality of life are aided by the specific items in each of the subscales.

Even though 35.7% (25) of the sample population in this study was profoundly and severely retarded, the items identified in the scales are not generalizable to lower functioning (non-verbal) clients without additional research. As in the research results reported by Schalock, Keith, Hoffman, and Karan (1989), it is difficult to obtain accurate reliability estimates for nonverbal persons with profound and severe mental retardation. A quality of life model must be adaptable to not only different client levels but flexible enough to fit the needs of different program settings.

The findings from this study also indicate that internal consistency reliability can be achieved in the development of subscales. This is an important consideration since quality of life is a multidimensional concept. Researchers need to know if the scales measure what they purport to measure from a validity standpoint as well. Given the fact that all long-term care providers will be required in connection with OBRA 87 to evaluate and utilize quality of life information in client program planning, the ability to accurately measure quality of life variables is of paramount importance.

Recommendations for Further Study

Based on the results of this study, seven recommendations for further study are made:

1. The size of the sample should be increased to approximately 350 clients for sufficient reliability (internal consistency, test-retest and inter-rater) and validity studies to be completed with the revised quality of life instrument developed as a result of this research (see Appendix D-5). The expansion of the pilot study should also include stratified samples of "low functioning," "high functioning," and even a grouping of "normal" persons to establish the proper standardized norms.

2. Independent measures of quality of care and client functioning need to be administered at the same time on all clients so one can begin to look at the complex interaction of these variables and their relationship with one another.

3. The multi-dimensional aspect of the quality of life assessment can be utilized to assess the frequency of case management monitoring for specific clients. With this information, policy makers can establish more efficient and effective case loads for case management followup. For example, individual clients falling below agency norms and standards for physical well-being may require monthly followup by a Registered Nurse. Clients exceeding those norms and standards may not require intensive nursing monitoring as frequently. This approach could help to promote a more efficient and effective use of these resources within the agency. An analysis of quality of life data could help to confirm the need for expanded case management resources or

demonstrate that resources are adequate.

4. Quality of Life assessments are needed for lower functioning (non-verbal) clients and possibly school age children to help focus priorities on the subjective inputs of these unique and different populations.

5. The items identified as most important in the measurement of quality of life should be further investigated. Schalock, Keith, Hoffman, and Karan (1989) point out that social indicators may be good for measuring the collective quality of community life but are insufficient for measuring an individuals perceived quality of life. These same authors also indicate that quality of life can be used as an important criterion for social policy analysis. For example, items used to identify unmet needs in relation to quality of life could be used to influence resource allocation decisions. This recommendation for further study is consistent with the work of Land and Spilerman (1975), Liu (1976), Milbrath (1979), and the "goodness-of-fit" model proposed by Murrell and Norris (1983).

6. Quality of life measurements and client functioning measures are needed to evaluate clients prior to placements out of large congregate care settings. Their progress could be tracked from the standpoint of quality of life as they are exposed to greater independence, choices, relationships, and opportunities for personal satisfaction. The same tracking mechanism, of course, could be used to evaluate client

movement from a group home into a semi-independent living arrangement. This recommendation is consistent with Schalock, Keith, Hoffman, and Karan's 1989 suggestion that quality of life criterion measures be used for evaluating the "goodness-of-fit" between persons and their environments. Higher quality of life is related to a "fit" or congruence between a person and their environment,

7. Personal notes and comments from respondents in this study suggest that quality of life research is highly valued. Instead of viewing quality of life measures as another opportunity to point out the evils of institutional settings, they could be used to evaluate the quality of living and working environments based on the subjective experiences of the client. How quality of life changes in a positive direction from that point on is more important than substantiating differences between existing environments. Quality of life inputs can have a positive impact on client functioning.

The model developed in Chapter One fulfills the requirements established by Harshman (1979) and can be used to help organize the different aspects of a quality assurance program. The model presented quality of care as a five-factor measure of services provided to the client and quality of life as a four-factor measure of client experience. Client functioning, however, is at the heart of the relationship between quality of care and quality of life. Technological

and Environmental factors related to quality of care and Interpersonal and Ecological factors related to quality of life also have an impact on client functioning. Thus, the model includes consideration for all aspects of the program.

Through the utilization of specific quality of life measurement tools, we can make use of the model as an integral part of an educational feedback system. Quality of life assessment data can be used by program planners in the development and monitoring of the Individual Habilitation Plans. The same data can be used by program monitors to evaluate progress of clients and to provide feedback to agency staff. This feedback in the form of either the presence or absence of quality factors can be used to predict potential problems in day program or residential settings.

The schematic sub-models for each of the four factors did identify the nature, intensity, and importance of the relationships between the variables as they comprise the quality of life construct.

The model's flexibility to fit the needs of a variety of programs is left to the mandates of various human service programs. These mandates need to be taken seriously by professionals in the field of mental retardation. The identification of the factors deemed important in quality of life research should help to educate policy makers who too often are unfamiliar with current trends in higher education and recent research findings. As policy makers, they should

know something about the presence or absence of quality in the service delivery system. Such knowledge is indispensable to rational management.

This study was based on the premise that the key to making use of such a model in a human service organization is measurement. Accountability in the human services field will not dramatically change until the performance of provider organizations is measured against expected changes in client functioning. Client functioning defines each individual's potential for both quality of care and quality of life. By identifying factors associated with quality of life it becomes possible to create a management environment where quality control has a measurement foundation.

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TABLE 9 Correlation Matrix Factor I (continued)

QL32	QL33	QL34	QL35	QL36	QL41	QL43	QL45	QL50	QL51
1.00000									
.51711	1.00000								
.38325	.54204	1.00000							
.57070	.56188	.45167	1.00000						
.49295	.30493	.28810	.50621	1.00000					
.55431	.35518	.21170	.68410	.48118	1.00000				
.54225	.38888	.27429	.44812	.50386	.42502	1.00000			
.53286	.32207	.31414	.45590	.48595	.48611	.34096	1.00000		
.26724	.08022	.21213	.35603	.47351	.26197	.30031	.42205	1.00000	
.42861	.54546	.40149	.32701	.36646	.23441	.49931	.28728	.02366	1.00000

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APPENDIX A:

Generation of the Data Base

A - 1 Review of the Literature

A - 2 Initial Item Pool

PALS Term Search-Quality Assurance Project for Automated Library System

A-1 Review of the Literature

0001	1953	50-100 binomial tables.	Romig, Harry Guteliu
0002	1979	Administering the quality control function/	Fuchs, Jerome H.
0003	1984	Analytical reference standards and supplement	Thompson, Robert E.
0004	1985-	Annual report, case mix reimbursement recomme	Minnesota. Interage
0005	1900-	Annual report /	Minnesota. Interage
0006	1978	Assessing and improving health care outcomes	Williamson, John W.
0007	1980	Assess Reserve Mining company's surface and g	
0008	1970-	Assess Reserve Mining Company's surface and g	
0009	1984	Assessing quality circles in health care sett	Orlikoff, James E.
0010	1975	Assuring product integrity /	Carrubba, Eugene R.
0011	1978	The assurance sciences : an introduction to	Halpern, Siegmund,
0012	1986	Best practices : how to avoid surprises in t	United States. Navy
0013	1972	Bituminous construction and quality Control;	
0014	1984	Brief report on quality assurance /	
0015	1984	Checklist for establishing a diagnostic radio	Bradley, Valerie J.
0016	1981	Client needs assessment and quality assurance	Kurowski, Bettina D.
0017	1984	Client protection in state hospitals and nurs	Minnesota. Quality
0018	1986	Clinical rehabilitation assessment and hearin	
0019	1974	Collaborative study of method for the determi	Hamil, Henry F.
0020	1986	Commit to quality /	
0021	1980	Computer aids and statistics in quality assur	National Research Co.
0021	1983	Composite materials, quality assurance, and p	
0023	1983	A compilation of opacity monitor performance	Plaisance, Steve.
0024	1981	Contractual relationships : an essential ing	
0025	1986	Creative nursing administration : participat	Porter-O'Grady, Timo
0026	1982	The criteria and standards of quality /	Donabedian, Avedis.
0027	1977	Dental quality assurance : bibliography and	
0028	1977	Effective methods of EDP quality assurance /	Perry, William E.
0029	1981	Effective methods of EDP quality assurance /	Perry, William E.
0030	1986	Facility manual for completing case mix requ	
0031	1984	Field surveys of carbon monoxide in commercia	Flachbart, Peter G.
0032	1978	Final report, quality assurance review : Met	Read, Joel.
0033	1987	Final report of the Interagency Board for Qua	
0034	1977	Food quality assurance /	Gould, Wilbur A.,
0035	1984	A framework for action : improving quality a	NASA Symposium on Pr
0036	1984	Geotechnical quality assurance of constructio	Spigolon, S.J.
0037	1974	Guide for the utilization review coordinator	Hospital Research an
0038	1975	Guide for the patient care audit assistant in	Hospital Research an
0039	1983	Guidlines for nursing care : process and ou	
0040	1980	Handbook for total quality assurance /	Stiles, Edward M.
0041	1987	Handbook of software quality assurance /	
0042	1982	Hatching the EDP quality assurance function /	Perry, William E.

A-1 Review of the Literature (Continued)

0043	1984	Hospital quality assurance : risk management	
0044	1983	How to run mixture experiments for product qu	
0045	1969	Human factors in quality assurance	
0046	1984	ICAM conceptual design for computer-integrate	
0047	1984	ICAM conceptual design for computer-integrate	
0048	1984	IEEE standard for software quality assurance	
0049	1977	Improving medical practice and health care :	Williamson, John W.
0050	1979	Initial quality assurance audit at Reserve Mi	Hansen, D. Alan.
0051	1976	Living with end-stage renal disease : a book	United States, Heal
0052	1985	Malpractice prevention and liability control	Orlikoff, James E.
0053	1985	The management of quality assurance /	Sinha, Madhav N.
0054	1982	Medical care quality and the public trust:	Williamson, John W.
0055	1986	Mental health services and quality assurance	Scheer, Marie.
0056	1984	Methods 6 and 7 quality assurance and quality	
0057	1982	Microbiology of Foods : the ecological essen	Mossel, D. A. A.
0058	1980	Minnesota model standards : the development,	Minnesota Management
0059	1980	Minnesota model standards, the development, t	Minnesota. Department
0060	1980	Minnesota model standards	Minnesota Management
0061	1986	NASA's quality assurance program : hearing b	United States, Cong
0062	1986	National dioxin study : analytical procedure	
0063	1985	NIFDA canned goods specifications manual /	Morin, Thomas H.
0064	1986	Nuclear regulation : oversight of quality as	United States. Gene
0065	1977	Nursing home directory and consumer guideline	Pennsylvania. Department
0066	1984	Nursing quality assurance : a unit-based app	
0067	1981	Outcome auditing : One component of a qualit	
0068	1977	Outcome auditing, one component of a quality	Minnesota, Department
0069	1987	Oversight review of quality assurance at the	United States. Cong
0070	1978	Patient care audit : a quality assurance pro	
0071	1983	Performance audit procedures for opacity moni	
0072	1982	Principles of quality assurance and cost cont	Williamson, John W.
0073	1985	Principles of quality assurance of chemical m	Taylor, John K.
0074	1974	The Problem-oriented record.	
0075	1984	Progress report :Interagency Board for Quality	Minnesota. Interage
0076	1976	Project management : a short course for prof	Silverman, Melvin
0077	1980	The QA guide : a resource for hospital quali	Kaplan, Karen Orloff
0078	1967	Quality assurance manual: procedures and for	Covino, Charles P.
0079	1971	Quality assurance and acceptance procedures.	National Research Co.
0080	1970	Quality assurance in highway construction	
0081	1962	Quality assurance manual; procedures and for	Covino, Charles P.
0082	1976	Quality assurance programs and controls in nu	Froebe,Doris J.,
0083	1975	Quality assurance : models for nursing educa	National league for
0084	1976	Quality assurance in health care /	
0085	1977	Quality assurance for patient care: nursing	Mayers, Marlene Glov
0086	1976	Quality assurance: models for nursing educa	National League for
0087	1977	Quality assuracne in long term care/	Ainsworth, Thomas H.
0088	1978	Quality assurance practices for health labora	

A-1 Review of the Literature (Continued)

0089	1979	Quality is free : the art of making quality	Crosby, Philip B.
0090	1978	Quality of care assessment and assurance : a	
0091	1978	Quality by objectives : a practical method f	
0092	1979	Quality sense : organizational approaches to	Smith, Martin R.,
0093	1979	Quality assurance : performance, sealers, an	National Research Co.
0094	1980	Quality planning and analysis : from product	Juran, J.M.
0095	1980	Quality assurance in ambulatory car /	Batalden, Paul B.
0096	1979	Quality assurance : research /	National Research Co.
0097	1980	Quality assurance : guidelines for nursing ca	Duke Hospital. Nurse
0098	1981	Quality assurance in nursing : a selected bi	Lang, Norma M.
0099	1981	Quality assurance in diagnostic radiology /	McLemore, Joy M.
0100	1978	Quality assurance in the surface water and ie	Peeney, Donald T.
0101	1982	Quality assurance for computer software /	Dunn, Robert,
0102	1980	A quality assurance system for ambulatory car	
0103	1982	Quality assurance in hospitals : strategies	
0104	1982	Quality assurance practices for the chemical	Friedman, Linda C.
0105	1981	Quality assurance in free-standing chemical d	Washburn, Anne E.
0106	1981	Quality assurance in the preparation of youth	
0107	1983	Quality assurance in hospital pharmacy : str	Lammim, Linda C.
0108	1983	Quality assurance primer : improving health	Ostrow, Patricia Cur
0109	1982	Quality assurance of recycled material : con	
0110	1983	Quality assurance for internal auditing /	Anderson, Urton.
0111	1983	Quality assurance in research and development	Roberts, George W.,
0112	1983	Quality assurance for local governments : fi	Maslin, William R.
0113	1983	The quality assurance and review program : c	Patten, Sharon K.
0014	1983	Quality assurance under prospective reimburse	United States. Cong.
0015	1983	Quality assurance plan for state facilities.	
0016	1983	Quality assurance at the Midland nuclear powe	Untied States. Cong.
0017	1984	Quality without tears : the art of hassle-fr	Crosby, Philip B.
0018	1983	Quality assurance for long-term care options	Polich, Cynthia L.
0019	1984	Quality assurance in mental health	Tischler, Gary L.
0020	1978	Quality Assurance and Review Program (PMR and Minnesota. Departme	
0123	1977	Quality Assurance and Review Program (PMR and Minnesota. Departme	
0124	1985	Quality assurance guidelines for managing the	
0125	1985	Quality engineering using design design of experimen	Supplier Symposium o
0126	1984	Quality engineering using design of experimen	Supplier Symposium o
0127	1984	Quality engineering using design of experimen	Supplier Symposium o
0128	1986	Quality assurance monitoring in Florida, Mass	Scheer, Marie.
0129	1987	Quality-assurance data for routine water anal	Peart, Dale B.
0130	1900-	Quarterly quality assurance audit of the Mile	Hansen, D. Allen
0131	1979-	Reports of the Technical Assessment Task Force	United States. Pres
0132	1977	Restructuring Medicaid for improving the qual	Minnesota. Departme
0133	1985	Risk management : a guide for health care pr	Monagle, John F.

A-1 Review of the Literature (Continued)

0134	1976	Sample criteria for short-stay hospital care pr	
0135	1979	Social work quality assurance programs : a c	Coulton, Claudia J.
0136	1984	Software system testing and quality assurance	Deizer, Boris,
0137	1984	Software engineering standards /	Institute of Electri
0138	1987	Software quality assurance and management /	Evans, Michael W.
0139	1987	Software quality assurance and management /	Evans, Michael W.
0140	1984	A summary of the 1982 EPA national performance	Streib, E. W.
0141	1982	Teaching quality assurance and cost containme	William, John, W.
0142	1985	Tutorial software quality assurance : a prac	
0143	1966	Zero defects; a new dimension in quality ass	Halpin, James F.

Appendix A-2

Initial Item Pool - Quality of Life Items (44 Items)

1) DO YOU HAVE ACCESS TO A PET?

YES, I HAVE MY OWN
YES, THERE IS ONE IN MY FACILITY
NO, I DON'T

2) HOW MANY PEOPLE SHARE YOUR ROOM?

ONLY MY SPOUSE (if applicable)
ONE OR TWO ROOMMATES
THREE OR MORE ROOMMATES

3) HOW OFTEN DO YOU DECIDE WHEN TO GO TO BED AND GET UP?

USUALLY
SOMETIMES
SELDOM

4) HOW DO PEOPLE IN THE COMMUNITY TREAT YOU?

VERY WELL
OK I GUESS
NOT VERY WELL

5) HOW DO YOU FEEL ABOUT THIS COMMUNITY?

I LIKE IT VERY MUCH
IT'S OK, I GUESS
I DON'T LIKE IT AT ALL

6) HOW OFTEN DO YOU TALK WITH PEOPLE IN THE COMMUNITY?

ALMOST EVERY DAY
AT LEAST ONCE A WEEK
HARDLY EVER

7) DO YOU EAT BY YOURSELF?

USUALLY
SOMETIMES
SELDOM

8) WHO DECIDES WHAT YOU WILL EAT?

I DO
I HELP OTHERS DECIDE
SOMEBODY ELSE DECIDES

Appendix A-2

Initial Item Pool (continued)

- 9) WHO GOES SHOPPING FOR YOU GROCERIES?
- I DO
I HELP SOMEONE ELSE
SOMEONE ELSE
- 10) WHO SELECTED THE DECORATIONS IN YOUR ROOM?
- I DID
I HELPED SOMEONE ELSE
SOMEONE ELSE
- 11) WHO CHOSE YOUR DOCTOR/DENTIST?
- I DID
I HELPED SOMEONE ELSE
SOMEONE ELSE
- 12) WHEN YOU NEED MEDICINE, WHO GIVES IT TO YOU?
- I DO
SOMEONE HELPS ME
SOMEONE ELSE GIVES IT TO ME
- 13) WHO MAKES YOU DOCTOR/DENTIST APPOINTMENTS?
- I DO
SOMEONE HELPS ME
SOMEONE ELSE DOES
- 14) HOW DO YOU FEEL ABOUT YOU JOB?
- I LIKE IT MOST OF THE TIME
I LIKE IT SOME OF THE TIME
I DON'T LIKE IT MUCH
- 15) DO THE PEOPLE YOU WORK FOR THINK YOUR JOB IS IMPORTANT?
- I THINK SO
MAYBE - I DON'T KNOW
I DON'T THINK SO
- 16) DO YOU USE PUBLIC TRANSPORTATION WHEN YOU NEED TO GO SOMEWHERE?
- MOST OF THE TIME
SOME OF THE TIME
NOT VERY OFTEN

Appendix A-2

Initial Item Pool (continued)

17) HOW DO YOU GET TO WORK?

I DRIVE MYSELF
I USE PUBLIC TRANSPORTATION
SOMEBODY TAKES ME

18) DO YOU EARN ENOUGH MONEY TO BUY THE THINGS YOU NEED?

YES I DO
I EARN SOME BUT NOT ENOUGH
I DON'T EARN ANY

19) DO FRIENDS COME TO VISIT YOU?

QUITE OFTEN
OCCASIONALLY
SELDOM

20) HOW OFTEN DO THE PEOPLE YOU LIVE WITH ANNOY YOU?

FREQUENTLY
SELDOM
ALMOST NEVER

21) ARE YOU FRIGHTENED BY THE PEOPLE YOU LIVE WITH?

SOMETIMES
SELDOM
ALMOST NEVER

22) CAN YOU LOCK YOUR HOUSE OR ROOM?

YES
I CAN WITH HELP
NO

23) ARE YOU LOCKED OUT OF PLACES YOU WOULD LIKE TO GO IN
YOUR HOME/FACILITY?

YES, QUITE A FEW
YES, SOME
NONE

24) DO YOU HAVE A CHANCE TO DECIDE WHAT YOU WANT TO DO?

YES, MOST OF THE TIME
SOME OF THE TIME
NOT VERY OFTEN

Appendix A-2

Initial Item Pool (continued)

- 25) DO YOU DECIDE HOW TO SPEND YOUR MONEY?
- I DO
I HELP SOMEONE ELSE
NO I DON'T
- 26) HOW OFTEN DO YOU GO OUT TO DO THINGS LIKE SHOPPING AND MOVIES?
- AS OFTEN AS I LIKE
MOST OF THE TIME
HARDLY EVER
- 27) CAN FRIENDS COME TO VISIT YOU WHEN YOU WANT THEM TO?
- YES USUALLY
ONLY WITH STAFF APPROVAL
ONLY ON VISITING DAYS
- 28) HOW OFTEN HAVE YOU BEEN VISITED BY YOUR FAMILY?
- NEARLY EVERY WEEK
SEVERAL TIMES A YEAR
HARDLY EVER
- 29) HOW DO YOU FEEL ABOUT VISITS FROM YOUR FAMILY?
- I LIKE THEM VERY MUCH
THEY ARE O.K.
I DON'T LIKE THEM
- 30) DO YOU HAVE FRIENDS ON THE STAFF?
- YES QUITE A FEW
YES SOME
HARDLY ANY
- 31) HOW DO STAFF MEMBERS TREAT YOU?
- PRETTY WELL
USUALLY O.K.
NOT VERY WELL
- 32) HOW DO YOU FEEL ABOUT THE STAFF HERE?
- I LIKE THEM VERY MUCH
THEY ARE USUALLY O.K.
I DON'T LIKE THEM

Appendix A-2

Initial Item Pool (continued)

33) HOW DO YOU FEEL ABOUT OTHERS WHO LIVE THERE?

I LIKE THEM VERY MUCH
I LIKE MANY OF THEM
I MOSTLY DISLIKE THEM

34) HOW DO YOU FEEL ABOUT YOUR ROOM?

I LIKE IT VERY MUCH
IT'S O.K.
I DON'T LIKE IT

35) ARE YOUR RELIGIOUS BELIEFS AND PRACTICES HONORED HERE?

YES NEARLY ALWAYS
YES SOME OF THE TIME
HARDLY EVER

36) ARE YOU FREE TO GO OUT WITH FRIENDS WHEN YOU WANT TO?

YES - USUALLY
SOME OF THE TIME
HARDLY EVER

37) CAN YOU CALL OR WRITE FAMILY AND FRIENDS WHEN YOU WANT TO?

YES - USUALLY
SOME OF THE TIME
HARDLY EVER

38) CAN YOU BE ALONE HERE WHEN YOU WANT TO?

YES - USUALLY
SOMETIMES
HARDLY EVER

39) WHO CHOSE YOUR CLOTHES?

I DID
SOMEONE HELPED ME DECIDE
SOMEONE ELSE DECIDED

40) WOULD YOU LIKE TO LIVE SOMEPLACE ELSE?

YES
I MIGHT
NO

Appendix A-2

Initial Item Pool (continued)

- 41) IS THIS PLACE TOO HOT OR COLD FOR YOU?
- YES - ALMOST ALWAYS
SOME OF THE TIME
NO - IT'S O.K.
- 42) HOW OFTEN DO YOU DECIDE ON THE WORK YOU WILL DO?
- MOST OF THE TIME
SOME OF THEM TIME
HARDLY EVER
- 43) HOW OFTEN DO YOU HEAR STAFF MEMBERS TALKING ABOUT
OTHER
CLIENTS?
- FAIRLY OFTEN
SOMETIMES
HARDLY EVER
- 44) HOW MANY OF THE STAFF MEMBERS SEEM HAPPY TO HAVE YOU
AROUND?
- MOST OF THEM
SOME OF THEN
VERY FEW

Appendix B:
Organization of Items

- B - 1 Listings of Qualified Mental Retardation Professionals
- B - 2 Initial Cluster Analysis
- B - 3 Listing of Seventy Items

APPENDIX B-1

Listing of Qualified Mental Retardation Professionals

Lake County Board of Mental Retardation (Lake County, Ohio)

1. Michael P. Christopher, MA (QMRP)
5638 Dolphin Road
Mentor-on-the-Lake, Ohio 44060
2. Gary Planicka, MA (QMRP)
11561 Cherry Hallow Drive
Chardon Township, Ohio 44024
3. Ms. Patricia Rolfe, MA,MSW (QMRP)
1865 Parkland Drive, #305
Shaker Heights, Ohio 44122
4. Ms. Florence Drage, MMSW (QMRP)
2090 Country Club
Wickliffe, Ohio 44092
5. Ms. Mary Ellen Condon, MA (QMRP)
319 East 323rd Street
Willowick, Ohio 44094
6. Jeffrey Mackey, MSW, (QMRP)
1061 Valewood Court
Painesville Township, Ohio 44077

APPENDIX B-2

Initial Cluster Analysis

ORPHOLOGAN (44 ITEMS, B148-3)

TO NO	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
22	---	-----																							
24	---																								
2																									
44																									
34																									
42																									
27																									
23																									
1																									
29																									
39																									
33																									
35																									
31																									
28																									
41																									
27																									
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8																									
12																									
16																									
26																									
37																									
25																									
40																									
3																									
39																									
11																									
9																									
17																									
5																									
7																									
4																									
6																									
32																									
18																									
43																									
15																									
14																									
19																									
29																									
16																									
TO NO	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25

Appendix B - 3 Item 4 QL-QC ITEMS

1. Do you get enough sleep at night?
2. Do you get tired during the day?
3. If you feel hungry, do you get enough to eat?
4. Do you exercise during your free time/weekends?
5. Do you use the bathroom when you need to?
6. Do you have any pain/problems when using the bathroom?
7. Do you get headaches?
8. Do you get stomach aches or other pains?
9. Do you get ear aches?
10. Do you feel physically comfortable?
11. Do you generally feel healthy?
12. Do you get colds?
13. If you feel thirsty, do you get enough to drink?
14. Do your feet hurt?
15. Do your teeth or dentures hurt?
16. Do you feel anxious or scared?
17. Do you feel tense or upset?
18. Do you feel sad or unhappy?
19. Do your eyes bother you?
20. Do you have a pet at home?
21. How often do you decide when to go to bed and get up?
22. Do you decide who you eat with?
23. Do you decide what you will eat?
24. Do you go shopping for groceries?
25. Can you select the decorations in your room?
26. Who chose your doctor/dentist?
27. When you need medicine, who gives it to you?
28. Who makes your doctor/dentist appointments?
29. Do you use public transportation when you need to go somewhere?
30. How do you get to work?
31. Do you have access to your own money to buy the things you need?
32. Can you lock your house or room?
33. Are you locked out of places you would like to go in your home/facility?
34. Do you have a chance to decide what you want to do?
35. Do you decide how to spend your money?
36. How often do you get out to do things like shopping/movies?
37. Do you have a chance to practice your religious beliefs?
38. Are you free to go out with your friends when you want to?
39. Can you call or write your family/friends when you want to?
40. Can you be alone here when you want to?
41. Do you chose what you wear each day?
42. How often do you decide on the work you will do?
43. How many people share your room?
44. How do people in the community treat you?
45. How often do you talk with people in the community?
46. Do you have any friends?

Appendix B - 3 (Continued)

47. Do you get a chance to make friends where you live?
48. Do you get a chance to make friends where you work?
49. Do the people you work for think your job is important?
50. Do friends come to visit you?
51. How often do the people you live with annoy you?
52. Are you frightened by the people you live with?
53. Can friends come to visit you when you want them to?
54. How often have you been visited by your family?
55. Do you have friends on the staff?
56. How do staff members treat you?
57. How often do you hear staff talking about other clients?
58. How many staff members seem happy to have you around?
59. How do you feel about this community?
60. How do you like the food you eat at home?
61. How do you feel about your job?
62. How do you feel about visits from your family?
63. How do you feel about the staff here?
64. How do you feel about others who live here?
65. How do you feel about your room?
66. Are you satisfied that you have enough clothes?
67. Would you like to live someplace else?
68. Is your home too hot or cold for you?
69. Are you able to do most of the things you like to do?
70. Do you feel a sense of belonging here?

Appendix B-4

Listing of Qualified Mental Retardation Professionals

Department of Human Services (State of Minnesota)

1. Myron Maleha M.D.
Anoka Metro Regional Treatment Center
Anoka, Minnesota
2. Mike Tessneer (QMRP)
301 N.E. 4th Street
Braham, MN 55006
3. Mark Pocrnich DDS
531 Dellwood
Cambridge, MN 55008
4. Suzzane Wenstrom (QMRP)
1185 S. Highway 65
Cabridge, MN 55008
5. Cathy Odegard RN (QMRP)
P.O. Box 464 Room #3
Isant, MN 55040
6. Ann Mross (QMRP)
P.O. Box 127 Room #2
Harris, MN 55037

APPENDIX C:

Refinement of Items

- C - 1 Survey form and Instructions to Participants
- C - 2 Importance Rankings (Staff, Clients, and
Parents)

Appendix C - 1

PHASE II SURVEY FORM AND INSTRUCTIONS TO PARTICIPANTS

YOUR NAME: _____

ADDRESS: _____

TELEPHONE: () _____

The following factors have been suggested as indicators that should be looked at in making judgements about a person's quality of life.

For each item, please indicate (1) how important you consider the indicator in relation to a person's quality of life and (2) whether you have any other specific recommendations to include for this questionnaire by measures of Quality of Life.

Please use the following scale when completing this form:

IMPORTANCE:

VERY IMPORTANT-SOMEWHAT IMPORTANT-NOT VERY IMPORTANT-NOT AT ALL IMPORTANT

4

3

2

1

Appendix C-2 Importance Rankings (Staff)

Quest	Respondents (STAFF)																						Total	Mean	Std.
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22			
52	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	88	4.00	0.00
56	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	88	4.00	0.00
70	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	3	4	4	4	3	4	4	86	3.91	0.29
40	4	4	4	3	3	4	4	4	3	4	4	4	4	4	4	4	4	4	4	4	4	4	85	3.86	0.34
34	4	4	4	4	3	4	4	4	4	4	4	4	4	3	4	4	4	4	4	3	4	4	85	3.86	0.34
39	4	4	4	4	3	4	4	4	4	4	4	4	4	3	4	4	4	3	4	4	4	3	84	3.82	0.39
13	4	4	4	3	3	4	4	4	4	4	4	4	4	4	4	3	4	3	4	4	4	4	84	3.82	0.39
63	4	4	4	4	3	4	4	4	4	4	4	4	4	4	4	4	3	3	4	4	4	3	84	3.82	0.39
58	4	4	4	4	4	4	4	4	3	3	4	4	4	4	4	4	3	4	4	3	4	4	84	3.82	0.39
46	4	4	4	4	3	4	4	4	4	4	4	4	4	4	4	4	3	3	4	3	4	4	84	3.82	0.39
50	4	4	4	4	3	4	4	4	4	4	4	4	4	4	4	4	2	4	3	3	4	4	83	3.77	0.52
57	4	3	4	4	3	4	4	4	4	4	4	4	4	3	4	4	4	4	4	2	4	4	83	3.77	0.52
38	4	4	4	4	3	4	3	4	4	3	4	4	4	4	4	4	4	4	4	3	4	3	83	3.77	0.42
35	4	4	4	4	3	4	3	4	4	3	4	4	4	3	4	4	4	4	4	3	4	4	83	3.77	0.42
69	4	4	4	4	4	4	3	4	3	3	4	4	4	4	4	4	3	4	4	3	4	4	83	3.77	0.42
37	4	4	4	4	3	3	4	4	4	3	4	4	4	4	4	4	4	4	4	2	4	3	82	3.73	0.54
36	4	4	4	3	3	3	3	4	3	4	4	4	4	4	4	4	4	4	4	4	4	3	82	3.73	0.45
31	4	4	4	3	3	4	4	4	3	4	4	4	4	4	4	4	4	4	4	3	3	3	82	3.73	0.45
62	4	4	4	4	3	4	3	3	4	4	4	4	4	4	4	3	4	3	4	4	4	3	82	3.73	0.45
54	4	4	4	3	3	4	4	4	4	3	3	4	4	4	4	3	3	4	4	4	4	4	82	3.73	0.45
25	4	3	4	3	3	4	4	3	3	3	4	4	4	4	4	4	4	4	4	4	4	4	82	3.73	0.45
67	4	3	4	4	4	4	4	4	3	3	4	4	4	3	4	4	4	4	4	4	3	4	82	3.73	0.45
16	4	4	4	4	3	3	4	4	4	3	4	4	4	4	4	3	4	3	4	3	4	4	82	3.73	0.45
64	4	3	4	4	3	3	4	4	4	4	4	4	4	3	4	4	3	4	4	4	4	3	82	3.73	0.45
47	4	4	3	4	3	4	3	4	4	4	4	4	4	4	4	4	4	3	3	3	4	4	82	3.73	0.45
3	4	3	4	3	3	4	4	4	4	4	4	4	4	3	4	4	4	4	4	3	4	3	82	3.73	0.45
5	4	4	3	3	3	4	4	4	3	4	4	4	4	4	3	3	4	4	4	4	4	4	82	3.73	0.45
18	4	3	4	4	3	3	4	4	4	3	4	4	4	4	4	3	4	3	4	3	4	4	81	3.68	0.47
65	4	4	3	4	3	3	4	4	4	3	4	4	4	3	4	4	4	4	3	4	4	3	81	3.68	0.47
53	4	4	4	3	4	4	3	4	3	4	4	4	4	4	4	3	4	4	4	3	3	3	81	3.68	0.47
17	4	3	4	4	3	3	4	4	4	3	4	4	4	4	4	3	4	3	4	3	4	4	81	3.68	0.47
11	4	3	4	3	4	4	3	4	4	3	4	4	4	4	4	3	3	3	4	4	4	4	81	3.68	0.47
6	4	4	3	3	2	3	4	3	4	4	3	4	4	4	4	4	3	3	4	4	4	4	80	3.64	0.57
10	4	3	4	3	4	4	3	4	4	4	4	3	4	4	4	3	4	3	4	3	3	4	80	3.64	0.48
48	4	4	4	3	3	3	3	4	4	4	4	4	4	4	4	4	3	3	3	3	4	4	80	3.64	0.48
1	4	4	4	4	3	4	4	3	3	3	4	4	4	4	3	4	3	3	4	4	3	4	79	3.59	0.49
19	4	3	3	4	3	4	3	4	4	3	3	4	4	4	4	4	3	3	4	4	4	3	79	3.59	0.49
61	4	3	4	4	3	4	4	3	3	3	4	4	4	4	4	4	4	4	3	3	3	3	79	3.59	0.49
32	4	4	4	3	3	4	4	4	3	3	3	4	4	2	4	4	3	4	4	3	4	3	78	3.55	0.58
15	3	3	3	4	3	4	3	4	4	3	3	4	4	4	4	4	3	3	4	3	4	4	78	3.55	0.50
49	4	4	4	4	3	4	4	3	3	3	4	4	4	3	3	4	3	4	3	3	4	3	78	3.55	0.50
45	3	4	4	4	3	4	3	4	3	3	4	4	4	4	4	4	4	3	3	3	3	3	78	3.55	0.50
44	4	4	4	4	3	4	3	4	4	3	4	4	4	4	4	3	3	3	3	2	3	3	77	3.50	0.58
51	4	3	4	4	3	4	3	4	3	3	4	4	4	4	3	2	3	4	4	3	3	4	77	3.50	0.58
22	4	3	4	3	3	3	4	3	3	4	4	4	4	4	3	4	3	4	3	3	4	3	77	3.50	0.50
60	4	3	3	4	3	4	4	4	3	4	4	4	4	4	4	2	3	3	3	3	3	3	76	3.45	0.58
9	3	3	3	3	3	4	3	4	4	3	3	4	4	4	4	4	2	3	4	3	4	4	76	3.45	0.58

Appendix C-2 Importance Rankings (Staff continued)

23	4	3	3	3	3	3	4	4	3	4	4	4	4	3	4	4	3	4	3	3	3	3	76	3.45	0.50
41	4	3	3	3	3	4	3	3	3	3	4	4	4	3	4	4	4	4	4	3	3	3	76	3.45	0.50
55	4	4	4	3	3	3	3	4	3	4	4	4	4	4	3	3	2	4	3	3	3	3	75	3.41	0.58
68	4	3	3	4	3	3	4	4	4	3	4	3	4	3	4	2	4	3	4	3	3	3	75	3.41	0.58
8	3	3	3	3	3	4	3	3	4	3	3	4	4	4	4	4	2	3	4	3	4	4	75	3.41	0.58
43	4	3	4	3	3	4	4	3	3	4	3	4	4	4	3	3	3	3	3	3	3	4	75	3.41	0.49
2	3	3	3	3	3	4	3	4	3	3	4	4	4	4	3	4	2	3	4	4	3	3	74	3.36	0.57
7	3	3	3	3	3	4	3	3	4	3	3	3	4	4	4	3	3	3	4	3	4	4	74	3.36	0.48
33	3	3	4	3	3	4	3	3	3	4	4	3	4	2	4	4	3	4	3	3	3	3	73	3.32	0.55
14	3	3	2	3	3	4	3	4	4	3	3	3	4	3	3	4	3	3	4	3	4	4	73	3.32	0.55
66	4	3	3	4	3	3	3	3	3	3	3	3	4	4	4	4	3	4	3	3	3	3	73	3.32	0.47
21	3	3	3	3	3	3	4	3	3	3	3	4	4	4	4	3	3	4	3	3	3	3	72	3.27	0.45
59	3	3	4	3	3	4	3	4	4	3	4	4	4	4	2	3	3	1	3	2	3	3	70	3.18	0.78
30	3	3	4	3	3	4	1	4	3	3	3	4	4	4	3	3	3	4	3	3	2	3	70	3.18	0.72
27	2	3	3	3	3	4	3	4	3	3	3	3	4	4	4	2	3	4	3	3	2	4	70	3.18	0.65
12	3	3	2	3	3	3	3	4	3	3	4	3	4	3	4	4	2	3	3	3	2	3	68	3.09	0.60
4	3	3	3	3	3	2	3	3	2	3	4	4	4	3	4	4	3	2	3	3	3	3	68	3.09	0.60
42	3	3	3	3	3	3	2	3	3	3	3	3	4	2	4	4	3	4	3	3	3	3	68	3.09	0.51
28	2	3	3	3	3	3	2	4	3	3	2	4	4	4	4	2	3	4	3	3	2	3	67	3.05	0.71
26	3	3	3	3	2	3	2	3	3	3	2	4	4	4	4	3	3	4	3	3	2	3	67	3.05	0.64
24	3	3	3	3	3	3	2	3	3	3	3	4	4	3	4	3	2	4	3	3	2	3	67	3.05	0.56
29	3	3	4	2	2	3	3	3	3	3	3	3	4	3	3	3	4	4	3	3	1	2	65	2.95	0.71
20	2	2	3	3	3	3	2	3	3	3	2	3	4	3	3	2	2	3	2	2	2	3	58	2.64	0.57
257	241	253	240	217	257	237	261	244	238	257	269	280	256	266	247	232	247	252	223	242	241				

Appendix C-2 Importance Rankings (Client)

RESPONDENTS (CLIENT)																														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	TOTAL	MEAN	STD.
56	4	4	4	4	4	4	3	4	4	4	4	4	4	4	3	4	4	4	1	1	4	4	4	4	4	4	4	169	3.70	0.81
61	4	4	4	4	4	3	3	4	4	4	4	4	4	4	4	4	4	4	1	3	4	4	3	2	4	4	4	99	3.67	0.72
35	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	3	4	4	1	3	4	1	4	3	4	4	98	3.63	0.82
63	3	4	4	4	4	4	3	4	4	4	4	4	3	4	4	3	4	4	1	3	4	4	1	3	4	4	4	96	3.56	0.83
34	4	4	4	4	4	3	4	4	4	3	4	4	4	4	3	3	4	4	1	3	4	1	4	3	4	4	4	96	3.56	0.83
50	4	4	4	4	4	3	4	4	4	4	4	4	4	4	3	4	3	4	4	1	1	4	1	3	4	4	4	95	3.52	0.96
16	4	4	4	4	4	4	4	4	4	4	3	4	4	3	3	1	4	4	1	3	4	4	1	4	4	4	4	95	3.52	0.96
12	4	4	4	4	3	3	4	4	4	4	4	4	4	4	3	3	4	4	1	3	3	4	1	3	4	4	4	95	3.52	0.83
31	4	4	4	4	4	3	4	4	4	4	4	4	4	4	3	4	4	4	1	3	1	2	1	4	4	4	4	94	3.48	1.00
69	4	4	4	4	4	3	4	4	4	4	4	4	4	3	4	3	4	4	4	1	1	4	4	1	2	4	4	94	3.48	1.00
3	4	4	4	4	4	4	4	4	4	4	4	4	4	1	4	4	3	3	4	1	3	3	1	4	3	4	4	94	3.45	0.96
13	4	4	4	4	4	3	4	4	3	4	4	4	4	4	3	3	1	4	4	2	3	3	4	3	4	3	4	94	3.46	0.74
58	4	4	4	4	4	4	4	4	4	4	4	4	4	3	1	4	4	1	1	4	4	1	2	4	4	4	4	93	3.44	1.07
65	4	4	4	4	4	4	4	4	4	4	4	4	4	3	4	1	4	4	1	1	4	1	3	3	4	4	4	93	3.44	1.07
59	4	4	4	4	4	4	4	4	4	4	4	4	4	4	3	3	4	4	1	1	4	1	3	1	4	4	4	93	3.44	1.07
55	4	4	4	4	4	4	4	4	4	3	3	4	4	4	3	3	4	4	1	2	4	4	1	1	4	4	4	93	3.44	0.99
26	4	4	4	4	4	3	3	4	4	1	4	4	3	4	4	3	4	4	1	3	3	4	1	4	4	4	4	93	3.44	0.96
60	4	4	4	4	4	3	4	4	4	3	4	4	4	3	4	3	4	4	1	1	4	1	3	3	4	4	4	93	3.44	0.96
40	4	4	4	4	4	1	4	4	3	4	4	4	4	3	3	3	4	4	1	3	4	2	4	2	4	4	4	93	3.44	0.92
11	4	4	4	4	4	4	4	4	3	4	4	4	4	3	4	1	3	4	1	3	4	4	2	3	2	4	4	92	3.44	0.92
66	4	4	4	4	4	4	3	4	4	4	4	4	3	3	3	3	3	4	1	3	4	1	3	2	4	4	4	92	3.44	0.87
41	4	4	4	4	4	3	4	4	4	4	4	3	3	3	3	3	4	4	1	3	4	1	3	2	4	4	4	92	3.44	0.87
70	4	4	4	4	4	3	4	4	4	4	1	4	4	4	2	4	4	4	1	1	4	4	3	1	4	4	4	92	3.41	1.10
49	4	4	4	4	3	3	4	4	4	3	4	4	4	4	4	4	1	4	4	1	1	4	3	3	2	4	4	92	3.41	0.99
48	3	4	4	4	4	4	4	4	4	4	4	4	4	3	3	3	4	4	1	3	1	4	2	1	4	4	4	92	3.41	0.99
39	3	3	4	4	4	4	4	4	4	4	4	4	3	4	3	4	3	4	1	3	4	1	1	3	4	4	4	92	3.41	0.95
42	4	4	4	4	4	4	2	4	4	3	4	4	4	4	4	1	4	4	4	1	1	4	1	2	4	4	4	91	3.37	1.13
28	4	4	4	4	4	3	3	4	4	2	4	4	1	4	4	4	4	4	1	3	4	1	1	4	4	4	4	91	3.37	1.09
17	4	4	4	4	4	4	4	4	4	3	3	4	4	3	4	3	4	1	3	4	3	2	4	1	3	4	4	91	3.37	0.99
38	3	3	4	4	4	4	4	4	4	4	4	4	4	4	3	3	3	4	1	3	4	1	1	3	3	4	4	91	3.37	0.95
1	4	4	4	4	4	4	4	4	4	4	4	3	4	3	4	3	3	4	1	3	1	1	3	4	3	3	4	91	3.37	0.95
46	3	4	4	4	3	3	4	4	4	4	4	4	4	3	4	3	4	4	1	3	1	3	2	2	4	4	4	91	3.37	0.91
44	4	4	4	4	3	4	3	4	4	3	4	4	3	3	3	3	3	4	4	1	2	4	2	1	4	4	4	91	3.37	0.91
30	4	4	4	1	4	3	2	4	4	1	4	4	4	4	3	4	4	4	1	2	4	4	1	4	4	4	4	90	3.33	1.12
36	3	3	4	4	4	3	4	4	4	4	4	4	4	4	3	3	4	4	1	3	4	1	1	1	4	4	4	90	3.33	1.05
5	2	4	4	1	4	4	3	4	4	4	4	3	4	3	4	3	3	4	3	4	4	2	2	3	4	2	4	90	3.33	0.86
10	4	3	4	4	3	3	4	4	4	3	3	4	4	3	3	1	4	4	1	3	4	3	3	3	4	3	4	90	3.33	0.82
25	3	3	4	4	3	4	4	4	1	4	4	3	4	4	4	4	4	4	1	3	3	4	1	2	4	2	4	89	3.30	1.01
67	4	3	4	4	4	4	4	4	4	3	4	4	4	3	3	1	4	1	1	4	4	4	1	4	4	3	1	88	3.26	1.14
47	3	3	4	4	4	4	4	4	4	3	4	4	4	3	4	3	4	4	1	1	1	3	2	1	4	4	4	88	3.26	1.07
18	4	4	4	4	4	3	4	4	4	4	3	4	4	3	4	1	3	4	1	3	4	4	1	2	3	3	1	87	3.22	1.07
23	3	4	4	4	4	3	3	4	4	2	4	3	4	4	3	3	3	4	1	3	1	2	1	4	4	4	4	87	3.22	0.99
53	3	4	4	4	3	4	4	4	4	3	4	4	4	3	3	2	4	4	1	1	4	1	1	1	4	4	4	86	3.19	1.16
64	3	1	4	4	4	4	4	4	4	3	4	4	4	3	1	3	4	4	1	1	4	1	3	2	4	4	4	86	3.19	1.16
22	4	4	4	4	4	1	4	4	4	3	4	4	3	3	4	1	3	4	1	4	1	2	1	3	4	4	4	86	3.19	1.16
8	4	4	4	4	4	3	4	3	4	4	3	4	4	3	3	1	4	4	1	1	3	4	2	3	2	3	3	86	3.19	0.98
54	4	4	4	4	1	4	3	4	4	3	4	4	1	2	3	4	4	4	1	1	4	1	3	2	4	4	4	85	3.15	1.18

Appendix C-2 Importance Rankings (Client continued)

29	4	4	4	4	4	3	1	4	4	1	4	4	3	3	3	3	4	4	1	1	4	1	3	2	4	4	4	85	3.15	1.15
24	4	2	4	4	4	3	2	4	4	1	4	4	3	3	4	3	3	4	1	3	1	1	3	4	4	4	4	85	3.15	1.08
45	4	4	4	4	4	3	1	4	4	1	4	4	3	3	3	3	4	4	1	1	4	1	3	2	4	4	4	85	3.15	1.15
57	4	2	4	4	4	3	2	4	4	1	4	4	3	3	4	3	3	4	1	3	1	1	3	4	4	4	4	85	3.15	1.08
37	3	4	4	4	3	3	3	4	4	3	4	3	3	4	3	3	4	4	1	3	1	1	1	3	4	4	4	85	3.15	1.01
21	4	4	4	4	4	3	3	4	4	3	4	4	3	4	3	4	3	4	1	3	1	1	1	1	4	2	4	84	3.11	1.13
62	4	4	4	4	1	3	3	2	2	1	4	4	2	1	4	3	4	4	1	2	4	3	4	4	4	4	4	84	3.11	1.13
27	4	4	4	4	3	3	3	4	4	1	4	3	3	3	4	3	4	1	1	3	4	1	1	3	4	4	4	84	3.11	1.10
43	4	2	4	4	4	3	3	4	4	4	4	4	4	3	3	3	4	4	1	2	1	2	2	1	4	2	4	84	3.11	1.07
19	4	4	4	4	3	3	4	4	4	3	3	4	4	3	4	3	2	4	1	1	3	4	2	3	3	2	1	84	3.11	0.99
32	4	4	4	4	2	3	1	4	4	3	1	4	1	4	4	4	3	4	1	3	1	1	3	4	4	4	4	83	3.07	1.21
7	4	4	4	4	3	3	4	4	3	4	3	4	1	4	1	1	4	4	3	1	3	4	4	1	2	3	3	83	3.07	1.12
68	4	2	4	4	4	4	4	4	3	4	1	4	3	4	4	1	4	4	1	3	2	4	1	2	2	3	3	83	3.07	1.12
4	4	4	4	4	4	4	4	4	4	3	4	3	4	3	3	1	3	1	1	1	1	4	3	1	4	1	3	80	2.96	1.23
9	4	4	4	4	3	3	4	4	4	4	1	4	4	3	3	1	1	4	1	1	3	4	2	3	4	2	1	80	2.96	1.20
51	2	4	4	4	1	2	3	4	4	2	1	4	1	3	3	3	4	4	1	3	4	4	1	3	3	4	4	80	2.96	1.14
33	4	4	4	4	2	4	2	4	4	1	4	4	3	4	1	4	2	4	1	3	4	1	1	2	4	1	3	79	2.93	1.25
2	4	3	4	3	3	3	3	4	4	4	3	3	4	4	4	1	1	4	3	1	3	2	1	3	2	2	3	79	2.93	1.02
14	4	3	4	3	4	4	4	4	4	4	2	4	4	3	3	1	2	4	1	1	2	4	1	3	3	1	1	78	2.89	1.20
6	4	3	4	4	3	4	4	4	4	3	1	3	1	3	4	3	3	4	3	1	3	4	1	1	3	1	2	78	2.89	1.13
15	4	3	4	3	4	4	4	4	4	4	1	4	3	3	2	1	2	4	1	1	1	4	2	3	3	2	1	76	2.81	1.19
52	4	4	4	4	4	4	3	4	4	3	1	4	1	3	4	1	4	1	1	1	4	4	2	1	2	1	1	74	2.76	1.35
20	4	4	4	4	4	3	4	3	4	1	3	4	4	4	1	1	2	1	1	1	1	4	1	1	4	2	1	71	2.63	1.36

Appendix C-2 Importance Rankings (Parents)

Quest	RESPONDENT (PARENTS)																					TOTAL	MEAN	STD
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21			
63	4	4	4	4	4	4	4	4	4	4	3	4	4	4	4	4	4	4	4	4	4	83	3.95	0.21
62	4	4	4	4	4	3	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	83	3.95	0.21
56	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	3	4	4	4	83	3.95	0.21
54	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	3	4	3	4	4	3	81	3.86	0.35
58	4	4	4	4	4	4	3	4	4	4	4	4	4	4	4	3	4	3	4	4	4	81	3.86	0.35
70	4	4	4	4	4	3	4	4	4	4	3	4	4	4	4	4	3	4	4	4	4	81	3.86	0.35
1	4	4	4	3	2	4	4	4	4	4	4	4	4	4	4	3	4	3	4	4	4	79	3.76	0.53
46	4	4	4	3	4	4	4	4	4	4	4	4	4	3	4	3	3	4	4	4	3	79	3.76	0.43
13	4	4	4	2	4	4	3	4	4	4	4	3	4	4	4	4	2	4	4	4	4	78	3.71	0.63
6	4	4	4	2	4	4	4	4	4	4	4	4	3	4	4	3	4	2	4	4	4	78	3.71	0.63
40	4	4	4	4	3	3	3	4	4	4	4	4	3	4	4	3	3	4	4	4	4	78	3.71	0.45
5	4	4	4	2	4	4	4	4	4	4	4	2	4	4	4	3	4	2	4	4	4	78	3.67	0.71
7	4	4	4	2	4	4	4	4	4	4	4	4	3	4	4	3	3	2	4	4	4	77	3.67	0.64
53	4	4	4	4	3	3	3	4	4	4	4	3	4	3	4	4	3	4	4	4	3	77	3.67	0.47
60	4	4	4	3	3	3	4	3	4	3	4	3	4	4	4	4	3	4	4	4	4	77	3.67	0.47
4	4	4	4	4	4	3	3	4	4	4	4	3	4	4	2	3	2	4	4	4	4	76	3.62	0.65
8	4	4	4	2	4	4	4	4	4	4	4	3	3	4	4	3	3	2	4	4	4	76	3.62	0.65
18	4	4	4	3	4	4	2	4	4	4	4	3	4	3	3	3	3	4	4	4	4	76	3.62	0.58
50	4	4	4	3	2	3	4	3	4	4	4	4	4	4	4	3	3	4	4	4	3	76	3.62	0.58
44	4	4	4	3	4	4	3	4	4	4	4	4	4	3	1	3	3	3	4	4	4	75	3.57	0.73
3	4	4	2	3	3	4	3	4	4	4	4	2	4	4	4	4	3	3	4	4	4	75	3.57	0.66
17	4	4	4	3	4	4	3	3	4	4	4	2	4	4	3	3	2	4	4	4	4	75	3.57	0.66
16	4	4	4	3	4	4	4	4	4	4	4	3	3	4	3	3	2	2	4	4	4	75	3.57	0.66
15	4	4	2	3	3	4	4	4	4	4	4	2	4	4	3	3	3	4	4	4	4	75	3.57	0.66
65	4	4	4	3	4	3	3	4	4	4	3	3	4	4	3	3	2	4	4	4	4	75	3.57	0.58
64	4	4	4	3	4	3	3	3	4	4	3	3	4	4	3	3	4	3	4	4	4	75	3.57	0.49
61	3	4	4	3	2	3	3	4	4	4	4	4	4	4	1	4	3	4	4	4	4	74	3.52	0.79
9	4	4	2	2	3	4	4	4	4	4	4	4	4	4	4	3	3	2	4	3	4	74	3.52	0.73
10	4	4	2	3	3	4	3	4	4	4	4	3	4	4	4	3	3	3	4	3	4	74	3.52	0.59
55	4	4	4	3	4	2	3	3	4	3	4	4	4	4	1	4	3	4	4	4	3	73	3.48	0.79
68	4	4	4	2	3	4	4	3	4	4	3	2	4	4	3	3	2	4	4	4	4	73	3.48	0.73
66	4	4	3	2	2	3	4	4	4	3	3	4	4	4	3	4	2	4	4	4	4	73	3.48	0.73
47	4	4	4	3	4	3	4	4	4	3	4	4	4	3	1	3	3	3	4	4	3	73	3.48	0.73
43	3	4	4	3	3	3	3	3	4	3	4	3	4	4	3	3	4	4	4	4	3	73	3.48	0.50
69	4	4	4	3	1	3	4	3	4	4	3	3	4	4	1	4	3	4	4	4	4	72	3.43	0.90
39	4	4	4	4	3	2	2	4	4	4	4	4	4	2	1	3	3	4	4	4	4	72	3.43	0.90
36	4	3	3	4	3	3	3	4	4	3	4	4	4	4	1	3	3	4	4	4	3	72	3.43	0.73
11	4	4	2	3	2	4	3	4	4	4	4	2	4	3	4	3	3	3	4	4	4	72	3.43	0.73
34	4	3	4	3	2	3	4	4	4	4	3	3	4	3	2	3	3	4	4	4	4	72	3.43	0.66
52	4	4	4	2	3	3	3	4	4	4	4	4	4	2	1	3	4	2	4	4	4	71	3.38	0.90
48	4	4	4	2	4	3	4	3	4	3	4	4	4	3	1	3	3	3	4	4	3	71	3.38	0.79
38	4	4	4	3	3	3	3	4	4	3	4	3	4	3	1	3	3	4	4	4	3	71	3.38	0.72
57	4	4	3	3	4	3	2	4	4	3	3	3	4	4	3	3	4	2	3	4	4	71	3.38	0.65
27	4	4	4	4	1	3	3	4	4	4	4	4	2	4	1	3	4	2	4	4	3	70	3.33	0.99
14	4	4	2	2	2	4	4	3	2	4	4	3	4	4	4	3	2	1	4	4	4	70	3.33	0.94
19	4	4	3	2	3	3	3	4	4	4	4	2	4	4	3	3	3	2	4	3	4	70	3.33	0.71
35	4	3	4	3	1	3	4	4	4	3	4	3	4	2	1	3	3	4	4	4	4	69	3.29	0.93

Appendix C-2 Importance Rankings (Parents continued)

28	4	4	4	2	1	3	2	4	4	4	3	3	4	4	1	3	3	4	4	4	3	68	3.24	0.97
49	3	4	4	2	2	2	4	2	4	4	4	3	4	4	1	3	3	3	4	4	4	68	3.24	0.92
67	4	3	3	3	2	3	4	4	4	4	3	2	4	3	1	3	3	4	4	4	3	68	3.24	0.81
30	3	4	4	3	3	2	3	3	4	4	4	3	4	3	1	3	3	4	4	3	3	68	3.24	0.75
2	3	4	3	2	3	3	3	3	3	4	3	3	3	3	4	3	4	3	3	4	4	68	3.24	0.53
45	4	4	4	3	3	2	4	3	4	4	3	3	3	2	1	3	3	3	4	4	3	67	3.19	0.79
51	4	4	3	2	3	3	3	3	4	3	3	3	4	3	1	4	3	3	4	4	3	67	3.19	0.73
31	4	4	4	3	1	3	3	4	4	3	4	3	4	2	1	3	3	1	4	4	4	66	3.14	1.04
12	3	4	3	2	1	3	3	4	4	4	3	4	3	3	3	3	2	2	4	4	4	66	3.14	0.83
41	3	3	3	3	2	2	3	3	4	3	3	3	4	3	1	3	3	4	4	4	4	65	3.10	0.75
59	3	4	3	2	2	3	3	3	4	3	4	3	4	2	4	4	1	1	4	4	3	64	3.05	0.95
32	3	4	3	1	1	2	4	2	3	3	4	4	4	2	1	3	4	4	4	3	4	63	3.00	1.07
26	4	4	3	3	1	2	2	2	2	4	4	2	3	4	1	3	3	4	4	4	3	63	3.00	0.98
37	4	3	4	2	2	2	2	3	4	4	3	2	4	3	1	3	3	2	4	4	4	63	3.00	0.93
42	3	4	3	2	1	3	3	3	4	3	3	3	4	3	1	3	3	3	4	4	3	63	3.00	0.82
23	3	3	3	3	2	2	4	3	4	3	3	2	3	4	1	3	2	3	4	4	4	63	3.00	0.82
29	3	4	4	3	1	2	3	3	2	3	4	4	3	2	1	3	3	4	4	3	3	62	2.95	0.90
33	3	4	2	2	1	2	4	3	4	4	3	4	3	2	1	3	3	2	4	2	4	60	2.86	0.99
22	3	3	3	3	2	2	2	3	3	3	3	3	3	3	1	3	1	4	4	4	3	59	2.81	0.79
25	4	4	2	2	3	1	2	2	4	2	2	3	4	3	1	3	3	2	4	2	4	57	2.71	0.98
21	3	2	2	2	2	2	2	3	3	3	3	3	3	3	1	3	2	4	4	4	3	57	2.71	0.76
24	2	3	2	3	2	1	3	3	3	2	1	4	2	2	1	3	2	4	4	4	3	54	2.57	0.95
20	3	4	2	2	2	2	3	3	2	3	2	1	2	3	1	3	2	1	4	4	4	53	2.52	0.96
262 269 243 196 194 214 231 247 269 255 251 225 260 239 168 224 208 223 278 270 257																								

APPENDIX D:

Administration of the Instrument

- D - 1 Initial Quality of Life Questionnaire
- D - 2 Item Master List
- D - 3 28 Item Revised Listing/Comparison
- D - 4 Final Quality of Life Questionnaire

APPENDIX D-1
Lake County Quality of Life Case Management Questionnaire

Question/Environmental Observation
Quality of Life Questionnaire (continued)

I. Physical Well-being

- | | | | | |
|--|---|---|---|---|
| 1. Do you get enough sleep at night? | 4 | 3 | 2 | 1 |
| 2. Do you get tired during the day? | 4 | 3 | 2 | 1 |
| 3. If you feel hungry, do you get enough to eat? | 4 | 3 | 2 | 1 |
| 4. Do you exercise during your free time and/or weekends? | 4 | 3 | 2 | 1 |
| 5. Do you use the bathroom when you need to? | 4 | 3 | 2 | 1 |
| 6. Do you have any pain or problems when you use the bathroom? | 4 | 3 | 2 | 1 |
| 7. Do you get headaches? | 4 | 3 | 2 | 1 |
| 8. Do you get stomach aches or other pains? | 4 | 3 | 2 | 1 |
| 9. Do you get ear aches? | 4 | 3 | 2 | 1 |
| 10. Do you feel physically comfortable? | 4 | 3 | 2 | 1 |
| 11. Do you generally feel healthy? | 4 | 3 | 2 | 1 |
| 12. Do you get colds? | 4 | 3 | 2 | 1 |
| 13. If you feel thirsty, do you get enough to drink? | 4 | 3 | 2 | 1 |
| 14. Do your feet hurt? | 4 | 3 | 2 | 1 |
| 15. Do your teeth or dentures hurt? | 4 | 3 | 2 | 1 |
| 16. Do you feel anxious or scared? | 4 | 3 | 2 | 1 |
| 17. Do you feel tense or upset? | 4 | 3 | 2 | 1 |
| 18. Do you feel sad or unhappy? | 4 | 3 | 2 | 1 |
| 19. Do your eyes bother you? | 4 | 3 | 2 | 1 |

Comments: _____

Quality of Life Questionnaire (Continued)

II. Independent Functioning/Choices

- | | |
|--|---------|
| 1. Do you have a pet at home? | 4 3 2 1 |
| 2. How often do you decide when to go to bed and get up? | 4 3 2 1 |
| 3. Do you decide who you eat with? | 4 3 2 1 |
| 4. Do you decide what you will eat? | 4 3 2 1 |
| 5. Do you go shopping for your groceries? | 4 3 2 1 |
| 6. Can you select the decorations in your room? | 4 3 2 1 |
| 7. Who chose your doctor/dentist? | 4 3 2 1 |
| 8. When you need medicine, who gives it to you? | 4 3 2 1 |
| 9. Who makes your doctor/dentist appointments? | 4 3 2 1 |
| 10. Do you use public transportation when you need to go somewhere? | 4 3 2 1 |
| 11. How do you get to work? | 4 3 2 1 |
| 12. Do you have access to your own money to buy the things you need? | 4 3 2 1 |
| 13. Can you lock your house or room? | 4 3 2 1 |
| 14. Are you locked out of places you would like to go in your home/facility? | 4 3 2 1 |
| 15. Do you have a chance to decide what you want to do? | 4 3 2 1 |
| 16. Do you decide how to spend your money? | 4 3 2 1 |
| 17. How often do you go out to do things like shopping and movies? | 4 3 2 1 |
| 18. Do you have a chance to practice your religious beliefs? | 4 3 2 1 |
| 19. Are you free to go out with friends or family when you want to? | 4 3 2 1 |
| 20. Can you call or write family and friends when you want to? | 4 3 2 1 |

II. Independent Functioning/Choices (continued)

- | | | | | |
|--|---|---|---|---|
| 21. Can you be alone here when you want to? | 4 | 3 | 2 | 1 |
| 22. Do you choose what you wear each day? | 4 | 3 | 2 | 1 |
| 23. How often do you decide on the work you will do? | 4 | 3 | 2 | 1 |

Quality of Life Questionnaire (continued)

III. Relationships/Social Interactions

- | | | | | |
|--|---|---|---|---|
| 1. How many people share your room? | 4 | 3 | 2 | 1 |
| 2. How do people in the community treat you? | 4 | 3 | 2 | 1 |
| 3. How often do you talk with people in the community? | 4 | 3 | 2 | 1 |
| 4. Do you have any friends? | 4 | 3 | 2 | 1 |
| 5. Do you get a chance to make friends where you live? | 4 | 3 | 2 | 1 |
| 6. Do you get a chance to make friends where you | 4 | 3 | 2 | 1 |
| 7. Do the people you work for think your job is important? | 4 | 3 | 2 | 1 |
| 8. Do friends come to visit you? | 4 | 3 | 2 | 1 |
| 9. How often do the people you live with annoy you? | 4 | 3 | 2 | 1 |
| 10. Are you frightened by the people you live with? | 4 | 3 | 2 | 1 |
| 11. Can friends come to visit you when you want them to? | 4 | 3 | 2 | 1 |
| 12. How often have you been visited by your family? | 4 | 3 | 2 | 1 |
| 13. Do you have friends on the staff? | 4 | 3 | 2 | 1 |
| 14. How do staff members treat you? | 4 | 3 | 2 | 1 |
| 15. How often do you hear staff members talking about other clients? | 4 | 3 | 2 | 1 |
| 16. How many of the staff members seem happy to have you around? | 4 | 3 | 2 | 1 |

Comments: _____

Quality of Life Questionnaire (continued)

IV. Personal Satisfaction/Fulfill

- | | | | | |
|--|---|---|---|---|
| 1. How do you feel about this community? | 4 | 3 | 2 | 1 |
| 2. Do you like the food you eat at home? | 4 | 3 | 2 | 1 |
| 3. How do you feel about your job? | 4 | 3 | 2 | 1 |
| 4. How do you feel about visits from your family? | 4 | 3 | 2 | 1 |
| 5. How do you feel about the staff here? | 4 | 3 | 2 | 1 |
| 6. How do you feel about others who live here? | 4 | 3 | 2 | 1 |
| 7. How do you feel about your room? | 4 | 3 | 2 | 1 |
| 8. Are you satisfied that you have enough clothes? | 4 | 3 | 2 | 1 |
| 9. Would you like to live someplace else? | 4 | 3 | 2 | 1 |
| 10. Is your home too hot or cold for you? | 4 | 3 | 2 | 1 |
| 11. Are you able to do most of the things you like
to do? | 4 | 3 | 2 | 1 |
| 12. Do you feel a sense of belonging here? | 4 | 3 | 2 | 1 |

Comments: _____

Appendix D-2

Item Master List

4F #	3F #	Item # QL-QC ITEMS	ORIG. CAT #
<hr/>			
1	1	21 How often do you decide when to go to bed and get up?	Ind. Func 2
1	1.2	22 Do you decide who you eat with?	Ind. Func 3
1	1	23 Do you decide what you will eat?	Ind. Func 4
1	1	24 Do you go shopping for groceries?	Ind. Func 5
1	1	25 Can you select the decorations in your room?	Ind. Func 6
1	1	27 When you need medicine, who gives it to you?	Ind. Func 8
1	1	28 Who makes your doctor/dentist appointments?	Ind. Func 9
1	1	29 Do you use public transportation when you need to go somewhere?	Ind. Func 10
1	1	32 Can you lock you house or room?	Ind. Func 13
1	1	34 Do you have a chance to decide what you want to do?	Ind. Func 15
1	1	35 Do you decide how to spend your money?	Ind. Func 16
1	1	36 How often do you get out to do things like shopping/movies?	Ind. Func 17
1	1.2	41 Do you chose what you wear each day?	Ind. Func 22
1	1	43 How many people share your room?	Relations 1
1	1	45 Do you have any friends?	Rel./Soc. -3
1	1	50 Do friends come to visit you?	Rel./Soc. 8
1	1	51 How often do the people you live with annoy you?	Rel./Soc. 9
1.4	1	33 Are you locked out of places you would like to go in your home facility?	Ind. Func 14
2	2	1 Do you get enough sleep at night?	Physical 1
2	2	2 Do you get tired during the day?	Ph. W. B. 2
2	2	4 Do you exercise during your free time/weekends?	Ph. W. B. 4
2	2	5 Do you use the bathroom when you need to?	Ph. W. B. 5
2	2	7 Do you get headaches?	Ph. W. B. 7
2	2	9 Do you get ear aches?	Ph. W. B. 9
2	2	11 Do you generally feel healthy?	Ph. W. B. 11
2	2	16 Do you feel anxious or scared?	Ph. W. B. 16
2	2	17 Do you feel tense or upset?	Ph. W. B. 17
2	2	19 Do your eyes bother you?	Ph. W. B. 19
2	2	59 How do you feel about this community?	Personal 1
2	2	66 Are you satisfied that you have enough clothes?	Pers. Sat 8
2	2	69 Are you able to do most of the things you like to do?	Pers. Sat 11
2.3	2.3	70 Do you feel a sense of belonging here?	Pers. Sat 12
3	3	14 Do your feet hurt?	Ph. W. B. 14
3	3	38 Are you free to go out with your friends when you want to?	Ind. Func 19
3	3	39 Can you call or write your family/friends when you want to?	Ind. Func 20
3	3	47 Do you get a chance to make friends where you work?	Rel./Soc. 5
3	3	48 Do you get a chance to make friends where you work?	Rel./Soc. 6
3	3	49 Do the people you work with think your job is important?	Rel./Soc. 7
3	3	54 How often have you been visited by your family?	Rel./Soc. 12
3	3	55 Do you have friends on the staff?	Rel./Soc. 13
3	3	56 How do staff members treat you?	Rel./Soc. 14
3	3	61 How do you feel about your job?	Pers. Sat 3
3	3	62 How do you feel about visits from your family?	Pers. Sat 4
3	3	63 How do you feel about the staff here?	Pers. Sat 5

Appendix D-2 Item Master List (continued)

3	2	64 How do you feel about others who live here?	Pers. Sat 6
3.2	2	58 How many staff members seem happy to have you around?	Rel./Soc. 16
4	3	3 If you feel hungry, do you get enough to eat?	Ph. W. B. 3
4	3	20 Do you have a pet at home?	Independe 1
4		40 Can you be alone here when you want to?	Ind. Func 21
4	3	60 How do you like the food you eat at home?	Pers. Sat 2
4	3	67 Would you like to live someplace else?	Pers. Sat 9
4		68 Is your home too hot or cold for you?	Pers. Sat 10
1		42 How often do you decide on the work you will do?	Ind. Func 23
2		44 How do people in the community treat you?	Rel./Soc. 2
		6 Do you have any pain/problems when using the bathroom?	Ph. W. B. 6
		8 Do you get stomach aches or other pains?	Ph. W. B. 8
		10 Do you feel physically comfortable?	Ph. W. B. 10
		12 Do you get colds?	Ph. W. B. 12
		13 If you feel thirsty, do you get enough to drink?	Ph. W. B. 13
		15 Do your teeth or dentures hurt?	Ph. W. B. 15
		18 Do you feel sad or unhappy?	Ph. W. B. 18
		26 Who chose your doctor/dentist?	Ind. Func 7
		30 How do you get to work?	Ind. Func 11
		31 Do you have access to your own money to buy things you need?	Ind. Func 12
		37 Do you have a chance to practice your religious beliefs?	Ind. Func 18
		46 Do you get a chance to make friends where you live?	Rel./Soc. 4
		52 Are you frightened by the people you live with?	Rel./Soc. 10
		53 Can friends come to visit you when you want them to?	Rel./Soc. 11
		57 How often do you hear staff talking about other clients?	Rel./Soc. 15
		65 How do you feel about your room?	Pers. Sat 7

Appendix D-3
Initial Extraction Statistics for Factor Analysis (Four Factors Identified)

VARIABLE	EST COMMUNALITY	FACTOR	EIGENVALUE	PCT OF VAR	CUM PCT
QL1	.95514	1	12.30057	17.6	17.6
QL2	.97609	2	7.91582	11.3	28.9
QL3	.95761	3	3.97064	5.7	34.6
QL4	.98884	4	3.52031	5.0	39.6
QL5	.96430	5	2.81298	4.0	43.6
QL6	.95655	6	2.77733	4.0	47.6
QL7	.98906	7	2.43015	3.5	51.0
QL8	.99357	8	2.38783	3.4	54.5
QL9	.96555	9	2.08238	3.0	57.4
QL10	.96878	10	1.85371	2.6	60.1
QL11	.99214	11	1.84053	2.6	62.7
QL12	.98756	12	1.68065	2.4	65.1
QL13	.96156	13	1.61617	2.3	67.4
QL14	.99381	14	1.49292	2.1	69.5
QL15	.97689	15	1.33887	1.9	71.5
QL16	.97653	16	1.28658	1.8	73.3
QL17	.94082	17	1.16551	1.7	75.0
QL18	.95837	18	1.12357	1.6	76.6
QL19	.96082	19	1.03919	1.5	78.1
QL20	.97750	20	1.01798	1.5	79.5
QL21	.99224	21	.90471	1.3	80.8
QL22	.97657	22	.84042	1.2	82.0
QL23	.99547	23	.79963	1.1	83.1
QL24	.99498	24	.75682	1.1	84.2
QL25	.98460	25	.74851	1.1	85.3
QL26	.94911	26	.70773	1.0	86.3
QL27	.97837	27	.68767	1.0	87.3
QL28	.97831	28	.65158	.9	88.2
QL29	.96871	29	.62113	.9	89.1
QL30	.97328	30	.55728	.8	89.9
QL31	.97491	31	.53696	.8	90.7
QL32	.99593	32	.48223	.7	91.4
QL33	.95693	33	.47312	.7	92.0
QL34	.96788	34	.44885	.6	92.7
QL35	.99077	35	.42694	.6	93.3
QL36	.97899	36	.39418	.6	93.8
QL37	.93980	37	.36037	.5	94.4
QL38	.97213	38	.34464	.5	94.9
QL39	.97588	39	.34028	.5	95.3
QL40	.98616	40	.31949	.5	95.8
QL41	.97450	41	.29419	.4	96.2
QL42	.98076	42	.26639	.4	96.6
QL43	.97547	43	.25095	.4	97.0
QL44	.99442	44	.21710	.3	97.3

TABLE D-3 Initial Extraction Statistics for Factor Analysis (Continued)

VARIABLE	EST COMMUNALITY	FACTOR	EIGENVALUE	PCT OF VAR	CUM PCT
QL45	.95815	45	.19994	.3	97.5
QL46	.98037	46	.19213	.3	97.8
QL47	.98668	47	.17903	.3	98.1
QL48	.94987	48	.17388	.2	98.3
QL49	.98593	49	.14925	.2	98.5
QL50	.91715	50	.13525	.2	98.7
QL51	.93311	51	.12593	.2	98.9
1				89/01/27.	15.25.22.
QL52	.97514	52	.09801	.1	99.1
QL53	.96174	53	.09093	.1	99.2
QL54	.96854	54	.07871	.1	99.3
QL55	.94629	55	.7525	.1	99.4
QL56	.96385	56	.07135	.1	99.5
QL57	.84595	57	.06008	.1	99.6
QL58	.97280	58	.04926	.1	99.7
QL59	.95800	59	.04285	.1	99.7
QL60	.97956	60	.04094	.1	99.8
QL61	.99519	61	.03508	.1	99.8
QL62	.97067	62	.02951	.0	99.9
QL63	.99306	63	.02405	.0	99.9
QL64	.99583	64	.02142	.0	99.9
QL65	.99407	65	.01531	.0	100.0
QL66	.98282	66	.01358	.0	100.0
QL67	.99196	67	.00724	.0	100.0
QL68	.93955	68	.00305	.0	100.0
QL69	.99169	69	.00286	.0	100.0
QL70	.98760	70	.00030	.0	100.0

APPENDIX D-4:

Revised Items and Schalock Comparison

1. How many people sleep in your bedroom?
1. **How many people share your room?**
2. How much control do you have when you go to bed and when you get up?
2. **Do you get to decide when to go to bed and when to get up?**
3. Who plans your meals?
3. **Do you get to choose the food you eat?**
4. Who shops for groceries?
4. **Do you go shopping for your groceries?**
5. Who chose the decorations in your bedroom?
5. **Can you select the decorations in your bedroom?**
6. If you have a regular doctor, who chose your doctor?
6. **Can you chose your own doctor?**
7. If you take medicines, who gives you the medicine?
7. **Who gives you the medicine when you need it?**
8. Who makes your doctor or dentist appointments?
8. **Do you make your own doctor or dentist appointments?**
9. How do you usually get to work?
9. **How do you get to work?**
10. Do you have guardian or conservator?
10. **No Questions:**
11. Do you have a key to your house?
11. **Can you lock your house or room?**
12. How many rooms or areas in your house are locked so you cannot get in them?
12. **Are you locked out of places you would like to go in your home or facility?**
13. Can you do what you want to do?
13. **Do you have a chance to decide what you want to do?**
14. Who decides how you spend your money?
14. **Do you decide how you spend your money?**
15. When can friends visit your home?
15. **Can friends come to visit your home when you want them to?**

Factor Two: Community Involvement

- 16. Does your job make you feel good?
- 16. Do you like your job?
- 17. Do you think your work is important to your employer?
- 17. Do the people you work for think your job is important?
- 18. How often do you use public transportation (handibus, taxi, city buss, etc.)?
- 18. Do you use public transportation when you need to go somewhere?
- 19. Do you earn enough money to pay for all the things you need?
- 19. Do you have access to your own money to buy the things you need?
- 20. Do you have friends over to visit your home?
- 20. Do friends come to visit you?
- 21. How frequently do you spend time in recreational activities in town?
- 21. How often do you get out to do things, like shopping or movies?

FACTOR THREE: Social Relations

- 22. How about your neighbors? How do they treat you?
- 22. How do people in the community treat you?
- 23. How do you like this town?
- 23. Do you like this community?
- 24. How often do you talk with the neighbors, either in the yard or in their home?
- 24. How often do you talk with people in the community?
- 25. If there are staff or family where you live, or if you live with another client or spouse, do they eat meals with you?
- 25. Do you decide who you will eat with?
- 26. Do you have any pets?
- 26. Are you allowed to have a pet at home?
- 27. Are there people living with you who have dangerous or annoying behavior problems?
- 27. Are you frightened by the people you live with?
- 28. What type of educational programs are you involved with?

APPENDIX D-5

LAKE COUNTY BOARD OF MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES
Quality of Life Case Management Questionnaire

Client: _____ Age: _____

Program/Agency: _____

Level of Functioning: _____

Surveyor: _____ Date: _____

Current Living Environment: (circle)

9. Independent Living (unlicensed home)
8. Semi-independent Living (less than 24 hour supervision)
7. Community Care Home (two or less persons)
6. Purchase of Service Foster Family Home (four or less persons)
5. Family Homes (five persons)
4. Purchase of Service Group Homes (five to twelve persons)
3. Small ICF/MR (20 to 26 beds)
2. Large ICF/MR (27 to 64 beds)
1. ICF/Generals

Current Work Environment: (circle)

7. Competitive Full-time Employment
6. Competitive Part-time Employment
5. Supportive employment (CLEO 3)
4. Creative Learning Employment Opportunities 1 & 2
3. Life Enrichment Program (Retirement program)
2. Production Floor 1, 2, or 3 (Work Activities Cntr.)
1. School environment (under 22 years old)

Directions: 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 non-verbal, have two staff independently evaluate the person on each item and use the average score. The scoring criteria are objective and therefore easily scorable. Scores can range from low (70) to high (210). If an item does not apply for some reason, please mark N/A by it and the score for this section will be adjusted accordingly.

Appendix D-5 (continued)

Lake County Quality of Life Case Management Questionnaire

Question/Environmental Observation	Scoring Categories/Criteria		
	3	2	1
<u>I. Physical Well-being</u>			
1. Do you get enough sleep at night?	Most of the time	Some of the time	Rarely
2. Do you get tired during the day?	Never	Seldom	Often
3. If you feel hungry, do you get enough to eat?	Usually	Sometimes	Hardly ever
4. Do you exercise during your free time and/or on weekends?	Usually	Sometimes	Hardly ever
5. Do you use the bathroom when you need to?	Usually	Sometimes	Hardly ever
6. Do you have any pain or problems when you use the bathroom?	Hardly ever	Some of the time	Almost always
7. Do you get headaches?	Never	Seldom	Often
8. Do you get stomach aches or other pains?	Never	Seldom	Often
9. Do you get ear aches?	Never	Seldom	Often
10. Do you feel physically comfortable?	Most of the time	Some of the time	Hardly ever
11. Do you generally feel healthy?	Usually	Sometimes	Hardly

Appendix D-5 (continued)

Quality of Life Questionnaire

12. Do you get colds?	Hardly ever	Sometimes	Fairly often
13. If you feel thirsty, do you get enough to drink?	Usually	Sometimes	Hardly ever
14. Do your feet hurt?	Hardly ever	Sometimes	Usually
15. Do your teeth or dentures hurt?	Hardly ever	Sometimes	Usually
16. Do you feel anxious or scared?	Rarely	Some of the time	Most of the time
17. Do you feel tense or upset?	Rarely	Some of the time	Most of the time
18. Do you feel sad or unhappy?	Never	Seldom	Often
19. Do your eyes bother you?	Seldom	Sometimes	Usually
	3's	2's	1's

Number by category _____

Score by category (# x factor) _____

Total Score (I. Physical Well-being): _____

Appendix D-5 (continued)

Quality of Life Questionnaire

II. Independent Functioning/Choices

1. Are you allowed to have a pet at home?	Yes, and I do	Yes, and I share one	No, I can't
2. Do you get to decide when to go to bed and get up?	Usually	Sometimes	Seldom
3. Do you decide who you eat with?	Usually	Sometimes	Seldom
4. Do you get to decide what you will eat?	I do	I help other decide	Somebody else decides
5. Do you go shopping for your groceries?	I do	I help someone else	Someone else helped me
6. Can you select the decorations your room?	Yes, I can	I helped someone else	Someone else helped me
7. Can you chose your own doctor?	Usually	Sometimes	Seldom
8. Who gives you medicine when you need it?	I do	Someone helps me	Someone else gives it to me
9. Do you make your own doctor appointments?	I do	Someone helps me	Someone else does
10. Do you use public transportations when you need to go somewhere?	Most of the time	Some of the time or There isn't any	Not very often
11. How do you get to work?	I drive myself	I use public transportation or I'm close enough to walk	Somebody takes me
12. Do you have access to your own money to buy things you need?	Yes, I do	I get some not enough	I dont get any
	#3's	#2's	#1's

Appendix D-5 (continued)

Quality of Life Questionnaire

13. Can you lock your house or room?	Yes	I can with help	No
14. Are you locked out of places you would like to go in your home/facility?	None of the time	Yes, some of the time	Yes, most of the time
15. Do you have a chance to decide what you want to do?	Most of the time	Some of the time	Hardly ever
16. Do you decide how to spend your money?	I do	I help someone else	No, I don't
17. How often do you go out to do things like shopping and movies?	As often as I like	Most of the time	Hardly ever
18. Do you have a chance to practice your religious beliefs?	Yes, nearly always	Yes, some of the time	Hardly ever
19. Are you free to go out with friends when you want to	Yes, usually	Some of the time	Hardly ever
20. Can you call or write family and friends when you want to?	Yes, usually	Some of the time	Hardly ever
21. Can you be alone here when you want to?	Yes, usually	Sometimes	Hardly ever
22. Do you choose what you wear each day?	Yes, usually	Some of the time	Hardly ever
23. How often do you decide on the work you will do?	Most of the time	Some of the time	Hardly ever

Number by category _____

Score by category (# x factor) _____

Total Score (II. Independent Functioning/Choices): _____

Appendix D-5 (continued)

Quality of Life Questionnaire

III. Relationships/Social Interactions

1. How many people share your room?	Alone or with my spouse (if applicable)	One or two roommates	Three or more roommates
2. How do people in the community treat you?	Very well	Ok, I guess	Not very well
3. How often do you talk with people in the community?	Almost every day	At least once a week	Hardly ever
4. Do you have any friends?	Yes, quite a few	Yes, some	None
5. Do you get a chance to make friends where you live?	Quite often	Occasionally	Seldom
6. Do you get a chance to make friends where you work?	Quite often	Occasionally	Seldom
7. Do the people you work for think your job is important?	I think so	Maybe-I don't know	I don't think so
8. Do friends come to visit you?	Quite often	Occasionally	Seldom
9. How often do the people you live with annoy you?	Almost never	Seldom	Frequently
10. Are you frightened by the people you live with?	Almost never	Seldom	Sometimes
11. Can friends come to visit you when you want them to?	Yes, usually	Only with staff approval	Only on visiting days
12. Does your family visit you?	Often	Seldom	Hardly ever
13. Do you have friends on the staff?	Yes, quite a few	Yes, some	Hardly any

Appendix D-5 (continued)

Quality of Life Questionnaire

14. How do staff members treat you?	Pretty well	Usually ok	Not very well
15. How often do you hear staff members talking about other clients?	Hardly ever	Sometimes	Fairly often
16. How many of the staff members seem happy to have you around?	Most of them	Some of them	Very few
	#3's	#2's	#1's

Number by category _____

Score by category (# x factor) _____

Total Score (III. Relationships/Social Interactions): _____

IV. Personal Satisfaction/Pulfillment

1. Do you like this community?	I like it very much	Its ok, I much	I don't like it at all
2. Do you like the food you eat at home?	Usually	Sometimes	Seldom
3. Do you like you job?	I like it most of of the time	I like it some of the time	I don't like it very much
4. Do you like the visits your family?	I like them very much	They are ok	I don't like them
5. Do you like the staff here?	I like them very much	I like some of them	I only like a few of them
6. Do you like the people you live with?	I like most of them	I like some of them	I only like a few of them

Appendix D-5 (continued)

Quality of Life Questionnaire

7. Do you like you room?	I like it very much	It's ok	I don't like it
8. Are you satisfied that you have enough clothes?	Most of the time	Some of the time	Hardly ever
9. Would you like to live someplace else?	No	I might	Yes
10. Is you home too hot or cold for you?	No, it is o.k.	Some of the time	Yes, almost always
11. Are you able to do most of the the things you like to do?	Most of the time	Some of the time	Hardly ever
12. Do you feel a sense of belonging here?	Most of the time	Some of time	Hardly ever
	#3's	#2's	#1's

Number by category _____

Score by category (# x factor) _____

Total Score (IV. Personal Satisfaction/Fulfillment): _____

Total Score for I. Physical Well-being: _____

Total Score for II. Independent Functioning/Choices: _____

Total Score for III. Relationships/Social Interactions: _____

Total Score for IV. Personal Satisfaction/Fulfillment: _____

Total Quality of Life Score: _____ (raw score) // _____ (%)