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A Comparison of Perceived Satisfaction with Quality of Life for  
Adults with Traumatic Brain Injury  
and Mental Retardation

by  
Todd Jarger

A Thesis

Submitted in partial fulfillment of the requirements of the  
Master of Arts Degree in the Graduate  
Division of Rowan University  
May 7, 1998

Approved by

~~Dr.~~ S. Jay Kuder

Date Approved 5/6/98

## ABSTRACT

Todd Jarger

A Comparison of Perceived Satisfaction with Quality of Life for

Adults with Traumatic Brain Injury

and Mental Retardation

May 1998

Dr. S. Jay Kuder

Graduate Program in Special Education

An exploratory study was conducted to examine the possible differences in satisfaction with specific quality of life indicators developed by Schalock (1996) between persons with mental retardation and those with acquired traumatic brain injuries. A survey comprised of a Likert-type scale was utilized to interview 41 adults with mental retardation and 27 adults with traumatic brain injury to obtain their perceived satisfaction with their quality of life. The analysis of the data suggests that a significant difference exists between the two groups. The sample of persons with brain injuries expressed lower levels of satisfaction on 10 of the 11 items analyzed. An analysis of variance revealed a statistically significant difference between the groups on seven of the analyzed items.

**MINI-ABSTRACT**

**Todd Jarger**

**A Comparison of Perceived Satisfaction with Quality of Life for**

**Adults with Traumatic Brain Injury**

**and Mental Retardation**

**May 1998**

**Dr. S. Jay Kuder**

**Graduate Program in Special Education**

**A survey was utilized to interview adults with mental retardation and adults with traumatic brain injury. Differences in satisfaction with specific quality of life indicators developed by Schalock (1996) between each group were examined. The analysis of the data suggests that significant differences exist between the two groups**

## Acknowledgments

One could not develop and complete a thesis without the assistance of many people. First, I would like to thank Dr. S. Jay Kuder for the guidance and support he has provided me, not only during the development of this thesis but throughout my academic and professional careers. I must also thank my wife Brenda, my son Steven, and my daughter Grace, for without their unconditional love and support, I could not have made it this far. I am also grateful to Dr. David Kapel who challenged me to tackle the world of statistics and taught me to “let the data talk.” Special thanks to Amy Van Pommel and James Brown, the interviewers who assisted in the data collection process and to the staff who worked with me to schedule the numerous interviews. Finally to my parents, who are always there to listen whenever I need them.

## Dedication

This work is dedicated to people who endure challenges  
in their lives, regardless of what those challenges may be.

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## Chapter One

Throughout the past decade, the subject of quality of life has taken hold as a key issue in the field of developmental disabilities. While quality of life has no single definition, definitions are based on common elements or domains. These domains may include: health care, living environment, family, social and emotional relationships, education, work, recreation, leisure and the individual's satisfaction related to each domain.

Studies that compare quality of life between disabled and non-disabled populations like Kozleski & Sands (1992) have attempted to evaluate the quality of life and satisfaction for people with disabilities using the perceptions of non-disabled peers for social validity. Kozleski & Sands (1992) cite Wolfensberger's concept of normalization as a basis for this comparison. Normalization has been described as a means to improve the living conditions of people with mental retardation, and more closely equate their everyday activities to those of non-disabled age peers. For example, encouraging those adults with disabilities not to carry the same types of lunch boxes as elementary school children or not to play with toys designed for preschoolers and young children. The basis of normalization has been to eliminate practices that reinforce the concept of mentally retarded adults as children in adult bodies or as having the "mind of a child."

Quality of life does not end with normalization. Published volumes dedicated to quality of life notably, Schalock, (1996) continue to define its dimensions, conceptual



framework, and measurement techniques. Schalock and others contend quality of life is embodied in and measured by adaptive behavior scales, accreditation standards and program development goals. However there is still no consistent definition for quality of life.

It would be naive to think that mental retardation professionals will ever agree on a universal conceptualization of quality of life (Borthwick-Duffy, 1996.) Early definitions include multidimensional indicators ranging from personal health, social interactions, and personal decision making to employment, membership in the community, and independence versus interdependence (Kozleski & Sands, 1992). Can opportunities for decision or choice making and satisfaction be applied to the other indicators to further qualify them? Could satisfaction and choices be quantified for comparative purposes? These questions are currently being addressed in dominant trends that have emerged within quality of life. Specifically, the focus has shifted from diagnosis and prognosis of professionals and agency interventions to being person-centered and outcome driven (Campo, Sharpton, Thompson and Sexton 1997; Middendorf, 1995). The means to obtain these outcomes often includes obtaining accreditation from outside peer organizations whom have established standards that are designed to promote service that foster quality service delivery. The premise is that quality services are foundation for quality of life.

Currently, national accreditation commissions incorporate consumer input and satisfaction outcomes as part of criteria for evaluating quality programs and services

(CARF 1997). These criteria suggest the inclusion of outcomes to organizational strategic planning of services. Quantification and analysis of these indicators have been effective methods to evaluate their use in these procedures. However, professional peer approval that quality services exist, does completely define quality of life anymore than merely identifying elemental domains. CARF, the rehabilitation accreditation commission (1997) particularly supports and encourages consumers and their families to actively participate in defining the type and quality of supports that one needs desires.

Despite the emphasis placed on quality of life indicators by conceptual frameworks, definitions and accreditation standards, there is not an equal accumulation studies that involve the collection of data published in the literature. Data based studies providing us with explicit information about existing conditions have not been the strength behind quality of life. Gardiner, Nudler, and Chapman (1997) have examined personal outcomes as a measure of quality. The data collected was used to support a paradigm shift from individualized organizational outcomes to a focus on personal outcomes. If quality of life is to continue to be a viable force in service delivery, its different dimensions and functions must be supported with data from similar applied research. Stark and Faulkner (1996) examined quality of life indicators across the life span. This perspective is examined throughout developmental stages based not only on age but functional level of people with developmental disabilities. Adults with traumatic brain injury are often subjected to similar models and standards of service delivery as adults with mental retardation. Differences in the etiology of their disability dictate that prior life experience of the brain injury population would affect perceived satisfaction with their lives. The

loss of ability to work in one's chosen career, drive an automobile, or perform activities of daily living, as a non-disabled person is unique to adults who survive traumatic brain injuries. These experiences differ for adults with mental retardation who have similar frustrations but have never functioned without their disability. Is one service delivery system sufficient to maintain or improve the quality of life in both populations? How does each disability impact the satisfaction with quality of life indicators differently? If quality of life indicators are an effective means of evaluation, examining indicators of the two populations should produce support to be utilized in the strategic planning of effective programs and services.

The research problem identified is as follows: Is there a difference in satisfaction with quality of life indicators between adults with developmental disabilities and adults with traumatic brain injury who reside in similar community based settings?

The hypothesis derived from the research question is: Adults with traumatic brain injury will report a lower level of satisfaction with quality of life indicators than adults with developmental disabilities who reside in similar community based settings.

Quality of life for the purposes of this study shall be considered a concept that can be measured by quantifying observable indicators related to a particular aspect of a person's life. Such factors include but are not limited to: opportunity to make choices and decisions regarding one's life experiences, employment, rights, personal possessions, and inclusion in the local community as well as satisfaction with related outcomes. Specific

dimensions of quality of life; Material Well Being, Self-Determination, Social Inclusion, and Rights as defined by Schalock (1996) were examined.

Strategic planning is a process which organizations utilize to effectively address the strengths and weaknesses of its programs and services as they relate to the needs of persons served by that organization.

The advent of improved trauma health care in the past 20 years has created a growing population of people with special needs whom require community re-entry services and support. Community based programs developed in the deinstitutionalization era were designed for people who never lived in the greater community. People suffering traumatic brain injury have acquired a disability, which has set them apart from a community to which they have previously belonged. Presumably, these two groups would require similar supports and services based on the result of their disabilities. Trends in care for these two populations have certain parallels as well. The mentally retarded entered the community from psychiatric hospitals, and traumatic brain injury survivors have re-entered the community from rehabilitation hospitals. Now many of these people are served by organizations that provide supports for both populations. Currently, in New Jersey and other states, programs for brain trauma survivors are licensed under the same standards and monitored by the same offices of state government. A difference develops when funding sources are examined. The mentally retarded are still funded from public sources, where as brain injury services are supported largely through insurance dollars. Private providers in the field of mental retardation have

expanded the scope of their services to diversify from public sources by creating programs for people with brain injuries. Although these programs are often administrated separately, they parallel each other in the model of support service delivery, often sharing internal resources such as day programs, employment services, medical services, and other support services.

One way to compare service delivery to each population is to examine the outcomes which are used as indicators of satisfaction with quality of life. Community participation and opportunity for choice are quality of life indicators shared by both populations. The expectations of each group could differ dramatically. People with developmental disabilities have never experienced life without a disability. Those who acquire a disability as a result from cerebral trauma, have a different perspective. They have experienced an existence that is disability free. This presents several implications for the proposed study. Given an organization that serves both populations, can similar models of service delivery help each achieve a satisfactory level of outcomes? Should we expect each group to desire similar outcomes? A logical solution is to systematically survey each group and evaluate satisfaction with their current quality of life. Examination of the results will produce support for planning service delivery to better meet the needs of each individual regardless of disability or how it was acquired. Empirical studies such as this are needed to support the conceptual frameworks for quality of life that have been developed during the last decade. Results could indicate to service providers ways not only to improve quality of services, but to enhance the actual quality of life by helping meet individual needs and desires to the satisfaction of their consumers. The implication

is the definition of quality is determined by the consumer not unlike any other service provided to people both disabled and non-disabled in any given community.

The researcher has not to this point discovered exploring quality of life and its relationship to these two populations. Established norms or other comparison do not exist to substantiate external validity. The sample size is relatively small for research purposes. Fifty people are included in each group. Quasi-random sampling was utilized to select each group. True random selection was limited since the researcher's access to a brain injury population was restrained. The people served with brain injuries in the sponsoring organization number less than sixty. Mortality and availability have reduced the sample sizes of each group to below 50.

The literature review explores the background of quality of life issues as they relate to both populations examined in this study. This study utilized persons with traumatic brain injury rather than spinal cord injury as in Chubon, Clayton, and Vandergriff (1995). Data was collected via the consumer interview survey, as part one comparative study rather than utilizing data from two separate studies as in Chubon et al (1995.)

## Chapter 2

Certain dominant trends have emerged within the study of quality of life. These trends include a shifting focus from diagnosis and prognosis and agency interventions to being person-centered and outcome driven (Campo, Sharpton, Thompson & Sexton 1997; Middendorf, 1995). Shalock (1996) describes the major components that have emerged throughout the development of the quality of life concept: conceptualization of quality of life, measurement of quality of life, conceptual and measurement issues, and quality of life as an organizing concept. These components are based on the following contentions:

- The conceptualization and measurement of quality of life includes core principles and dimensions.
- Instead of an entity that one has or does not have to some degree, quality of life should be viewed as an organizing concept.
- As an organizing concept, quality of life can be used for a number of purposes, including evaluating consensual core dimensions associated with a life quality; providing appropriate services; and using the resulting data for multiple purposes.
- We need to move away from viewing quality of life as composed of various subjective and objective indicators to the realization that there are a consensual set of core quality life dimensions and associated indicators that can be measured from a multimethodological perspective based on the investigator's purpose.
- The multidimensional perspective includes three measurement techniques: participant observation, performance-based assessment, and standardized instruments.

Researchers have utilized a myriad of instruments and definitions for examining both subjective and objective aspects of quality of life (Campo et al. 1997). A review of literature by Hughs, Hwang, Kim, Eisenman, & Killian, (1995), found that researchers have utilized at least 1,243 measures to examine the quality of life construct. Most of these studies have focused on the experiences of those with mild to moderate disabilities. Hughs et al. (1995) exemplifies studies to explain that although the same general quality of life dimensions are important for all individuals, regardless of the severity of their disability, differences may exist in the criteria or dimensions used to measure these dimensions (Campo et al. 1997). The unique impact a disability has on one's quality of life could be compared to expectations one has for one self based on his/her cultural, family, and socio-economic background. A consistent way to address these individualities regardless of basis is to provide the opportunity for individuals to make choices and provide supports to assist them accordingly.

Choice is a prevalent topic in quality of life literature. This particular aspect appears in almost every conceptualization of the quality of life construct (Hughes et al. 1995). The opportunity to make choices regarding one's life is elemental to the non-disabled population and often taken for granted. The issue of choice making for those with significant disabilities is often limited. These individuals are considered to be an underserved population. Belfiore and Toro-Zambrana, (1994) identify a community-based assessment and instruction for choice making as the top educational priorities for the severely disabled. Many individuals do not possess the language skills necessary to communicate preference in a traditional sense. Observations of these persons' behavior is



key to assessing whether a particular setting is preferred and reinforcing that individuals functional behaviors. Settings and behaviors are identified for each individual, and a data collection procedure is developed. Belfiore and Toro-Zambrana, (1994) collected their data in 30, one-minute observation intervals over approximately seven sessions for each person. During this time period, functional attentive behaviors like eye contact, head orienting and reaching for objects were measured against sleeping, aggression and stereotypical behaviors that were not functional. These behaviors were observed in high stimulation community settings which included 15 or more people, low stimulation settings with less than ten individuals and each person's regular day activity center setting. In both high and low stimulation community settings the subjects exhibited significantly higher functional behaviors than in the center based settings on the same activities. The researchers stated that these findings indicated subject preference for community-based settings over standard enter-based settings. Belfiore and Toro-Zambrana, (1994) helped support that by conducting treatment in a preferred environment, even those with more severe disabilities can enhance skill acquisition. By utilizing choice to determine preferences, Belfiore and Toro-Zambrana, (1994) added to the quality of life of those in the study by increasing their opportunity for choice and participation in community settings.

Stancliffe (1997) examined choice making as it relates to staff presence and living unit size for adults with mental retardation. Stancliffe (1997) conducted a within-type comparison for community-based living units consisting of one to five persons and the effects of staff presence. In addition to supporting findings that living unit size

significantly impacts choice, Stancliffe (1997) established correlation (.62) for staff presence and smaller living unit size. These findings were contradictory to other studies like Conroy, (1996); and Tosseboro, (1995), whose results indicated size effects choice independently of staff presence. Stancliffe (1997) concludes that individuals who can cope reasonably safely during intervals without staff may experience enhanced choice. Since choice is a well-established quality of life indicator as defined by Schalock (1996), programmatic implications for the impact of, staff presence and choice exist regarding person-centered outcomes of various types.

Stancliffe & Abery (1997) compared the effects of deinstitutionalization on choice in persons with mental retardation. The study involved 127 adults with mental retardation. Of these, 56 were classified as movers (those who moved to community-based settings) and 71 were called stayers (those who remained in the institutional setting). Baseline data was taken on all subjects before the movers relocated to their new community-based settings. The 71 stayers remained in the institutional setting throughout the course of the study. Both groups were demonstrably similar on a range of characteristics including levels of adaptive and challenging behaviors as measured by the Inventory for Client and Agency Planning (ICAP), age and scores from and the author's Consumer Choice Scale. The greatest difference was shown in the challenging behavior category. The stayers exhibited more challenging behavior than the movers. Logically, the movers would experience lower rates of adaptive behavior since this is often a prerequisite for community placement.

The Consumer Choice Scale is a multiple-choice survey with questions about nine specific everyday choices. These include choices such as bedtime, mealtime, clothing, social activities, and participation. The instrument appeared to be a Likert-type scale ranging from zero to two, with two representing the greatest opportunity for choice. The individuals were surveyed approximately 15 months after the change to community placement took place. In each instance, except for mealtime, the movers were rated to have greater opportunity for choice. The authors did not specifically discuss the lack of difference in choice for mealtime between placements. Mealtime was included as part of a general statement about decisions that involve others being more limited for choice.

Stancliffe & Abery (1997) also concluded that the benefits of deinstitutionalization did not differ according to level of mental retardation. Although participants with profound mental retardation had significantly lower baseline choice scores than those with less severe retardation, they benefited equally from the move to a community setting. The authors contend their results provide empirical support for continued deinstitutionalization for all individuals with mental retardation despite the degree of severity disability. Case study research like Belfiore and Toro-Zambrana (1994) which were discussed earlier in this chapter also supports this contention.

Serious brain injury has devastating effects not only on the individual receiving the trauma but that person's significant others as well. Manifestations and sequelae of brain injury, such as role and relationship disruptions, cognitive/behavioral changes, and significant personality alterations, affect the brain injured person's social interaction and

functioning not only during the acute and rehabilitative phases of treatment but often permanently thereafter (Romano, 1989). Such dramatic changes certainly impact the injured person's quality of life and his satisfaction with its constructs and measurable indicators.

Current community-based treatment options available today provide the opportunity for the person to actively participate in goal setting for their treatment in contrast with the traditional medical model where patients are treated more as passive recipients of care, personal and family values are considered relatively immaterial to the process, and the emphasis of treatment is removal or cure for the pathology. Romano (1989) indicates the rehabilitative approach incorporates input from the patient's family for information about direct participation in the setting of treatment goals with the ultimate view toward an outcome of maximized autonomy. The rehabilitative approach inherently focuses toward quality of life issues.

In the field of developmental disabilities there has been a recent re-emphasis on methods to empower families and encourage participation in the service delivery process. Organizations can provide the appropriate amount of supports each family needs. Training, case management, and respite services, can assist families to be active participants in the process. The re-emphasis or focus could possibly be attributed to the person-centered planning and service delivery model. Person-centered planning is as significant a construct in human services as quality of life. Person-centered planning places the individual served at the heart of the service delivery process rather than at the

receiving end. The individual, with supports from family and service providers, coordinates his services. Many states have adapted elements of this process and incorporated them into licensing requirements for habilitation planning. The family's role is often more of participant and enabler in this process rather than advocate, guardian and overseer.

According to Pieper & Singer (1991) there is a need to translate the philosophical positions and practices from the field of mental retardation to the field of head injury. Alternatives to traditional case management systems in the head injury field would be necessary to implement person-centered methods from the mental retardation models in the rehabilitation process. Romano (1989) supports such a model for family involvement in the rehabilitation process.

The progression of service delivery for people with traumatic brain injuries has followed a similar course to that of the mentally retarded. Considering the issues of individual and family involvement in the planning and treatment process examined by Romano (1989) and Pieper & Singer (1991), it would be practical to regard quality of life to be an up-and-coming issue for survivors of traumatic brain injury as well. Inasmuch as service delivery research and trends for the mentally retarded have been the predecessor for brain injury services, it could be for quality of life issues as well. Just as adaptations to service delivery and case management constructs for the mentally retarded have been deemed necessary to accommodate the different needs of those with brain injuries, similar

considerations will need to be examined for the quality of life construct in respect to the two different disabilities.

Chubon Clayton, & Vandergriff (1995), compared the quality of life of people with developmental disabilities to spinal cord injury patients. The objective of this study was to reveal possible differences in quality of life issues as they relate to disability type. The assessment of quality of life is considered to be an appropriate program outcome measure in recognizing disability, service delivery, and rehabilitation issues. Such outcome-based-assessments can also help measure progress during the rehabilitation process. Intergroup comparisons of quality of life may contribute to the understanding of nuances of differences between people with different disabilities. A prudent assumption would be that different disabilities have different effects on the domains within the construct of quality of life (Chubon, et al., 1995). Assessments, which could help identify these differences, would have greater potential for practical application to modify services for each population.

Chubon et al. (1995) conducted an ex post facto investigation that used data from separate studies to compare the perceived quality of life of persons with spinal cord injuries and mental retardation and attempt to identify the different impacts of the two disabilities. The sample of spinal cord injury patients was comprised of 100 volunteer subjects who were (a) at least two years post injury, (b) had to utilize a wheelchair to ambulate, (c) had at least a ninth-grade education, and (d) had no evidence of cognitive impairment. One hundred twenty persons with mental retardation were selected from a

group of 2,500 persons served in the state of South Carolina. The 120 represented a stratified random sample that included four levels of mental retardation (mild, moderate severe and profound) and equal representation from all residential options available in that state.

The instrument used in the Chubon et al (1995) study is a seven point Likert-type rating scale consisting of 20 items. Chubon developed the Life Situation Survey (LSS) for a study of persons with and without disabilities in 1987. The reading level of the self-administered instrument was estimated to be at fifth grade. Oral administration was utilized when individuals were not able to complete the form independently. Chubon also completed reliability and validity studies on the instrument. The validity and reliability data is available in the LSS manual (Chubon, 1990).

Results of Chubon et al. (1995) indicate that the spinal cord injury subjects have a higher perception of their quality of life than their fellow South Carolinians with mental retardation. The authors point out several possible confounding variables in their study. The first is that the spinal cord injury sample may have been biased due to the nature of their volunteer status. Also only two subjects in the spinal cord injury group lived in a setting similar to that of the group with mental retardation, who all resided in programs provided in the state. Despite this potential bias, support is given for the difference of impact for each disability. Of the twenty items on Chubon's LSS, the mentally retarded group scored in the negative range of perception on seven items versus four for the spinal cord group. Another possible confounding variable exists in the administration of the

LSS. Most of the persons with spinal cord injuries self-administered the survey, while an oral administration was needed for all participants with mental retardation. No data is available to establish equivalency for alternate administration procedures.

Chubon et al (1995) contend that the total analysis of the LSS scores suggests that quality of life differs between the two groups. The two disabilities seem to have diverse and distinctive impacts on each group. They also assert that the suggested differences provide a foundation for future research. The current study I have designed is based on that assertion. However, several fundamental differences exist between the two studies. First, one sample consists of individuals with brain injuries instead of spinal cord injuries. Second, both samples reside in similar community-based settings. Finally, both groups were assessed as part of the same study. The latter two considerations address concerns for error stated by Chubon et al. (1995) regarding the inconsistencies that could exist between place of residence and separate studies. The current study design is also based on Stancliffe (1997) where the two samples are studied within a community-based residential setting. Stancliffe analyzed the variable of staff presence on choice, where this study explores the different impact of disability on satisfaction with quality of life.

The purpose of this thesis is to utilize quality of life as an organizing concept in the planning of service delivery through the assessment of satisfaction with person centered outcomes. Therefore, it is structured according to guidelines suggested by Shallock (1996). The data from this study should provide informative feedback to change programs and develop procedures that would impact the lives of those served. For the



purpose of this study, material well being, rights, and self-determination dimension are assessed. A detailed description of the study design, data collection tool, and method are provided in chapter three.

## Chapter Three

### Method

Data collected for this study is also included in the annual consumer satisfaction survey for the sponsoring organization. The survey was administered to 41 people with mental retardation and 27 persons with traumatic brain injury who live in similar community based settings operated by the same private not-for-profit organization. The purpose of the survey is to provide consumers with an opportunity to express their level of satisfaction or dissatisfaction with the specific quality of life construct built into each question.

### Participants

The two samples of participants were selected from the population of people served by a private, not-for-profit organization that provides community based residential, vocational and educational services to people with mental retardation and those who have suffered traumatic brain injuries. All individuals in each sample receive employment, vocational services, and residential services provided by the same organization. All individuals participating are between the ages of 21 and 70, and agreed to participate in the study.

The sample group of persons with mental retardation consisted of a total of 41 people, 32 male, and 9 female. The mean IQ of this sample is 52. The age range for this group is 26 to 70 with a mean of 45. The sample group of persons with Traumatic Brain Injury consisted of 27 people, 24 male, and 3 female. The mean IQ of this sample is 74.62. Unfortunately, only 17 of the 27 individuals' IQ scores were available. The age range for this group is 23 to 60 with a mean of age of 33. Table 1 illustrates the demographic characteristics of both samples.

Table 1: Demographic information of subjects

<b>Sample group</b>	<b>Age Range</b>	<b>Mean Age</b>	<b>Median Age</b>	<b>Standard Deviation</b>	<b>Number of Males</b>	<b>Number of Females</b>	<b>Mean IQ</b>
<b>MR</b>	26-70	46.75	43.5	14.7	32	9	52.4
<b>TBI</b>	23-60	35.9	35	10.6	24	3	74.6

The participants live in several community-based settings. These settings include single family-type group homes with four to six residents, apartment and condominium style residences with one to three people per living unit, and a congregate style location consisting of 16 apartments and two group homes. The congregate style apartments house two to three per people unit and the group homes have seven people in each unit.

Quasi-random sampling was utilized to achieve equally sized samples from the two populations. People with mental retardation were selected at random from list that met criteria for age, and residential placement. For purposes of this study, non-verbal individuals that did not have a fluent or functional means of communication were eliminated from the sample. A cell of 50 was selected. This sample was stratified to assure that people from each residential program for adults, operated by the organization was represented. Nine subjects could not participate due to time constraints in place by their jobs, activity schedule, and availability of the assigned surveyor. A final sample of 41 from the mental retardation group participated in the study.

The entire population of adults with brain injuries served by the sponsoring organization numbers 48; hence, the entire group was targeted as a sample. 33 subjects could not participate due to employment, vocational and activity schedule constraints that conflicted with the availability of the surveyors. The final cell size for the study numbered 27. Although 27 could be considered a relatively small sample size for this type of study, it is a truly representative sample of the population served by the organization.

#### Measurement Tool

The Consumer Survey has been utilized by the sponsoring organization since 1991. It was adapted from the Consumer Satisfaction Survey (Temple University, 1988). The instrument was designed to evaluate consumer satisfaction with services delivered by service providers. Kozleski and Sands (1992) also modified the same instrument for their

study on social validity, discussed in Chapter 2. The instrument has been used for six consecutive years at the cooperating organization. The instrument consists of 21 items; the latest revision included the addition of questions to evaluate satisfaction with choices, day program, and community interaction. Six additional questions assess satisfaction with employment situation. The original format of the Temple instrument has been preserved. The responses to the survey are anchored to a four point Likert-type scale. Three (3) indicates the highest level of agreement or satisfaction with an item, one (1) the least and zero (0), indicates the person did not respond. The inter-observer reliability data generated in this study will be utilized by the sponsoring organization to determine continued use of this instrument.

Trained graduate and undergraduate interns conducted interviews. The interviewers selected to assist with data collection met the following criteria: Two bachelor level staff persons from the organization whom did not work with people from either participating sample. One post graduate level professional enrolled in a special education program that has a background of interviewing people. One undergraduate student enrolled in the special education program with limited experience working with adults with special needs. No interviewer was responsible for service delivery to any individual in the study. Such a situation would create a conflict of interest and possibly corrupt the reliability of responses. Research (Matikka&Vesala, 1997) has indicated that persons with mental retardation tend to acquiesce and naysay under similar circumstances. Each interviewer was trained by the researcher to ensure consistent and valid administration of the survey. The following key points were addressed during training:

- Each surveyor conducts interviews in a 15-20 minute one to one session with a person served. It was important to allow enough time for the person to answer the questions completely and express his/her opinion. The time limit is a framework for the interviewer. Periods longer than 15 20 minutes tax the person's attention span and interest level. This experience should be short, and non-intrusive but meaningful, just as if a non-disabled person were to participate in a commercial survey at the mall. Selecting the appropriate environment is essential to provide the interviewer and persons served with the best conditions possible to facilitate a successful interview. Key criteria for interview locations are:

- Comfortable and private area. This should help facilitate the consumer to speak freely, but close enough to still provide support if needed by either consumer or interviewer. Basic needs of the person like restroom, water, and sufficient lighting were available as needed.
- Distractions were minimized to the greatest extent possible without compromising any daily routines of others in the nearby area. Interviewing locations were utilized that were not adjacent to common and high-traffic areas.
- The time slots shelled for each consumer were acceptable to the consumer and did not interfere with any planned activity. No person was placed in a position to choose between an activity and the survey.

Proper clarification methods were instructed to obtain clarification by restating questions.

- For example, if the consumer did not respond to “Do you like your day program?” the interviewer could ask the question with a concrete focus. “Do you like the greenhouse?” would be a restatement if that was where the person’s day program was located.

Utilizing a friendly but neutral manner was emphasized so the subjects were not led into any particular response. Restatement and phrases is stressed to ensure valid responses. That is why “Do you like the greenhouse,” is better than “You like the green house, right?”

#### Procedure

Participants were interviewed individually by the researcher and assistants trained using the procedure described earlier in this chapter. There were four interviewers including the researcher, three men, and one woman. Two interviewers, one male and one female were students from a local university and the other male was a staff member from the organization. He did not interview any of the people with whom he worked. Each interview was conducted in a semi-private area with minimized distractions and lasted approximately 15 minutes. A total of 68 persons between both groups were interviewed.

The randomization factor was analyzed with a single-factor analysis of variance (ANOVA.) The F values obtained are considered significant for the purposes of this study if they indicate that  $p < .05$ . The researcher has also collected inter-observer reliability data with assistance from the two bachelor’s level professionals and the

undergraduate student. The mean inter-observer reliability coefficient is .907 or 90.70%.

The inter-observer reliability data was collected with two interviewers across four subjects. The researcher checked reliability with two subjects for each of two interviewers.



## Chapter Four

The purpose of the study is to determine if there is a significant difference between the satisfaction with quality of life indicators as expressed by the individuals in each of the comparison samples. Questions 1, 3, 9,10, 11, 16,17, 18 v2 v3 and v4 directly related to indicators of quality of life as defined by Schalock (1996.) Results of those questions were compiled and analyzed for trends and significant difference both statistical and functional. Since the survey tool was developed prior to current research that defines quality of life dimensions and indicators, Schalock (1996), questions 2, 4, 5, 6, 7, 8, 12, 13, 14, 15 were not analyzed for the purposes of this study. Those items remain on the survey since they measure other areas of satisfaction, which are useful to the sponsoring organization.

Question v1 “What type of work do you do?” was not analyzed since the response is not scored. The items are scored on a four point Likert-type scale from 0 (No response) to 3 (Yes/Satisfied.) A mean above 2 indicates that there is some degree of satisfaction, a response of 3 would indicate that someone is completely satisfied.

Question 1, “Do you like living at (the organization?)” measured overall satisfaction with each individual’s residential experience. The people in the mental retardation group were overwhelmingly satisfied, with a mean response of 2.85, with their residential situation in comparison to a mean of 1.96 for the individuals from the brain injury sample. A single-factor ANOVA was conducted with the mean scores from each group.

The results of the ANOVA  $F(1,67) = 46.02, P < .001$  indicated a statistically significant difference between the groups.

Question 3, “Do you like your day program?” measured overall satisfaction with the person’s day program experience. The people in the mental retardation group were more satisfied with their day program (mean 2.63) in comparison to the individuals from the brain injury sample (mean 2.38.) A single-factor ANOVA was conducted with the scores from each group. The results of the ANOVA  $F(1,67) = 9.46, P < .01$  indicated a statistically significant difference between the groups.

Table 2: results and analysis of Questions 1 and 3

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>P</b>	<b>df</b>
MR Q1	41	2.85	.42	46.02	<.001	67
TBI Q1	27	1.96	.85			
MR Q3	41	2.63	.69	9.46	<.01	67
TBI Q3	27	2.38	.89			

Questions 9 and 10 measured how often people participate in activities with friends from the community and their satisfaction with the frequency of their participation. Question 9, “How often do you do things with friends outside of (the organization?)” indicated a similarity, rather than a difference between the groups. The differences between the mean responses for each group on question 9 were smaller than that of most other questions. The mental retardation group barely crossed the satisfaction threshold (2.07), while the brain injury group was below the threshold (1.79.) The single factor

ANOVA results of question 9,  $F(1,67) = 1.97, P > .10$ , did not reveal a statistically significant difference in the means for either group.

Question 10 “Are you happy with this?” meaning the person’s response to question 9, indicated significant difference between the individuals’ satisfaction with the frequency of their social interactions with individuals from outside the provider’s realm. The mean response for people in the mental retardation group was 2.59. The mean response for the people in the brain injury group was 1.50, once again below the satisfaction threshold. The ANOVA results,  $F(1,67) = 40.40, P < .05$  indicated a statistically significant difference between the groups. The results of questions 9 and 10 support the hypothesis.

Table 3: Results and analysis of questions 9 and 10.

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>p</b>	<b>df</b>
MR Q9	41	2.07	.90	1.97	>.10	67
TBI Q9	27	1.79	.75			
MR Q10	41	2.59	.11	40.40	<.05	67
TBI Q10	27	1.50	.69			

Question 11 “Did you decide where you live?” examines the level of satisfaction with and amount of choice a person had in selecting where he/she lives. The people in the mental retardation group were considerably more satisfied with the amount of input they had in selecting their current living setting, their mean was 2.34, well over the satisfaction threshold. The mean for people in the brain injury group (1.74) did not reach the satisfaction threshold. The ANOVA for question 11, ,  $F(1,67) = 17.00, P < .001$ , revealed a significant difference of the difference between the two groups.

Table 4: Results and analysis of question 11

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>P</b>	<b>df</b>
MR Q11	41	2.34	.53	17.00	<.001	67
TBI Q11	27	1.74	.71			

In question 11, a 3 response indicates, that the person felt it was their decision where to live. A 2 response indicates that some one else made the decision but the person agreed, and a 1 indicates that someone else made the decision and the person disagreed with the choice. Choice with location of residence and with whom we reside is a basic entitlement essential to quality of life for all adults. This fits into several dimensions and exemplary indicators defined by Schalock (1996). The key dimensions/indicators include Self-Determination/Decisions, Social Inclusion/Residential Placement, and Material Well-being/Shelter. The result of this analysis also supports the hypothesis.

Schalock (1996) specifically designates an entire Quality of Life Domain to the issue of rights; specifically included are the right to privacy, voting, access, due process, ownership, and civic responsibilities. These rights are guaranteed to all by the constitution and have been reinforced for people with disabilities by additional federal legislation, most significantly the ADA and the IDEA. Rights are also a basic element in licensing and national accreditation (CARF, 1997) standards. The issue of rights has been at the forefront of service delivery since the field of special education entered its era of enlightenment. State agencies and accreditation commissions require that organizations educate their persons with disabilities regarding their rights. Question 16

“Do you know what your rights are?” attempts measure the outcome of the effectiveness of rights education. This was the only question, which the people in the mental retardation sample scored lower with (mean of 1.92) than the individuals in the brain injury sample whose mean was 2.37, well into the agree/satisfaction range. However, the ANOVA results,  $F(1,67) = 4.14, P > .10$ , were not statistically significant.

Table 5: Results and analysis of question 16

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>p</b>	<b>df</b>
MR Q16	41	1.92	.93	4.14	>.10	67
TBI Q16	27	2.37	.88			

Question17 “Does your staff help you exercise/stand up for your rights?” revealed an interesting result. The sample of persons with mental retardation indicated that staff supported them in this area with a mean response of 2.41, while the people from the brain injury sample felt less satisfied with their supports in this area. The mean for the brain injury subjects was 2.0. Once again, the ANOVA results,  $F(1,67) = 7.09, P > .10$ , were not statistically significant, but supported the hypothesis.

Table 6: Results and analysis of question 17

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>p</b>	<b>df</b>
MR Q17	41	2.41	.53	7.09	> .10	67
TBI Q17	27	2.00	.71			

The driving force of the program from which any person receives services is the plan by which services are delivered. Input from the individual served is mandated by federal law. Theoretically, everyone or his/her guardian has input to the service delivery plan. This however does not necessarily support that the person served is satisfied with the amount of input he/she has in that plan. Question 18 “Did you help select your (IHP/IRP) goals?” provides the opportunity for the individuals to indicate their level of satisfaction. While the group of subjects with mental retardation rated their satisfaction well above the satisfaction threshold means 2.63), the group with brain injuries was significantly less satisfied (mean 1.89). The ANOVA results  $F(1,67) = 19.00, P < .001$ , showed a significant difference between the groups.

Table 7: Results and analysis of question 18

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>p</b>	<b>df</b>
MR Q18	41	2.63	.70	19.00	<.001	67
TBI Q18	27	1.89	.64			

Another indicator from the Material Well-Being Quality of Life Domain identified by Schalock (1996) is employment. Job satisfaction is something for which we all strive. No matter what the job, or ultimate vocational goal, satisfaction is essential each step of the way. Employment is addressed by vocation question 2 (v2) “Do you like your job?” Although both group means were above the satisfaction threshold, the group with mental retardation (mean 2.83) indicated a significantly higher level of satisfaction with their job placement situation than the people with brain injuries (mean 2.62.) The ANOVA results  $F(1,57) = 9.40, P < .05$ , indicated the difference between the groups to be significant.

Although the means of both groups rated above the satisfaction threshold, the brain injury group still rated their job satisfaction lower than the people in the mental retardation group did, thus supporting the hypothesis. It should be noted that 10 of the persons with brain injuries are not currently employed but are engaged in job development. Therefore, only 17 of the 27 people from the brain injury sample could respond to questions v2, v3, and v4.

Table 8: Results and analysis of question v2

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>p</b>	<b>df</b>
MR Qv2	41	2.82	.44	9.40	<.05	1, 57
TBI Qv2	17	2.33	.82			

Question v3 “Did you select your job?” and v4 “Do you earn enough money to buy things you want?” followed the same pattern as question v2, with both groups rating above the threshold, with the brain injury group reporting lower level satisfaction/agreement each time. On question v3, the group with mental retardation (mean 2.73) felt they had more input into selecting their current job than the group with brain injuries (mean 2.23.) The results of the ANOVA  $F(1,67) = 9.40, P < .05$  indicated a statistically significant difference between the groups.

Similar results were obtained for question v4. The group with mental retardation (mean 2.77) was still higher than the brain injury group (mean 2.38) despite the fact that both means exceeded the satisfaction threshold. The results of the ANOVA  $F(1,67) = 29.4, P < .01$  indicated a statistically significant difference between the groups.

Table 9: Results and analysis of question v3 and question v4

<b>Group</b>	<b>Total</b>	<b>Mean Response</b>	<b>Std. Deviation</b>	<b>F</b>	<b>P</b>	<b>Df</b>
MR Qv3	41	2.73	.70	9.40	<.05	1,57
TBI Qv3	17	2.23	.64			
MR Qv4	41	2.77	.60	29.4	<.01	1,57
TBI Qv4	17	2.38	.81			

Seven of the eleven questions regarding the degree of individuals' satisfaction with the quality of life domain indicators supported the hypothesis that people who have suffered traumatic brain injuries will be less satisfied with their quality of life than a similar sample of people with developmental disabilities. The brain injury group scored higher on the one question (16) that measured the each person's perception of whether they knew their rights. This data neither supports nor rejects the hypothesis.

The statistical analysis performed with the data collected, was a single-factor analysis of variance (ANOVA.) The ANOVA for questions 1, 3, 11, 18, V2, v3, and v4 indicated that the results of the survey were significant at or below the .05 level. Two of the analyses were significant at or below the .01 level. Three of the ANOVAs were significant at or below the .001 level.

The means for all questions are illustrated in Figure 1. The trend demonstrated by the series clearly shows the means of the subjects with brain injuries occurring lower than the means for the subjects with mental retardation. Question 16 is the one exception where awareness of rights by the people with brain injuries was higher than that of the mean for people with mental retardation.



## Chapter Five

### Discussion

This study was designed to compare the satisfaction with quality of life dimensions and indicators between people with mental retardation and people who have survived a traumatic brain injury. Each sample group resided in supervised community based programs provided by the same organization. Given these similar living situations and the differences in the etiology and onset of their disability, it was theorized that the group with acquired brain injuries would be less satisfied with their quality of life than their peers with mental retardation.

The two sample groups were administered a survey as a part of the sponsoring organization's annual consumer satisfaction assessment process. The participants were asked to rate their satisfaction with quality of life indicators by an interviewer who was not responsible for service delivery to the participants he or she interviewed. The participants' responses were anchored to a four point Likert-type scale. The sample of people with mental retardation rated their satisfaction on each quality of life indicator higher than the sample of people with traumatic brain injuries.

The results showed that the subjects with brain injuries indicated a lower satisfaction rating on all quality of life indicators than the group with mental retardation. Eight of the eleven questions revealed a statistically significant difference in the groups. Although the subjects with brain injuries scored lower on two of the remaining three items, the

differences were not statistically significant. The group with mental retardation rated satisfaction with their residential experience (Question 1) highest (2.85) of all items analyzed. This was not the case for the group with brain injuries; they rated their residential experience below the satisfaction threshold (1.96). The results of this question not only support the thesis, but also provides the underlying assumption for the research question. The research question was developed based on observations made by the researcher of persons with brain injuries and their expressed dissatisfaction with their situation. Considering the devastating physical and psychological effects manifested in someone who acquires a serious brain injury, one experience with the indicators within their quality of life domains is significantly reduced. When such a sudden change in life status occurs to this the extent, these experiences and losses would be considered anything but satisfying.

Certain other trends were discovered in the data. Questions 3, v2, v3, and v4 were related to satisfaction with day/vocational programming and jobs. These items were the questions the group with brain injuries rated highest for their satisfaction and the only ones that that were above the satisfaction threshold of 2.0. These questions were three of the four highest rated by the group with mental retardation. Question 3, "Do you like your day program?" and Question v2, "Do you like your job?" examine satisfaction in two similar areas, vocational programming/training, and actual vocational experiences. This information is valuable outcome data for the sponsoring organization. These data indicate that the people served by the sponsoring organization from both groups indicate that the vocational services provided are satisfactory. Further examination could help to determine which components of the vocational programs are the most effective to elicit such a rating

from both groups. Question v3, “ Did you help select your job?” could be a key factor in supporting the high rating for questions 3 and v2. Both groups indicated high level satisfaction (above 2.5) with their amount of input to their job selection. Consumer input to program and services is a key element in all frameworks for quality of life indicators. Major national accreditation organizations require consumer input in their standards and place significant emphasis on it (CARF, 1997; Gardiner et al, 1997.)

Question v4, “ Do you earn enough money from your job to buy the things you want?” is also a valuable outcome measure in supporting each group’s satisfaction with their vocational situation. Kozleski and Sands (1992) contend that that increasing support for services that foster indicators such as fulfillment and participation can increase quality of life a both disabled and non- disabled populations. This study supports that earning money, having input into job selection, and being satisfied with one’s job can be included as indicators for fulfillment and participation, which supports the contention made by Kozleski and Sands (1992).

Stancliffe and Abery (1997) and Toro and Zambrana (1994) found that individuals in community based settings showed increased opportunities for choice regardless of the severity of their disability than peers in an institutional setting. The current study utilized individuals exclusively from community based settings and compared satisfaction based on the type of disability rather than severity. Each group in the current study had similar opportunities for choice given the similarity of the programmatic structure provided to both programs by the sponsoring organization. Both groups in the current study indicate they

had a satisfactory level of input into their vocational programming. Therefore, the impact of increased opportunities for choice in community and institutional settings should be compared for people with brain injuries in institutional and community settings. Should the results of such a study support similar conclusions to Stancliffe and Abery (1997) and Toro and Zambrana (1994) the implication would be to encourage the development of more community based programs and supports for individuals with severe and complex brain injuries who are currently served in institutional type settings.

Chubon et al. (1995) compared the perceived quality of life between individuals with spinal cord injuries and those with mental retardation. This study also served as inspiration for the current study. Chubon et al. (1995) found that the individuals with spinal cord injuries rated were more satisfied with their quality of life than the people with mental retardation. The implication in Chubon et al. (1995) is that quality of life relates to disability type. The current study supports that implication, considering the results reported in chapter four. Two significant differences exist between the spinal cord injury group from Chubon et al (1995) and the current sample of people with brain injuries. There was no evidence of cognitive impairment resulting from the spinal injury, whereas the individuals in the brain injury sample experience cognitive impairment compared to their pre-accident level of functioning. Also, only two of 100 persons with spinal cord injury from Chubon et al. (1995) lived in similar settings as the group with mental retardation in that study. The two samples from the current study reside in similar community-based settings as described in chapter 3. However, despite the differences between the two studies, type of disability seems to have a distinct impact on perception of and satisfaction with quality of life.

Question 16 “Do you know what your rights are?” is as basic to quality of life as consumer input is to the quality of program. The emphasis that accreditation organizations place on input was discussed earlier in this chapter. The group with brain injuries indicated they knew their rights, with a response of 2.37, whereas the group with mental retardation responded below the threshold (1.92). It was also the only question of that group to fall below the 2.0 threshold level. Education could be considered a contributing factor to this difference. Unfortunately, complete education records of all the subjects in the brain injury sample were not readily available. Therefore, this contention could not be explored further in this study. Rights are reviewed to each person with served by the sponsoring organization as part of the annual program planning process; state and federal law require this review of rights. The concept of rights is rather abstract and therefore more easily comprehended by people who process information with higher level thinking skills. Mental retardation by its nature limits the development of such higher level cognitive processes, while a traumatic brain injury does not necessarily effect these processes to as severe an extent in every case. The mean IQ (74.6) of the brain injury group is 22.2 point higher than the group with mental retardation (53.4.) Such a significant difference in general could possible explain the discrepancy in perception of rights. Although IQ is not a complete measure of functioning, it can provide a general indicator and reference point for purposes of discussion.

The participants were asked in question 17 if their staff assisted them in exercising their rights. A reciprocal response was obtained from these groups.

For the specific intent of Question 9, “ How often do you do things with friends outside of (the organization?), a 3 response indicates “Often” instead of a specific time frame typical of most Likert-type instruments. Tying the responses of persons served to specific frequencies would not be appropriate for the survey nor would it be reasonable to expect them to recall such specific information. Such information could easily be obtained from program logs. However, the purpose of the question is to obtain each person’s perception of his/her social activity. Although the response format of this question could be considered a limitation, it is appropriate for the purposes of this study and the outcome measurement process for the sponsoring organization.

In addition to the limitations delineated in Chapter 3, several other limitations were discovered during the study. Four of the dimensions of quality of life Material Well Being, Self-Determination, Social Inclusion, and Rights (Schalock 1996), were examined for the purposes of this study. Quality of life is a comprehensive construct; therefore, additional research to include Emotional Well- Being, Interpersonal Relations, and Physical Well-Being should be completed to determine if similar results are attained. This study should serve as a foundation for studies examining other specific dimensions and indicators within quality of life.

Due to mortality and uncontrollable factors such as employment status, only 17 of the 27 people from the brain injury sample were employed. Although the sample size was large enough to be representative of the population served by the sponsoring organization, a larger sample of employed persons with brain injuries would provide data that are more

suitable for a research base. Mortality not only occurred with subjects, but assistants as well. Two interviewers recruited to administer surveys did not complete their designated number of interviews. The first interviewer, an employee of the sponsoring organization, self-terminated his employment and his participation in the study. The other interviewer, a student, elected to pursue another setting for her fieldwork. This left the bulk of the interviewing to the researcher and two students. Conversely, attaining inter-observer reliability was less complicated than initially anticipated since it involved only the researcher and the two interviewers. However, enlisting more assistants in future research will facilitate the process of studying larger groups.

Although inter-observer agreement (.91) was significantly above minimal standards, a trend was discovered where the disagreements were occurring. Ninety-two percent of the disagreements occurred when the consumer wavered and did not commit to a “Yes” response. The following responses were characteristic of ones where disagreements occurred: “Well, its okay,” “Yeah, sort of,” “Uh, I guess it’s okay.” Interpretation of these responses was difficult for the researcher and the other interviewers. Should the researcher replicate the study, these and other specific “middle of the road responses” will be utilized to develop operational definitions for interviewer training sessions.

Results of this study and Chubon et al. (1996), despite their limitations, suggest that different disabilities have unique and comprehensive impacts on quality of life. The differences revealed in each of these studies supports future research. The results of Chubon et al. (1996) and this study suggest a subsequent study examining the effects of

disabilities that impact cognitive function and those that do not. Research of this type could be useful in designing and revising service delivery founded on outcomes and satisfaction rather than projection and assessment. These two studies also support the notion of expanding quality of life research to other fields of rehabilitation. As discussed in chapter 2, current quality of life research is strongly influenced by the field of mental retardation and developmental disabilities, where the overwhelming majority of the concepts and constructs were developed.

## Conclusion

An exploratory study was conducted to examine the possible differences in satisfaction with specific quality of life indicators developed by Schalock (1996) between persons with mental retardation and those with acquired traumatic brain injuries. A survey comprised of a Likert-type scale was utilized to interview 41 adults with mental retardation and 27 adults with traumatic brain injury to obtain their perceived satisfaction with their quality of life. The analysis of the data suggests that a significant difference exists between the two groups. The sample of persons with brain injuries expressed lower levels of satisfaction on 10 of the 11 items analyzed. An analysis of variance revealed a statistically significant difference between the groups on seven of the analyzed items.



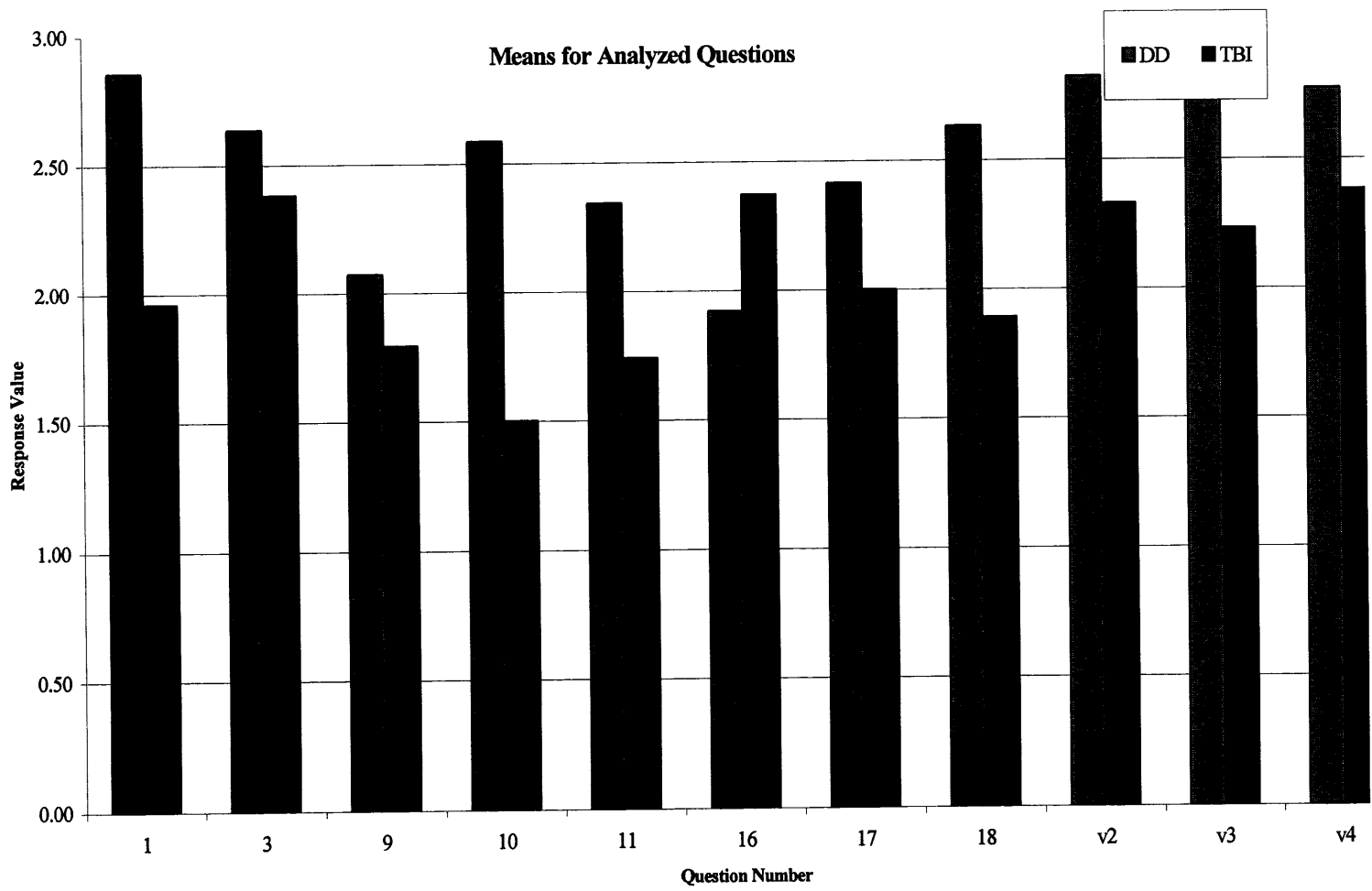


Figure 1

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