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## QUALITY OF LIFE DIMENSIONS FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

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ABSTRACT OF DISSERTATION

Kathleen Sheppard-Jones

The Graduate School  
University of Kentucky  
2002

QUALITY OF LIFE DIMENSIONS FOR ADULTS WITH DEVELOPMENTAL  
DISABILITIES

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ABSTRACT OF DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in the  
in the College of Education  
at the University of Kentucky

By  
Kathleen Sheppard-Jones

Lexington, Kentucky

Director: Dr H. Thompson Prout, Professor of School Psychology  
Lexington, Kentucky

2002

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## ABSTRACT OF DISSERTATION

### QUALITY OF LIFE DIMENSIONS FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

Quality of life is a phrase that most people are familiar with, regardless of whether or not they can define it. Much research has been conducted across disciplines in an effort to explain the construct. As human service programs become more focused on outcomes, there is greater interest in measuring quality of life as an indicator of service quality and success. This study was designed to test whether or not quality of life differences exist between adults with developmental disabilities and the general population at an item, scale, and composite level. The quality of life dimensions that were tested included items related to well-being, community participation, access to services and human rights, and choice and decision-making. Differences were found in well-being and decision-making. Differences were also present in certain access items. The two groups also differed in overall quality of life with those with developmental disabilities having lower quality of life. A logistic regression model that was comprised of the life dimensions differentiated between the two groups with over 90% accuracy. Overall results indicate that adults with developmental disabilities are at a significant disadvantage with regard to quality of life in comparison with the general population.

KEYWORDS: Quality of Life, Developmental Disability, Well-Being, Access,  
Community Participation, Autonomy

Kathleen Sheppard-Jones

December 11, 2002

QUALITY OF LIFE DIMENSIONS FOR ADULTS WITH DEVELOPMENTAL  
DISABILITIES

By

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December 11, 2002

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DISSERTATION

Kathleen Sheppard-Jones

The Graduate School  
University of Kentucky  
2002



QUALITY OF LIFE DIMENSIONS FOR ADULTS WITH DEVELOPMENTAL  
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Though a dissertation is an exercise in independent thought and product, it is by no means a process that takes place in a vacuum. There are not many opportunities in life to appropriately thank those who have been instrumental in helping one to achieve goals. I would like to first and foremost thank my committee for their guidance and patience as I found my way through this process. My dissertation director, Dr. Tom Prout has been a calming and knowledgeable voice who has helped me to maintain my focus in this effort. Dr Fred Danner is a continuous reminder to me that research and teaching should be about re-invention and true sense of joy for what you do. Dr. Ralph Crystal has accompanied me since the beginning of my journey in the field and I am very grateful for his guidance. I will be forever thankful for the opportunity that I have to work with and learn from Dr. Harold Kleinert, whose dedication, passion for his work, and expertise truly inspires me. I would also like to thank Dr. Susan Effgen, my outside reader, for taking the time from her busy schedule to assist me and provide valuable insight during this process.

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## TABLE OF CONTENTS

Acknowledgements.....	iii
List of Tables .....	viii
List of Files .....	ix
Chapter One: Introduction	
Literature Review.....	1
Quality of Life Construct .....	1
Methodological Issues .....	9
Utilizing Quality of Life as Outcome Indicators in Disability Services.....	14
Research Questions.....	22
Variables .....	23
Chapter Two: Methods	
Instrumentation .....	24
Development.....	24
Instrument Components .....	25
Instrumentation Alterations for General Population Administration.....	26
Participants.....	27
General Population Group .....	27
Consumer Group.....	28
Data Collection .....	29
General Population Data Collection .....	29
Consumer Data Collection.....	30
Aggregate Dataset.....	31
Research Design.....	31
Analysis of Data.....	32
Adjustment of Data Used for Analysis .....	32

Establishing Current Psychometric Properties of the Instrument .....	33
Multivariate Analysis.....	34

### Chapter Three: Results

Sample .....	39
General Population Sample.....	39
Consumer Sample .....	39
Demographic Characteristics .....	40
Quality of Life Dimension Item Responses .....	41
Quality of Life Dimension Scales.....	42
Logistic Regression.....	43

### Chapter Four: Discussion

Limitations of the Investigation .....	70
Conclusions.....	72
Implications for Future Research.....	75

### Appendices

Appendix A: General Population Group Telephone Survey .....	78
Appendix B: Demographic Characteristics by Unadjusted Group .....	89
Appendix C: Unadjusted Group Item Responses .....	93
Appendix D: Unadjusted Group Item T-Tests .....	104
Appendix E: Unadjusted Group QOL Dimension Indicator Scale T-Tests .....	112
Appendix F: Unadjusted Group Scale Means & Correlations .....	114
Appendix G: Unadjusted Group Initial Logistic Regression.....	116
Appendix H: Unadjusted Group Final Logistic Regression .....	118
Appendix I: Unadjusted Group Classification Table.....	120
Appendix J: Comments From General Population Participants .....	122

References.....126

Vita.....135

## LIST OF TABLES

Table One, QOL Dimension Item Composition .....	36
Table Two, QOL Dimension Scales .....	38
Table Three, Group Characteristics .....	45
Table Four, Item Responses.....	48
Table Five, Item T-Tests.....	58
Table Six, QOL Dimensions Indicator Scales .....	65
Table Seven, Means and Correlations .....	66
Table Eight, Initial Logistic Regression .....	67
Table Nine, Final Logistic Regression.....	68
Table Ten, Classification Table .....	69

## LIST OF FILES

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## Chapter I Introduction

### *Literature Review*

#### *The Quality of Life Construct*

Quality of life is a phrase that everyone is familiar with, regardless of profession, community, or education. However, the meaning of the phrase can have very different connotations to different people. Quality of life was first coined during the 1950's as a concept that was professed by politicians who promised to improve their constituents' quality of life and their pursuit of happiness, or more accurately, their socioeconomic status if they were elected. Finding out what it meant to live the "American Dream" became important, but it was obvious that the concept meant different things depending on whom was asked.

In the field of disability, the construct was further studied in the 1970's and the 1980's by those in mental health, but perhaps more noticeably by those behind the deinstitutionalization movement. Proponents recognized that a person's quality of life was not solely tied to material wealth, but to the more elusive but no less important aspect of individual happiness and community belonging. Quality of life has since begun receiving a second look by those in other human service fields as providers have begun to recognize quality of life to be a viable outcome that can be measured. Over the past 20 years, quality of life moved from merely bandying about theoretical aspects of the construct to practical concerns about accurately applying it to the service delivery system as a more appropriate means for developing and evaluating services being provided to persons with disabilities (Schalock, Brown, Brown, Cummins, Felce, Matikka, Keith & Parmenter, 2002).

But questions regarding the appropriate definition of the construct must first be answered before it can possibly be applied as a reliable indicator of service delivery. From a theoretical perspective, researchers have attacked the concept from a variety of angles, all with the same goal of determining what constitutes a life of quality, but most arriving at different conclusions depending on the type of research they were performing. This has resulted in better than 100 researcher specific definitions of quality of life (Schalock, 2000) that most ably served the research purpose without necessarily looking at the larger meaning of the phrase. Quality of life means something to everyone, but the manner of accurately defining it in terms that are

agreeable to all is no easy task. How does one determine the quality of a person's life? What makes one individual's existence of a higher caliber than someone else's? How does the influence of disability factor into the equation? Though people are typically able to assess their level of quality of life inherently, the manner of determining what components of the construct are included and how to assign them value can be more difficult to articulate.

Quality of life is a concept that is amorphous at best, confounding at worst. There is much debate regarding what life situations constitute a higher quality of life than others. To define quality of life, it is helpful to consider the definitions of each term. Quality can be considered a distinguishing characteristic, level or variation in grade. Life refers to the characteristics of a person's existence, both in an environmental sense, a physical sense and a sense of mental and spiritual life. One's life is comprised of components such as events and circumstances of that existence (American Heritage Dictionary of the English Language, 2000).

There has historically been little agreement among researchers as to a working definition of quality of life. Some argue that this construct is purely subjective, and is interchangeable with one's sense of well-being and happiness (Taylor & Bogdan, 1996). This definition is a very narrow one. By this way of thinking, perceptions are all that matter, and the reality of a person's situation have no bearing. This approach is troubling to most researchers, however, who contend that the construct is multidimensional and contains both objective and subjective aspects.

In order for measures of quality of life to have meaning, they must accurately represent the individual's point of view. Therefore, it has been suggested that one must combine objective and subjective elements to obtain a truly holistic and more complete picture (Post, DeWitte, and Schrijvers, 1999; Schalock, 1996; Schalock, 2000). The objective component of the measure is described as that which can result from basic properties of the human-environmental interaction such as safety, health, and shelter. This is also referred to as the socioeconomic or demographic component. It is the more easily measured, and less personally perceived than the subjective. The subjective aspect of quality of life lies in the perceived satisfaction of the individual with regard to his or her life. It can be considered to have both domain specific as well as general life aspects.

This point is worth reiterating in that the critical factor of the subjective aspect is that it is concerned solely with the individuals' interpretation or point of view. We can all recall the story of Goldilocks and the Three Bears (Cummins, 1923). When Goldilocks sampled bowls of

porridge that belonged to each of the three bears, she declared one too hot, too cold, and one “just right”. However, to the Mama Bear, the porridge of the correct temperature was the one that Goldilocks considered too hot. A person’s perceptions are impacted by his or her relationships, age, sex, geographic location, and developmental stage in life (Felce, 1996; Schalock, 1996; Stark & Faulkner, 1996). Therefore, quality of life can not be considered a one-size fits all construct.

The term well-being is sometimes used interchangeably with quality of life. Overall consensus indicates that well-being is more accurately defined as the subjective aspect of the construct, and refers to one’s happiness (Borthwick-Duffy, 1996; Schalock, 1996). Subjective well-being at a global level could be operationalized by an individual’s self-rating of his or her overall happiness. Domain specific well-being is far more narrow. It would be operationalized in terms of one’s rating of satisfaction with specific areas. Examples could include a person’s happiness with work, living situation, relationships, quality of health care, and community connectedness.

While much research has been done in this realm, there is a strong contention that well-being consists of more than just happiness within general and specific domains (Ryff, 1989; Ryff & Keyes, 1995). Ryff (1989) articulated that well-being is actually comprised of several dimensions. These are: self-acceptance, autonomy, positive relationships, environmental mastery, personal growth, and sense of purpose. This line of thinking expands well-being from a more general sense of satisfaction to a construct that includes environmental components as well. Well-being, like quality of life, is multidimensional and is most reliable when several items are used as scales rather than attempting to assess it as a simple, global item of satisfaction or happiness.

Quality of life research has its foundations in the field of medicine. Health-related quality of life (HRQOL) has been studied extensively, resulting in a variety of application-specific instruments (Coulter, 1997). The literature is rich with studies that examine relationships between a variety of impairments and their impact on a person’s perceived place in the world (Angermeyer, Holziner, Kilian, & Matschinger, 2001; Bishop, Bervin, Hermann, & Chan, 2002; Brown, Gordon, & Haddad, 2000; Salkever, 2000). However, for social scientists who choose to generalize findings, these limitations are too constricting to provide a holistic indicator of quality of life. Some social researchers approach quality of life as the level at which individuals have

goals and an expectation of fulfilling them, also known as goodness-of-fit (Waismann, 1988). Post, DeWitte, and Schrijvers (1999) define quality of life somewhere in between, as well-being combined with material circumstances. In their definition, well-being encompasses one's overall sense of happiness as well as more domain specific life issues. It comprises the subjective component of quality of life. The authors posit that the objective component of quality of life refers solely to one's material circumstances that includes factors related to health, economic resources, and housing.

Because much of the quality of life literature contains health related component to quality of life, it is worthy to discuss implications for persons with disabilities where health-related quality of life is concerned. Many researchers follow the World Health Organization's definition of health which indicates that health is "a state of complete physical, mental and social well-being, not merely the absence of infirmity" (Coulter, 1997). This definition becomes very important in its application to people with disabilities because it is a more holistic view of health. Health is defined in such a way that being healthy is not solely dependent upon the presence or absence of disability, but instead recognizes that there are other factors that should be taken into account when assessing this aspect of quality of life. This is a common sense response to those who fear that a disability label would automatically put one at a disadvantage as far as health related quality of life is concerned.

Presence of disability is not automatically equated with decreased health-related quality of life. Just as two people with the same disability are as different as any two people, so too is the health-related impact that disability imposes on quality of life. To be well and to flourish involve much more than one's objective level of health (Ryff & Singer, 2000). Therefore, the real value of this indicator is its meaning to the individual (Coulter, 1997). Concurrence with this definition provides a bridge between the health and holistic views of quality of life.

In the world of research, the construct quality of life has undergone some substantial shifts. Measuring quality of life can provide a tempting opportunity to inject one's own interpretation of the construct. However, to measure quality of life that accurately represents the individual's perspective, it has been suggested that one must combine objective and subjective elements. The objective component of the measure can result from basic properties of the human condition such as safety, health, and shelter. The subjective component lies in the satisfaction of the individual with regard to domain specific as well as general life issues.

Because developmental and environmental changes occur throughout the lifespan, so too, does the importance that an individual may place on the various components of his or her quality of life (Felce, 1996; Ryff, 1989; Ryff, 1995; Stark & Faulkner, 1996). Therefore, while work may have been important to a person from young adulthood through his or her late 50's, as retirement approaches and thoughts shift toward an existence without the world of work, this major life activity may become devalued. Concurrently, the person's relationships with family may take a more predominant position. This reinforces the fact that quality of life must be maintained as a highly individualized notion that can constantly evolve and be measured across a variety of dimensions.

Edgerton (1996) argues that the subjective components of quality of life have been shown to be relatively unchanging in individuals and that when the highs and lows of life occur, there may be some brief alterations in one's perceptions of happiness, these levels will eventually return to the baseline. This translates into some people just being inherently happier than others. We are probably all familiar with some individuals who have a characteristically sunny outlook on life, even when events are stacked against them. As a result, the more objective aspects of a person's existence can provide more malleable indicators of the construct. While this may lead to the conclusion that the objective dimension of quality of life is the only one that can be changed through provision of services, this may not always be the case. The subjective global and domain specific dimensions are alterable in that inaccurate self-perceptions can be changed through interventions such as counseling and/or medication (Livneh, 2001; Roessler, 1990). Indeed, one's perceptions may change markedly through rehabilitative efforts (Schalock et. al., 2002).

When adding the element of disability to the quality of life arena, the defining waters muddy yet again. Over the past 15 years, a body of knowledge has been amassed across disability fields that stress the importance of utilizing the construct in order to better serve those with disabilities. Barbotte, Guillemin, Chau, & the Lorhandicap Group (2001) reviewed general population quality of life studies. Their results indicated that there was relatively little disability research examining health-related quality of life issues that was generalizable to the general population. Some research that has been conducted purports that quality of life results can be confounded by disability type. In the somewhat limited amount of comparative research that has been conducted between those with disabilities and the general population, individuals with disabilities have been shown to have lower quality of life than those without disabilities

(Lehman, Ward, & Lnn, 1982; National Organization on Disability, 2000; Ruth, 2002; Ruth & Struxness, 1994). Other research shows that those who have more severe disabilities experience the largest gaps (Chubon, Clayton, & Vandergriff, 1995).

The consideration of quality of life for those with developmental disabilities such as mental retardation really began to take flight in the late 1960's and early 1970's. Facilities began to undergo institutional reform and the subsequent deinstitutionalization process began. From this point forward, greater numbers of providers began looking at services and supports for people with significant disabilities that more closely mirrored the non-disabled population. This change in thinking began a new age that further opened the door to quality of life issues.

However, not everyone has been so quick to embrace quality of life studies particularly aimed at people with mental retardation because they provide a means to further demonstrate differences between those individuals and the general population (Taylor & Bogdan, 1996). Several studies have shown that those with developmental disabilities have lower quality of life than those with other kinds of severe disabilities (Chubon, Clayton, & Vandergriff, 1995). However, there are others who contend that quality of life is an aspect of the human condition that need not be controlled for by presence or absence of disability (Cummins & McCabe, 1994; Schalock, 1996). In a study of consumers with developmental disabilities, Schalock, Bonham, & Marshand (2000) found that life satisfaction was not directly related to ability measures (including IQ labels).

As interest in the quality of life arena has expanded, it is prudent to ascertain what disability researchers have considered to be the most appropriate variables to include when operationalizing the construct, and whether or not disability specific quality of life measures are necessary. Hughes and Hwang (1996) sought to determine if consensus could be reached on the components of quality of life definitions that, historically, had seemed almost as varied as the researchers themselves. Their literature review examined a broad base of studies of people with and without disabilities between 1970 and 1993. The aggregate results included over 9,000 respondents who primarily participated in either survey research or follow-up interviews and questionnaires. The studies employed 44 different definitions of quality of life.

Upon analysis, the operationalized components fell into 15 discreet categories: psychological well-being and personal satisfaction; social relationships and interpersonal interactions; vocation; physical and material well-being; self-determination, autonomy, and

choice; self-efficacy, community adjustment, and independent living; community integration; social acceptance, social status, and ecological fit; personal development and fulfillment; living environment; recreation and leisure; normalization; individual and social demographics; civic responsibility; and support services received. Findings of this overall review of the quality of life literature support the stance that this is a construct that can be relevant for people regardless of disability. As has been demonstrated through the work of other researchers, the fact the construct is multidimensional is truly not in question. It is more a matter of honing the involved variables into an accurately working definition.

So what is the most appropriate technique for determining quality of life indicators in the presence of developmental disabilities? The fundamental decision must be to first throw out the stereotypes that accompany the term mental retardation (Taylor & Bogdan, 1996). Schalock (1997) argues that, for the sake of operationalizing the construct, what is first necessary is recognizing that certain principles are inherent to any study seeking to provide accurate information regarding quality of life outcomes, regardless of the population being studied. These principles indicate that quality of life is: 1) made of dimensions that are important to all people, regardless of presence or absence of disability; 2) experienced when a person has his or her basic needs met and when opportunities are available to pursue goals; 3) a multidimensional concept that is comprised of subjective and objective aspects; 4) enhanced when individuals are integrated within their communities, participate in work and meaningful relationships; and; 5) is driven by the perspective of the person's choices and through his or her empowerment (Schalock, 1997; Schalock et. al., 2002).

All of these concepts reinforce the person-centered approach and serve to reduce the introduction of researcher bias. Schalock considers these principles to be ubiquitous, applying to people with or without a disability. He argues that the key elements of the quality of life construct can and should still be measured in the presence of disability. This can be done even if the individual has severe, complex disabilities. In this situation, it is merely a matter of choosing the most appropriate techniques (Schalock, 1997).

Schalock's model further compacted Hughes and Hwang's 15 dimensions into what he considered to be eight independent core indicators of quality of life. They are: emotional well-being, relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. To gain a comprehensive view of the person, it is

important to measure all of these components. The indicators have received a great deal of support, and are largely recognized in the more recent quality of life literature. Upon review, they appear to be relevant for all people, regardless of presence or absence of disability, type of disability, or severity of disability. The remainder of this paper will use these eight core components, both in the subjective and objective sense as appropriate, as the base determinants for operationalizing the quality of life construct.

There are some apparent conclusions that can be reached about quality of life as a construct. The first is that it has not been as easy a concept to operationalize as it might first appear it should be, particularly because everyone is somewhat familiar with it, and what they think it means for themselves. But as a result of the hard work of many dedicated professionals, an emerging picture of quality of life is becoming clearer. It shows a construct that is multifaceted and multidimensional, one that contains components that are based not only in the subjective and highly personal appraisals of one's situation but also what are perhaps the more easily quantifiable objective components of physical environment, health, and other demographic information. It is the blending of the subjective and the objective that provide the most rich quality of life data. For it is not only important to know where a person lives or what he or she does during the day, but also how that individual feels about that living situation and day activity.

What may be the most interesting conclusion that can be drawn from this discussion is that, perhaps more than any other construct in the social and medical sciences, quality of life can and should be considered a concept that is unique to the human experience, one that crosses lines of disability, of gender, of age, and of socioeconomic status. Some dimensions even cross cultures (Ryff & Singer, 2000). In that sense, it can be a great equalizer for society members that can heighten awareness about the lives of quality that our neighbors are leading, so long as one does not make the incorrect leap in assuming that quality of life is independent of culture (Schalock et.al., 2002). The abundance of disability literature indicates that it is far easier for researchers to determine the presence of impairments or illness than it is to agree upon what constitutes a life of quality. But when the core factors of quality of life are employed, results can and should be generalizable to the general population (Cummins & McCabe, 1994; Schalock, 1996). Quality of life has many layers and many intricacies, but when the appropriate



methodology is employed, it is also a construct that can yield very telling and very important results for all people.

*Methodological Issues Surrounding the Measurement of Quality of Life in the General Population as Well as for Persons with Mental Retardation*

As with all research, once the construct has been identified and operationalized and the research questions are posed, the discussion then shifts to carrying out the study using techniques that are both valid and reliable. Validity can be thought of as a measure's ability to measure what it is supposed to measure. Reliability refers to the ability of the measure to provide results that can be repeated. Instrument testing for levels of both validity and reliability provide researchers with information about the psychometric strengths of the measure as well as the potential limitations of the strength of those findings.

Validity of an instrument is typically considered in terms of construct, content, predictive and concurrent validity. Construct validity refers to an instrument's ability to accurately measure the construct in question. Content validity is the ability of a test to accurately reflect the universe of content. An instrument is considered to have good predictive validity when it can be used as a measure that predicts some future event (for example the SAT and ACT are supposed to have high predictive ability for a student's success in a postsecondary environment). Concurrent validity exists when a measure corresponds with another instrument that measures the same construct.

Reliability refers to the repeatability or level of agreement of an instrument. Level of test-retest agreement should be high when an instrument is chosen for a study. For how much value does the instrument have if it does not provide consistent, repeatable results? In survey research, inter-rater agreement (values assigned by different interviewers to the same individual) is also used as a reliability measure. Acceptable levels of validity and reliability are also highly variable across researchers. The bottom line is that the validity and reliability of an instrument dictates its usefulness and generalizability.

Some general themes do exist when examining the methodologies of quality of life studies. The measurement instruments can be objective or subjective, or a combination, as previously described. Measures can also be used to provide either relative or absolute indicators of quality of life (Heal & Sigelman, 1996). In other words, quality of life scores can be used "as

is” (compared to pre-test measures or against others within the same group) or they can be compared against some norm group. Quality of life studies can also operate as compilation of existing data, by direct report or interview with the individual, or the information can be obtained by another person, referred to as a proxy.

Schallock, Bonham, & Marshand (2000) summarized nine instruments that have been specifically designed to assess quality of life in people with disabilities that also have published psychometric results. These measures also include a variety of factors to get at the construct. But when the construct of quality of life is tied to an individual, how can one be assured that it is measured accurately if that individual has a severe disability such as mental retardation? Some of the issues in this area are further discussed to shed light on some potential complications that can throw a monkeywrench in this kind of research if not addressed at the outset.

Accurately obtaining quality of life information from people with cognitive disabilities such as mental retardation can present some challenges to researchers (Heal & Sigelman, 1996; Borthwick-Duffy, 1996; Schallock; 1996). In some instances, study participants with cognitive disabilities may: 1) choose to not participate, or; 2) be unable to participate if the severity of their disability is such that they are unable to convey their responses in a study situation. For this reason, research has looked at the benefits and drawbacks of proxy interviewees.

Research results have been somewhat mixed with regard to the validity of proxy responses. Some contend that while quality of life is inherent to a person, it can be validly and reliably ascertained by those with intense familiarity to that person (Borthwick-Duffy, 1996; Heal & Sigelman, 1997). Those with less frequent contact (service providers who are present intermittently or relatives who live in other states) are less desirable reporters. The value of proxies can be enhanced when a variety of those in the support network (circle of support) of the individual are involved, sharing their varying perspectives (family, support staff, service providers, advocates) (Schallock, 1996). McVilly, Burton-Smith, and Davidson (2000) examined self-reports of those with mild mental retardation versus first-degree relatives or support staff. They found highly concurrent results. In a study conducted by Larsson and Larsson (2001), high levels of agreement were found on a quality of care survey between individuals with developmental disabilities, a parent, and a caregiver. However, in this study, those with disabilities were unable to ascribe their relative ratings of importance of the various care questions, an important component of quality of life. In a contrary study, (Budd, Sigelman &

Sigelman; 1981) found only a 52% agreement between consumer and caregiver in a yes-no survey.

As an additional complicating factor, issues related to active participation from individuals with cognitive disabilities must be considered. In a study in the early 1980's, the level of responsiveness and acquiescence of study participants with cognitive disabilities was shown to be directly related to their IQ (Sigelman, Schoenrock, Spanhel, Hromas, Winer, Budd, & Martin, 1981). Subjective questions or those that deal with more abstract concepts appear to lend themselves to decreased responsiveness. Therefore, those questions that refer to well-being can screen out people with more significant disabilities (Hatton, 1998). For these reasons, the construction, content, and sources used to obtain information for instrument questions can largely impact responsiveness.

Acquiescence has traditionally been a problematic area when interviewing people with cognitive disabilities (Heal & Sigelman, 1996). Acquiescence can be an issue anytime a question is worded in such a way that respondents are given an option of answering affirmatively, thus indicating agreement. Detecting and minimizing the effect of acquiescence in item responses is possible through different means. The most obvious is to delete questions that are worded in such a way that they lend themselves to the respondent providing either positive or negative answers. However, in situations where large amounts of data are being collected and open-ended interviews are not an option, yes-no questions can be difficult to eradicate entirely. Therefore, an alternative is necessary. Another way to negate the effects of acquiescence is through item-reversal. Item-reversal is a technique that is used when two questions are asked which are diametrically opposed to each other. For example, the participant is asked, "Do you feel happy today?". At a later point in the interview the respondent is asked, "Do you feel sad today?". Responses of "yes" to each question indicates acquiescence.

In addition, the phenomena of acquiescence may interact with social desirability factors in that "persons with mental retardation may say yes to many yes-no questions in order to be agreeable and may say no to questions that mention socially undesirable behaviors to deny any associations with these taboos" (Heal & Sigelman, 1996). Another construction issue revolves around either-or questions (example: "Do you usually feel safe or afraid?"). Budd, Sigelman & Sigelman (1981) found that when an either-or question was asked, respondents were more likely to choose the second choice given. When the question was asked again and the choices reversed,

the new second choice was preferred by respondents, even though it resulted in inconsistent responses.

Another area of potential of concern arises when responses are supplied on scales. Traditional Likert scales have shown to have limited utility for people with more significant cognitive disabilities (Cummins & McCabe, 1994). This requires that questions have pre-collapsed or dichotomous response choices to obtain more valid responses from those who demonstrate difficulty with responding to scales (Larsson and Larsson, 2001). Some quality of life instruments, such as the Comprehensive Quality of Life instrument (COMQOL-I) and the Quality of Life Questionnaire (QOLQ), include pre-tests to determine appropriate question formatting.

Reliability and validity testing of instruments used with population samples of those that have developmental disabilities show that much work still needs to be done to strengthen the argument that such measures are appropriate for this population. Low numbers of appropriate respondents and few replicated studies have led some researchers to less than stellar psychometric properties (Cummins & McCabe, 1994; Human Services Research Institute, 2000; Larsson and Larsson, 2001).

The Comprehensive Quality of Life (COMQOL) developed by Cummins and the Core Indicators consumer survey (CIPCS) are two instruments that have been used specifically for populations with mental retardation to assess their quality of life. Their psychometric properties are therefore worthy of further description.

Cummins' Comprehensive Quality of Life survey (COMQOL) (1991) is a 35 item self-report scale that has been shown to be a relatively easily administered test. It was developed with seven domains: material well-being, health, productivity, intimacy, safety, place in society, and emotional well-being. The scale contains both subjective and objective components. Within each scale, subscales were created to address importance and satisfaction. The addition of variables of importance enables scores to be weighted, thus recognizing the idiosyncratic amount of value that is highly individualized. Satisfaction questions are Likert type, with response ranges on a seven point scale. The importance questions utilize a five point scale.

Parallel forms of the COMQOL have been created, including the COMQOL-I which is intended for use with people with cognitive disabilities. Internal consistency of the objective subscale has been established at 0.39, importance subscale at 0.65, and satisfaction at 0.73 when

tested on college students and staff (Cummins & McCabe, 1994). Instrument validity has been examined anecdotally as a high level of agreement between subscales and domains and content of the quality of life literature (Cummins & McCabe, 1994). Validity is also addressed by a pre-test protocol that screens out those who are unable to meet the cognitive demands of the test. The pre-test responses dictate the number of Likert choices that will be available to the respondent. Those with higher degrees of cognitive involvement could, therefore, have binary choices. This results in great difficulty in generalizing results and in comparing them to the general population. Therefore, this instrument's greatest utility is for those with less significant degrees of mental retardation (Verri, Cummins, Petito, Vallero, Monteath, Gerosa & Nappi, 1999).

The Core Indicators Project Consumer Survey (CIPCS) was developed largely in response to a study done by the Colorado state developmental disability authority, the Colorado Progress Assessment Review (COPAR) (Ruth & Struxness, 1994). Results of this study of individuals with mental retardation and the general population in Colorado showed that tremendous disparities existed across many life domains, with those with disabilities coming up short. To provide a means of addressing satisfaction with services and overall life satisfaction of consumers with mental retardation, the CIPCS was developed by participating members of the National Association of State Directors of Developmental Disability Services. This instrument addresses the multidimensionality of quality of life across eight domains. These are: relationships, goals reached, perception of safety, access to health care, level of available choice making opportunities, community participation, employment participation, and rights. Responses may be obtained through self-report or by proxy who is familiar with the day to day routine of the individual.

The instrument has undergone test-retest reliability testing with individuals with developmental disabilities (.80). Inter-rater agreement has been measured at .92-.93. Validity of the instrument has been expressed as percentage of individuals who were able to participate in self-report responses during face-to-face Core Indicators Project consumer interviews who were also able to self-report on another quality of life measure (69%) (Human Services Research Institute, 2001). However, this represents a degree of concurrent validity, and does not assess whether or not the instrument content truly measures the construct in question.

Each of these instruments shows great promise for use with individuals with mental retardation, but there are also limitations that exist. There are issues related to accurately

determining validity of responses as well as the generalizability of the results to the general population, mainly because little comparative testing with general population samples have been conducted. Regardless of type of instrument used in quality of life studies, care must be taken to reduce researcher bias. For this type of research becomes truly meaningless if a researcher does not accurately record participants' information, and instead injects his or her own perspective on the respondent. Training is critical for surveyors who perform direct interviews with individuals or proxies to maintain a nonjudgmental, person-centered approach to obtaining data on quality of life. When questions of valid responses arise in interview situation, interviewers should probe appropriately to determine the actual meaning of individuals' responses. This becomes particularly important when those questions relate to satisfaction (Schalock, 1996). This holds true not only for participants with mental retardation, but for proxies as well.

Many questions that compose quality of life measures could be answered using a variety of techniques. This is considered a strength when operationalizing the construct in this manner. To improve the validity of results, multiple methodologies should be used whenever possible (Heal & Sigelman, 1996). When studies employ sound methodological practices, the information they yield is not only theoretical and practical, but in our changing human services delivery system, they can provide data that can be used to guide policy development.

#### *Utilizing Quality of Life as Outcome Indicators in Disability Services: Implications for Future Policy Development and Resource Allocations*

Quality of life is a multidimensional construct that has the potential to move beyond being a concept of one's personal situation to organizing and largely directing human services. This vision is seen a plausible and achievable goal for services for people with developmental disabilities (Wagner, 2000). How service systems can incorporate research findings related to quality of life indicators can appear to be a daunting task (Fabian, 1990). However, determining how consumers of services feel about themselves and the services they receive is not a new concept.

In the corporate world, consumer satisfaction studies have been conducted as a means to assess how successful a business has been in serving its customer, typically as some form of self-report survey measure. These customer service surveys adhere to the following specific principles. To provide useful information, they must: 1) first determine the performance

indicators that result in customer satisfaction; 2) assess the company performance versus the competition; 3) establish priorities and make improvements as needed and; 4) monitor progress of the entity (Dutka, 1995).

These principles are not so different when considering agency performance in disability practice. Though human services programs used to be predominantly one option situations by public providers, these entities now find themselves in competition for consumer dollars with more private entities, perhaps as a result of poor quality services from the public providers in the first place. High levels of consumer satisfaction can help to generate increased referrals from word of mouth and good public relations, which can, in turn, provide impetus for continued and increased program funding. In order to be successful, providers must determine the needs of the consumer and find ways to meet those needs (Gardner & Nudler, 1997) as opposed to fitting consumers into the services they have. In fact, the Council on Quality and Leadership in Supports for People with Disabilities has redefined quality to mean “responsiveness to people” and away from its earlier definition: “compliance with organizational process” (Gardner, Nudler & Chapman, 1997). The Council further recognizes personal outcomes in the accreditation process.

Survey research has an important place in evaluating human services programs. Consumer satisfaction surveys can be particularly helpful in determining the effectiveness of particular aspects of these programs. Two scales that are enjoying popularity for assessing consumer satisfaction outcomes across service delivery systems are the Client Satisfaction Questionnaire-8 and the Service Satisfaction Scale-30 (Attkisson & Greenfield, 1994). Because of the relative transferability of the terms used in these measures and their acceptable psychometric properties, the CSQ-8 and the SSS-30 are considered good outcome measures of satisfaction. In today’s climate of decreased funding and the struggle to provide quality services within limited budgets, agencies must remain cognizant of the consumers they serve, not to mention the fact that publicly funded programs are mandated to do so (Rehabilitation Act Amendments, 1998). One way to do this has been by directly assessing consumers’ satisfaction of the services they have received. This information can serve as an informal “report card” and can indicate areas of service provision that may need further investigation.

It is important to remember that the consumer satisfaction survey represents only one piece of the overall performance of an agency. It is a snapshot in time and, as such, is susceptible

to change (Felce & Perry, 1996). Individual responses may be biased by other factors and may not be truly indicative of the quality of the services received. The true value of consumer satisfaction surveys lie in performing them on a consistent basis for use as an overall monitoring tool for performance. While consumer satisfaction measures have become accepted in the field of disability services, encompassing the additional dimensions of quality of life require that these providers broaden their view of what their responsibilities are to those they serve.

Ascertaining improved quality of life as an outcome in the human services system is increasingly important, particularly when resources are in short supply. For persons with developmental disabilities, the self-determination and person-centered movements make appropriate and complementary corollaries to shifting to quality of life outcomes. For persons with disabilities, the self-determination movement is grounded in the principles of freedom, authority, support, and responsibility. Increasing self-advocacy efforts show that people with disabilities and their families are demanding lives of higher quality (Schalock et. al., 2002). The swelling support of people with disabilities for the self-determination movement fits well with Ryff's definition of well-being, as she included autonomy and self-direction as one dimension (1989; 1995). Likewise, autonomy is a prominent element for those with disabilities who become more self-directed.

Person-centered planning in human services relies on: focus and direction that is provided by the individual; creation of circle of support consisting of people with significance to the person; emphasis on strengths instead of limitations, and; determining ways of achieving goals that are as community based and naturally derived as possible (Butterworth, Steere & Whitney-Thomas, 1997). In effect, person-centered planning is the determination of what a person's ideal life would look like and the development of a plan to move toward that life. The overlap with self-determination and quality of life are obvious and apparent. The interrelationships between self-determination, person-centered planning, and quality of life all necessitate that human services attend to individualizing services to meet the needs of the consumer as well as ensuring that the consumer has a level of control in order to drive the provision of those services.

Evaluation of program worth must be based upon more than simply number of hours of service received or dollars allocated per person. Regardless of size, if the consumer does not find value in the service, does the service have value? Human service organizations have moved toward including quality of life indicators, and specifically satisfaction levels (Schalock, 1997).



When valid and reliable measures of quality of life are used, they can provide a higher level outcome goal in human services (Livneh, 1988). As states are moving toward creating more flexible and consumer-driven disability service systems (Moseley, 2001), to also include outcomes that measure success from the consumers' perspective is a logical follow-up.

Because measuring quality of life for persons with disabilities such as mental retardation can pose interesting methodological issues, when agencies decide to utilize these indicators for program development and appraisal purposes, certain considerations must be kept in mind. As outlined throughout this paper, the appropriate response is to: 1) provide a variety of measurement techniques that capture the subjective and objective aspects of the construct including measures of consumer satisfaction, 2) measure quality of life in ways that capture the multidimensionality of the construct, 3) recognize the use of proxies as necessary but never to the exclusion of the person receiving services, 4) determine a means of assessing acquiescence, 5) use statistical procedures to reduce respondent bias and strengthen the confidence of findings, and 6) recognize and commit to assess quality of life over time because an individual's quality of life is not a static indicator (Felce, 1997; Schalock, 1996; Schalock, 1997).

The recognition of quality of life as an outcome can be particularly useful for developing agencies' hierarchies of goals. For example, in vocational rehabilitation, the goals of employment and independent living may appear to be competing, but when put in a context of improving quality of life, the goals become consumer-driven and empower the individual to have services that are meaningful to him or her (Roessler, 1990). It has been suggested that improving consumers' quality of life is the true goal of rehabilitation services (Livneh, 2001). Does it not logically follow that rehabilitation outcomes should therefore also include the impact those services had upon one's quality of life?

There is great benefit to agencies that adopt quality of life as an outcome measure. A quality of life orientation adopts a wellness perspective, stresses a holistic, person-centered view of consumers, and emphasizes the importance of not only recognizing the individual, but also the environment in which that person exists (Roessler, 1990). Because of this changed orientation, the delivery system becomes more responsive to consumer needs that are not solely from a health-related quality of life stance. This in turn, provides another route for agencies to effectively work toward their quality assurance and quality enhancement goals (Schalock, 1994).

When quality of life and individual needs are viewed as dynamic, assessing quality of life takes on great practicality for providers (Wolf, 1997; Neumayer, 1996), particularly because provider services can very directly impact the quality of life of consumers (McVilly, 1998). Salkever (2000) found that young adults with developmental disabilities who had no work or day activities had significantly less satisfaction with their lives.

Challenges to imposing quality of life outcomes in human services evaluation can appear monumental in light of the myriad of available specialty instruments created for use with specific disability populations, issues related to validity and reliability, and abundance of working construct definitions (Fabian, 1991). Achieving consensus of what components comprise the quality of life construct takes on even greater importance in the realm of service delivery applications. Professionals and those they serve do not always agree in this area (Angermeyer, Holzinger, Kilian & Matschinger, 2001). It is only when a more holistic and person-centered view of people with disabilities becomes the rule that the service system as a whole will be more consumer-driven and responsive to the needs of the people it serves. Because quality of life can be understood as a component of our shared humanity, the term is one that "...sensitizes us to look at how people with mental retardation feel about and experience their lives and situations" (Taylor & Bogden, 1996).

However, it is also critically important that human services policymakers recognize that improved quality of life is not simply a "warm and fuzzy" concept, but is one that can be operationalized and impacted by service providers. If quality of life is to be a recognized outcome for people with disabilities, public policy must work in concert with developing programs that may result in the potential for improving quality of life (Turnbull & Brunk, 1997). State and national directives are changing focus to adopt more empowering programs that emphasize consumer choice and involvement for people with disabilities. This began through the deinstitutionalization movement and the belief that more integrated settings for people with disabilities would result in increased quality of life.

Though research results attesting to the reality of improved quality of life for all as a result of these shifts has been contradictory, there has been increased emphasis on the importance of greater consumer involvement in determining the shape of programs that are developed for consumers with disabilities. The Rehabilitation Act Amendments of 1998 (P.L.102-569), the Ticket to Work and Work Incentives Improvement Act of 1999, (P. L. 106-

170), and the Olmstead decision (Olmstead vs. L.C., 1999) are all impacting the future direction that disability services will take with the recognition that the people with disabilities must be given the power to create positive change in their lives. Therefore, the quality of life construct has the power to influence both the providers and the consumers of services.

Quality of life is, indeed, becoming increasingly recognized by policymakers as a means to: shape and direct public programs; determine the manner in which consumer services will be delivered, and; evaluate the specific and overall effectiveness of those programs (Schalock, 1997). It has been suggested that “improvement in quality in human services should directly result in improvements in quality of life for those served” (Dean & Mank, 1997). To gain further momentum for public policy to take this stance, providing an understanding of quality of life for those with disabilities and those who are not disabled can be of great merit. For, as Turnbull & Brunk (1997) assert, public policies must be created that enhance the lives of all citizens.

The importance of utilizing quality of life dimension indicators is not solely an American concept. Other countries, including Australia, Norway, and Finland have implemented measures of quality within their respective service systems (Jones, Lawn, Mattika & Tossebro, in press). In fact, Australia has employed the Core Indicators Consumer survey as part of their monitoring mechanism, while Norway uses a life condition survey for comparative study that tracks social change for its constituents both with and without disabilities (Jones et al, in press).

In rehabilitation, theories and research methodologies are evolving to meet needs of program evaluation and policy development. The consumer directed theory of empowerment (CDTE) has been gaining popularity as a means of providing a theoretical framework for evaluating disability services and for developing future policy. Kosciulek and Merz (2001) found significant relationships existed between levels of consumer direction and community integration and quality of life. Additionally, participatory action research is suggested as a means of integrating quality of life concepts into service and needs assessment that best meet the needs of consumers through: continuous individual involvement and responsiveness to the issues that are important to the person (Whitney-Thomas, 1997). These both represent examples of the paradigm shift in human services. Indeed, some entities are tying their outcomes to measures of quality of life (De l’Aune, Williams, & Welsh, 2000; Human Services Research Institute, 2001).

However, there may be some difficulty in using quality of life as an outcome indicator because a logical question that arises from the data is ‘So what? Are we measuring quality of life

for people with developmental disabilities only against others with disabilities, and if so, what do we consider success? Should we not be measuring quality of life of the population as a whole? Historically, research examining quality of life between those with and without disabilities has been sparse. The bi-annual National Organization on Disability Harris poll surveys those with and without disabilities with regard to employment, income, education, health care, access to transportation, entertainment/socializing, participation at religious services, political participation, and life satisfaction (National Organization on Disability, 2000).

According to the Harris poll, less than one-third of people with disabilities work (full or part-time) compared to 79% of those who are not disabled. Twenty percent have not graduated from high school as opposed to nine percent of those without disabilities. One-third report household incomes below \$15,000, nearly three times more than non-disabled households. What is perhaps the most startling statistic is that 33% of those with disabilities are very satisfied with life in general in comparison to 67% of people without disabilities. This gap grows even wider when considering that only 26% of those with severe disabilities are very satisfied with their lives (National Organization on Disability, 2000). Quality of life for people with disabilities, as a whole, has shown some moderate increases in the late 1990's and early 21<sup>st</sup> century, but to a lesser degree than for the non-disabled population (National Organization on Disability, 2000).

Wehmeyer and Schalock (2001) summarize the importance of quality of life to the developmental disability community as 1) a point of reference from the person's perspective that emphasizes the person within the environment, 2) a social construct with larger implications for improving the person's situation, and 3) part of a vision that emphasizes "a life of quality". While it is important to make longitudinal gains in consumer outcomes within a service delivery system, it is equally imperative that the service system reflects the citizenry as a whole. Quality of life data can be used to: assess satisfaction with services; to determine baseline measures against which future service delivery can be measured; to report to stakeholders; to assess needs that are not being addressed, and; to implement new policy or changes in policy direction.

However, several caveats must be offered prior to implementing an evaluation system that is wholly based on quality of life principles for people with disabilities. The first is that a body of knowledge regarding quality of life and those who happen to have disabilities is rapidly being amassed. However, it appears to be predominantly based upon relative indicators of quality of life of others with disabilities. When conducting simple global literature searches using

“quality of life” as the key term, results consistently yield articles and text that pertain to the human condition as it experiences life altering situations, such as the acquisition of disease, loss of a loved one, radical change in living environment, or onset of disability. Unless further study is done to gain a better picture of our communities that are composed of those with and without disabilities, there is a grave risk of simply using quality of life indicators to further illustrate differences between people (Taylor & Bogdan, 1996; Turnbull & Brunk, 1997).

Second, there must be an understanding that making what we might consider positive changes in the service delivery system may not result in significant increases in one’s subjective quality of life (Edgerton, 1996; Hatton, 1998). With choice and availability of resources comes the reality that not everyone will take full advantage of, or reap the benefits from what they are offered. All that can be demanded is opportunity. What is done with that opportunity is the responsibility of the individual. That is all anyone should expect.

Finally, as service delivery models shift to a more flexible and person-centered approach, to focus wholly on quality of life indicators as measures of success may prove to impose values upon people that they do not, necessarily hold dear (Bostwick-Duffy, 1996; Hatton, 1998). At a more ominous level, quality of life scores could provide a new screening tool for agencies to determine those who are worthy of services versus those “hopeless cases” with the odds stacked against them and who may appear to have less potential for success if services are provided. Sounds outrageous? This actually took place when infants with spina bifida were either afforded treatment or passed over based on a quality of life equation (Ward & Keith, 1996). Though this is an extreme and grim example, it serves to remind us that whenever a construct is operationalized in such a way that resultant scores can lead to changes in service provision, it is advisable to take a step back and consider the ramifications. The ultimate irony of using quality of life to assess outcomes is that it involves objectifying, scoring and rating experiences that are considered inherently personal and thus, standardizes the subjective and invades the privacy of those it purports to better respond to (Hatton, 1998).

We are living in the midst of the quality revolution. It is an exciting time because the longtime grassroots efforts of people with disabilities are finally succeeding in creating more consumer-driven, person centered services. The shifts are becoming more obvious and apparent, particularly in the realm of service delivery for persons with mental retardation, as common ground is found with proponents of service delivery that espouses the importance of self-

direction (Schalock, 1996; Schalock, Bonham, & Marshand, 2000). The paradigm shifts are, by no means, flawless, and will require further investigation to get at some of the aforementioned dilemmas that are present when using quality of life as an outcome measure.

Schalock (1997) further encapsulates the shifts in human services in the 1990's as shifting away from programming, passivity of consumers, process, deficiencies of the person, labels, dependency and schedules. These changes in the service delivery system will help all people in their quest to live lives of quality that are of their choosing. That is what everyone deserves, regardless of the presence or absence of disability. Broader studies of quality of life at state, national, and international levels will provide us with better understanding of ourselves, and greater respect for our neighbors of the world. The shifts in the way that services are provided to our community members with disabilities and the subsequent focus on quality outcomes of these services lead to greater interest in understanding what the blueprints of our communities look like.

#### *Research Questions*

The following research questions were examined through the course of this study in an effort to develop increased understanding of the kinds of lives people of one southern state are living.

- 1) Did item-level differences exist on quality of life items between people with and without developmental disabilities?
- 2) Did quality of life dimension scales (relationships, well-being, access (to services and rights), community participation/integration, and autonomy) exhibit differences between people with and without developmental disabilities?
- 3) Could a quality of life dimension model predict whether or not a study participant has a developmental disability?

This research study sought to begin to draw a picture of quality of life for those with and without disabilities. Specifically, whether or not differences existed with regard to emotional well-being, health status, safety, autonomy, community participation, rights, and access to services was determined. It was hypothesized that people without disabilities exhibited differences in the quality of life dimensions listed above. As the literature has shown, measuring quality of life for people with significant disabilities is both possible and practical. When the measure is sound, it can and should be used to assess quality of life indicators for all members of

a community. This study utilized a telephone interview with 590 randomly selected participants and compared it to a dataset of 502 consumers of developmental disability services. Findings were used to determine if there were differences in quality of life as determined by life dimension indicators between those with developmental disabilities who receive services from the state developmental disability authority and those in the general population.

#### *Variables*

The independent variable in this study was disability status (presence or absence of a developmental disability). Demographic variables included education level, marital status, gender, age, living situation, and yearly household income. In addition, disability was operationalized by whether or not the individual received services through the state developmental disability authority. The dependent variables in this study were the quality of life dimension indicators (well-being, relationships, access (to services and rights), autonomy, and community participation/ integration) as well as individual items that were used to create the dimension indicators.

## Chapter II

### Methods

This investigation was conducted to determine if quality of life dimension differences exist between adults with developmental disabilities and those in the general population. This section details the instrumentation used for this purpose, the recruitment of participants, and the subsequent basis upon which potential differences were based. The two groups of interest in this study were those adults, aged 18 and over, with developmental disabilities, heretofore referred to as the “consumer group”, and the comparison group, referred to as the “general population group”. Greater description of the groups will be detailed in this chapter.

#### *Instrumentation*

*Development.* The Core Indicators Consumer survey was used as the basis for this study. This instrument was developed in 1997 as a tool to ascertain life outcomes for individuals with developmental disabilities who receive state funded services through their state developmental disability authority. The instrument was developed and piloted by seven member states of the National Association of State Directors of Developmental Disability Services and the Human Services Research Institute, in conjunction with national methodology and development disability professionals (Human Services Research Institute, 2001). Content was developed to identify core indicators of performance of state providers of developmental disability services with an emphasis on comparing performance between states as well as longitudinally. Fifteen state service provider authorities have actively participated in the development of the instrument. The number of states taking part in this effort has increased from seven who pilot tested the instrument in 1997. There are presently 22 states and two counties within non-participating states that engage in the Core Indicators survey on an ongoing basis. Ideally, states administer this survey yearly and measure progress against other states and longitudinally.

The Core Indicators consumer survey instrument has undergone four reliability tests, as recorded by the Human Services Research Institute (2001). An initial test of inter-rater reliability in 1997 found 93% agreement between raters (n=30). In 1998, both inter-rater and test-retest reliability data were collected. Results for inter-rater reliability (n=25) were 93%. The test-retest



reliability (n=27) resulted in 80% agreement between the two administrations. An additional test of inter-rater reliability was conducted in 1999, with 92% agreement in scoring.

Validity of the instrument has been expressed as percentage of individuals who were able to self-report responses during face-to-face Core Indicators interviews versus those who were unwilling or unable to do so. It is believed that this is considered an important psychometric property of the instrument, because it is intended for direct use with consumers. The instrument has attained a 71.7% self-report rate. This is compared to self-report responses to an ARC of Maryland study which found that 80% of consumers were able to respond on their own behalf. A concurrent validity study conducted in Vermont yielded 69% of individuals self-reporting on both the Core Indicators survey and another instrument designed to measure consumer satisfaction (Human Services Research Institute, 2001). However, this is a limiting validity study in that it does not assess whether or not the instrument content truly measures the construct in question, but instead provides a better measure of ability to self-report based on another instrument. The process that is used to exclude individual surveys as invalid is outlined in detail later in this chapter.

*Instrument Components.* The Core Indicators consumer survey instrument consists of three sections. Section one contains demographic, diagnostic and health information as well as data on current services received. This section is typically completed by service coordinators, case managers, or other program staff at the agency providing services to the individual. This individual may choose to provide the information in concert with family members and consumers themselves. Demographic and health data collected as part of section one is automatically considered valid.

Section two of the instrument is the first half of the direct interview. Data collected from this section relates to emotional well-being, relationships, access, and rights. Because section two contains questions pertaining to satisfaction, it is to be answered only by the person receiving services. Ideally, the direct interview is completed in a face to face setting between interviewer and consumer; however, it is permissible to have others present at the request of the consumer or if interpretation is needed to assist if communication issues arise. If the consumer of services is unwilling or unable to complete section two, the responses are coded as “no response” and no proxy responses are allowed.

Section three of the Core Indicators Consumer survey may be answered by proxy. This person should be someone who knows the individual well (family member, friend, or caregiver) if the consumer is unwilling or unable to participate in section two. This is considered an acceptable practice by researchers in the field of developmental disability methodology (McVilly, Burton-Smith & Davidson, 2000; Schalock, 1996). If the consumer answered on his or her own behalf in section two, ideally, he or she will continue to participate in section three. However, it is also acceptable to have a proxy respond solely or in tandem with the consumer in this section. Data collected as part of section three related to health, community participation/inclusion, autonomy, rights, and access. Most questions asked as part of the direct interview are either “yes” - “no” or utilize a three point scale that includes a central, neutral response category. One open-ended response related to unmet need is recorded if the participant indicates that services are needed. Respondents could choose to refuse to answer any questions. Average time to administer the Core Indicators Consumer survey was 38 minutes (Human Services Research Institute, 2001).

*Instrumentation Alterations for General Population Administration.* The Core Indicators Consumer Survey was designed primarily as a tool for use by developmental disability service providers. As such, it is typically administered in a face to face setting. For the purposes of the general population comparative study, the instrument was administered via telephone. Because some questions on this instrument pertained to specific services received by people with developmental disabilities through their state developmental disability authority, these questions were omitted from the present study (see Appendix A for the survey question list). Specifically, those questions related to day and residential support staff, support coordination, advocates and guardians, attendance at self-advocacy meetings, and ability to access the telephone were not asked as part of the general population telephone survey.

Question construction was maintained as much as possible for administration of the general population survey. However, a pilot study was conducted prior to initiating the telephone survey. This was done in order to examine construction of the survey questions and determine ease of administration. Ten individuals of varying demographic backgrounds and varying knowledge of the disability services field who reside in Kentucky were asked to consent to participate in the telephone survey. The survey was administered, and at the conclusion of the survey, pilot participants were asked to share their reactions with regard to the overall content

and flow of the survey. This was done in order to ascertain any issues with regard to appropriate level of language or any cumbersome worded questions. Question order and some construction items were altered as a result of the pilot survey, primarily because some information that would typically be answered prior to direct interview of consumers was now integrated into the telephone survey. In addition, questions were added to collect needed demographic information from the general population group. Questions asked to the general population group that were not part of the original instrument included: education level, household income, occupation, presence of disability or impairments (and subsequent open-ended descriptions thereof), and comments at the conclusion of the survey.

Following pilot testing, the study was conducted as a telephone survey using the facilities of the University of Kentucky Survey Research Center (UKSRC), a well recognized resource with regard to data collection that involves large samples. The UKSRC received the survey script which was entered into the ACS-Query Computer-Assisted Telephone Interviewing (CATI) system. This system enabled data to be entered concurrently with survey administration. The UKSRC used a 22-line telephone bank and a pool of interviewers who received training on the scripted survey prior to implementation of this study.

The mean survey administration time was approximately 5.7 minutes ( $SD = 2.58$ ) with a range of three to thirty-five minutes in length. Each randomly selected telephone number that was generated was randomly assigned to an interviewer for attempted contact. If there was no answer or an answering machine responded to the call, the result was logged and the call was attempted at another time of day. A minimum of fourteen attempts were made before the potential participant was removed from the sample. Upon reaching 500 completions, those contacts that have had some attempts made were continued to be worked until: 1) there was a refusal, 2) 14 attempts were made, or; 3) there was a completion. Therefore, there were 590 total general population participants who took part in the study. This was done to keep the integrity of the randomly drawn telephone numbers in the sample.

### *Participants*

*General Population Group.* Total participants in the telephone survey were 590 Kentuckians who were non-institutionalized, age 18 and over, with access to a telephone. Participants were randomly selected to take part in this study using the Waksberg random-digit

dialing procedure. The Waksberg procedure is a computer program that contains all Kentucky telephone area codes and local three digit combinations. These number combinations are randomly assigned to four digit numbers that are also randomly selected, resulting in a randomly selected telephone number that is dialed. The generated number may or may not be a number that is in service. Those numbers that are not working numbers are not included in calculating participation refusal rates. The Waksberg procedure ensures that every Kentuckian who has a telephone will have an equal chance of being selected, regardless of whether or not his or her phone number is unlisted or available to the public.

Participation in the telephone survey was completely voluntary. Potential participants were informed about the purpose of the survey and asked if they would give verbal consent to take part in the telephone interview. The script used to administer the general population survey is found in Appendix A. Participants could choose to discontinue the interview at any time during the study and could also choose not to answer any question they did not want to. The anonymity of participants was assured and the potential for risk or harm was not considered to be an issue. However, as a part of interviewer training, all interviewers were instructed to provide the statewide toll-free telephone number for mental health counseling for any participant or potential participant who might become distressed as a result of being contacted or from the line of questioning related to quality of life issues.

*Consumer Group Participants.* The consumer sample for this study consisted of individuals with mental retardation or other developmental disabilities who participated in the Core Indicators Consumer survey instrument between August, 2001 – February, 2002, for a total of 502 individuals. Selection of the sample of consumers with developmental disabilities was randomly drawn through the research and data management team for the Kentucky Division of Mental Retardation. The state's data system was utilized to select a random sample of people who were currently receiving funding through the Supports for Community Living (SCL) waiver, state general funds, or state Supported Living program. A 1,000 person oversample was drawn with the intent of achieving a minimum 500 interviews. The oversample took into account those consumers who may have been ineligible to participate if they were no longer receiving services, if they had relocated, if they had changed service providers within the last year, or if they had become deceased. In addition, consumers (or their guardians if applicable) could refuse to participate in the survey.

Individuals who were included as potential participants were those who received at least one service in addition to case management for at least one year through the Division of Mental Retardation public and private service providers. All participants were 18 or older. No individual who had participated in the Core Indicators Consumer survey within the prior two year survey periods was eligible to participate in the current year survey. All consumers and guardians (as applicable) who took part in the Core Indicators Consumer survey gave their written consent to do so.

### *Data Collection*

*General Population Data Collection.* The general population data were collected in the form of a telephone survey. Study data were compiled by the University of Kentucky Survey Research Center (UKSRC). The UKSRC employs interviewers who received training on interviewing, data entry, and the revised Core Indicators consumer survey instrument. Interviewers used the ASC Query Computer-Assisted Telephone Interviewing (CATI) system. The CATI allowed the interviewer to enter participant responses to each question directly into the computer at the time of the interview. The CATI program provided automatic skips, preprogrammed prompts, and the routine coding of all open-ended questions. In addition, the CATI logged all attempted calls and provided an automatic scheduling algorithm which ensured that phone numbers were attempted at different hours and on different days until contact was made. This was done to ensure the overall integrity of the random sample selection.

General population data were collected in conjunction with the UKSRC over an approximate three week period, from May 16, 2002 through June 12, 2002, upon receipt of the University's Institutional Review Board exemption certification that was submitted to the University's Office of Research Integrity. No personal identifiers were collected. Additionally, in order to maintain confidentiality, the Survey Research Center did not release respondent telephone numbers as part of the dataset. The UKSRC provided this researcher: an electronic portable file containing each participant's responses; a text file containing all open ended responses with the associated respondent identification number; a file containing survey response coding, and; the final disposition report including the response rate and attempts made.

With respect to the general population group surveys that were excluded from analysis, the last item coded in each telephone survey was the surveyors' rating of the subject's

understanding level of the questions asked overall, as indicated by a subjective interviewer rating of excellent, good, fair, or poor. Three subjects in the general population group who were considered by the interviewer to have a poor understanding of the survey were not included in data analysis. In addition, one respondent whose self-reported age was seventeen years was also excluded from analysis. Ten respondents terminated the interview prior to providing their ages and were also excluded. A total of 576 general population participants were included in the full sample.

*Consumer Data Collection.* Data from consumers with developmental disabilities was collected from both face to face interviews and telephone surveys using the Core Indicators Consumer survey. All surveys completed from this sample have been collected from interviewers with extensive backgrounds in the disability field who completed standardized interviewer training as conducted by Kentucky's Core Indicators Project staff under the direction of the Human Services Research Institute. Project staff received background and pre-survey information packets (section one of the instrument) directly from providers who were serving randomly selected consumer participants. The packets contained demographic information, contact information and guardian status, as well as any communication needs that may have been present.

Core Indicators project staff contacted either the consumer or guardian (as appropriate) to request participation in the survey. If written consent was received, the Core Indicators Consumer survey was administered. The interview could be conducted either in person or via telephone, at the discretion of project staff and preference of participants. If the consumer was able to communicate over the telephone, the survey may have been completed by telephone. If the consumer preferred to be seen in person or was unable to communicate over the telephone, a face to face interview was conducted. If a guardian, caregiver, or friend completed the survey on behalf of the consumer (and the consumer did not wish to be present for the interview), a face to face interview was employed, unless the individual preferred to be interviewed by telephone. Method of administration was not recorded as part of the process. The interviewer coded responses directly on the survey instrument. Upon completion of the survey, the interviewer completed an interviewer feedback form indicating any problem questions. Completed surveys were returned to the state Core Indicators office, where project staff entered responses into an SPSS spreadsheet for subsequent analysis.

Under certain circumstances, cases were considered invalid and excluded from analysis. Incomplete, inconsistent or invalid responses from the consumer group were removed as outlined by Core Indicators Consumer Survey protocol (Human Services Research Institute, 2001). Consumer data were excluded from descriptive and inferential analysis under the following circumstances: 1) if the consumer answered less than half of the section two questions; 2) if the consumer provided inconsistent responses to the consistency check questions, or; 3) if the consumer was indicated by the interviewer as not understanding the questions. However, because all demographic information for the consumer sample was derived from service coordinators, those data were not excluded from analysis, regardless of whether or not the direct interview data were excluded. In addition, if a proxy responded for section three of the survey, responses were considered valid unless the individual answered less than half of the questions in section three. Four subjects were removed from analysis because both sections of the direct interview were invalid. Based upon the population being surveyed, this might seem a small number of exclusions. However, interviewers were instructed not to complete the final section of an interview with only the person receiving services if they established that (in section two) the individual who was self-reporting was not providing consistent responses. In these instances, proxy interviewees were contacted to complete the interview in conjunction with the consumer. Three subjects were removed from the consumer group because there was no age included in the survey data. This resulted in a total of 502 consumer participants included in this analysis.

*Aggregate Dataset.* The data collected as a result of the telephone study were combined with data collected from the sample of individuals with developmental disabilities representing results from Kentucky's third year of participation in the Core Indicators Project. The aggregate dataset was compiled to determine: 1) whether differences of quality of life dimensions existed between the two groups at an item level; 2) if there were differences between the two groups on the developed quality of life dimension scales, and finally; 3) if differences between the groups existed on a global level as demonstrated through a predictive model that determined membership within each group based upon particular independent variables.

### *Research Design*

This study involved survey research in comparing 2 non-equivalent groups (one group received services through the state developmental disability authority, the other did not).

Therefore it contains components of a static group comparison. Because the study employed a previously compiled dataset of responses from individuals with developmental disabilities as one of the comparison groups, one component of this research is also considered ex post facto research. The overall research can be considered a survey research component of program evaluation.

### *Analysis of Data*

Analysis of data were conducted to determine if differences in quality of life as measured across the chosen life dimensions existed between the two groups. Data were analyzed using the Statistical Package for Social Sciences (SPSS) software. The University of Kentucky Survey Research Center (UKSRC) provided raw data in a portable SPSS file. This information was merged into an aggregate data file that also contained the consumer data. All participants were labeled with a group identification number with those in the consumer group=0 and those in the general population group=1. In order to assure that a gender bias was not present, a subsample of general population participants was drawn. This random group was selected to maintain a proportion of males and females that was roughly equivalent to the consumer sample. Data were analyzed for both the full general population sample and the gender adjusted subsample.

*Adjustment of Data Used for Analysis.* Prior to performing statistical analyses needed to answer the research questions posed in this study, variables were assessed for normality and frequency distribution. Variable means, standard deviations, mode and skewness were examined. The general population sample exhibited a gender bias (66.5% female). While survey research indicates that gender bias of this type is not unusual for a telephone survey (R. Langley, personal communication, August, 15, 2002), it was decided that a random subsample that would provide approximately equal gender distributions between the general population and consumer groups be drawn. This resulted in 344 general population participants and 502 consumer participants. However, full general population results were still calculated. Those results can be found in Appendices B through I. In addition, all variables that were used to create scales were recoded so that:

- 2=most positive aspect of the variable in question;
- 1=in between aspect of variable in question, and;
- 0=most negative aspect of variable in question.



This coding enabled easy comparison between groups, in that whichever group scored higher on a given scale would be the more desirable of the two groups in which to have membership.

#### *Establishing Current Psychometric Properties of the Instrument*

Basic psychometric properties of the instrument were established for this study.

Cronbach's alphas were computed to determine the cohesion of survey items that composed the life dimension subscales. Because people with developmental disabilities provided the basis for development of the instrument, the consumer group was used to determine the alpha levels of the four Life Dimension Scales. The Life Dimension Scales were based on items that had common characteristics in accordance with Shalock's (1996) determinants of those global areas that comprise quality of life for an individual. Table One contains items used to create the scales.

Because of the relative brevity of the instrument, some areas were combined to create more reliable scales. This is the case for the access scale which contained eleven items regarding access to transportation, access to services, access to privacy, and access to medical and dental care. The autonomy scale included eight items relating to choice, from everyday decisions to those that have major impacts on one's life. The well-being scale consisted of eleven items related to level of happiness, fears, and satisfaction with specific activities. The community participation/integration scale was made of six items that signified the membership or involvement with community activities. Not all instrument questions were included in the scales, but frequency distributions for each item and item-level t-tests are presented in Chapter III.

To be included as a life dimension scale, at least half of the items that made up the scale must have been responded to. Those items that formed the autonomy scale held together well ( $\alpha=.80$ ). Community participation ( $\alpha=.62$ ), access ( $\alpha=.60$ ) and well-being ( $\alpha=.53$ ) were slightly less cohesive, but still within acceptable limits (Sprinthall, 2000). When scale reliability was examined with regard to the general population, reliability dramatically decreased. Table Two contains the standardized item alphas that were computed for each group.

Frequencies were reported on each item for each group, as well as for the entire sample. Means and standard deviations were also reported as appropriate. T-tests were performed on each item and each scale to determine if significant differences between people in the general population and the consumer samples existed. In addition, a total quality of life dimension score was generated for each subject through the averaging of the four scales (autonomy, community

participation, well-being, and access). A t-test was also calculated on the total score statistic. The significance level was set conservatively, at  $.05/40$ . The numerator,  $.05$ , represents the alpha typically accepted error rate in much social research. The denominator represents the total number of items used to comprise the scales (36) plus the number of individual scales (4). This resulted in the alpha level for this experiment being set at  $.0013$ . Therefore, any results that are less than  $p=.0013$  will have an asterisk attached, to indicate their significance.

### *Multivariate Analysis*

In order to make inferences about the populations being studied, techniques appropriate for multivariate analysis were conducted. Logistic regression was chosen as the method of choice, because this is an appropriate technique to employ when a group of predictor variables and a dichotomous outcome variable are present and a researcher wants to determine the degree to which it is possible to predict to which group a case belongs. Several assumptions were met as closely as possible prior to conducting the regression. The outcome variable must be a simple dichotomous (two choice) one. In this study, the dichotomous variable was the group status. The group that an individual belonged to was either the developmental disability group or the general population group. For the purposes of this study:

0 = consumer group

1 = general population group

The other assumption was that membership in the outcome variable was mutually exclusive. An individual could not participate in both groups. This did not preclude the possibility that individuals in the general population sample may have had disabilities; however, those in the developmental disability group were exclusively those who received services through the state's developmental disability authority. Because it is theoretically possible (though extremely unlikely) that an individual may have been surveyed once as part of the Core Indicators interviews and then subsequently contacted as part of the telephone survey, all birth dates of general population participants who indicated having a disability were cross-checked against birth dates of the consumer group. No exact matches were found, and therefore, the mutually exclusive assumption was met as closely as possible for this study.

The logistic regression was run using each of the quality of life dimension scales to determine which, if any, independent study variables were significant contributors to the

dependent variable. Prior to conducting the regression analysis, all variable means, standard deviations, and skewness were examined to ensure that the variables were appropriate to use. Non-interval, categorical data including gender, marital status, and race were recoded into dummy variables to allow their inclusion in the logistic regression. The race variable was combined and recoded into white, African American, and other (Asian, American Indian, Alaska Native, mixed race, and other). Correlation matrices were also conducted and multicollinearity noted, if present.

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Table One. QOL Dimension Item Composition

**Table One**

**Items Used to Comprise Quality of Life Dimension Indicators**

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Dimension

Item

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Well-Being

Feels happy

Feels sad

Likes day activity

Likes people at day activity

Likes home

Afraid at home

Afraid in neighborhood

Has friends

Has a best friend

Feels lonely

When going out, goes (alone or with others)

Access

Can be alone at home

People knock before entering home

People knock before entering bedroom

Mail is not opened without permission

Can be alone with guests

Can see friends when wanted

Length of time since last medical visit

Length of time since last dental visit

Length of time since last ob/gyn visit

Gets needed services

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Table One (continued). **QOL Dimension Item Composition**

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Dimension	Item
Access continued	Has adequate transportation
Community Participation	Goes shopping Goes out for entertainment Goes out on errands/appointments Goes out to eat Goes to religious services Belongs to community club(s)
Autonomy	Chooses where to live Number of places visited before moving to residence Chooses who to live with Chooses daily schedule Chooses what to do in free time Chooses what to do during the day Number of day activities considered before choosing current day activity Chooses what to buy with spending money

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Table Two. **QOL Dimension Scales**

**Table Two**  
**QOL Dimension Scales by Group**

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Dimension	Consumer	General Population
Access	.60	.24
Community Participation	.62	.55
Well-Being	.53	.36
Autonomy	.80	.30

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## Chapter III

### Results

This section provides an overview of results for each group that participated in the quality of life dimensions survey and determines if significant differences existed between the groups at an item and scale level. In addition, the results of the logistic regression indicate whether or not the developed life dimension indicators were predictive in assessing membership between the two groups (i.e., differentiating as to whether an individual belonged to the general population group or the consumer group).

#### *Sample*

*General population sample.* The general population survey was conducted from May 16 to June 12, 2002. There were 590 respondents along with 1,032 refusals. This represented a 36.4% eligible response rate. This was somewhat low (Dillman, 2000), but considered acceptable for this mode of general population survey administration (Tuckel & O'Neill, 2002). Invalid cases were removed from the data set as outlined in Chapter II, leaving 576 general population participants suitable for analysis. Because a large difference in gender existed between the two groups (33.5% male in the general population group versus 56.2% male in the consumer group), a random subsample of females from the general population group which provided a gender composition similar to the consumer group consisted of 344 participants was drawn. This resulted in 344 participants (56.1% male) selected for the gender adjusted general population subsample.

All results were calculated both with the full general population sample and with the subsample of the general population group. The full sample results can be found in Appendices B through I. Any notable differences between the subsample and full sample are noted appropriately. The remainder of this narrative focused on the subsample results. Unless otherwise indicated, the full general population sample did not produce results that were significantly different from the subsample results.

*Consumer sample.* The ex post facto consumer sample consisted of 502 consenting respondents after validity checks were run. This represented an 80% response rate. Because

some surveys were completed by proxy, items related to satisfaction could not be answered. For this reason, the n's in the areas related to personal perception of satisfaction (i.e., well-being, satisfaction and relationship items) may be somewhat smaller than the group n's for the remaining items that were considered acceptable to be answered by proxy.

### *Demographic Characteristics*

Table Three shows characteristics of the two groups in the study. Because a random sample was drawn to adjust for the gender discrepancy between the groups, the gender frequencies are nearly identical. There was a five year age difference between the groups, with the consumer group averaging 40 years of age versus 45 for the general population ( $t=5.1$ ,  $p<.001$ ). While there were slightly more white participants in the general population group (92% versus 88%) and less African Americans in the consumer group, the difference was not statistically significant (at  $p=.05$ ).

Education data were not compiled for the consumer group, but were for the general population. Nearly 15% percent did not graduate from high school, approximately one third were high school graduates or had a GED, and slightly over half had advanced training beyond high school. With regard to marital status, vast differences were apparent ( $\chi^2=494.3$ ,  $df=2$ ,  $p<.001$ ). Ninety-five percent of consumers were single as opposed to 20% of the general population group. Over 60% of the general population were married compared to 3% of consumers. Approximately 20% of the general population had been married previously versus 2% of consumers.

The nature of the sample was such that all individuals in the consumer group had mental retardation or other developmental disability. Many had multiple disabilities. Nearly one-third also had mental illness, 16% had cerebral palsy, 5% had autism, and over 40% had some other disability in addition to a developmental disability. Approximately 20% of the general population indicated having a disability. Of those who specified what his or her disability was, three percent indicated mental illness was their primary disability. However, most (14.8%) fell into the "other" category. These disabilities included: back injury, chronic pain, arthritis, diabetes, a variety of orthopedic impairments, hearing impairment, visual impairment, cardiac impairment, hepatitis, amputation, skin disorder, and cancer.



Of those in the general population sample, virtually all lived in their own, privately owned residence or with family (99%). One respondent resided in a retirement home and three respondents lived in military housing. These four cases were classified as “other”. The consumer group represented more varied living arrangements. Approximately 40% owned, rented, or lived with family. Another 40% lived in group homes (staffed residences), with foster families, or in agency-owned housing. Nearly 15% of consumers lived in institutions or nursing homes.

#### *Quality of Life Dimension Item Responses*

Response frequencies were calculated at an item level to determine if differences existed between the two groups. Table Four provides the frequency distributions for each question and Table Five shows means, standard deviations, and t-test results for each item. Several significant differences were found between the two groups at the item level. An item was considered to be significantly different between the two groups at  $p=.0013$ . With regard to items concerning well-being, the consumer group was more lonely ( $t= 4.15, p<.001$ ), wanted to work more hours ( $t=-10.4, p<.001$ ), and was more afraid at home ( $t=4.84, p<.001$ ). There were no differences between groups with respect to happiness and satisfaction with home and work (or day activity) or in level of satisfaction with people at work (or day activity). Additionally, there was no difference in level of fear in their neighborhood. Those in the consumer group were less likely to have friends ( $t=4.98, p<.001$ ), but those consumers who did indicate having friends were as likely to have a best friend and to be able to see friends and family when wanted as the general population group.

There were no significant differences found in health-related items between groups at  $p=.0013$ . Both groups were equally likely to have had received recent medical, dental and ob/gyn exams. In addition, no significant differences existed in terms of participating in some form of exercise.

Every item related to choice was significantly different between consumers and the general population ( $p<.001$ ). Those who were in the consumer group found themselves less likely to choose where they lived ( $t=9.24$ ), with whom they lived ( $t=16.42$ ), what they did for a day activity ( $t=17.83$ ), what their daily schedule was ( $t=16.64$ ), what they did in their free time ( $t=7.12$ ), and what they purchased with their own money ( $t=5.86$ ). Consumers also had fewer

options to choose from with regard to day activities ( $t=17.83$ ) and their place of residence ( $t=8.41$ ).

In terms of community integration and participation, no differences were found between those with disabilities and the general population at  $p=.0013$ . Consumers and the general population group were both equally likely to eat out, to go out for other forms of entertainment, and to take part in other community or civic clubs. In addition, no significant differences existed between the two groups with respect to attending religious services.

Several differences were found with regard to rights restrictions. Consumers were more likely to have their mail opened without giving their permission ( $t=5.86$ ,  $p<.001$ ) as well as were less likely to have privacy when guests would come to visit in their homes ( $t=6.44$ ,  $p<.001$ ). No significant differences were present for the items regarding people entering the home or bedroom without permission, or in the ability of the person to have privacy if wanted. In terms of access, there was no difference between the groups with respect to needing services, but the consumer group was more likely to experience significantly more difficulty in obtaining needed transportation services ( $t=6.44$ ,  $p<.001$ ).

At the conclusion of the telephone survey, those in the general population group were asked if they had any additional comments they would like to share. Thirty-six individuals did choose to make a statement. Those responses can be found in Appendix J.

### *Quality of Life Dimension Scales*

Four scales that captured related quality of life dimensions were created from survey items. These scales represented well-being, access, autonomy, and community participation/integration. Items used to comprise the scales and the resultant reliabilities of the scales can be found in Chapter II. T-tests were generated to determine whether differences existed between the groups at a subscale level. When comparing the general population group and the consumer group (Table Six), significant differences were found between two of the four scales. The autonomy scale ( $t=17.07$ ,  $p<.001$ ) showed great dichotomy between the two groups, with the general population scoring nearly one-half point higher than consumers on the scale. This would be expected, as the general population group had an advantage over consumers in every choice-related item on the instrument. With regard to well-being, the consumer group again fell short ( $t=12.89$ ,  $p<.001$ ). Neither the access scale nor the community participation scale

proved to be significant at the more conservatively set alpha of  $p = .0013$ . Each of the four scales were then averaged to come up with a final composite quality of life dimension score, which is shown in Table Six as the total score. The total score was also significantly different between the consumer and the general population groups ( $t=14.18, p<.001$ ) with the consumer group receiving a lower average total scale score. This indicates that differences do, indeed, exist with regard to these quality of life dimension scales between the groups.

### *Logistic Regression*

Because the well-being scale was only calculated for consumer group members who responded for themselves ( $n=308$ ), the logistic regression was run using this smaller subset of the consumer group. Means, standard deviations, and correlations are presented first for the predictor variables in Table Seven. Significant positive correlations were found between almost all of the scales. The well-being scale was correlated with access ( $r=.23, p<.01$ ), autonomy ( $r=.27, p<.01$ ), and community participation ( $r=.22, p<.01$ ). The access scale was also correlated with the autonomy scale ( $r=.11, p<.01$ ) and the community participation scale ( $r=.27, p<.01$ ). In addition, age and access were slightly positively correlated ( $r=.09, p<.05$ ) as were age and gender ( $r=.10, p<.05$ ) (older respondents were slightly more likely to be female). However, because none of these correlations were above .30, concerns associated with multicollinearity and associated relationships between predictor variables were greatly lessened (Licht, 1998).

Logistic regression techniques were used to determine if the independent variables could be used to predict the probability that a particular observation belonged either to the consumer group or to the general population group. The independent variables used in the logistic regression were: well-being scale, community participation/integration scale, access scale, and autonomy scale. Age, race, marital status, and gender were also entered into the logistic regression to see what role, if any, they played in distinguishing between the groups.

The logistic regression model did prove to be predictive ( $\chi^2=582.15, p<.001$ ). It was able to explain between 59% – 79% of variance that was present in the sample. This model correctly predicted group membership 90.9% of the time. Table Eight shows the initial results of the regression. Well-being, community participation, and autonomy were found to be significant predictors, along with marital status. However, the access scale, gender and race were not statistically significant at  $p=.0013$ .

The regression was run again, dropping the non-significant variables, to show the final model. Those results are found in Table Nine. The second run of the revised model correctly classified 89.5% of general population participants and 92.2% of consumer participants for an overall average Percentage Accurately Classified (PAC) of 90.8% of all subjects in the study. The regression was able to classify both groups well, with a slight advantage given to those in the consumer group. Table Ten contains the classification table for this analysis.

With regard to predictive power of the independent variables, as autonomy and well-being scores increased, individuals were more likely to belong to the general population group. Higher community participation scores were more indicative of belonging to the consumer group. In comparison to single respondents, those who were married or who had been married were more likely to belong to the general population group. The marital variable was the strongest predictor, followed by well-being and autonomy. Because of the nature of the results, direct comparison of predictive value of community participation is not possible; however, in this model it was also a very strong predictor. The significant predictors included in the final logistic regression model were able to explain 59% - 79% of overall variance of the sample.

Table Three. **Group Characteristics**

**Table Three**  
**Demographic Characteristics by Group**

Characteristic	<u>General Population</u>			<u>Consumer</u>		
	n	%	Years	n	%	Years
<b>Gender</b>						
Male	193	56.1		282	56.2	
Female	151	43.9		220	43.8	
<b>Age</b>			45.0			40.1
<b>Education</b>						
				Not collected		
No School	1	0.3				
Grade School	12	3.5				
Some High School	13	10.5				
High School Grad	91	26.5				
GED	21	6.1				
Votech degree	9	2.6				
1-2 Years College	48	14				
Jr/Comm College	7	2				
3-4 yrs college	22	6.4				
Bachelors degree	55	16				
Some grad school	9	2.6				
Grad degree	32	9.3				

Table Three (continued). **Group Characteristics**

Characteristic	<u>General Population</u>			<u>Consumer</u>		
	n	%	Years	n	%	Years
<b>Race</b>						
African American	14	4.1		40	8	
White	316	92.1		442	88	
American Indian/ Alaska Native	4	1.2		1	0.2	
Asian	2	0.6		6	1.2	
Mixed Race	0	0		1	0.2	
Other	7	2.0		12	2.4	
<b>Marital Status</b>						
Single	70	20.3		473	94.8	
Married	209	60.8		14	2.8	
Single now, married in past	65	18.9		12	2.4	
<b>Disabilities</b>						
Of Those Who Specified	68	19.8		502	100	
Mental Retardation	0	0		N/A		
Cerebral Palsy	1	0.3		80	15.9	
Mental Illness	10	2.9		151	30.1	
Autism	0	0		26	5.1	
Neurological	2	0.6		7	1.4	
Other	51	14.8		201	40.1	

Table Three (continued). **Group Characteristics**

Characteristic	<u>General Population</u>			<u>Consumer</u>		
	n	%	Years	n	%	Years
<b>Living Arrangement</b>						
Owens or rents	313	91.5		36	7.2	
Family home	25	7.3		166	33.2	
Group	0	0		138	27.6	
home/staffed res.						
Agency owned	0	0		19	3.8	
apt/home						
Foster family	0	0		57	11.4	
Nursing Facility	0	0		9	1.8	
Institution	0	0		62	12.4	
Other	4	1.2		13	2.6	

Table Four. **Item Responses**

**Table Four**  
**Item Response Frequencies by Group**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
Are you happy or sad today?	342		300	
Happy		79.2		83.7
In Between		12.3		10.7
Sad		8.5		5.7
Do you ever feel lonely?	343		292	
No		73.5		54.8
Sometimes		19.8		36.6
Yes		6.7		8.6
Do you like your home?	344		304	
Yes		91		91.4
In Between		2.9		3
No		6.1		5.6
Do you like work/day activity?	244		273	
Yes		86.9		90.8
In Between		5.7		4
No		7.4		5.1



Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
Would you like to work more? <sup>a</sup>	244		256	
Yes		10.7		49.6
No		89.3		50.4
Are you ever afraid at home?	343		302	
Most of the time		0.9		3.6
Sometimes		5		14.6
Rarely		94.2		81.8
Are you ever afraid in your neighborhood?	344		301	
Most of the time		2.3		3.7
Sometimes		4.7		11.3
Rarely		93		85
Are you sad or happy today?	344		301	
Happy		83.1		85
In Between		9.9		9.6
Sad		7		5.3

Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
Do you have friends?	344		296	
Yes		94.5		78.4
Yes, but all friends are family		2.3		15.9
No		3.2		5.7
Do you have a best friend?	332		271	
Yes		87.3		87.1
No		12.7		12.9
Can you see your friends when you want to? <sup>b</sup>	333		272	
Yes		84.1		81.3
Sometimes		6.3		14.7
No		9.6		4
Can you see your family when you want to? <sup>a</sup>	315		279	
Yes		85.1		72.4
Sometimes		5.7		19
No		9.2		8.6

Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Do you like people (staff) at your work/ day activity?	242		266	
Yes		89.3		93.6
Some		10.3		4.5
No		0.4		1.9
When going out, who do you go with?	342		490	
Friends/family		83.6		46.3
Goes in group		5		33.3
Goes alone		11.4		20.4
Who chose where you live?	321		328	
Person chose without help		36.1		19.5
Person had input		55.8		40.9
Someone else chose		8.1		39.6
How many places did you visit before you moved there?	318		290	
More than one		65.1		38.3
One only		28		32.4
Did not visit prior to moving in		6.9		29.3

Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
Who chose who you live with?	261		301	
Person chose without help		74.3		22.6
Person had input		21.5		28.2
Someone else chose		4.2		49.2
Who decides your daily schedule?	343		497	
Person decides		87.5		48.9
Person has help deciding		9		32.8
Someone else decides		3.5		18.3
Who decides how you spend your free time?	343		490	
Person decides		77.6		59
Person has help deciding		21.6		27.6
Someone else decides		0.9		13.5
Who chose where you work or go during the day?	252		419	
Person chose without help		90.9		28.4
Person had input		7.5		40.1
Someone else chose		1.6		31.5

Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
How many places did you visit before working (going) there?	234		396	
More than one		49.1		36.1
One only		50.9		41.7
Did not visit prior		0		22.2
Who chooses how you spend your spending money?	344		489	
Person decides		59.9		45.4
Person has help deciding		37.5		39.7
Someone else decides		2.6		14.9
Do you sometimes go out to eat?	344		485	
Sometimes eat out		87.8		85.4
Eats at home all the time		12.2		14.6
Do you go out for entertainment?	344		490	
Yes		74.4		81.4
No		25.6		18.6

Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
Do you go on errands or appts?	344		501	
Yes		97.4		94.6
No		2.6		5.4
Do you go shopping?	344		500	
Yes		93		91
No		7		9
Do you go to religious services?	344		479	
Yes		68.6		58
No		31.4		42
Do you go to clubs or other community meetings?	344		488	
Yes		36		27
No		64		73
Do people read your mail without your permission?	341		403	
No		92.7		77.7
Sometimes		5.3		12.2
Yes		2.1		10.2

Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
Do people knock before entering your home?	343		240	
Yes		87.8		92.5
Sometimes		7.3		2.5
No		5		5
Do people knock before entering your bedroom?	336		248	
Yes		77.1		82.3
Sometimes		3.3		6
No		19.6		11.7
Can you be alone if you want?	283		284	
Yes		92.6		92.6
No		7.4		7.4
Can you be alone with guests?	331		354	
Yes		97.6		80.8
Some restrictions		0.6		10.5
No		1.8		8.8

Table Four (continued). **Item Responses**

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
When was your last medical visit?	344		443	
Within the last year		82		89.2
Over one year ago		18		10.8
When was your last ob/gyn visit ? <sup>a</sup>	150		151	
Within the past year		62.7		62.9
Over a year ago		36		25.2
Never had one		1.3		11.9
Do you exercise or play sports?	343		495	
Yes		62.4		58
No		37.6		42
When was your last dental visit?	341		372	
Within the last six months		51		57.8
Over six months ago		49		42.2
When you want to go somewhere, can you always get there?	333		293	
Yes		96.8		72
Sometimes		0.6		23.5
No		2.6		4.4



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Table Four (continued). **Item Responses**

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<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Do you get the services you need?	158		487	
Yes		77.8		78.2
Sometimes, or don't get enough		1.9		7.6
No		20.3		14.2

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<sup>a</sup> not included in quality of life dimension scale

<sup>b</sup> included in access scale

Table Five. **Item T-Tests**

**Table Five**  
**Item T-Tests by Group**

Item	General Population			Consumer			t-val	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Are you happy or sad today?	342	1.71	.61	300	1.78	.54	-1.58	640	.11
Do you ever feel lonely?	343	1.67	.60	292	1.46	.65	4.15	633	.000*
Do you like your home?	344	1.85	.50	304	1.86	.48	-.25	646	.80
Do you like work/day activity?	244	1.8	.56	273	1.86	.48	-1.37	515	.17
Would you like to work more?	244	.21	.62	256	1.00	1.00	-10.4	498	.000*
Are you ever afraid at home?	343	1.93	.28	302	1.78	.49	4.84	643	.000*

Table Five (continued). **Item T-Tests**

Item	General Population			Consumer			t-val	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Are you ever afraid in neighborhood?	344	1.91	.36	301	1.81	.48	2.81	643	.005
Are you sad or happy?	344	1.76	.57	301	1.80	.52	-.83	643	.41
Do you have friends?	344	1.91	.38	296	1.73	.56	4.98	638	.000*
Do you have a best friend?	332	1.75	.67	271	1.74	.67	.10	601	.92
Can you see your friends when you want?	333	1.74	.62	272	1.77	.51	-.58	603	.56
Can you see your family when you want to?	315	1.76	.61	279	1.64	.64	2.37	592	.02

Table Five (continued). **Item T-Tests**

Item	General Population			Consumer			t-val	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Do you like people/staff at work/day activity?	242	1.89	.33	266	1.92	.34	-.98	506	.33
When you go out, who do you go with?	342	1.72	.66	490	1.26	.78	9.02	830	.000*
Who chose where you live?	321	1.28	.60	328	.79	.75	9.24	647	.000*
How many places did you visit before you moved there?	318	1.58	.62	290	1.09	.82	8.41	606	.000*
Who chose who you live with?	261	1.70	.54	301	.73	.81	16.4	560	.000*

Table Five (continued). **Item T-Tests**

Item	General Population			Consumer			t-value	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Who decides your daily schedule?	343	1.84	.45	497	1.31	.76	11.64	838	.000*
Who decides how you spend your free time?	343	1.77	.44	490	1.46	.72	7.12	831	.000*
Who chose the place where you work/go during the day?	252	1.89	.36	419	.97	.77	17.83	669	.000*
How many places did you visit before working/going there?	234	1.49	.50	396	1.14	.75	6.38	628	.000*
Who chooses how you spend your money?	344	1.57	.55	489	1.30	.72	5.86	831	.000*

Table Five (continued). **Item T-Tests**

Item	General Population			Consumer			t-value	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Do you always eat at home, or sometimes go out to eat?	344	1.76	.66	485	1.71	.71	1.00	827	.32
Do you go out for entertainment?	344	1.49	.87	490	1.63	.78	-2.43	832	.02
Do you go on errands/appointments?	344	1.95	.32	501	1.89	.45	1.96	843	.05
Do you go shopping?	344	1.86	.51	500	1.82	.57	1.05	842	.29
Do you go to religious services?	344	1.37	.93	479	1.16	.99	3.10	821	.002
Do you go to civic clubs / community meetings?	344	.72	.96	488	.54	.89	2.78	830	.006

Table Five (continued). **Item T-Tests**

Item	General Population			Consumer			t-value	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	N			
Do people read your mail without your permission?	341	1.91	.36	403	1.67	.65	5.86	742	.000*
Do people knock before entering home?	343	1.83	.49	240	1.88	.46	-1.17	581	.24
Do people knock before entering your bedroom?	336	1.57	.80	248	1.71	.67	-2.10	582	.04
Can you be alone if you want to?	283	1.85	.53	284	1.85	.52	-.01	565	.99
Can you be alone with guests?	331	1.96	.28	354	1.72	.62	6.44	683	.000*
When was your last medical visit?	344	1.64	.77	443	1.78	.62	-2.90	785	.004

Table Five (continued). **Item T-Tests**

Item	General Population			Consumer			t-value	df	2-tail signif
	N	Mean	Std Dev	N	Mean	Std Dev			
When was your last ob/gyn visit?	150	1.61	.52	151	1.51	.70	1.46	299	.15
When was your last dental visit?	341	1.02	1.0	372	1.16	.99	-1.8	711	.07
Do you exercise or play sports?	343	1.25	.97	495	1.16	.99	1.28	836	.20
When you want to go somewhere, do you always have a way to get there?	344	1.94	.33	293	1.68	.56	7.48	635	.000*
Do you get the services you need?	158	1.58	.81	487	1.64	.72	-.95	643	.34

\*p<.0013



Table Six. QOL Dimensions Indicator Scales

**Table Six**  
**QOL Dimensions Indicator Scales by Group**

	General Population			Consumer			T- Value	DF	Sig
	N	Mean	Std Dev	N	Mean	Std Dev			
Well Being	344	1.80	.26	308	1.55	.23	12.89	650	.000*
Access	344	1.70	.24	502	1.65	.33	2.49	844	.013
Autonomy	344	1.65	.24	501	1.15	.50	17.07	843	.000*
Community Participation	344	1.52	.40	502	1.46	.45	2.12	844	.034
Total Score	344	1.67	.18	502	1.42	.28	14.18	844	.000*

\*p<.0013

Table Seven. Means and Correlations

**Table Seven**  
**Description of Sample and Correlations**

Variable	Mean	Std Dev	1	2	3	4	5	6
1. Well Being	1.68	.27	1					
2. Access	1.70	.25	.23**	1				
3. Comm. Part	1.56	.38	.22**	.27**	1			
4. Autonomy	1.49	.38	.27**	.11**	.03	1		
5. Gender	1.44	.50	0	-.04	-.01	.04	1	
6. Age	42.66	14.35	.06	.09*	-.01	.01	10*	1

gender 1=male, 2=female

\*p<.05

\*\*p<.001

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Table Eight. **Initial Logistic Regression**

**Table Eight**  
**QOL Dimension Initial Logistic Regression**

Variable	B	SE	sig	Exp(B)
Autonomy	3.69	.55	.000	39.905
Access	-.57	.59	.340	.568
Well-Being	4.66	.67	.000	105.836
Community Part	-2.11	.44	.000	.122
Race-Black	-.15	.69	.830	.863
Race-Other	-.40	.67	.551	.673
Married	5.11	.49	.000	165.14
Married in Past	3.67	.53	.000	39.167
Gender	-.02	.01	.217	.986
Age	-.33	.30	.266	.718
Constant	-9.79	1.57	.000	.000

gender 1=male, 2=female

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Table Nine. **Final Logistic Regression**

**Table Nine**  
**QOL Dimensions Final Logistic Regression**

Variable	B	SE	sig	Exp(B)
Autonomy	3.65	.54	.000	38.326
Well-Being	4.63	.66	.000	102.274
Community Part	-2.18	.42	.000	.113
Married	4.92	.45	.000	137.659
Married in Past	3.42	.48	.000	30.448
Constant	-11.52	1.39	.000	0

gender 1=male, 2=female

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Table Ten. **Classification Table**

**Table Ten**

**Final Logistic Regression Classification Table**

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Actual Group	Predicted Group		% Correct
	Consumer	General Population	
Consumer	283	24	92.2
General Population	36	308	89.5
Total			90.8

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## Chapter IV

### Discussion

This study was conducted to determine whether differences in quality of life dimensions existed between individuals with developmental disabilities and the general population residing in one southern state. Specifically, this study addressed areas that related to well-being, community integration, choice and decision making, and access to services and basic rights. These areas were examined at an item level as well as at a scale level, with dimensional scales created to envelop related items. The developed life dimensions were then used to determine if a model could be created that would correctly determine whether an individual was a member of the consumer (developmental disability) group or the general population group. A quality of life instrument that has been used by a large number of states around the country to assess quality of life indicators for people receiving services through their state developmental disability authority was used as the means of data collection.

This chapter discusses the limitations present in this study, the overall conclusions that can be drawn from the results, implications this study has for the field, and considerations for future studies that can be used to build upon this body of work.

#### *Limitations of the Investigation*

There are limitations that are inherent to this type of study. These include the multimodality of administration of the instrument, the modifications made to the original instrument as well as its psychometric limitations, the dissimilarities between the two groups with regard to elimination of invalid cases and refusal rates, and a heterogenous mix of characteristics among the two groups.

One limitation present in these findings arises from the reality that the two groups received surveys administered by different means. The consumer group largely responded to the survey in a direct face to face personal interview format that was administered by individuals skilled in interviewing people with significant disabilities. While approximately ten percent of those in the consumer group were surveyed via telephone, the larger proportion participated in a face-to-face setting (Sheppard-Jones,

2002) to facilitate the process. On the contrary, all of the general population participants consented to respond to the survey in a telephone administration. This dichotomous methodology does not equate to a completely complementary treatment of the two groups. Therefore, obtained results must be examined with a degree of caution. However, as the methodology is outlined for the Core Indicators Consumer Survey, interview by telephone is permitted at the discretion of the interviewer. Telephone administration is considered appropriate for those individuals for whom comprehension of items is not deemed to be compromised via this methodology. It was for this reason that the general population sample was administered via telephone administration. In addition, the consumer survey may be answered by proxy on behalf of the consumer while the general population survey was conducted solely as a self-report. The person responding to the telephone survey was answering on his or her own behalf. Though proxy responses are considered appropriate (Schalock, 1996), it might be considered an unequal treatment of the groups.

Because the Core Indicators Consumer Survey was developed as a tool for human services agencies and, as such, contained specific questions regarding satisfaction with services, some modifications were needed in order to administer it to the general population. Those questions which related to service coordination and satisfaction with those services were all omitted. Additionally, some demographic items that were completed by service staff for the consumer group were included as part of the telephone survey to the general population group. Finally, certain questions were asked to the general population group that were not asked to the consumer group (e.g., household income, education level, occupation, and description of any disabilities or impairments). The nature of the rapid adoption of this instrument by nearly half the states suggests good face validity, but there has been relatively little psychometric testing of the Core Indicators Consumer Survey. Internal consistencies (alpha levels) calculated in this study were moderate for the consumer group. The internal consistencies for the general population group were relatively low, and this represents a limitation to this study.

Large disparities were present with regard to response rates between the two groups. The general population group took part with a 34.6% response rate of eligible participants. While this was considered acceptable for an unsolicited phone survey

(Dillman, 2000), it is a lower rate than experienced by the consumer group (at 80.0%). A likely reason for the very high participation rate of consumers was the fact that contact information was completed by service providers in an attempt to give interviewers several individuals who might respond on behalf of the person with a disability if that individual was unwilling or unable to do so. This effective means of “stacking the deck” also enabled the person with a disability to have someone who knew him or her well help to explain what the survey was about and provide reassurance to the individual.

A very low number of general population interviews (fourteen) were considered ineligible for inclusion in data analysis. However, the consumer group experienced a great degree of variability in valid numbers of cases that were used in data analysis. Because proxies could be used for those questions that did not relate to perceptions of satisfaction or well-being, numbers of valid responses for those questions were higher. With regard to the logistic regression model, because the life dimension scales were comprised of a combination of questions that might be answered by proxy or self-reported by the person with a developmental disability, only those individuals who responded on their own behalf were included in that analysis.

### *Conclusions*

Although there are limitations present in this study, there are several significant conclusions that can be drawn. There were some unexpected commonalities exhibited as well as some very significant differences that were found between the general population and consumer groups. In addition, the information gathered through the study proved to be highly effective in predicting membership between the two groups.

While the overall intent of this study was to outline differences between the consumer and general population groups, the similarities that existed between the two groups were quite interesting. A very surprising finding was that there were very few appreciable differences in terms of community participation between groups. People with and without developmental disabilities were equally likely to take part in a variety of offerings present in their cities and towns. This is somewhat conflicting with the National Organization on Disability Harris poll findings (2000) that show people with disabilities enjoying less opportunity to participate in leisure activities. However, the Harris poll was



not limited to those with developmental disabilities. Also, community participation items in the Core Indicators Consumer Survey were yes-no items while the Harris poll considered frequency of activities. It is quite likely that, if the items on this instrument allowed for a wider range of responses, these inequities would have resurfaced.

In addition, most of those items related to access were also found to be roughly equivalent between the groups. It is notable that, though access to services was considered equal, the number of general population participants was very small (n=158). Nearly 200 of those in the general population group believed this question was not applicable to them. One could speculate that, if specific services were given as options rather than requiring the individual to respond in a simple yes-no format, that the responses this question may have been different.

Examination of the differences that were present between the two groups in this study are, to a great degree, indicative of discrepancies that may be present across the state. It is quite apparent that those individuals in the consumer group have less choice, from the mundane day-to-day decision making of what to do in their free time to the more important life decisions of where to live and work. Because a high proportion of those in the general population group were married, it was expected that respondents would also indicate that they might find themselves with less complete decision-making authority if they felt that they were part of a decision making team with their spouse or family. Even in light of this, the general population group still considered themselves to be far more autonomous than the consumer group, who by and large, had been removed from all choosing capacities. This finding in conjunction with the roughly equivalent levels of community participation leads to further questions as to the shape of the person's activities that are taking place in integrated settings. For example, these results show that one would expect either group to go out to eat at the same level; however, a person with a developmental disability who goes out is far less likely to have decided where to go when eating out.

Results also show that those in the consumer group are at a disadvantage with regard to access to transportation and some basic human rights. Consumers experienced more rights restrictions in the form of less privacy with guests and others opening their mail for them. This study also reinforces the fact that inadequate transportation is a grave

concern for people with disabilities (National Organization on Disability, 2000). Given the highly rural nature of the southern state in which this study was conducted, it is recognized that transportation can be an issue for everyone. However, these results indicate that when a significant disability is present, a lack of transportation is an even greater problem. This could further explain the discrepancies that were found in the employment item, where a significantly higher percentage of the consumer group indicated that they wanted to work more hours. For how can one be expected to maintain a job or some kind of day activity outside of the home if there is not a consistent means to get there?

Overall well-being as measured by this instrument was significantly different between the groups. This was a disheartening, but not totally unexpected finding. The largest contributor to the overall variance, however, was marital status. In fact, if the marital status variable was removed from the logistic regression, well-being was the most significant predictor by far (though this also led to PAC decrease of 10%). Some disturbing item level differences were present, indicating that consumers were at a significant disadvantage. Those with disabilities were more likely to be lonely, more likely to be afraid in their homes, and less likely to have friends. Therefore, though consumers in this study were going out in their community at equal levels with their non-disabled counterparts, one must again question the means through which this occurs if people are taking part in what can be considered social activities but are still lonelier and have fewer meaningful relationships than the general population.

At a more global level, when considering overall quality of life, consumers again were at a significant disadvantage while the general population experienced what could be considered a significantly better overall quality of life. The statistical model that was used to determine if the chosen life dimensions could accurately predict whether a person was a general population participant or a consumer participant was an extremely strong tool. This reinforces the fact that the life dimensions between the two groups were so different that, nine out of ten times, they alone could determine whom a person was. This finding alone is a sad indicator of the discrepancies that are present in the lives between people with developmental disabilities and the general population. As this study sought to find answers to the question of whether differences existed between the two groups, it

appears that whether one looks at an item level, a scale level, or a more holistic regression model, many quality of life differences are apparent between individuals with developmental disabilities receiving services and the general population.

The quality of life construct has undergone changes in its level of importance in human services over the last 20 years. It is now considered by leaders in the field to be “a sensitizing notion, social construct, and unifying theme” (Schalock et. al., 2002), going from a wholly individual concept to one that can indeed shape and direct policy. As such, it will doubtless undergo further debate, but this will also lead to great potential for future research.

### *Implications for Future Research*

With regard to the external validity of this research, care should be taken when generalizing the results of this study. Results are not generalizable to all individuals with disabilities, nor are they generalizable beyond residents of one southern state with developmental disabilities who are currently receiving services through the state’s Division of Mental Retardation. Findings may be substantially different for people with developmental disabilities who are not receiving any services, or by those in service systems which operate outside the state’s publicly funded developmental disability agencies. Replication of this study on a broader scale could be used to determine if these findings hold up nationally.

This study provided some interesting insight into quality of life and its subsequent differences experienced by those with developmental disabilities who receive services through one state’s developmental disability authority. While the differences that were found are certainly well worthy of future study, so too are some of the similarities. Although no significant differences were found in the health-related items, one must still define what constitutes acceptable levels of participation in exercise and recency of medical and dental preventive care. It is important to recognize that these findings do not indicate that those in the disability group are healthy or exemplary in their levels of community participation. Rather, it could mean that those in the disability group are as unhealthy, as uninvolved, or as likely to experience rights restrictions as the general population.

At a surface level, the two groups in this study appear to be separated by a single difference: presence or absence of a developmental disability. However, the groups also presented other differences in composition that are worthy of further exploration. Nearly 20% of the general population participants indicated having some kind of disability. Given the large size of this dataset, a sub-sample analysis of this group and comparison between both the general population and the consumer group could add another distinct layer of understanding to this quality of life dimension study. An examination of this subset could yield telling information. This group can be compared against the rest of the general population sample as well as against the consumer group. The relatively large number of participants in the dataset would enable multivariate analysis across a variety of variables. Because this analysis would include people with a variety of disabilities, results could also be compared with the most recent National Organization on Disability Harris poll (2000). In addition, 30% of consumers were reported as also having mental illness. This group could be compared with the remainder of the consumer group to determine if quality of life differences exist for those with dual diagnoses. A variety of other sub-group analyses could be valuable, including analyses based on consumer's level of mental retardation (if specified) and residential setting (community integration versus institution).

Replication of this study over time would provide valuable information about trends that are occurring. One midwestern state served as a frontrunner in the early 1990's by creating a comparative study between individuals with developmental disabilities and the general population that led to the creation of the Core Indicators consumer survey that is now used by nearly half of all state developmental disability authorities. Yet this same state still uses the general population data that were collected in 1993 as the yardstick to compare current quality of life data of those with developmental disabilities (Ruth, 2002). Does this mean that we should expect people with disabilities to try and measure up to the general population's level of quality of life nearly ten years earlier? One would hope that is not the case.

Though the methodology employed in the present study was, by no means, a flawless one, it nonetheless provides a picture of difference in quality of life dimensions for persons with developmental disabilities in one state. Future research should focus on

better defining the psychometric properties of the Core Indicators consumer survey. Given that the instrument is used in nearly half of the states in the United States, it has the potential to yield very powerful quality of life data. Should other states consider conducting their own general population comparative study, new options would become available to determine what provides the best data against which to compare: longitudinal, national, or state general population? This researcher believes that each has unique merit; however, the state general population will provide information about the composition of that state at that time, and can be a very accessible comparison, be it for families of individuals with disabilities, for human service providers, for legislators, and for the public at large.

But perhaps most importantly, this study can serve as a foundation for future comparative longitudinal replication. For it is important not only to establish that differences are present for certain groups of community members, but to then take that knowledge and develop strategies to erase those gaps. This study is not intended to solely highlight the chasms that exist within our society, but to provide data that can be used to help to bridge them. The state in which this study was conducted currently ranks near the bottom in its services to people with developmental disabilities (Braddock, 2002). Clearly, studies such as this one provide further proof that lack of services have a strong detrimental impact on life outcomes directly compared to the state's general population.

This study was designed to test whether or not quality of life differences exist between adults with developmental disabilities and the general population at an item, scale, and composite level. The quality of life dimensions that were tested included items related to well-being, community participation, access to services and human rights, and choice and decision-making. Differences were found in well-being and decision-making along with certain item-level differences in access. The two groups also differed in overall quality of life with those with developmental disabilities having lower quality of life. A logistic regression model that was comprised of the life dimensions differentiated between the two groups with over 90% accuracy. Overall results indicate that adults with developmental disabilities are at a significant disadvantage with regard to quality of life in comparison with the general population.

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Appendix A  
General Population Group Telephone Survey

## Quality of Life Dimensions Telephone Survey

Hello, my name is \_\_\_\_\_. I am calling from the University of Kentucky Survey Research Center. We are doing a telephone survey with adult Kentuckians to ask them questions about where they live, their work, friends and family. If you agree to participate, it should take no more than ten minutes of your time. All information you provide will be anonymous and combined with other people's responses. In all, there will be about 500 people taking part in this survey.

Would you be willing to participate?

(Check to ensure person is not a minor)

If I have your permission, I will start by asking:

1 In general, are you feeling happy or sad today?

Happy

A little of both/In between

Sad

The next questions are about your general daytime activities.

2 Do you work, volunteer, or go to school?

Yes, work

Yes, volunteer

Yes, school

No

3 Where do you work? (open end)

4 Do you like where you work?

Yes

Sometimes/In between/It depends

No

- 5 Thinking about the people you work with, would you say that you:
- Like most of them
  - Like some of them
  - Do not like most of them
- 6 What is your occupation or job title in this job?
- 7 Would you like to work more hours, fewer hours, or are you working about the right hours?
- More hours
  - About right
  - Fewer hours
- 8 Now I'm going to ask you about where you live. Do you like your home or where you live?
- Yes
  - Somewhat/In between
  - No
- 9 Which of the following best characterizes your housing situation. Do you...
- Own your home
  - Rent your home
  - Live with your parents, or
  - Have some other arrangement (if other – describe)
- 10 How many other people live at your residence? (open end)
- 11 How many different places have you lived in the past year?



12 Can you get away to be alone if you want to?

Yes

No

13 How often are you afraid or scared when you are at home? Would you say:

Most of the time

Some of the time

Hardly ever

14 How often are you afraid when you are out in your neighborhood? Would you say:

Most of the time

Some of the time

Hardly ever

15 Do people knock or ask permission before they come into your home?

Yes

Sometimes

No

16 Do people knock or ask permission before coming into your bedroom?

Yes

Sometimes

No

17 Now I'm going to ask you about friends. Do you have friends that you like to talk to or do things with?

Yes, friends are not staff or family

Yes, all friends are staff or family

No

18 Do you have a best friend, or someone you are really close to?

Yes

No

19 Can you see your friends when you want to see them?

Yes

Sometimes/It depends

No

20 How often do you ever feel lonely? Would you say:

Not very often

Sometimes, or

Often

21 Not including family that you live with, do you have family that you see or visit?

Yes

No

22 Can you usually see your family when you want to?

Yes

Sometimes/It depends

No

23 When you want to go somewhere, do you always have a way to get there?

Yes

Sometimes

No

24 Do you go shopping? For example, to buy groceries, clothes, furniture...

Yes

No

25 Do you go out on errands or appointments? For example, to get a haircut, or to go to the doctor or dentist/

Yes

No

26 Do you always eat at home or do you sometimes go out to eat?

Yes always eat at home

No sometimes eat out

27 Do you go out for other types of entertainment such as movies, plays, or museums?

Yes

No

28 Do you go to religious services (church or synagogue)?

Yes

No

29 Do you go to clubs or other community meetings (not bars or nightclubs) (ex. Neighborhood association, PTA, VFW)?

Yes

No

30 When you go out, whom do you most often go with? Do you mostly go:

Alone

With friends or family

With roommates

Other people

31 Do you exercise or play sports? [if yes, probe to find out where]

Yes in a community setting

Yes at home

No

Now I'm going to ask you about some decisions you may have made or helped make.

32 Who chose the place where you live? Would you say:

You chose without help

You had some input

Someone else chose

33 How many places did you visit before moving there?

More than one

Visited one place only

Did not visit before moving in

34 Who chose the people you live with? Would you say:

You chose

You had some input

Someone else chose

35 Who decides your daily schedule? (when to get up, sleep, eat). Do:

You decide

You have help deciding

Someone else decides

36 Who decides how you spend your free time? Do:

You decide

You have help deciding

Someone else decides

- 37 Who chose where you work, volunteer, or go to school? Would you say:
- You chose
  - You had some input
  - Someone else chose
- 38 At the time you were looking for your current job, were there other jobs your were also considering, or was this the only one you were interested in?
- Considered more than one
  - Only looked at one
  - Did not look beforehand
- 39 Not counting rent and groceries, who chooses what you buy with your spending money? Would you say:
- You choose
  - You help choose or have set limits
  - Someone else chooses
- 40 Do people read your mail without your permission?
- No
  - Some mail is read w/o permission
  - Yes, mail is always read w/o permission
- 41 If you want to, can you be alone with friends who come over to visit, or are you only allowed to be alone with friends in certain areas or if someone else is present?
- Friends don't visit
  - Can be alone
  - Some restrictions
  - Someone else always must be present

42 Do you feel that you get the government services that you need such as transportation, medical care, etc?

Yes

Sometimes or not enough

No

I do not need government services

43 If #42 = No or sometimes, What services do you need that you are not getting, or not getting enough of? (open ended)

The next group of questions asks about the people living in your household. This information is important to help us understand differences and similarities between various kinds of families.

44 In what year were you born?

45 Are you currently married?

Yes

No, but have been married

No, never married

46 I am required to ask: What is your gender?

Male

Female

47 What was the last grade in school you completed?

48 How would you describe your racial background?

White

African American

American Indian, Eskimo, or Aleut

Asian or Pacific Islander

Other

49 Last year, what was your total household income from all sources before taxes?

Under 5,000

5 - 7,500

7,500 – 10,000

10 – 12,500

12,500 – 15,000

15,000 – 20,000

20 – 25,000

25 – 30,000

30 – 40,000

40 – 50,000

50 – 70,000

70 – 90,000

90 – 120,000

Over 120,000

50 When was your last dental visit? Was it:

In the past six months,

Over six months ago

51 When was your last doctor visit? Was it:

In the past 12 months

Over 12 months ago

52 If female, when was last ob/gyn visit? Was it:

Within the last year

Over one year ago

Never had one

53 Do you have any disabilities or impairments?

54 If yes, please describe your disabilities or impairments (open end)

55 Finally, now that we have talked a bit about your life situation, let me double check: in general, are you feeling sad or happy today?

Happy

In between

Sad

56 That is the end of the survey. Are there any other comments on this topic you would like to share? (open end)

57 Respondent's understanding of the questions was:

Excellent

Good

Fair

Poor



Appendix B  
Demographic Characteristics by Unadjusted Group

---

## Unadjusted Group Characteristics

### Demographic Characteristics by Unadjusted Group

Characteristic	<u>General Population</u>			<u>Consumer</u>		
	n	%	Years	n	%	Years
<b>Gender</b>						
Male	193	33.5		282	56.2	
Female	383	66.5		220	43.8	
<b>Age</b>						
			46.2			40.1
<b>Education</b>						
				Not collected		
No School	3	0.5				
Grade School	22	3.8				
Some High School	61	10.6				
High School Grad	152	26.4				
GED	28	4.9				
Votech degree	16	2.8				
1-2 Years College	88	2.8				
Jr/Comm College	14	2.4				
3-4 yrs college	42	7.3				
Bachelors degree	83	14.4				
Some grad school	13	2.3				
Grad degree	53	9.2				

---

## Unadjusted Group Characteristics

Characteristic	<u>General Population</u>			<u>Consumer</u>		
	n	%	Years	n	%	Years
<b>Race</b>						
African American	23	4.0		40	8	
White	538	93.6		442	88	
American Indian/ Alaska Native	5	0.9		1	0.2	
Asian	2	0.3		6	1.2	
Mixed Race	0	0		1	0.2	
Other	7	1.2		12	2.4	
<b>Marital Status</b>						
Single	107	18.6		473	94.8	
Married	339	58.9		14	2.8	
Single now, married in past	130	22.6		12	2.4	
<b>Disabilities</b>						
Of Those Who Specified	115	20.0		502	100	
Mental Retardation	0	0		N/A		
Cerebral Palsy	1	0.2		80	15.9	
Mental Illness	17	3.0		151	30.1	
Autism	0	0		26	5.1	
Neurological	8	1.4		7	1.4	
Other	89	15.5		201	40.1	

---

## Unadjusted Group Characteristics

Characteristic	<u>General Population</u>			<u>Consumer</u>		
	n	%	Years	n	%	Years
<b>Living Arrangement</b>						
Owns or rents	530	92.0		36	7.2	
Family home	37	6.4		166	33.2	
Group	0	0		138	27.6	
home/staffed res.						
Agency owned	0	0		19	3.8	
apt/home						
Foster family	0	0		57	11.4	
Nursing Facility	0	0		9	1.8	
Institution	0	0		62	12.4	
Other	9	1.6		13	2.6	

---

Appendix C  
Unadjusted Group Item Responses

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## Unadjusted Group Item Responses

### Item Response Frequencies by Unadjusted Group

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Are you happy or sad today?	573		300	
Happy		79.9		83.7
In Between		12.4		10.7
Sad		7.7		5.7
Do you ever feel lonely?	574		292	
No		71.3		54.8
Sometimes		21.1		36.6
Yes		7.7		8.6
Do you like your home?	575		304	
Yes		91.7		.4
In Between		2.3		3
No		6.1		5.6
Do you like work/day activity?	392		273	
Yes		88.3		90.8
In Between		4.8		4
No		6.9		5.1

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Would you like to work more? <sup>a</sup>	392		256	
Yes		9.7		49.6
No		90.3		50.4
Are you ever afraid at home?	573		302	
Most of the time		1.0		3.6
Sometimes		4.5		14.6
Rarely		94.4		81.8
Are you ever afraid in your neighborhood?	571		301	
Most of the time		1.6		3.7
Sometimes		6.1		11.3
Rarely		92.3		85
Are you sad or happy today?	575		301	
Happy		84.3		85
In Between		9.0		9.6
Sad		6.6		5.3

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Do you have friends?	575		296	
Yes		92.5		78.4
Yes, but all friends are family		3.5		15.9
No		4.0		5.7
Do you have a best friend?	552		271	
Yes		88.0		87.1
No		12.0		12.9
Can you see your friends when you want to? <sup>b</sup>	552		272	
Yes		83.9		81.3
Sometimes		7.1		14.7
No		9.1		4
Can you see your family when you want to? <sup>a</sup>	532		279	
Yes		84.6		72.4
Sometimes		6.2		19
No		9.2		8.6



---

## Unadjusted Group Item Responses

---

<u>Item</u>	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Do you like people (staff) at your work/ day activity?	388		266	
Yes		87.9		93.6
Some		11.3		4.5
No		0.8		1.9
When going out, who do you go with?	554		490	
Friends/family		85.6		46.3
Goes in group		3.5		33.3
Goes alone		11.0		20.4
Who chose where you live?	544		328	
Person chose without help		33.5		19.5
Person had input		55.5		40.9
Someone else chose		11.0		39.6
How many places did you visit before you moved there?	540		290	
More than one		62.6		38.3
One only		28.3		32.4
Did not visit prior to moving in		9.1		29.3

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Who chose who you live with?	426		301	
Person chose without help		74.6		22.6
Person had input		21.4		28.2
Someone else chose		4.0		49.2
Who decides your daily schedule?	575		497	
Person decides		87.7		48.9
Person has help deciding		9.2		32.8
Someone else decides		3.1		18.3
Who decides how you spend your free time?	574		490	
Person decides		79.6		59
Person has help deciding		19.2		27.6
Someone else decides		1.2		13.5
Who chose where you work or go during the day?	411		419	
Person chose without help		91.2		28.4
Person had input		7.5		40.1
Someone else chose		1.2		31.5

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
How many places did you visit before working (going) there?	375		396	
More than one		45.1		36.1
One only		54.9		41.7
Did not visit prior		0		22.2
Who chooses how you spend your spending money?	574		489	
Person decides		62.7		45.4
Person has help deciding		34.8		39.7
Someone else decides		2.4		14.9
Do you sometimes go out to eat?	576		485	
Sometimes eat out		89.9		85.4
Eats at home all the time		10.1		14.6
Do you go out for entertainment?	576		490	
Yes		72.7		81.4
No		27.3		18.6

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Do you go on errands or appts?	575		501	
Yes		97.9		94.6
No		2.1		5.4
Do you go shopping?	576		500	
Yes		95.5		91
No		4.5		9
Do you go to religious services?	576		479	
Yes		70.0		58
No		30.0		42
Do you go to clubs or other community meetings?	576		488	
Yes		34.2		27
No		65.8		73
Do people read your mail without your permission?	570		403	
No		94.6		77.7
Sometimes		4.2		12.2
Yes		1.2		10.2

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Do people knock before entering your home?	575		240	
Yes		88.9		92.5
Sometimes		6.6		2.5
No		4.5		5
Do people knock before entering your bedroom?	558		248	
Yes		78.5		82.3
Sometimes		3.2		6
No		18.3		11.7
Can you be alone if you want?	462		284	
Yes		92.9		92.6
No		7.1		7.4
Can you be alone with guests?	549		354	
Yes		97.4		80.8
Some restrictions		0.9		10.5
No		1.6		8.8

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
When was your last medical visit?	575		443	
Within the last year		85.9		89.2
Over one year ago		14.1		10.8
When was your last ob/gyn visit ? <sup>a</sup>	379		151	
Within the past year		59.1		62.9
Over a year ago		37.7		25.2
Never had one		3.2		11.9
Do you exercise or play sports?	574		495	
Yes		61.1		58
No		38.9		42
When was your last dental visit?	570		372	
Within the last six months		49.5		57.8
Over six months ago		50.5		42.2
When you want to go somewhere, can you always get there?	555		293	
Yes		96.4		72
Sometimes		1.2		23.5
No		2.4		4.4

---

## Unadjusted Group Item Responses

---

Item	<u>General Population</u>		<u>Consumer</u>	
	n	%	n	%
Do you get the services you need?	262		487	
Yes		76.3		78.2
Sometimes, or don't get enough		1.5		7.6
No		22.1		14.2

---

<sup>a</sup> not included in quality of life dimension scale

<sup>b</sup> included in access scale

\* There was a significant difference based on gender for this question ( $t=2.96$ ,  $p=.003$ ). Women were more likely to consider only one job than men.

\*\* There was a significant difference based on gender for this question ( $t=4.87$ ,  $p<.001$ ). Women were more likely to have had a doctor visit within the past 12 months.

Appendix D  
Unadjusted Group Item T-Tests



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## Unadjusted Group Item T-Tests

### Item Level T-Tests by Unadjusted Group

Item	General Population			Consumer			t-val	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Are you happy or sad today?	573	1.72	.60	300	1.78	.54	-1.40	871	.16
Do you ever feel lonely?	574	1.64	.62	292	1.46	.65	3.83	864	.000*
Do you like your home?	574	1.86	.50	304	1.86	.48	-.08	877	.934
Do you like work/day activity?	392	1.81	.54	273	1.86	.48	-1.07	663	.284
Would you like to work more?	392	.19	.59	256	1.00	1.00	-12.7	646	.000*
Are you ever afraid at home?	573	1.93	.29	302	1.78	.49	5.75	873	.000*

---

### Unadjusted Group Item T-Tests

Item	General Population			Consumer			t-val	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Are you ever afraid in neighborhood?	571	1.91	.34	301	1.81	.48	2.81	877	.18
Are you sad or happy?	575	1.78	.55	301	1.80	.52	-.52	874	.605
Do you have friends?	575	1.89	.43	296	1.73	.56	4.66	869	.000*
Do you have a best friend?	552	1.76	.65	271	1.74	.67	.39	821	.694
Can you see your friends when you want?	552	1.75	.61	272	1.77	.51	-.56	822	.577
Can you see your family when you want to?	532	1.75	.61	279	1.64	.64	2.53	809	.011

---

### Unadjusted Group Item T-Tests

Item	General Population			Consumer			t-val	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Do you like people/staff at work/day activity?	388	1.87	.36	266	1.92	.34	-1.66	652	.098
When you go out, who do you go with?	574	1.74	.64	490	1.26	.78	20.7	1062	.000*
Who chose where you live?	544	1.22	.63	328	.79	.75	9.26	870	.000*
How many places did you visit before you moved there?	540	1.54	.66	290	1.09	.82	8.53	828	.000*
Who chose who you live with?	426	1.71	.54	301	.73	.81	19.5	725	.000*

---

### Unadjusted Group Item T-Tests

Item	General Population			Consumer			t-value	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Who decides your daily schedule?	575	1.85	.44	497	1.31	.76	14.43	1070	.000*
Who decides how you spend your free time?	574	1.78	.44	490	1.46	.72	9.12	1062	.000*
Who chose the place where you work/go during the day?	411	1.90	.34	419	.97	.77	22.38	828	.000*
How many places did you visit before working/going there?	375	1.45	.50	396	1.14	.75	6.75	769	.000*
Who chooses how you spend your money?	574	1.60	.54	489	1.30	.72	7.75	1061	.000*

---

### Unadjusted Group Item T-Tests

Item	General Population			Consumer			t-value	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	Std Dev			
Do you always eat at home, or sometimes go out to eat?	576	1.80	.60	485	1.71	.71	2.27	1059	.02
Do you go out for entertainment?	576	1.45	.89	490	1.63	.78	-3.36	1064	.001
Do you go on errands/appts?	575	1.96	.29	501	1.89	.45	2.90	1074	.0004*
Do you go shopping?	576	1.91	.42	500	1.82	.57	2.97	1074	.003
Do you go to religious services?	576	1.40	.92	479	1.16	.99	4.06	1053	.000*
Do you go to civic clubs / community meetings?	576	.68	.95	488	.54	.89	2.52	1062	.012

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### Unadjusted Group Item T-Tests

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Item	General Population			Consumer			t-value	df	2-tail Signif
	N	Mean	Std Dev	N	Mean	N			
Do people read your mail without your permission?	570	1.93	.30	403	1.67	.65	8.34	971	.000*
Do people knock before entering home?	575	1.84	.47	240	1.88	.46	-0.88	813	.381
Do people knock before entering your bedroom?	558	1.60	.78	248	1.71	.67	-1.82	804	.069
Can you be alone if you want to?	462	1.86	.52	284	1.85	.52	.13	744	.898
Can you be alone w/guests?	549	1.96	.27	354	1.72	.62	7.95	903	.000*
When was your last medical visit?	575	1.72	.70	443	1.78	.62	-1.55	1016	.122

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### Unadjusted Group Item T-Tests

Item	General Population			Consumer			t-value	df	2-tail signif
	N	Mean	Std Dev	N	Mean	Std Dev			
When was your last ob/gyn visit?	379	1.56	.56	151	1.51	.70	.85	528	.394
When was your last dental visit?	570	0.99	1.0	372	1.16	.99	-2.60	938	.01
Do you exercise or play sports?	574	1.22	.98	495	1.16	.99	1.05	1067	.29
When you want to go somewhere, do you always have a way to get there?	576	1.94	.33	293	1.68	.56	8.80	867	.000*
Do you get the services you need?	262	1.54	.83	487	1.64	.72	-1.70	747	.09

\*p<.0013

Appendix E  
Unadjusted Group QOL Dimension Indicator Scale T-Tests



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## Unadjusted Group QOL Dimension Indicator Scale T-Tests

### QOL Dimensions Indicator Scales T-Tests by Unadjusted Group

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	General Population			Consumer			T-Value	DF	Sig
	N	Mean	Std Dev	N	Mean	Std Dev			
Well Being	576	1.80	.24	308	1.55	.23	6.3	882	.000*
Access	576	1.66	.22	502	1.65	.33	2.52	1076	.016
Autonomy	576	1.63	.24	501	1.15	.50	20.52	1075	.000*
Community Participation	576	1.53	.38	502	1.46	.45	2.92	1076	.004
Total Score	576	1.66	.18	502	1.42	.28	17.14	1076	.000*

\*p<.0013

Appendix F  
Unadjusted Group Scale Means & Correlations

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## Unadjusted Group Scale Means and Correlations

### Unadjusted Group Sample Scale Means and Correlations

Variable	Mean	Std Dev	1	2	3	4	5	6
1. Well Being	1.72	.24	1					
2. Access	1.66	.23	.29**	1				
3. Comm. Part	1.56	.37	.29**	.26**	1			
4. Autonomy	1.52	.35	.17**	.14**	.04	1		
5. Gender	1.59	.49	.06	0	-.01	.11**	1	
6. Age	44.04	15.25	.04	.03	-.06	.02	.14*	1

gender 1=male, 2=female

\*p<.05

\*\*p<.001

Appendix G  
Unadjusted Group Initial Logistic Regression

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## Unadjusted Group Initial Logistic Regression

### QOL Dimension Initial Logistic Regression Using Unadjusted Groups

Variable	B	SE	sig	Exp(B)
Autonomy	3.39	.43	.000	29.72
Access	-.16	.55	.770	.85
Well-Being	1.70	.55	.000	5.47
Community Part	-1.46	.36	.000	.23
Race-Black	.28	.60	.641	1.32
Race-Other	-.90	.59	.126	.41
Married	5.17	.42	.000	175.22
Married in Past	3.99	.46	.000	54.02
Gender	.67	.25	.006	1.95
Age	-.03	.01	.003	.97
Constant	-6.69	1.30	.000	.00

gender 1=male, 2=female

Appendix H  
Unadjusted Group Final Logistic Regression

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## Unadjusted Group Final Logistic Regression

### QOL Dimensions Final Logistic Regression Using Unadjusted Groups

Variable	B	SE	sig	Exp(B)
Autonomy	3.41	.42	.000	30.14
Well-Being	1.81	.53	.001	6.09
Community Part	-1.50	.34	.000	.22
Married	4.79	.38	.000	120.14
Married in Past	3.53	.39	.000	34.17
Constant	-7.08	1.08	.000	.001

gender 1=male, 2=female

Appendix I  
Unadjusted Group Classification Table



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## Unadjusted Group Classification Table

### Final Logistic Regression Classification Table Using Unadjusted Groups

Actual Group	Predicted Group		% Correct
	Consumer	General Population	
Consumer	260	47	84.7
General Population	57	519	90.1
Total			88.2

Appendix J  
Comments From General Population Participants

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## Comments from General Population Participants

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1. the place the mrb live is very nice place.somehow teenagers under 18 have less outdoor activities around lexington
2. Life is pretty good for me. I got everything I want. But the reason I'm sad is that my mother is dying now. She's dying each and every day of some disease.
3. There is not enough free time for people's spiritual needs and personal time.
4. We should rephrase the race question. She is not an african american. She is Colored american, with other races mixed in, including Native American.
5. Some of the questions could have been restated to more fitted to the individual, and been more open ended.
6. I have a very happy home situation, I live with my adult sister, and we get along very well
7. Very interesting questions.
8. Very happy.
9. The only thing I'm not happy about my life is my job. I want to get paid more.
10. I am satisfied with my life. My friends and family come by to visit me. They come often and very regular.
11. Happy with my life in general.
12. You asked silly question.
13. I would like to know when the survey would be published, and I would like to be contacted and provided with the pertinent info about the survey.
14. Respondent thinks the government should do more about the medical care for the people who need it.

15. The questions' set up would not lead to an accurate answer such as decisions being taken, persons going out with, etc.,
16. I got great friends, work, great health. I live in a great community. Life is good.
17. Simply hopes that answers to survey will help someone.
18. I am happy and try to live a Christian life. I am a happy person.
19. Thinks the survey should be shortened.
20. Govt should with medical.
21. Wonderful to be retired with extra income.
22. I have learned to be happy, it's not something that just happens. Misery is an addiction, and it is hard to get past it.
23. Sometimes strange questions
24. Government should be able to bring older people together in social functions and not ignore them.
25. Sad because I'm alone. No significant other.
26. I think retirement is great!!!
27. Smoking killed my husband.
28. I am happy with the community we live in.
29. Make the HMOs pay their bills when they are supposed to.
30. If you a question that always answered by previous question don't include it to next question. If you already answered in previous question skip it.
31. I hope that these questions are very good to ask people.
32. Had bad day at work. She's not really sad.
33. How can you stand to do this?

34. I am happy with life. Always have been, always will be.
35. In my opinion, people raised in Kentucky, where ever they go will always come back to Kentucky to live because it is a very good place to live.
36. We are a family of 7 out of which 6 are still living and my elder brother is going to celebrate his 101st birthday next week and all my brothers and sisters are in good health and in their 80 s and 90 s and I am very happy. We all stay active, eat without restrictions.

## References

- American Heritage Dictionary of the English Language, Fourth Edition. (2000). [electronic version]. Boston, MA: Houghton Mifflin.
- Angermeyer, M.C., Holziner, A., Kilian, R., & Matschinger, H. (2001). Quality of life as defined by schizophrenic patients and psychiatrists. *International Journal of Social Psychiatry*, 47(2), 34-43.
- Attkisson, C.C., & Greenfield, T.K. (1994). Client satisfaction questionnaire-8 and service satisfaction scale-30. In M.E. Maruish (Ed.), *The Use of Psychological Testing for Treatment Planning and Outcome Assessment* (pp. 402-420). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Barbotte, E., Guillemin, F., Chau, N. & the Lorhandicap Group (2001). Prevalence of impairments, disabilities, handicaps and quality of life in the general population: A recent review of recent literature. *Bulletin of the World Health Organization*, 79(11), 1-9.
- Bishop, M., Berven, N.L., Hermann, B.P., & Chan, F. (2002). Quality of life among adults with epilepsy: An exploratory model. *Rehabilitation Counseling Bulletin*, 45(2), 87-95.
- Borthwick-Duffy, S.A. (1996). Evaluation and measurement of quality of life: Special considerations for persons with mental retardation. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.105-120). Washington DC: American Association on Mental Retardation.
- Braddock, D. (Ed.). (2002). *Disability at the dawn of the 21<sup>st</sup> century and the state of the states*. Washington DC: American Association on Mental Retardation.

- Brown, M., Gordon, W.A. & Haddad, L. (2000). Models for predicting subjective quality of life in individuals with traumatic brain injury. *Brain Injury*, 14(1), 5-19.
- Budd, E.C., Sigelman, C.K., & Sigelman, L. (1981). Exploring the outer limits of response bias. *Sociological Focus*, 14, 297-307.
- Butterworth, J., Steere, D.E., & Whitney-Thomas, J. (1997). Using person-centered planning to address personal quality of life. In R.L. Schalock (Ed.), *Quality of life volume II: Application to persons with disabilities* (pp.5-23). Washington DC: American Association on Mental Retardation.
- Chubon, R.A., Clayton, K.S., & Vandergriff, D.V. (1995). An exploratory study comparing the quality of life of south Carolinians with mental retardation and spinal cord injury. *Rehabilitation Counseling Bulletin*, 39(2), 107-116.
- Coulter, D.L. (1997). Health-related application of quality of life. In R.L. Schalock (Ed.), *Quality of life volume II: Application to persons with disabilities* (pp.95-103). Washington DC: American Association on Mental Retardation.
- Cummins, R.A. & McCabe, M.P. (1994). The comprehensive quality of life scale (comqol): Instrument development and psychometric evaluation on college staff and students. *Educational & Psychological Measurement*, 54(2), 172-183.
- Cummins, S.L. (1923). *Goldilocks and the three bears*. New York: George H. Doran Company.
- De l'Aune, W.R., Williams, M.D., Welsh, R.L. (1999). Outcome assessment of the rehabilitation of the visually impaired. *Journal of Rehabilitation Research & Development*, 36(4), 273-294.

- Dean, J.E. & Mank, D.M. (1997). In R.L. Schalock (Ed.), *Quality of life volume II: Application to persons with disabilities* (pp.228 -244). Washington DC: American Association on Mental Retardation.
- Dillman, D.A. (2000). *Mail and internet surveys: The tailored design method*. New York: John Wiley & Sons.
- Dutka, A. (1995). *AMA handbook for customer satisfaction: A complete guide to research, planning & implementation*. Lincolnwood, IL: NTC Publishing Group.
- Edgerton, R.B. (1996). A longitudinal-ethnographic research perspective on quality of life. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.83-90). Washington DC: American Association on Mental Retardation.
- Fabian, E.S. (1991). Using quality of life indicators in rehabilitation program evaluation. *Rehabilitation Counseling Bulletin*, 34(4), 344-357.
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41, 126-135.
- Felce, D. & Perry, J. (1996). Assessment of quality of life. In R.L. Schalock, & G.N Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.63-70). Washington DC: American Association on Mental Retardation.
- Gardner, J.F. & Nudler, S. (1997). Beyond compliance to responsiveness: Accreditation revisited. In R.L Schalock (Ed.), *Quality of life volume II: Application to persons with disabilities* (pp.135-148). Washington DC: American Association on Mental Retardation.



- Gardner, J.F., Nudler, S., & Chapman, M.S. (1997). Personal outcomes as measures of quality. *Mental Retardation*, 35(4), 295-305.
- Hatton, C. (1998). Whose quality of life is it anyway? Some problems with the emerging quality of life consensus. *Mental Retardation*, 36(2), 104-115.
- Heal, L.W. & Sigelman, C.K. (1996). Methodological issues in quality of life measurement. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.91-104). Washington DC: American Association on Mental Retardation.
- Hughes, C., & Hwang, B. (1996). Attempts to conceptualize and measure quality of life. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.51-62). Washington DC: American Association on Mental Retardation.
- Human Services Research Institute: (2001). Consumer survey phase II technical report. Retrieved December 16, 2001, from [http://www.hsri.org/cip/docs/7Other/PhaseII\\_Consumer\\_Survey\\_Report\\_new.pdf](http://www.hsri.org/cip/docs/7Other/PhaseII_Consumer_Survey_Report_new.pdf)
- Jones, G.P., Lawn, R., Mattika, L.M., & Tossebro, J. (2002). International innovations in monitoring service quality. In V.J. Bradley & M. Kimmich (Eds.), *Quality enhancement in developmental disabilities: Challenges and opportunities in a changing world* (pp. -). Baltimore, MD: Paul Brookes.
- Kosciulek, J.F. & Merz, M. (2001). Structural analysis of the consumer-directed theory of empowerment. *Rehabilitation Counseling Bulletin*, 44(4), 209-216.
- Larsson, G. & Larsson, B.W. (2001). Quality of care and service as perceived by adults with developmental disabilities, their parents, and primary caregivers. *Mental Retardation*, 39(4), 249-258.

- Lehman, A., Ward, N., & Linn, L. (1982). Chronic mental patients. *American Journal of Psychiatry*, *139*, 1271-1276.
- Livneh, H. (2001). Psychosocial adaptation to illness and disability: A conceptual framework. *Rehabilitation Counseling Bulletin*, *44*(3), 151-161.
- Livneh, H. (1988). Rehabilitation goals: Their hierarchical and multifaceted nature. *Journal of Applied Rehabilitation Counseling*, *19*(3), 12-18.
- McVilly, K.R., Burton-Smith, R.M., & Davidson, J.A. (2000). Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual & Developmental Disability*, *25*(1), 19-40.
- McVilly, K.R. (1998). Quality of life issues in the development and evaluation of services for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *23*(2), 199–215.
- Moseley, C. (2001, May). Thoughts on self-determination. *Common Sense*, *8*, Retrieved January 8, 2002, from <http://www.self-determination.org/newsletter1249/pdf/may2001.pdf>
- National Organization on Disability. (2000). *2000 NOD/Harris survey of Americans with disabilities*. (Study No. 12384). New York: Author.
- Neumayer, R. (1996). Personal lifestyle preferences of people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, *21*(2), 91–104.
- Olmstead v. L.C, 98 S. Ct. 536 (1999).
- Post, M.W., DeWitt, L.P., & Scrijvers, A.J. (1999). Quality of life and the ICDH: Towards an integrated conceptual model for rehabilitation outcomes research. *Clinical Rehabilitation*, *13*(1), 5-15.

Rehabilitation Act Amendments of 1998, Public Law No. 102-569, United States Code, Section 701.

Roessler, R. (1990). A quality of life perspective on rehabilitation counseling. *Rehabilitation Counseling Bulletin*, 34(2), 82-91.

Ruth, J. (2002). Colorado developmental disabilities services accountability focus series: Outcomes of services and supports. Denver, CO: Colorado Department of Human Services.

Ruth, J. & Struxness, L. (1994). A report on outcomes of services and supports for persons with developmental disabilities. Littleton, CO: Colorado Department of Human Services.

Ryff, C. (1989). Happiness is everything or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069-1081.

Ryff, C., & Keyes, C.L. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, 69(4), 719-727.

Ryff, C. & Singer, B. (2000). Interpersonal flourishing: A positive health agenda for the new millennium. *Personal & Social Psychology Review*, 4(1), 30-45.

Salkever, D.S. (2000). Activity status, life satisfaction and perceived productivity for young adults with developmental disabilities. *Journal of Rehabilitation*, 66(3), 4-14.

Schalock, R.L. (1994). Quality of life, quality enhancement, and quality assurance: Implications for program-planning and evaluation in the field of mental retardation and developmental disabilities. *Evaluation and Program Planning*, 17(2), 121-131.

- Schalock, R.L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.123-139). Washington DC: American Association on Mental Retardation.
- Schalock, R.L. (1997). Can the concept of quality of life make a difference? In R.L. Schalock (Ed.), *Quality of life volume II: Application to persons with disabilities* (pp.245-267). Washington DC: American Association on Mental Retardation.
- Schalock, R.L. (2000). Three decades of quality of life. *Focus on Autism and Other Developmental Disabilities, 15*(2), 116-128.
- Schalock, R.L., Bonham, G.S., & Marchand, C.B. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction. *Evaluation and Program Planning, 23*(1), 77-87.
- Schalock, R.L., Brown, I., Brown, R., Cummins, R.A., Felce, D., Matikka, L., Keith, K.D., & Parmeter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation, 40*(6), 457 – 470.
- Sheppard-Jones, K. (2002). *Kentucky Core Indicators Project Results*. Unpublished manuscript.
- Sigelman, C., Schoenrock, C., Spanhel, C., Hromas, S., Winer, J., Budd, E., & Martin, P. (1981). Asking questions of retarded persons: A comparison of yes-no and either-or formats. *Applied Research in Mental Retardation, 2*, 347-357.
- Sprinthall, R.C. (1998). *Basic statistical analysis, fifth edition*. (p. 437). Boston MA: Allyn & Bacon.

- Stark, J. & Faulkner, E. (1996). Quality of life across the lifespan. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp. 23-32). Washington DC: American Association on Mental Retardation.
- Taylor, S.J., & Bogden, R. (1996). Quality of life and the individual's perspective. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.11 -21). Washington DC: American Association on Mental Retardation.
- Ticket to Work and Work Incentives Improvement Act of 1999, Pub. L. No 106-170, United States Code, Section 1305.
- Tuckel, P. & O'Neill, H. (2002). The vanishing respondent in telephone surveys. *Journal of Advertising Research*, 42(5), 26-49.
- Turnbull III, H.R. & Brunk, G.L. (1997). Quality of life and public policy. In R.L. Schalock (Ed.), *Quality of life volume II: Application to persons with disabilities* (pp.201-210). Washington DC: American Association on Mental Retardation.
- Verri, A., Cummins, R.A., Petito, F., Vallero, E., Monteath, S., Gerosa, E., & Nappi, G. (1999). An Italian-Australian comparison of quality of life among people with intellectual disability living in the community. *Journal of Intellectual Disability Research*, 43(6), 513-522.
- Wagner, B.R. (2000). Presidential address 2000: Changing visions into reality. *Mental Retardation*, 38(5), 436-443.
- Ward, N & Keith, K.D. (1996). Self-advocacy: Foundation for quality of life. In R.L. Schalock, & G.N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp.5-10). Washington DC: American Association on Mental Retardation.

Wehmeyer, M.L. & Schalock, R.L. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children*, 33(8), 1-16.

Whitney-Thomas, J. (1997). Participatory action research as an approach to enhancing quality of life for individuals with disabilities. In R.L. Schalock (Ed.), *Quality of life volume II: Application to persons with disabilities* (pp.181-197). Washington DC: American Association on Mental Retardation.

Wolf, J. (1997). Client need. *Psychiatric Rehabilitation Journal*, 20(4). 16-27.



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<b>SPECIAL EDUCATION &amp; REHABILITATION COUNSELING DEPARTMENT UNIVERSITY OF KENTUCKY</b>	<b>LEXINGTON, KENTUCKY</b>
UK ENGAGING DIFFERENCES Adult Learning Specialist	November, 1999 – December, 2000
<b>HUMAN DEVELOPMENT INSTITUTE UNIVERSITY OF KENTUCKY</b>	<b>LEXINGTON, KENTUCKY</b>
KY DEPT OF VOCATIONAL REHABILITATION CONTRACT Project Coordinator	October, 1998 - September, 1999
HDI ASSESSMENT CLINIC Family and Clinical Services Director	January, 1998 - December, 1998
ENHANCING EMPLOYMENT OPPORTUNITIES Project Coordinator	October, 1997 – November, 1999
KENTUCKY EDUCATION AND EMPLOYMENT INITIATIVE Project Director	February, 1997 – October, 1997
KENTUCKY AGRABILITY Program Staff	October, 1996 – November, 1997
TECHNOLOGY TOOLS FOR TRANSITION Training Coordinator	October, 1996 – February, 1997
KENTUCKY EMPLOYMENT INITIATIVE Staff Assistant	August, 1996 - September, 1996
KENTUCKY DEPARTMENT OF VOCATIONAL REHABILITATION LEXINGTON, KENTUCKY	
Rehabilitation Counselor Intern	August, 1995 - December, 1995
CARDINAL HILL REHABILITATION HOSPITAL LEXINGTON, KENTUCKY	
Case Manager Practicum Student	June, 1995 - July, 1995
LE CHEVAL, LTD. LEXINGTON, KENTUCKY	
Office Manager	April, 1992 - August, 1994



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UNIVERSITY OF VERMONT COLLEGE OF AGRICULTURE  
BURLINGTON, VERMONT  
Extension Assistant

January, 1990 - May, 1991

## **TEACHING EXPERIENCE**

Co-Instructor: (May intersession, 2002) IHDI 604; Leadership Seminar.  
Co-Instructor: (Spring, 2002). IHDI 602; Interdisciplinary Supports.

## **PUBLICATIONS AND SCHOLARLY PRESENTATIONS**

Sheppard-Jones, K. (in press). Quality of Life: Interpreting the construct and implications for service delivery. *Rehabilitation Professional*.

Garrett, B., Huff, M., & Sheppard-Jones, K. (in press). Rehabilitation and education Partnerships: Nurturing positive communities. *Journal of Rehabilitation Administration*.

Sheppard-Jones, K. A., Krampe, K., Danner, F., & Berdine, W. (2002). Investigating postsecondary staff knowledge of students with disabilities using a Web based survey. *Journal of Applied Rehabilitation Counseling*.

Huff, M., Garrett, B., & Sheppard-Jones, K. (2001). Invitation to present: "Rehabilitation and Education Partnerships: Providing Opportunities for a Competitive Advantage". National Association of University Centers on Disabilities National Conference: Washington, D.C.

Sheppard-Jones, K, Bishop, M. (2001). "Survey Research on the Internet. Reaching Diverse Cultures and Disability Groups through the Internet". Poster Presentation at the Alliance for Rehabilitation Counseling Symposium: St. Louis, Missouri.

Invitation to present. (2001). "Quality Assurance and the Kentucky Division of Mental Retardation: The Core Indicators Project". Outcomes to Quality Conference: Lexington, Kentucky.

Invitation to present. (2001) "Survey Research Using Internet Techniques". University of Kentucky Educational & Counseling Psychology Research Colloquium: Lexington, Kentucky.

## **RESEARCH SUPPORT AND GRANT APPLICATION ACTIVITIES**

Real Choices Contract; Kentucky Division of Mental Retardation. \$100,000 – 3/1/02 – 6/03.

KY-GROW. U.S. Department of Education, NIDRR. \$304,000. 10/01 – 9/04.

Belonging in the Community; Kentucky Division of Mental Retardation. \$640,000. 7/99 - 6/03.

## AWARDS AND ACTIVITIES

University of Kentucky Fellows Society	2002 - present
University of Kentucky Staff Senate	2002 – 2005
Anne Rudigier Award for Achievement in the field of Developmental Disabilities	2001
Secretary, Kentucky Association of Higher Education and Disability	2000 – 2002
Coordinator, Kentucky Advance	2000 – 2001
Advisory Committee Member, University of Kentucky RC Program	2000 – present
Featured in two episodes of <i>Workplace Essential Skills</i>	2000
Advisory Committee Member, AgDare	1998 - 2000
Mentor, Kentucky Mentor Initiative	1998
Volunteer, Central Kentucky Riding for the Handicapped	1996 - 1997
Freelance writer for <i>The Morgan Horse</i>	1997
Rehabilitation Counseling Student Association Vice-President	1994 - 1995
Rehabilitation Services Association Federal Training Grant	1994 - 1995
Member, Chi Sigma Iota, Rehabilitation Counseling Honor Society	1995
Member, National Rehabilitation Association	1995 - 2001
Member, Kentucky Rehabilitation Association	1995 - 2001
World Champion Morgan Horse Association Youth of the Year	1991
Member, Sigma Alpha Mu, Agricultural Sorority	1991
Member, Mortar Board, Senior Undergraduate Honor Society	1990 - 1991
George Walker Award, University of Vermont	1991
Merck Award of Excellence Recipient	1991