USING THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING TO CONCEPTUALIZE AND MEASURE QUALITY OF LIFE AMONG INDIVIDUALS WITH DISABILITIES

By

Allison R. Fleming

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ABSTRACT

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Quality of life (QOL) is the underlying goal of all rehabilitation interventions. Researchers and policy makers have proposed that QOL is an important and useful way to measure the impact of services. However, conceptual ambiguity, difficulty with operational definitions and measurement, and the inherent vulnerability to value bias have challenged the adoption and utility of QOL as a practical application in rehabilitation counseling. Given the challenges that individuals with disabilities have faced in securing employment, social and economic independence, and freedom to function at the highest possible level, it is not surprising that improvements to QOL related to service provision have been operationalized by more tangible impacts such as employment or increased independence. Results from previous research provide strong reason to believe that QOL is much more complex, individually based perception than is indicated by a single measure as is typically used in outcome measurement. In this study, a comprehensive framework (the ICF) is used to conceptualize and measure QOL in two samples of adults with disabilities receiving educational and vocational services. Participants were recruited from a university resource center for persons with disabilities and from a large community rehabilitation service provider (CRP).

The sample reported quality of life levels that are more typically observed in the general population (i.e., most people reported satisfaction), which lends support to the notion that reports of lower levels of QOL in individuals with disabilities is not universal, and may not be due to

disability itself. When function, activity, participation, personal factors and environment were regressed on quality of life, one personal factor (level of education) and several components extracted from the ICF emerged as having strong relationships with QOL. These included level of education, difficulty with social relationships and inclusion, difficulty with mobility and selfcare, the impact of the disability or health condition on the person or their family, and relational support and attitudes of family, friends, and acquaintances. When the student sample and CRP sample were analyzed separately, differences emerged that may be related to life circumstances (e.g., age, student status). The full model explained 26% of the variance in reported QOL. When the information that is typically used as outcomes of rehabilitation services (e.g., employment and independent living) were regressed on quality of life with demographic characteristics, a substantially lower proportion of the variance in QOL was explained by the data, indicating that the additional information provided by the ICF model improves our ability to conceptualize QOL. The results of the within-groups analysis provided more information specific to each sample. For students, the work/school and non-work activities added a more substantial portion of variance explained than in the CRP client sample.

Function, activity, and participation data largely supported the domains of the ICF, with the exception that "participation" showed two dimensions: one related to social relationships and the other related to the impact of disability on self and family. The dimensions of environment were also examined, and findings indicated that there is significant overlap between social support and attitudes toward disability. The present study provides us with initial results to that support the utility of the ICF for conceptualizing disability and its impact in a way that is inclusive of personal and environmental factors, and providing a more comprehensive picture of QOL.

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LIST OF ABBREVIATIONS

ADHD	Attention deficit hyperactivity disorder
DAR	Disability and rehabilitation team
НОН	Hard of hearing
ICD-10	International statistical classification of disease and health-related problems- 10th edition; International list of causes of death
ICF	International classification of functioning
ICIDH	International classification of impairments, disabilities, and handicaps
LD	Learning disability
QOL	Quality of life
RCPD	Resource Center for Persons with Disabilities
TBI	Traumatic Brain Injury
VI	Visual impairment
WHO	World health organization

Chapter 1

Introduction

Improving quality of life (QOL) remains the ultimate goal of social programs and medical interventions. Understanding how QOL is constructed, assessed, measured, and improved has been the subject of considerable thought, debate, and anecdotal and empirical inquiry, resulting in a deep and expansive literature base crossing numerous social science disciplines (Bishop, Chapin, & Miller, 2008). Written record of the conceptualization of the philosophical roots of quality of life date back to the times of Aristotle (Bishop et al., 2008; Herman, 2008). In rehabilitation counseling, we are faced with a much more practical QOL issue: QOL is the underlying goal of all rehabilitation interventions (Crewe, 1980) and researchers and policy makers have proposed that QOL is an important and useful way to measure the impact of services (Alexander & Willems, 1981; Cardus, Furher, & Thrall, 1981; Chan, Rubin, Kubota, Chronister, & Lee, 2003; Frisch, 2004). However, conceptual ambiguity, difficulty with operational definitions and measurement, and the inherent vulnerability to value bias have challenged the adoption and utility of QOL as a practical application in rehabilitation counseling (Bishop et. al, 2008; Dijkers, 1997).

According to the U. S. Office of Labor, Bureau of Labor Statistics (2011) approximately 50 million Americans have disabilities, with two-thirds of these individuals considered to have severe disabilities. The already ambiguous concept of quality of life becomes even more confounded when one considers how the experience of having a given disability or medical condition within our society might impact quality of life. As stated by Smart (2001, p. 314):

[F]or PWD [persons with disabilities], quality of life is thought to be social and economic independence (within the limits of the disability); the freedom to function at one's highest

level; social support, including family life; and the right to medical and psychological care.

Unpacking this statement requires consideration of the non-disability factors that play an important role in QOL for individuals with disabilities. Independence, freedom, and access are highlighted as key aspects of QOL and are often diminished for individuals with disabilities as a result of discrimination and lack of accommodations and accessibility (Smart, 2001). Work is a prime example of an area where individuals with disabilities are often limited; August 2011 data indicates that adults with disabilities had a labor participation rate of 21%, while adults without disabilities had a labor participation rate of 70% (Bureau of Labor Statistics, 2011). Chan, Wang, Muller, and Fitzgerald (2011) link these figures with QOL by putting opportunities for work and community participation into a broader context: "without a doubt, lack of employment opportunities and work incentives excludes people with disabilities from full community participation, significantly affecting the quality of their lives" (p. 3). This statement clearly demonstrates the interrelationships that exist between employment and other typical adult activities, disability, community integration or inclusion, and quality of life. It is not surprising that the result of service provision, particularly in the state-federal vocational rehabilitation programs and in community rehabilitation services, is often an employment outcome. However, some are left to question whether an employment outcome truly represents a milestone that is inclusive enough of the aim and philosophy of rehabilitation services (Chan et al., 2003).

The challenges that individuals with disabilities have faced in securing employment, social and economic independence, and freedom to function at the highest possible level (Smart, 2001) suggests a connection between those milestones and QOL. However, QOL is multidimensional, individually constructed construct (Cummins, 1996; Deiner, 1984), which is likely not well

captured by one aspect of individual experience (e.g., employment). This study will apply the ICF international standards to develop a more complex and consistent model of QOL based on the perceptions of individuals with disabilities, examine how the components of this more complex measure combine to form an overall measure of QOL, and test the adequacy of traditional measures of services and QOL by comparing them with the more complex method of assessment developed in this study.

QOL Definition and Measurement

The World Health Organization (WHO, 1998) defines QOL as "individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (p. 2). This definition reflects subjective QOL, which is used interchangeably with subjective well-being or life satisfaction (Roessler, 1990). Over time, components of QOL have been investigated, confirmed, and organized into what are known as life domains. Common life domains in QOL assessment include: physical health, psychological/emotional health, social support/social relationships, level of independence, employment/productive activity, environment, material/economic well-being, and spirituality/religion/personal beliefs (Bishop, 2005; WHO, 1998). Researchers have attempted to verify these life domains empirically through several methods including factor analysis (Kinney & Coyle, 1992), meta-analysis (Hughes, Hwang, Kim, Eisenman, & Killian, 1995) and comprehensive review of QOL definitions (Cummins, 1996). At this point, although there is no universal structure of life domains, sufficiently similar structures have emerged based on broad coverage of possible areas (Deiner, 1984; Bishop et al., 2008; Trauer & MacKinnon, 2001). Despite the definitional ambiguity of QOL, these empirically derived domains give at least some operational framework for measurement.

There has been substantial growth in the number of available QOL measures, particularly among disease-specific instruments; however, there is little standardization in how QOL is defined, conceptualized, and measured (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). Problems identified in the literature include developing instruments on a theoretical basis, (i.e., no common definition or understanding of QOL), lack of cultural relevance, lack of general utility beyond health related QOL assessment, and weak psychometric properties (Bishop et al., 2008; Frisch, 2004; Gill & Feinsten, 1994; WHO, 1998). Complicating measurement is positive bias inherent in reported QOL level; worldwide, most people report being about 70% satisfied with their lives and variation in QOL is relatively small despite substantial differences in living conditions and cultural factors across the globe (Cummins, 2003). This information raises many questions regarding the accuracy of QOL measurement. Some of these questions are potentially rooted in the lack of accuracy of self-report on cognitive processes and their cause (Nisbett & Wilson, 1977). In addition to more careful attention to the theoretical framework and cultural issues, further investigation into the utility of Likert-scales, recommended number of points, and ability of instrument users to discriminate between points on the scale have been recommended to strengthen the accuracy of measures (Cummins, 2003; WHO, 1998).

QOL research for persons with disabilities has been complicated with the question of how to assess QOL given the range of abilities to understand the concepts involved and accurately selfassess in this population (e.g., Cummins, 2002; Fabian, 1991). Several authors have investigated the validity of responses among people with particular disabilities, such as, severe mental illness and intellectual impairments (e.g., Cummins, 2002, Lustig & Crowder, 2000). Results indicate that people with disabilities are capable of giving their perspective on their own well-being, although some individuals are influenced by social desirability or acquiescence (Fabian, 1991).

The use of proxy responders is not encouraged since overall proxies are largely unable to avoid the influence of their own personal values and have proven to be largely inaccurate (Cummins, 2002).

Despite these difficulties and complications in measurement, being able to get information about subjective QOL is critically important (WHO, 1998) because of the centrality of improving QOL to the underlying goal of all healthcare interventions (Bishop et al., 2008; Frisch, 2004). Across sectors of healthcare, including mental health treatment and rehabilitation, clinicians are challenged to prove that treatment is effective in ways that are clinically significant (Frisch, 2004). Demonstration of effectiveness is particularly important in the current political climate and emphasis on accountability and evidence-based practice (Bishop et al., 2008; Jenney & Campbell, 1997). QOL assessment is client-centered and focuses on changes that are clinically significant to the client (Frisch, 2004), and thus is a useful indicator of the impact of a practice or service. For a variety of reasons, including historical roots and legislative mandates, the outcome measurements of rehabilitation (particularly in the public sector) have largely been limited to employment and to a lesser extent independent living. However, in the literature we find frequent suggestions that this narrow focus leaves us with a limited understanding of the results of rehabilitation services (Bishop et al., 2008; Chapin Miller, Ferrin, Chan, & Rubin, 2004) and a broader measure including components of QOL would be more useful (Bishop & Fiest-Price, 2001; Chapin et al., 2004).

QOL Research in Rehabilitation

Rehabilitation researchers have undertaken important studies of how incurring a disability, undergoing treatment, managing disability related symptoms, and experiencing resulting changes in roles and activities impacts QOL of persons with disabilities. Researchers have also sought to

compare how people with disabilities report their QOL as compared with the general population. Findings have indicated that as a group, people with disabilities report lower levels of life satisfaction than the general public, although disability severity is not directly related to how people report QOL (Fuhrer, Rinalta, Hart, Learman, & Young, 1992; Fuhrer, 1994). Of greater importance are community and contextual factors, such as employment, leisure, social relationships, income, self-assessed health, contact with friends and acquaintances, safety, and opportunity to take part in activities that are customary based on age, gender, and culture (Clayton & Chubon, 1994; Crewe, 1980; Fabian, 1991; Fuhrer et al., 1992; Fuhrer, 1994; Kennedy, Lude, & Taylor, 2006; Kinney & Coyle, 1992; Kirtchman, 1985; Lehman, Ward, & Linn, 1982; Whiteneck, Brooks, Harrison-Felix, & Gerhart, 2004).

Motivation to re-visit the conceptual framework utilized to assess QOL for persons with disabilities stems from the growing momentum to include other measures of well-being (e.g., QOL) as an outcome measure (Chan et al., 2003) with the understanding that efforts to apply QOL to field-based interventions have been complicated with concerns about definition and measurement (Bishop et al., 2008). A model of health and functioning that takes into account environment, personal, contextual, and cultural factors potentially provides a more comprehensive basis for evaluation that goes beyond areas of life that are typically the focus of services. The following section describes the International Classification of Functioning (ICF) developed by the World Health Organization to classify aspects of function, disability, and health in a way that accounts for contextual influences and portrays health and disability as a normal part of the human condition (WHO, 2002).

A Model of Functioning, Disability, and Health

In 2001, the WHO completed and released the International Classification of Functioning (ICF) as a "framework for describing and measuring health and disability" (WHO, 2002). Peterson and Rosenthal (2005a) described the ICF as "a classification system developed by the WHO that portrays health as a dynamic interaction between an individual's functioning and disability within a given context" (p. 95). The ICF emphasizes impact, rather than the cause, of disability. Attention is paid to the environment and social aspects of disability and their relationships with disability and functioning (WHO, 2002). The ICF represents a major paradigm shift, away from the medical model and disability as a problem experienced by a person with medical treatment as a solution, to a biopsychosocial model where the emphasis is on environmental factors as barriers or enhancements to health and functioning (Peterson & Rosenthal, 2005a). The ICF is consistent with the philosophy of rehabilitation counseling that views health and disability as holistic and allows for inclusion of "medical, psychosocial, and environmental aspects of health and functioning" (Peterson & Rosenthal, 2005a, p. 96). This widespread acceptance and support of the ICF indicates promise of the model for use in rehabilitation and disability research.

The ICF was developed to reflect changes in health and disability policy consistent with the 1980 WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH). It uses more neutral language describing disability, health, and function, as well as having cross-cultural applicability because of the flexibility in how "personal factors" and "environment" are described. The ICF was designed to bring a common language for describing and measuring health and disability, as well as to serve as a tool for developing outcome measures such as those

resulting from health interventions and QOL (Cieza & Stucki, 2005; Peterson & Rosenthal, 2005a).

The ICF was accepted in 2001 by the 54th World Health Assembly for international use, and has been accepted as the international standard for classifying health and health related states by 191 countries (Bruyere, Van Looy, & Peterson, 2005). Other examples of its adoption include its use as the framework for the Disability and Rehabilitation (DAR) team in the World Health Assembly's Department of Violence Prevention and Injury Prevention and Disability. Iit has been utilized as the structure for the WHO world report on disability and rehabilitation, and it has been accepted as one of the United Nation's social classification. The ICF is also consistent with the United Nations Convention on the Rights of Persons with Disabilities framework for understanding function as a universal experience (Cieza & Stucki, 2008).

The core structure of the ICF model is divided into: (a) Function and Disability, including a listing of body functions, body structures and activities and participation related to each of the listed body functions and structures; and (b) Contextual Factors, including environmental and personal factors that serve to either facilitate or hinder activities and participation (WHO, 2002). The ICF is based on a model of disability that displays the dynamic interactions between components (e.g., disorder, function and disability, and contextual factors), where the disorder or disease influences a dynamic interaction between the body functions and body structures, and activities and participation of the individual (Peterson & Rosenthal, 2005b). The ICF is considered exhaustive; it covers the spectrum of health and health-related domains involved in the experience of disability and function, as well as the full range of potentially influential environmental factors (Cieza & Stucki, 2008).

Figure 1





Note: from Towards a Common Language for Functioning, Disability and Health: ICF. World Health Organization, 2002, Geneva: Author. Copyright 2002 by the World Health Organization. Reprinted with Permission.

Applying the ICF model to QOL research

Previous research has acknowledged the compatibility between the ICF and investigations related to QOL, particularly in the areas of health-related QOL. The ICF has been used to evaluate measurement tools (Cieza & Stucki, 2005), as well as in initial attempts to investigate the relationship between environment, participation, activity, and quality of life (e.g., Kennedy et al., 2006; Whiteneck et al., 2004). Initial findings from these studies indicate that there is some relationship between environmental factors, personal factors, participation, and QOL; for example, the role of environmental supports in reducing the gap in participation and influence on QOL ratings. However, these relationships need further empirical study and clarification (Whiteneck et al., 2004). A review of several commonly used QOL instruments revealed that the ICF provides a good representation of content of the instruments; although contextual and

environmental factors are "scarcely represented" in the instruments themselves (Cieza & Stucki, 2008, p. 1235), indicating a need to gather additional information in these areas for a more complete QOL assessment.

Pre-ICF research efforts to determine the impact of disability and contextual factors on QOL for individuals with disabilities have provided mixed results. Nolte (2000) utilized the pre-ICF ICIDH model to assess the relative contribution of injury-related factors and contextual factors on level of handicap (e.g., integration) and QOL. Although results indicated only a small contribution to QOL based on disability and handicap, social support was the only contextual factor that was significant. These results are similar to findings in other studies where effects were related to non-disability factors (e.g., Fuhrer, 1994), such as ability to fulfill social roles or satisfaction with personal relationships and opportunities for leisure. Community integration and participation, however, did not contribute to the prediction of QOL among persons with traumatic brain injury in the sample. A potential explanation for the lack of relationship between integration and participation with QOL is the weakness of the ICIDH model itself and its lack of attention to the role of the environment in functioning and health (Cieza & Stuki, 2008). This research is suggestive that future efforts, such as the present study, may benefit from the updates in the ICF that more clearly delineate activities, participation, and contextual factors for assessing health, disability, and functioning.

Study Significance

Given the challenges faced by individuals with disabilities in securing employment, social and economic independence, and freedom to function at the highest possible level (Smart, 2001), it is not surprising that improvements to QOL related to service provision have been operationalized by more tangible impacts such as employment or increased independence. Labor

participation rates for individuals with disabilities are consistently and substantially lower than the general population; recent figures include a participation rate of 64% for the general population compared with 18% for individuals with disabilities (Chan, Wang, Mueller, and Fitzgerald, 2011). Without reducing the significance of the economic and employment situation, there is a strong reason to believe that QOL is much more complex (Cummins, 1996; Deiner, 1984), individually based perception than is indicated by a single measure as is typically used in outcome measurement. It is likely, but not certain, that one aspect of individual experience (e.g., employment) is not sufficient to capture the more complex and nuanced view of QOL. Additional information on how non-disability factors such as environment, community participation, and daily activities impact QOL are useful in guiding advocacy efforts, individual service planning, and evaluation of the effectiveness of rehabilitation services.

Goal, Method, and Research Questions

The goal of this dissertation was to utilize a comprehensive framework (the ICF) to conceptualize and measure QOL in two samples of adults with disabilities representing different groups of individuals receiving disability-related services. A sample of university students with disabilities represents a group of individuals who are likely higher functioning with a history of success in education and strong potential for future employment. Also included is a sample of individuals receiving community-based services represents individuals with varying life circumstances, levels of functioning, and past history of success in education and / or employment who are more typical of those receiving community-based disability-related services. The study compares how well typical measures of employment and independent living predict the more comprehensive measure of QOL and how this relationship varies by the two different samples included in the study.

The goal of the study was accomplished by measuring ICF-based factors relevant to the determination of QOL, disability related factors (e.g., structure and function), activities and participation (e.g., employment, community access, etc), and contextual factors (e.g., age, race/ethnicity, education, income, living situation, environment, etc.) in two samples. The QOL assessment selected was the World Health Organization Quality of Life- Brief version (WHOQOL-BREF) instrument. The World Health Organization Disability Assessment Schedule version 2.0 (WHODAS 2.0) and a modified version of the environmental section of the ICF checklist (WHO, 2003) were used to ascertain information on health and function, activity, participation, and contextual factors. To enhance response, the survey was offered in electronic format to the university students and in both electronic and in-person paper format to the sample of adults utilizing community-based rehabilitation services.

The following research questions were addressed:

- 1. Are the hypothesized components of the ICF model (function, activity, participation, and environmental factors) supported empirically?
- 2. What is the relationship between disability-related factors, activities, participation, environmental and personal factors with QOL? Do these results vary by sampling group?
- 3. Do the components of the ICF model provide an improved way to measure QOL above typically derived outcomes of services (e.g., employment or independent living)?

Definition of Terms

The following terms are offered for clarification:

Quality of Life. The World Health Organization (WHO, 1998) defines QOL as "individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (p. 2). This

definition reflects subjective QOL, which for the purpose of this study is used interchangeably with subjective well-being or life satisfaction (Roessler, 1990).

International Classification of Functioning. The World Health Organization developed the ICF to be a classification system to describe health and function "that portrays health as a dynamic interaction between an individual's functioning and disability within a given context" (Peterson & Rosenthal, 2005a, p. 95).

Medical model of Disability. View of disability as a person-level attribute, caused by disease, trauma, or health condition requiring professional intervention to treat or correct (Jette, 2006).

Social model of Disability. View of disability as a socially created problem rather than a person-level attribute. Disablement is a result of an environment that is not accommodating (structurally and/or socially) and requires a political or societal-level response (Jette, 2006).

Biospychosocial model of Disability. View of disability that integrates the medical and social models where, "disability is viewed as the consequence of biological, personal, and social forces. The interactions among these various factors results in disablement" (Jette, 2006, p. 727).

Activities & participation: Operationalized via impairment, activity limitations, and level of participation in community activities (Üstün et al., 2010a).

Environmental factors: Operationalized via products and technology, natural environment, social support, attitudes of others, and service systems and policies (WHO, n.d.)

Personal factors: person level characteristics, such as age, gender, race/ethnicity, educational experience, marital status, occupational status, type and duration of disability or chronic health condition.

Attitudes toward Disability: Are the observable outcomes of beliefs, norms, customs, practices, and values. May contain one or more of the following components: affective (feelings), cognitive (beliefs or thoughts), or behaviors (actions; Chan, Livneh, Pruett, Wang, & Zheng, 2009; Chubon, 1992).

Assumptions and Limitations

This exploratory study was proposed with the knowledge of some assumptions and limitations at the outset. For one, the investigator assumed that the participants were able to provide accurate information about their level of functioning, activity, participation, as well as information about their environment and quality of life. Previous research supports this assumption (e.g., Cummins, 2002; Fabian, 1991; Lustig & Crowder, 2000). Also, the instruments selected for the present study have been validated with samples of individuals with disabilities and chronic health conditions (WHO, 1998; WHO, 2002). In addition the two samples were assumed to be distinct, representing the range of thus are likely not representative of individuals with disabilities served by rehabilitation agencies. Additional study limitations are examined in the discussion section.

Summary

QOL is the underlying goal of all rehabilitation interventions (Crewe, 1980). Researchers and policy makers have proposed that additional measures of well being are needed as outcome measures of services (Chan et al., 2003; Frisch, 2004). QOL represents a potential outcome measure that is multidimensional in nature. Previous research efforts have not systematically explored the relationship between typically derived measures of service outcomes (e.g., employment, independence) and QOL in a way that is inclusive of contextual factors. The ICF provides an empirically supported and conceptually accepted model to accomplish this goal.

Results of the present study provide information on how well typical outcome measures of services predict a more comprehensive assessment of QOL in the two distinct populations studied. Additional information gained on how non-disability factors such as environment, community participation, and daily activities relate to QOL can be applied to advocacy efforts, individual service planning, and evaluation of the effectiveness of rehabilitation services.

Chapter 2

Review of the Literature

The purpose of this study was to measure Quality of Life (QOL) in a sample of adults with disabilities within the conceptual framework of health and functioning provided by the World Health Organization's (WHO) International Classification of Functioning (ICF) and compare how this comprehensive method of assessment compares with more typical measures associated with the outcomes of rehabilitation services. QOL is a multidimensional, individually constructed perception of well-being, comprised of a number of different aspects of the individual experience (Bishop, 2002; Deiner, 1984). The ICF is a model of health and disability as holistic and allows for inclusion of "medical, psychosocial, and environmental aspects of health and functioning" (Peterson & Rosenthal, 2005a, p. 96) that is consistent with the philosophy of rehabilitation counseling. The additional factors included in the ICF (e.g., environment, community participation) are hypothesized to have a relationship with QOL and may provide valuable information above current outcome measures of rehabilitation services.

The underlying goal of all rehabilitation interventions is to increase QOL (Crewe, 1980). In the rehabilitation counseling literature, it has been acknowledged that in order to have an impact on QOL, interventions must target the body, the self, and the social system, or include both person-based and environment-based aspects because of the complex relationship among function, environment, and QOL (Roessler, 1990). The ICF provides a useful framework for assessing QOL among persons with disabilities because it acknowledges the role of function and disability related factors (i.e., body structures and function, and activities and participation), as well as contextual factors (i.e., environmental and personal factors) in disability and health. The following is a review of relevant literature from three broad areas: a) the ICF model; b) quality of

life; and b) utilization of the ICF model for assessing QOL among persons with disabilities in non-clinical settings. This information provides the background for the present study, where the goal is to investigate the impact of inclusion of more rigorous environmental and contextual factors into the measurement of QOL.

The International Classification of Functioning

In 2001, the WHO completed and released the ICF as a "framework for describing and measuring health and disability" (WHO, 2002). Peterson and Rosenthal (2005a) described the ICF as "a classification system developed by the WHO that portrays health as a dynamic interaction between an individual's functioning and disability within a given context" (p. 95). A key aspect of the ICF is that the emphasis is on the impact rather than the cause of disability. There is attention paid to the environment and social aspects of disability and an acknowledgment of how those issues play into disability and functioning (WHO, 2002).

The ICF represents a major paradigm shift away from the medical model and the idea that disability is a problem experienced by a person, with the solution being medical treatment, to a social model where there is acknowledgement that environmental factors can be barriers or enhancements to health and functioning (Peterson & Rosenthal, 2005a). The following is a discussion of the development of the ICF, its utilization in health-related and disability research and policy, and the components of the ICF model. Evaluative and measurement information on the ICF is included, as well as the potential utility of the ICF for rehabilitation counseling research.

Development and Application of the ICF

The ICF was developed to reflect changes in health and disability policy since the release of the 1980 WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH), and the differences between these two classification systems are significant for the

context of rehabilitation and the disability community (Cieza & Stucki, 2008; Peterson & Rosenthal, 2005a). The ICIDH was a system for classifying disability-related impairments, and was released for trial purposes only. Much of the criticism of the ICIDH from the disability community was directed at the negative language (e.g., "handicaps") and the lack of recognition of the role of the environment in disability, functioning, and health (Cieza & Stucki). The ICF was developed as a complement to the International Statistical Classification of Diseases and Related Health Problems, 10th Edition (ICD-10; WHO, 2007), which is more commonly known as the International List of Causes of Death or by the acronym, ICD. The ICD provides a classification of disorders, diseases, injuries, while the ICF focuses on functioning, and the impact of disease or disorder, as well as contextual factors that facilitate or hinder activity and participation (Peterson & Rosenthal, 2005b). Reflected in the more neutral language describing disability, health, and function, as well as the cross-cultural applicability of the model, the ICF was designed to bring a common language for describing and measuring health and disability, as well as to serve as a tool for developing outcome measures such as those resulting from health interventions and QOL (Cieza & Stucki, Peterson & Rosenthal, 2005b).

While the ICIDH was never approved by the World Health Assembly, the ICF has been more widely adopted. It was accepted in 2001 by the 54th World Health Assembly for international use, and was accepted as the international standard for classifying health and health related states by 191 countries (Bruyere, Van Looy, & Peterson, 2005). Other examples of its adoption are that it is used as the framework for the Disability and Rehabilitation (DAR) team in the World Health Assembly's Department of Violence Prevention and Injury Prevention and Disability; it has been adopted as the structure for the WHO world report on disability and rehabilitation; and it has been accepted as one of the United Nation's social classifications.

Despite not being explicitly mentioned, the ICF is also consistent with the framework for understanding function as a universal experience, as is the stance of the United Nations Convention on the Rights of Persons with Disabilities (Cieza & Stucki, 2008). The wide adoption of the ICF is an indication of its potential usefulness as a framework for considering the impact of chronic illness and disability on various aspects of life, activity, and community participation across cultures (Chan, Wang, Muller, & Fitzgerald, 2011).

Components of the ICF Model

The core structure of the ICF model is divided into: (a) Function and Disability, including a listing of body functions, body structures and activities and participation related to each of the listed body functions and structures; and (b) Contextual Factors, including environmental and personal factors that serve to either facilitate or hinder activities and participation. The following is a brief description of each of the components of the ICF model (WHO, 2002).

Figure 2



The ICF model components and interactions

Note: from Towards a Common Language for Functioning, Disability and Health: ICF. World Health Organization, 2002, Geneva: Author. Copyright 2002 by the World Health Organization. Reprinted with Permission.

Function and disability.

Body functions. This portion of the ICF contains a list of body functions, including (1) mental (consciousness, orientation, intellect, energy, drive, etc.); (2) sensory (seeing, hearing, taste, touch, pain, etc.); (3) voice and speech (e.g., articulation, voice, fluency, etc.); (4) cardiovascular, hematological, immunological, and respiratory systems (e.g., related to heart, lung, blood vessel, and immune system functioning, etc.); (5) digestive, metabolic, and endocrine systems (e.g., digestion, weight maintenance, water/electrolyte balance, etc.); (6) genitourinary and reproductive (e.g., urination, reproduction, etc.); (7) neuromusculoskeletal and movement-related (e.g., joint, bone, and muscle function; motor reflexes, gait patterns; etc.); and (8) skin and related structures (e.g., protective/repair/sensation functions of the skin, hair, nails, etc.).

Body structures. This portion of the ICF contains a list of body structures, including: (1) nervous system (e.g., brain, spinal cord, sympathetic and parasympathetic nervous systems, etc.); (2) ear, eye, and related (e.g., eye socket, eyeball; inner, middle, and external ear; etc.); (3) voice and speech (e.g., nose, mouth, larynx, etc.); (4) cardiovascular, immunological, and respiratory (e.g., heart, arteries, bone marrow, spleen, lungs, etc.); (5) digestive, metabolic, and endocrine (e.g., salivary glands, intestines, liver, etc.); (6) genitourinary and reproductive (e.g., kidney, urethra, ovaries, prostate, etc.); (7) movement (e.g., bones, muscles, ligaments, etc.); and (8) skin and related (e.g., skin, glands, nails, etc.).

Activities and participation. This portion of the ICF contains a list of activities and methods of community/societal participation related to impairments in body functions due to irregularities or other problems within particular body structures. While the activities and participation are displayed separately in the WHO model, they are often discussed and measured together due to significant overlap (Cieza & Stucki, 2008). The following are included: (1) learning and applying knowledge (e.g., watching, listening, copying, reading, calculation, etc.); (2) general tasks and demands (e.g., planning, initiating, carrying out a single simple or complex tasks, completing a daily routine, stress management, etc.); (3) communication (e.g., communicating and receiving spoken, written, non-verbal, and American Sign Language-based messages; conversing; engaging in discussion with one or more people; etc.); (4) mobility (e.g., maintaining or changing body position, transferring, walking, driving, carrying, etc.); (5) self-care (e.g., washing, dressing, toileting, maintaining health including diet and fitness, etc.); (6) domestic life (e.g., acquiring a place to live, preparing meals, cleaning, assisting others, etc.); (7) interpersonal interactions and relationships (e.g., expressing appreciation, tolerance, and conflict in interactions with others; relating with strangers, friends, family, and intimate partners; etc.); (8)

major life areas (education, acquiring work, keeping a job, terminating employment, economic self-sufficiency, etc.); and (9) community, social, and civil life (e.g., recreation and leisure, local clubs and ethnic groups, participating in religious and non-religious ceremonies, citizenship, etc.).

Contextual factors.

Environmental factors. This section of the ICF contains environmental factors that may facilitate or hinder function and activities and participation, including: (1) products and technology (i.e., natural or human-made products and systems, equipment, and technology in the immediate environment.); (2) natural environmental and human made changes to the environment (i.e., elements of the natural and physical environment, components of the environment that have been modified, and human populations within the environment); (3) support and relationships (i.e., people or animals that provide physical or emotional support, nurturing, protection, or assistance in the home, work, or community); (4) attitudes (i.e., attitudes that are the observable consequences of norms, customs, and values, influencing levels ranging from political/legal structures to interpersonal interactions); and (5) services, systems, and policies (i.e., public, private, services that provide benefits and programs designed to meet the needs of the public, systems established by governments at the national and local level, policies that regulate the systems and services).

Personal factors. There is no specified component of the ICF delineating personal factors that may facilitate or hinder activities and participation because this facet was determined to be too dependent on culture to be presented in a universally defined way as the other facets. However, personal factors may include things such as age, gender, race, fitness, lifestyle habits, coping styles, upbringing, profession, education, etc. (Peterson & Rosenthal, 2005b). While

many of these factors might also be considered social factors, what makes them personal is the unique combinations that are attributed to individual-level differences.

Relationships within the ICF model.

The ICF is based on a model of disability that displays the dynamic interactions between the components (e.g, disorder, function and disability, and contextual factors), where the disorder or disease influences a dynamic interaction between the body functions and body structures, and activities and participation of the individual. The environmental and personal factors (the facets within the contextual factors) serve to facilitate or hinder function, activities, and participation (Peterson & Rosenthal, 2005b).

Development of the World Health Organization Disability Assessment Schedule

The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) is not the only assessment of functioning and disability that is related to the ICF model, however, it is the only one that was built based on the ICF framework and is therefore uniquely applicable to the present study (Üstün, Kostanjsek, Chatterji, & Rehm, 2010b). It is designed to measure levels of functioning, regardless of type of disability, as operationalized through questions on impairments, activity limitations, and participation restrictions (Üstün et al., 2010b). According to the WHO, the WHODAS 2.0 is, "a practical, generic assessment instrument that can measure health and disability at the population level or in clinical practice" (p. 4). The WHODAS 2.0 captures information within six domains of functioning, including: cognition, mobility, self-care, getting along with others, life activities (i.e., Activities of Daily Living or ADLs), and participation. The WHODAS 2.0 is based on the framework of the WHO's ICF, and provides a general measure of functioning and disability in a way that is applicable across nations and cultures (Üstün et al., 2010a). In the development phase, the WHO team reviewed existing measures and existing literature on both conceptual and measurement aspects of disability and function (Üstün et al., 2010a). Information from approximately 300 existing measures were entered into a database, and then reviewed by a panel of experts who pooled items using the ICF as their framework. Since a major goal of the development team was to create a cross-cultural instrument, emphasis was given to understanding how health status is assessed in different countries and within different cultures. In addition to the review of literature and existing measures, the team also conducted focus groups and key informant interviews as an additional step in item generation. The first version of the instrument contained 96 items for field testing (Üstün et al., 2010a).

The team tested the WHODAS 2.0 in two waves of cross-national field testing. First the 96 item version was assessed for redundancy of items, screener performance in predicting results of the full instrument, rating scales, and the suitability of different recall time frames (e.g., weeks, months, etc.). The first wave also included interviews with participants to determine how well they understood questions and gauge reactions. The second wave of field testing was aimed at gathering reliability and validity data for the 36 item instrument, consistent with both classic test theory and item response theory (Üstün et al., 2010b). Participants for the first study (Wave 1) were gathered from 21 field sites in 19 different countries (N = 1,431). Sample recruitment (limited to adults 18 years of age and older- 75.3% under 55; 24.7% over 55) focused on gender (45.5% male, 54.5% female), and individuals who were in apparent good health (18.3%), individuals who had physical disorders (29.3%), individuals with mental or emotional disorders (27.6%), and individuals with drug (11.3%) and alcohol (13.6%) use issues. Data collected through this first field study were used to reduce the instrument to versions with fewer questions (36-item, 12+24-item, and 12-item versions) that would maintain the factor structures of the six

domains (Üstün et al., 2010b). A second wave of field testing was done to evaluate the psychometric properties of the shortened versions. This instrument provides a method for assessing disability that is directly linked to the WHO ICF model.

Critical Evaluation of the ICF

Researchers have evaluated the ICF for content validity, completeness, and utility for research and clinical applications. It is considered exhaustive in that it covers the spectrum of health and health-related domains involved in the experience of disability and function, as well as the full range of potentially influential environmental factors (Cieza & Stucki, 2008). The ICF was evaluated for width, and was judged to cover relevant aspects of the patient experience by professionals in the medical, psychological, and applied health fields. The ICF was also evaluated for precision and depth, or the degree to which the ICF can distinguish between health and health-related domains. No clear distinctions were made between activities and performance, with relation to specific ICF categories. However, there is clear separation between the domains of structure and function (Cieza & Stucki, 2008). For the purposes of the present study, these two domains were evaluated with a single instrument (WHODAS 2.0).

Within the rehabilitation counseling literature, Chan, Tarvydas, Blalock, Strauser, and Atkins (2009) noted the importance of having an integrative framework that can be used to systematically investigate aspects of disability and chronic illness. This framework must meet a set of criteria in order to fit the philosophy and values of rehabilitation counseling and be of use to rehabilitation researchers; most notably, it must be culturally sensitive, and it must allow for consideration of both personal characteristics and environmental factors, and how the interaction of these factors impacts functioning and community integration and participation (Chan et al., 2009). The ICF provides a framework where the medical and functional/social aspects of

disability are considered complementary (Smart, 2005), it is compatible with the philosophy and values of rehabilitation counseling (Bruyere, 2005; Peterson & Rosenthal, 2005a; Smart, 2005), and it has several applications in research and practice.

Peterson and Threats (2005) noted the consistency of the ethical provisions of the ICF with the ethical tenets of counseling and psychology, particularly in the areas of respect and confidentiality, clinical use, and social use. Smart (2005) suggested that "use of the ICF will build upon the model and foundation of rehabilitation counseling" (p. 195). The ICF provides standardization of definitions and terms across different professions and countries, where a common language can be used and understood (Peterson & Rosenthal, 2005a); this is particularly important in rehabilitation, where teams are often multidisciplinary and professionals often interface with people from other disciplines. Bruyere et al. (2005) summarized previous authors' optimistic comments about the ICF, proposing that "the ICF's new language is an exciting landmark for rehabilitation, potentially leading to a stronger position for rehabilitation within the medical community, enhanced multiprofessional communication, and improved communication between patients and rehabilitation professionals" (p. 113). Suggested uses of the ICF model in rehabilitation counseling include the following areas: funding and reimbursement systems, assessment of eligibility for services, service provision, staff training and preparation, outcome assessment, and research and knowledge generation (Bruyere, 2005; Smart, 2005).

Wade and Halligan (2003) and Whiteneck and Dijkers (2009) discussed some of the limitations of the ICF and recommended some modifications to the model to increase its utility for explaining human behaviors and human experiences, aside from those associated with illness and disease. Recommended additions included consideration of temporal factors and adding a quality of life component to make the tool more person-centered. Additional clarifications were

recommended in some of the more ambiguous aspects of the model, particularly related to how we should interpret "participation" and "environment." Whiteneck and Dijkers (2009) argued, as others have, that the difficulty in separating activity and participation creates a barrier to practical use of the ICF model. Several conceptual shifts for participation were suggested, among them was to more accurately describe participation as a social perception of functioning, or how the person fills social roles. Whiteneck and Dijkers also pointed out the difficulty in assuming a direct relationship between environmental barriers and participation. Rather, that the relationship between environment and barriers to participation (or inclusion) is more complex, citing findings that in some cases, individuals who report higher numbers and more complex barriers are those with active social and professional lives. Individuals who do not fill as many social and professional roles do not encounter as many barriers; however, their participation is lower.

Wade and Halligan recommended empirical testing of the model in clinical practice. The suggested additions and clarifications to the model were particularly relevant for the present study where the goal was to examine QOL within the context of function, activity, participation, and environment. As noted by Whiteneck and Dijkers (2009), strength of the model is that it does include community participation and environmental factors in the conception of disability and the impact; however, care must be taken in how these parts of the model are measured and participant responses are interpreted. Wade and Halligan also suggested that the lack of QOL measurement in the model itself is indicative of a larger limitation: that the ICF does not inherently take into account the differences in perception between the person and the external observer (e.g., medical staff) in the assessment and evaluation of function and contextual factors. As authors noted, specifics such as the age of onset of the health condition, the circumstances of
the onset, the expected course and prognosis of the condition, stage of life, and stage of illness impact people and their experiences with the condition, treatment, and impact on activities and participation. Adding a QOL component to the ICF serves to add greater focus on personal values and makes the ICF more person-centered, allowing for a comparison between personal perspective and more objective external measures of health and function.

Quality of Life and Rehabilitation Counseling

Despite the fact that discussions of defining and utilizing QOL as an outcome measure of rehabilitation services have been going on for several decades (e.g., Alexander & Willems, 1981; Cardus, Furher, & Thrall, 1981), the relationship between currently utilized outcome measures of rehabilitation services and a comprehensive measure of QOL has not been thoroughly evaluated. The majority of research concerning quality of life has gone on outside of rehabilitation and disability studies (Dijkers, 1997). Campbell, Converse, and Rodgers (1976) made the following statement about quality of life and the challenge associated with focusing on it in clinical practice and research: "Quality of life is a vague and ethereal entity, something that many people talk about, but which nobody very clearly knows what to do about" (p. 471). The issues described well by these authors result in many different descriptions and operational definitions, and, to some, make QOL less useful as a concept (Dijkers, 1997). The following is a discussion of QOL, including definitions, current status of measurement, assessment issues, and findings from QOL research in the general literature and in rehabilitation counseling.

Defining Quality of Life

Defining QOL is difficult. Authors have referred to it as "ambiguous," "defying definition," and "individualistic in meaning" (Bishop & Feist-Price, 2002, p. 36). Common criticisms of QOL research, and particularly measurement, include that definitions are missing

from instruments, there is disagreement of what concepts are included within QOL consideration, and instruments lack an underlying theoretical framework (Dijkers, 1997). Admittedly, there is no universally accepted definition; QOL has different meanings and applications largely based on context (Bradford, Rutherford, & John, 2002). This is not surprising, given that QOL research is conducted in a variety of fields and for many different reasons.

There has been a clear evolution of thinking on QOL, what should be considered and what assumptions are inherent within each view. To give a broad historical context, Alexander and Willems (1981) explained that many efforts to measure QOL stem from the value of material well being, economic security prevalent in the 1950s and earlier, and the aspects of the human condition (e.g., personal freedom, leisure, intensity/emotion, enjoyment) that were valued in the social upheaval associated with the 1960s. Historical methods of assessing life quality have ranged from relying on social indicators such as population statistics and characteristics (i.e., wages, unemployment, gross national product, or housing) to create an aggregate group-level measurement, to more individually-based psychological assessments of happiness and general sense of well-being (Bishop, Chapin, & Miller, 2008; Felce & Perry, 1995). More subjective QOL measurement fits well with an empowerment model, and is essentially the reaction (as measured by positive or negative affect) to the level of congruence between aspirations or expectations and accomplishments (Dijkers, 1997). However, sole use of subjective QOL measurement does not account for the details of a person's situation, for example, safety, basic needs, and other aspects of life that are clear to the external observer but subject to personal interpretation.

Objective measurement of QOL is the sum of the measures of characteristics that can be pre-determined. The objective model of QOL fits well with the beneficence model; measures are determined by the researcher or clinician, and it is assumed that he or she knows what is best for the person. There is a clear idea of what is "good" and "bad," for example, among levels of income or education. A weakness of the objective QOL model is that it has a high likelihood of being impacted by researcher/clinician bias and dominant culture (Dijkers, 1997). It is generally accepted that a complete definition of QOL includes a combination of objective and subjective indicators, crosses life domains, and is inclusive of individual values (Felce & Perry, 1995). QOL has been used broadly to refer to a range of closely related constructs (Bishop, 2005), but for the purposes of this study I have focused on the subjective aspects of quality of life, and this term is used synonymously with subjective well being and life satisfaction.

The World Health Organization (WHO, 1998) defined QOL as "individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (p. 2). QOL can be understood as how satisfied a person is with life in general and with particular aspects of life and is often expressed as a result of the person's internal assessment and subjective perception of some personally meaningful standards (Bishop & Feist-Price, 2002; Terry & Huebner, 1995; WHO, 1998). Evidence has been found that this multiple-factor definition of quality of life applies to children as young as third grade (Terry & Huebner, 1995) and that perceptions of QOL are variable over time (Bishop et al., 2008).

Consistent with the assumption that QOL is a multidimensional construct, researchers have proposed that in order to gain a better understanding we must consider several different areas or life domains (Deiner, 1984). While each of these domains is part of our QOL perception, none

of them completes the picture. Commonly highlighted life domains to be included in QOL assessment are: physical health, psychological/emotional health, social support/social relationships, levels of independence, employment/productive activity, environment, material/economic well-being, spirituality/religion/personal beliefs (Bishop, 2005; WHO, 1998). Researchers have attempted to empirically verify these life domains through several methods, including factor analysis (Kinney & Coyle, 1992), meta-analysis (Hughes, Hwang, Kim, Eisenman, & Killian, 1995) and review of QOL definitions (Cummings, 1996). Findings have revealed that across studies common themes emerge. Kinney and Coyle interviewed 790 adults with physical disabilities to find what life domains they considered when assessing QOL. Results of a factor analysis demonstrated that satisfaction in seven domains explained 41% of the variance in life satisfaction: leisure, self-efficacy, standard of living, religion, family, civic participation, and health and accessibility. Hughes et al. (1995) reported that in their review of 87 studies where one or more QOL components was assessed as part of a conceptual framework, the target group was adults or young adults with disabilities, and outcomes assessed related to community based, integrated outcomes rather than ones that were sheltered or segregated. The authors compiled a list of 15 dimensions (presented in descending order of frequency): psychological well-being and personal satisfaction; social relationships and interaction; employment; physical and material well-being; self-determination, autonomy and personal choice; personal competence, community adjustment, and IL skills; community integration; social acceptance, social status, and ecological fit; personal development and fulfillment; residential environment; recreation and leisure; normalization; individual and social demographic indicators; civic responsibility; and support services received. Cummins (1996) reported that in an analysis of 27 definitions of QOL, the following domains were consistently

referenced: 85% included emotional well-being, 70% included health, 70% included social or family involvement, 59% included material wealth or well-being, and 56% included work or productive activity. Consistency among life domains that people most often consider when determining QOL and are present in definitions of QOL has been supported with empirical findings.

While the conceptualization of QOL as a determinant based on satisfaction within several life domains is consistent with previous research and makes sense intuitively, several critiques exist (Moons, Budts, & De Geest, 2006). For one, there are a limited number of domains and facets that can be included. Thus, not all aspects of life can be addressed (Moons et al., 2006). In measurement, this issue is clearly demonstrated in a less than perfect correlation between domain scores and the overall QOL score (Hsieh, 2004); simply put, it is impossible to include everything that is important to everyone. Research based on pre-set domains is based on the assumption that feeling satisfied with these domains is a valid determinant of QOL. At this point, it is relatively well accepted that while there is not a universal structure of life domains, sufficiently similar structures have emerged based on broad coverage of possible areas, followed by consensus and convergence over several decades of research (Deiner, 1984; Bishop et al., 2008; Trauer & McKinnon, 2001).

Challenges to QOL Assessment

Garratt, Schmidt, Mackintosh, & Fitzpatrick (2002) conducted a systematic analysis of QOL measures through the year 2000 and identified 1275 different instruments. They concluded that there are several types of measures, including: disease or population-specific, generic, dimension-specific (i.e., focused on a particular aspect of health such as depression), utility (i.e., developed for economic evaluation, producing a single index), and individualistic measures (i.e.,

patient-generated domains or domain weights). There has been growth in the number of available QOL measures, particularly among disease-specific instruments; however, there is little standardization in how QOL is defined, conceptualized, and measured (Garratt et al., 2002). Several other complications in QOL measurement exist, including how assessment is conducted of people in different developmental stages (i.e., children, adolescents, and adults), how to gather information from individuals with differing levels of ability to understand the concepts or provide accurate self-analysis (e.g., individuals with significant cognitive or affective disabilities and the use of proxies) and the known problem with accuracy of self-report on cognitive processes and their cause (Cummins, 2002; Jenney & Campbell, 1997; Nisbett & Wilson, 1977).

Additional issues in QOL assessment have to do with the limited trustworthiness of many instruments. Specific problems identified in the literature include: often instruments are not developed based on one conceptual definition or framework for understanding QOL, are not culturally relevant, are not general enough to be useful aside from health-related QOL assessment; or the psychometric properties have not been thoroughly evaluated to establish reliability and/or validity (Frisch, 2004; Gill & Feinsten, 1994; WHO, 1998). An additional complication noted is the phenomenon that people have been observed to have a relatively consistent reported QOL level worldwide; reports are approximately 70% (75% in Western nations), meaning that most people report being about 70% satisfied with their lives. In fact, worldwide, the variation in QOL report is relatively small despite great variation in living conditions and cultural factors that contribute to construction of QOL perception (Cummins, 2003). This information raises many questions regarding the accuracy of QOL measurement. Further investigation into the utility of Likert-scales, recommended number of points, and ability of instrument users to discriminate between points on the scale is recommended to strengthen the

accuracy of measures, in addition to more careful attention to the theoretical framework and cultural issues (Cummins, 2003; WHO, 1998).

Despite these difficulties or complications in measurement, being able to get information about QOL perceptions is critically important (WHO, 1998) because of the centrality of improving QOL to the underlying goal of all healthcare interventions, and the importance and utility as an outcome measure (Bishop et al., 2008; Frisch, 2004). Across sectors of healthcare, including mental health treatment and rehabilitation, clinicians are challenged to prove that treatment is effective in ways that are clinically significant (Frisch, 2004). This is particularly important in the current climate, with its emphasis on accountability and evidence-based practice (Bishop et al., 2008; Jenney & Campbell, 1997). QOL assessment is client-centered, and focuses on changes that are clinically significant to the individual (Frisch, 2004).

World Health Organization QOL Instrument

The World Health Organization Quality of Life (Brief Version; WHOQOL-BREF) was developed by the World Health Organization to be a culturally portable, internationally relevant tool to measure QOL perception. It represents an effort to address some of the shortcomings that exist in other QOL instruments was been selected for use in the present study. The WHOQOL-BREF has been used extensively in both research and clinical settings, and has been thoroughly evaluated for reliability and validity. The following is a description of the underlying conceptual framework and instrument development.

WHO researchers went through several stages to define and refine the domains in their instrument including internal expert review and simultaneous qualitative pilots in 12 countries (15 centers) including focus groups and item generation from both experts and the public (Saxena & Orley, 1997). The WHO used this information to first develop a comprehensive

measure of QOL, called the WHOQOL-100. Items were generated from the participating centers (n = 1800 items), and were reviewed by WHO staff for duplication among items and consistency with criteria, leaving 236 questions to be field tested in the 14 centers. Data from the field centers was used to refine the instrument into 100 items in its final version. This 100-item questionnaire was designed to provide a detailed assessment of individual facts of QOL, including six domains: physical capacity, psychological, level of independence, social relationships, environment, and spirituality / religion / personal beliefs (WHO, 1998). The WHO field tested this instrument multi-nationally, at 15 field centers, with a total sample of 8,294 participants. Participants were recruited according to age (50% over age 45, 50% 45 or younger), gender (50% male, 50% female), and health status ("well" and "ill" participants). During recruitment, specific attention was paid to including "ill" participants who were representative of health care users with a variety of diagnoses and varying degrees of disease and/or disability, and a quota was set to include at least 250 "ill" participants and 50 "well" participants from each center (WHO, 1998). The final version of the WHOQOL-100 included 100 questions on 24 facets relating to QOL in 7 life domains.

The WHOQOL-BREF was developed from the database of items and their validation data from the WHOQOL-100, as well as another data set that was not used for the WHOQOL-100 study. The database included information from centers from the original pilot (5 centers; 4,802 participants), field testing of WHOQOL-100 (13 centers; 4,104 participants), and new centers involved in field testing the WHOQOL-100 (5 centers; 2,369 participants). At least one item was selected from each of the 24 facets in the original instrument. Individual items were then examined by a panel to establish representativeness of the item for the facet as an effort to establish content validity. The instrument was revised based on recommendations from the

panel, including removing six items, and substituting four items that were judged to be more useful measures of the concept (WHO, 1998).

Empirical Evidence of Influences on QOL

In the general QOL literature, significant attention has been paid to defining influences on quality of life, including those internal to the person (e.g., age, gender, race, personality), social and participation related factors (e.g., education, employment, environment), and those related to happenstance or life events (Bowling, 1995; Campbell, 1976; Cummins, 1995; Deiner, 1984; Deiner & Suh, 1997; Dijkers, 1997; Herman, 2008; Wheeler, 1991). Findings indicate that there are observable patterns relative to how people consider and rate their subjective well being or QOL. The following is a sample of areas that have been investigated empirically, much of the findings come from a meta-analysis carried out by Deiner (1984).

Demographic factors.

Age, race, income, gender, personality, and biological factors have all been evaluated for influence over subjective well-being, and researchers have found that individual characteristics do influence QOL ratings (Herman, 2008). People with chronic illnesses, people with physical disabilities, and people from minority backgrounds consistently rate QOL lower than other people in the U.S. (Bowling, 1995; Cummins, 1995; Deiner, 1984). Findings on race are likely complicated by factors such as education, wealth, and urbanicity (Deiner). In terms of income, people who live in richer countries report higher levels of well being than those living in poor countries, and the same is true of individuals of high and low incomes. However, income seems to be less influential once basic needs are met. This measure seems to be sensitive to impact of social comparison, power and influence, and the complex relationship between income and one's ability to impact other life domains (Bowling; Deiner). In a national survey by Campbell,

Converse, and Rodgers (as cited in Campbell, 1976) from 1957-1972, when economic/social indicators of QOL in the U.S. were increasing, the proportion of the population who described themselves as 'very happy' declined steadily; and the most apparent decline was among the most affluent.

For age, research findings are inconsistent. In fact, results of a meta-analysis put the correlation near zero. The author noted that the lack of longitudinal studies may reflect age cohort differences rather than actual age differences (Deiner). Related to gender, where only small differences have been observed, for example, findings have included that younger women report higher levels of well being than younger men, and older men report higher levels than older women; however, differences seem small and authors question practical significance (Deiner). When personality factors were evaluated, the author was unsure of the representativeness of studies, but found that demographics only account for 10-15% of variance in subjective well-being. Other issues included the questions about the direction of the relationship, for example, do personality factors influence ratings of subjective well being, or does subjective well-being influence personality factors? For example, high self-esteem, locus of control, extraversion, and person-environment match as positively related to higher ratings of subjective well-being. Confounding variables such as life circumstances, levels of sociability, cultural context, and life circumstances were noted by the authors in the original studies. Intelligence was found to have no relationship with subjective well-being, and in some studies was reported as negative (Deiner, 1984).

Social and participation factors.

Several factors related to social relationships, associations, interactions and community participation have been evaluated for their relationship with QOL. Social relationships are

consistently recognized as a part of our QOL determinations; however, research indicates that the relationship between social contact and well-being is positive but may be complicated by other factors (Bowling, 1995). This is another instance where direction of the relationship is unknown: are people with a higher sense of well being more social, or are more social people more likely to have a higher sense of well being? The quality and type of social contact matters, and there are different findings related to the importance of acquaintances, close friends, and significant others when determining impact on well-being (Deiner). The impact of marriage and family has been found to be positive with QOL, but the effect is not always strong. However, marriage and family satisfaction are one of the strongest predictors of well-being in empirical studies (Deiner).

Studies of what contributes to well-being have also included participation factors, most notably employment, education, and religion (Bowling, 1995; Deiner, 1984; Herman, 2008). Findings have indicated that these variables do impact QOL ratings. For example, unemployed people had lower ratings of well-being, even after controlling for income differences. This suggests that the effect of unemployment goes beyond financial hardship. Additionally, job satisfaction has been found to be related to subjective well-being (Deiner). Education was found to have a small effect, and the authors noted that this is likely reflective of an interaction with other variables (e.g., income). In studies of participation in religion there were mixed results, the authors found support for positive relationship among faith, the importance of religion, religious traditionalism, and subjective well-being; however, other studies found no differences. Researchers are unsure of what factors interact, e.g., when does religious involvement impact well-being?

Life events.

People actively seek to maintain an internally set level of QOL, even in the presence of major life changes such as the onset of chronic illness or disability that causes an initial drop in QOL (Bishop, 2005). Overall, there is a consistent but modest relationship between life events and subjective well-being (Deiner, 1984). Three strategies are typically employed to deal with the impact of this significant life change, including changing situations, changing how we perceive situations, or accepting the new reality of the situation. For example, if a person is no longer satisfied in a life domain that was previously important, the person can either try to change their level of satisfaction, change their perception and possibly reduce their feelings of importance attached to that domain, or do nothing and accept the situation. Often, perceived control is related to QOL in adults experiencing chronic health conditions (Bishop, 2005), this is also true of adults adapting to other life changes (Deiner, 1984).

QOL Research in Rehabilitation

Rehabilitation counseling as a discipline has always had a focus on aspects of Quality of Life (QOL), as demonstrated through the concern for function and emotional and social wellbeing (Dijkers, 1997). Within rehabilitation, QOL research appears to have evolved under the assumption that QOL for people with disabilities is inherently different than for the general population. Initial findings from studies comparing quality of life ratings in samples of people who have disabilities with samples of people who do not have shown apparent differences in reported QOL (Fuhrer, 1994; Fuhrer et al., 1992; National Organization on Disability, 2004; Sacks & Kearn, 2008). However, some of these findings may be questioned on the basis of biased measurement; for example, relying on external objective measures or instruments that include references to relying on others to carry out daily living or questions about extent of use

of healthcare interventions (Kirchman, 1984; Schwartz et al., 2007), and must be balanced against findings from other studies where individuals with significant disabilities did not rate their QOL lower than others (Stensman, 1985). As was pointed out by the National Institute of Disability and Rehabilitation Research (1988), "operational definitions/determinants reflect researchers beliefs about what it is in life that really matters..." (p. 2), and thus, QOL research and results are influenced by researcher values and bias.

Additional efforts have been put into measuring health-related QOL and finding what contributes to QOL for people with a particular condition or receiving a particular treatment (e.g., Fuhrer et al., 1992; Kirchman, 1985; Miller & Chan, 2008; Shikako-Thomas et al., 2009). Other researchers have focused specifically on finding unique aspects of QOL for people with disabilities in general, through several methods including focus groups, interviews, and use of formal instruments (e.g., Lustig & Crowder, 2000; Pain, Dunn, Anderson, Darrah, & Kratochvil, 1998). Findings have informed the conceptualization of QOL as it is applicable to rehabilitation counseling, for example, highlighting the importance of the family and maximizing potential (Pain et al., 1998). Other areas of research have been QOL as it relates to adaptation to disability, including aspects of control and disability management (e.g., Bishop, 2005), and work contributing to the potential use of QOL as an outcome measure (e.g., Cardoso, Blalock, Allen, Chan, & Rubin, 2004; Dijkers, 1997; Wade & Halligan, 2003).

Within the rehabilitation QOL literature, there has been discussion of how to assess QOL given the range of ability to understand the concepts involved and accurately self-assess (e.g., Cummins, 2002; Fabian, 1991). Several authors have investigated the validity of responses among people with particular disabilities, for example, severe mental illness and intellectual impairments (e.g., Cummins, 2002, Lustig & Crowder, 2000). Results have indicated that

proxies are inaccurate reporters of QOL, and that people with disabilities are capable of giving their perspective on their own well-being, although some individuals are vulnerable to social desirability or acquiescence (Fabian, 1991). The use of proxies is particularly problematic when the rating is not well represented by observable behavior, when the proxy must estimate the functional status of the person. This is explained by the fact that, overall, proxies are largely unable to avoid the influence of their own personal values. If proxies must be used, researchers recommend that multiple people be approached, and, if possible, peers be utilized given their shared perspective (Cummins, 2002).

In summary, QOL research efforts in rehabilitation counseling have spanned several decades, and have reflected the evolution of prevalent models of disability in terms of methods used to evaluate QOL (e.g., external objective, subjective, function, etc.), interpretations of findings, and resulting conclusions and recommendations for practice. While researchers have considered contextual variables such as satisfaction with family life, social contacts, employment, access, control, adjustment, and the like, it is difficult to explain individual differences in ratings that may be due to contextual factors or personal factors without a conceptual framework that is inclusive of these factors.

Utilization of the ICF Model in QOL and Related Research

Previous research has acknowledged the compatibility between the ICF and investigations related to QOL, particularly in the areas of health-related QOL. The ICF has been used as a method of evaluating measurement tools (Cieza & Stucki, 2005), and in initial attempts to investigate the relationship between environment, participation, activity, and quality of life (e.g., Whiteneck, Brooks, Harrison-Felix, & Gerhart, 2004; Kennedy, Lude, & Taylor, 2006). The following is a brief review of these empirical works.

Pre-ICF, Fuhrer et al. (1992) investigated the relationship between life satisfaction, impairment, disability, and handicap among persons with spinal cord injuries living in the community. Findings indicated that while degree of disability or impairment did not directly influence life satisfaction ratings, social roles and activities did. The authors reported greater life satisfaction among individuals who were more active in maintaining social relationships, spent more time engaging in activities that were appropriate to the given age, gender, and culture of the participant, and were able to access their local environment. Additional findings were that 40% of the variance in life satisfaction was explained by self-assessed health, perceived control, and social support, as well as social integration, occupation, and mobility. Authors discussed the implications of these findings for the WHO model of disability, which at the time did not include contextual factors.

Also pre-ICF, Heinemann and Whiteneck (1995) used the ICIDH model to assess the relationships between disability, handicap, and life satisfaction among individuals with Traumatic Brain Injuries (N = 758) living in the community. Researchers used secondary data analysis to explore how personal factors, details of the injury, severity of impairments, individual performance on home and work activities, and community integration impacted reported life satisfaction. Findings indicated that the strongest predictors of life satisfaction were social and productive activity, but not home activities (e.g., taking care of household responsibilities). The model only explained 13% of the variance in reported life satisfaction, and authors suggested that more precise measurement techniques were required to clarify these relationships.

Cieza and Stucki (2005) utilized the ICF to evaluate health related QOL instruments in an effort to make content-based comparisons. Previous authors had noted the growth in the number of available QOL measures, particularly among disease-specific instruments; however, since

there is little standardization in how QOL is defined, conceptualized, and measured, and thus while psychometric properties can be compared, it is difficult to compare content (Cieza & Stucki, 2005; Garratt et al., 2002). Authors compared six commonly used generic measures (e.g., European QOL instrument, Medical Outcome Study- Short Form, Nottingham Health Profile, Quality of Life Index, WHO Disability Schedule, and WHOQOL-BREF) and linked the concepts of the measures to the most appropriate ICF category (or categories). For the six instruments, a total of 226 concepts were linked to the ICF for the 148 items. A total of 91 ICF categories were represented in the instruments in the sample, including 17 from body functions, 60 from activities and participation, 14 from environmental factors, and 14 from general or unspecified ICF concepts. The authors concluded that the content of the instruments was represented by the ICF categories, and therefore the ICF is a useful tool for comparing QOL instruments due to the common framework that it provides. Comparison of instruments allows clinicians and researchers to make more informed decisions about content when selecting instruments for use (Cieza & Stucki). Relevant to the present study, the authors also noted that contextual and environmental factors were "scarcely represented" in the six instruments in the sample, pointing to the need to gather additional information for a more complete assessment (p. 1235).

In a multi-national study, Kennedy et al. (2006) surveyed people with spinal cord injuries (N= 1000) in the UK, Germany, Austria, and Switzerland, in order to identify areas of unmet need in community integration. The authors also assessed mood, cognitive appraisal style, coping style, functional independence, and perceived manageability of disability. Results indicated that individuals in the sample were generally well-integrated into the community, except in the areas of occupation and economic self-sufficiency. Overall, participants were

judged to be psychologically well-adjusted to their disability. Almost half of the participants were dissatisfied with their employment situation, leisure, and ability to manage self-care. Most were satisfied with family life, contact with friends and acquaintances, and relationship with partners, although 70% were dissatisfied with their sexual lives. Pain had an impact on reported QOL. The results of this research highlight limitations in community participation that are common among samples of persons with disabilities and may play a role in QOL assessment.

Researchers have made some initial attempts to empirically validate the relationship between environmental factors, participation, and QOL. In a series of three studies with different samples, Whiteneck et al. (2004) attempted to use information on functional limitations and perceived environmental barriers to describe the kinds of barriers experienced, and the pervasiveness of barriers as related to participation, and to predict participation and reported life satisfaction. In the first study, the sample included individuals with and without disabilities, and results indicated a substantial gap in participation, particularly for individuals with severe disabilities in the sample. The participation gap was reduced when demographic factors, information on functioning, and environmental variables were included in the model.

In the second study, researchers studied the impact of environmental factors on participation and life satisfaction in a sample of individuals with Traumatic Brain Injury (N= 73). Results indicated that people who are married, older, unemployed, or not in school reported the most barriers to participation. The correlations between barriers reported were significant for the following areas: cognitive independence, mobility, occupational status, and life satisfaction. Results support the importance of environmental factors in both participation and QOL.

The third study was aimed at determining the relative impact of environmental factors compared with demographic characteristics, injury characteristics, and activity limitations among

a sample of individuals with spinal cord injuries (N=2762) one to twenty-five years post-injury. Environmental factors when considered with other factors were not significant factors in predicting participation, but substantially and significantly predicted life satisfaction. The authors proposed a revised conceptual model where participation is a moderator between environmental factors and QOL; and they recommended that continued research was needed to clarify these theoretical relationships.

Summary

Recommendations for utilizing QOL as an outcome measure of rehabilitation services have been going on for several decades (e.g., Alexander & Willems, 1981; Cardus, Furher, & Thrall, 1981). However, the relationship between currently utilized outcome measures of rehabilitation services and a comprehensive measure of QOL has not been thoroughly evaluated. Within the general QOL literature and in the rehabilitation counseling QOL literature, substantial efforts have gone into explaining how people construct their perception of QOL, what factors influence QOL ratings, and how QOL can and should be measured. For practical reasons, more direct measures of services are utilized, such as employment or increased independence. In order to determine the relationship between the currently accepted measures of service outcomes and QOL, a conceptual model of disability that recognizes the interactive relationship among impairment, function, and context is applied to QOL assessment. The use of the ICF framework allows the integration of medical and functional status, activities, participation, personal factors, and environmental factors in order to create a more complete picture of QOL and a greater understanding of aspects of QOL in a way that is inclusive, neutral, and culturally sensitive. The present study was designed to provide a comparison between typically defined and measured outcomes of rehabilitation services and a more comprehensive model of QOL.

Chapter 3

Methods

The purpose of this study was to utilize a comprehensive framework (the ICF) to conceptualize and measure QOL in two samples of adults with disabilities representing a range of individuals receiving disability-related services. The results provide a basis of comparison for how well typical measures of employment and independent living predict the more comprehensive measure of QOL and how this relationship varies by the two different samples included in the study. This study used a cross sectional survey method for data collection. The following sections include the research questions that were addressed, the sampling and procedures for recruiting participants, descriptions of the instruments including empirical validation, and a summary of the data analysis.

The specific research questions that were addressed:

- 1. Are the hypothesized components of the ICF model (function, activity, participation, and environmental factors) supported empirically?
- 2. What is the relationship between disability-related factors, activities, participation, environmental and personal factors with QOL? (Sub-question- do these results vary by sampling group?)
- 3. Do the components of the ICF model provide an improved way to measure QOL above typically derived outcomes of services (e.g., employment or independent living)?

Participants

Before planning this study, the researcher consulted with several key informants who are leaders in the disability community on areas of design, instrumentation, procedures, and sample recruitment. Two samples of individuals with disabilities were recruited, including university

students receiving services from the on-campus Resource Center for Persons with Disabilities (RCPD) and adults receiving services from a Community-based Rehabilitation Program (CRP). The university is a large, public university in the Midwest, with a resource center that arranges educational accommodations and support for students with documented disabilities. The CRP agency is also in the Midwest, and provides a range of services (both employment and residential) to individuals involved with vocational rehabilitation agencies, employment agencies, schools, and other community support service systems. These two recruitment sites were selected because they cater to two groups of individuals with disabilities, although both groups of individuals receive rehabilitation services related to education and employment. The sample of university students represents a group of individuals who are likely higher functioning with a history of success in education and strong potential for future employment. The sample of individuals receiving community-based services represents individuals with varying life circumstances, levels of functioning, and past history of success in education and / or employment. The two samples represent a range of individuals served by rehabilitation counselors, and having both ensured participants with variability in several key characteristics, such as age, education, work experience, life circumstance, etc.

The investigator reached out to key leaders from relevant organizations to get advice and assistance with participant recruitment. Advertising materials were developed and distributed through these outlets. Because of the historic difficulty of response rates for samples of adults with disabilities, the researcher attempted gather participants through targeted outreach and provided incentives for participation.

Instrumentation

The survey includes four sections that represent parts of the ICF model and QOL as the outcome of interest: (1) demographic information; (2) function, activities, and participation; (3) environmental facilitators or barriers to participation; and (4) quality of life. Due to the several decades of work available on QOL and instrument design, a validated instrument was selected for the present study. Additional validated instruments based on the ICF were used to gather data on function, activity, participation, and environmental factors. The following is a description of each section, including the name of the instrument, definitions and sample questions, and evaluation and psychometric information where applicable.

Demographic Information

Demographic information was collected in the following areas: area of residency (county), age, gender, highest level of education, marital status, occupational status (e.g., employment status), and type and duration of disability or chronic health condition. These questions were adapted from the WHOQOL-BREF (described below), and suggestions from the key informants that were consulted by the researcher prior to planning this study. These demographic variables were considered to be critical to include based on previous QOL research (c.f., Cummins, 2003; Deiner, 1984).

Function, activity, and participation

The World Health Organization Disability Assessment Schedule version 2.0 (WHODAS 2.0) was selected among available measures of disability function, activities, and participation for several reasons. The researcher secured a non-exclusive, royalty free license to use the WHODAS 2.0 and related materials for this study. The WHODAS 2.0 is the only instrument of function and disability based on the ICF framework (Üstün, Kostanjsek, Chatterji, & Rehm,

2010b). It is designed to measure levels of functioning, regardless of type of disability, as operationalized through questions on impairments, activity limitations, and participation restrictions (Üstün et al., 2010b). According to the WHO, the WHODAS 2.0 is, "a practical, generic assessment instrument that can measure health and disability at the population level or in clinical practice" (p. 4). The WHODAS 2.0 captures information within six domains of functioning, including: cognition (e.g., understanding and communicating with others), mobility (e.g., getting around), self-care (e.g., dressing, feeding), getting along with others (e.g., dealing with strangers, getting along with friends and family), life activities (i.e., Activities of Daily Living or ADLs), and participation (e.g., difficulty experienced taking part in typical community activities, dealing with barriers and hindrances). The WHODAS 2.0 is based on the framework of the WHO's ICF, and provides a general measure of functioning and disability in a way that is applicable across nations and cultures (Üstün et al., 2010a). The 36-item self-administered version was selected for the present study because it is considered the most detailed and allows for calculations of both domain scores and overall functioning score (Üstün et al., 2010b). See table 1 below for domain assessment areas and sample questions.

Table 1

Domains, assessment areas and sample questions from the WHODAS 2.0 (Üstün et al., 2010b)

Domain Cognition (i.e., understanding and communicating)	Assessment areas Communication and thinking activities, specifically: concentrating, remembering, problem solving, learning, and communicating.	Sample question In the past 30 days, how much difficulty did you have in learning a new task, for example learning how to get a new place?			
Mobility	Activities such as standing, moving around inside the home, getting out of the home and walking a long distance.	In the past 30 days, how much difficulty did you have moving around inside your home?			
Self-care	Hygiene, dressing, eating, and staying alone	In the past 30 days, how much difficulty did you have getting dressed?			
Getting along with others	Interactions with other people, and difficulties that might be encountered with this life domain due to a health condition; in this context, other people includes both those who are close to the person (e.g., spouse/partner, family, close friends), and those the person does not know well (e.g., strangers)	In the past 30 days, how much difficulty did you have in making new friends?			
Daily life activities	Daily life activities (i.e., those that people do most days such as domestic responsibilities, work, school, leisure activities)	In the past 30 days, how much difficulty did you have doing your most important work/school tasks well?			
Participation	Social dimensions such as community activities, barriers and hindrances in the persons immediate environment, and problems with other issues such as maintaining personal dignity. Also includes contextual factors affected by the person's health condition.	In the past 30 days, how much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way that anyone else can?			

Evaluation and Psychometric Properties of the WHODAS 2.0

Researchers from the WHO evaluated the psychometric properties of the WHODAS 2.0 utilizing several methods, including: test-retest reliability, internal consistency, confirmatory factor analysis, cross-cultural sensitivity to change, face validity, concurrent validity, and construct validity. These data were collected during a second wave of studies following instrument development, from sites in 16 countries (with the US containing multiple locations). Participants (N = 1,565) were recruited to ensure representation by age, gender, and health status. The ratios of individuals by characteristic are as follows: Gender (59.0% male; 41.0% female), age (18-54 years 83.3%; 55 and over 16.7%), individuals in good apparent health (23.4%), individuals who had physical disorders (25.9%), individuals with mental or emotional disorders (25.7%), and individuals with drug (10.7%) and alcohol (14.4%) use issues (Üstün et al., 2010b).

In order to evaluate test-retest reliability, interviews for participants were scheduled within seven days of each (mean interval 2.4 +/- 1.6 days) and conducted by two different interviewers. Test-retest reliability had an intra-class coefficient ranging from 0.69-0.89 at the item level, 0.93-0.96 at the domain level, and 0.98 at the overall level, indicating that were high levels of overlap between participants' answers between interviews. Cronbach's alpha was calculated as a measure of internal consistency, with results by domain as follows: Domain 1 (Cognitive) 0.59-0.70; Domain 2 (Mobility) 0.74-0.79; Domain 3 (Self-care) 0.47-0.73; Domain 4 (Getting along) 0.52-0.76; Domain 5 (Daily life activities) 0.88-0.94; and Domain 6 (Participation) 0.54-0.74. These values ranges vary, but meet the standards of acceptable to very good internal consistency (Üstün et al., 2010b).

The WHO research team conducted a confirmatory factor analysis to test the association between the factor structure of the items and the domains and any cross over among dimensions. The results supported the independent structure of the domains, and results were similar across testing sites (coefficients ranged from 0.82-0.98 across domains). In the responsiveness study, the WHODAS 2.0 was found to be at least as sensitive to change across time as similar measures of social functioning, and results held across individuals from socioeconomic and demographic factors indicating that the instrument is applicable to individuals from different cultures (Üstün et al., 2010b).

Validity of the WHODAS 2.0 was evaluated in several ways, including face, concurrent, and construct validity. The research team asked a group of experts to review the instrument, and 64% agreed that the content of the instrument measures disability according to the ICF framework. Additionally, results from the two waves of testing showed scores that were expected based on characteristics (e.g., the treatment groups scored significantly higher indicating disability than the general population). Relationships between participant group characteristics and instrument scores were all in the expected directions (Üstün et al., 2010b). These two results were taken as evidence of face validity, or that the questions on the instrument measure what is intended. Concurrent validity was assessed through administration of the WHODAS 2.0 along with other known instruments measuring similar constructs (e.g., The Medical Outcomes Study 36-item Health Survey, the Functional Independent Measure), as expected, the highest correlations were found among similar domains (e.g., instruments that have a mobility dimension), and results indicated that the WHODAS 2.0 has levels of similarity (0.45-(0.65) with these instruments but is measuring something unique from them. In terms of construct validity, authors proposed that this measure is consistent with the underlying concepts of health and functioning. Evidence of sensitivity to change after treatment and ability to differentiate samples of people with and without health problems were presented to support the

construct validity of this instrument (Üstün et al., 2010b). The WHOQOL-BREF (the selected QOL instrument for this study) was among the instruments evaluated, and authors were careful to note that although there is some correlation between instruments (0.68), they measure different aspects of the same domains. The WHODAS 2.0 measures what a person does in each domain, and the WHOQOL-BREF measures how a person feels about that domain (Üstün et al., 2010b). The use of these two instruments together in the present study to measure the different aspect of the same domains is important because it provides richer data on the participants, allowing the researcher to gather information on functioning, activity, participation and a more subjective measure of feelings about each domain.

Environmental Factors

Environmental factors, specifically whether the factors are a barrier or a facilitator of community participation were assessed through a modified version of a section of the ICF checklist, which is a clinical interview form that was created based on the ICF. The ICF checklist was found on the WHO website, and can be accessed at

http://www.who.int/classifications/icf/training/icfchecklist.pdf. The environmental questions were adapted from the structured interview, and were selected based on applicability to the study and recommendations gathered from key informants prior to study planning. Participants were asked about the following environmental factors: products and technology (e.g., assistive technology, medication); natural environment (e.g., climate); relationships and social support (e.g., family, friends, personal care or healthcare staff); attitudes of others (e.g., family, friends, personal care or healthcare staff); and services, systems, and policies (e.g., transportation, housing, employment, education). Participants were presented with the following scale to answer whether they feel the given environmental factor represents a barrier or facilitator: 1 =

Severe barrier; 2 = Moderate barrier; 3 = Mild barrier; 4 = Neither a barrier nor a help (facilitator); 5 = Mild facilitator; 6 = Moderate facilitator; or 7 = Substantial facilitator.; This section of the survey includes 18 questions and was designed to determine the person's perception of their community and immediate social environment and whether these aspects support or hinder their participation.

Quality of Life

The World Health Organization Quality of Life- Brief version (WHOQOL-BREF) was selected from the wide array of available QOL instruments for several reasons. The WHOQOL-BREF was developed by the World Health Organization to be a culturally portable, internationally relevant tool to measure QOL perception. It has been used extensively in both research and clinical settings, and has been extensively evaluated for reliability and validity. The following is a description of the instrument itself, how it was developed, and results from psychometric evaluation.

The WHOQOL-BREF is a 26 item instrument that measures subjective QOL. Items include 26 questions: 24 items representing the four life domains and two items aimed at measuring overall QOL. The domains include physical health and functioning (e.g., experience of pain, fatigue, difficulty with sleep), psychological health and functioning (e.g., mood, feelings, self-esteem), social relations (e.g., satisfaction with personal relationships, social support), and environment (e.g., feelings of safety and security, satisfaction with accessibility and quality). Table 2 contains information on each of the life domains and a sample question.

Table 2

Domains, facets, and sample questions from the WHOQOL-BREF

Domain	<u>Facets</u>	Sample question		
Physical capacity	The experience of pain and discomfort, energy levels and fatigue, and sleep and rest	To what extent do you feel that physical pain prevents you from doing what you need to do?		
Psychological	Positive feelings; thinking, feeling, memory, and concentration; self-esteem; body image and appearance; and negative feelings	How often do you have negative feelings such as blue mood, despair, anxiety, depression?		
Social relations	Personal relationships; social support; and sexual activity	How satisfied are you with your personal relationships?		
Environment	Physical safety and security; home environment; financial resources; health and social care: accessibility and quality; opportunities for acquiring new information and skills	Have you enough money to meet your needs?		

Evaluation and Psychometric Properties of the WHOQOL-BREF

The WHO carried out extensive evaluation of the WHOQOL-BREF, including a confirmatory factor analysis of the domain structure, a comparison between the WHOQOL-BREF and the WHOQOL-100, measures of internal consistency, discriminate validity, and the importance of each domain in assessing overall QOL (WHO, 1998). Based on results from the confirmatory factor analysis of the original instrument, instrument developers carried out the same test on the WHOQOL-BREF, seeking a model solution with a comparative fit index (CFI) of 0.9 or greater. This solution is an indication that the data fits the hypothetical model asserted by the structure of the instrument (e.g., the domains and facets). Using both data sets (the

original pilot centers (n=15); initial field trial centers (n=13), developers achieved a four-factor solution with CFIs of 0.906 and 0.903 respectively. Using the new data, the initial CFI was 0.87, suggesting that the data was not a good fit for the model. Authors made some alterations (e.g., allowing error variances for three items to co-vary, and two items to cross-load on other domains), and the CFI increased to 0.91. Authors concluded that the data was a good fit for the model utilized by the instrument (WHO, 1998). The WHO development team also performed correlational analysis to determine the relationship between domain scores on the WHOQOL-100 and items on the WHOQOL-BREF. Results indicated strong, positive relationships between the domains on each instrument within each data set, ranging from 0.89 in the social relationships domain to 0.95 in physical health (WHO, 1998). Cronbach alpha scores were calculated as a measure of internal consistency for each domain, and results indicated good internal consistency (scores ranged from .66 for social relationships to .84 for physical health; WHO, 1998). Authors cautioned that the scores for the social relationship domain were calculated with only three scores rather than four which is the generally acceptable minimum. The development team also evaluated the ability of the WHOQOL-BREF to discriminate between "ill" and "well" samples. Results of t-tests from all three data sets showed similar values and significant differences between samples in all domains, indicating that the WHOQOL-BREF is comparable to the WHOQOL-100 in discriminating between groups (WHO, 1998). Finally, the instrument was evaluated to determine the importance of the domains in assessing overall QOL. A multiple regression analysis was used to calculate the contribution of each domain to explain the observed variance in Overall QOL and General Health. Results showed that the combination of domain scores explained approximately 62% of the variance,

with physical health contributing the most (standardized beta = 0.31 - 0.38) and social relationships contributing the least (standardized beta = 0.13 - 0.15; WHO, 1998).

Miller et al. (2008), an external research team, also performed a confirmatory factor analysis on the WHOQOL-BREF with a sample of individuals who have incurred spinal cord injuries. Their results confirmed the four-factor solution (CFI = 0.96), consistent with the WHO team as well as other external researchers. Researchers also correlated the WHOQOL-BREF results with selected demographic characteristics to test for convergent validity. Results showed the relationships that were expected, for example, higher income was positively related to physical, social, and environmental well-being; and self-esteem and acceptance of disability were found to be positively correlated with QOL scores (Miller et al., 2008).

Data Collection

Procedures

Data was collected using two procedures tailored to the needs and characteristics of the two samples. The researcher discussed this study with several community partners, including several leaders involved with Independent Living Centers and community-based rehabilitation organizations, as well as contacted the University Resource Center for Persons with Disabilities to strategize methods of data collection. To plan the dissemination method for each sample, the researcher worked with appointed staff from each organization to determine the most effective and convenient way for the potential participants to participate. At this time, the researcher also solicited advice on the incentive that would be most appropriate. One procedure, an online dissemination of the survey was carried out for the university student sample and a combination of in-person, paper based and online dissemination methods were carried out for the sample of adults receiving community-based rehabilitation services.

Informed consent procedures were followed in a verbal explanation and written document when the data is collected in person, and a written document that appeared as part of the online survey. In order to protect confidentiality, no identifying information was collected. Paperbased data is stored by the researcher, and raw data was not provided to others aside from the dissertation chair and committee members if necessary. The online data is stored on a password protected server. Downloaded data is stored on the researcher's computer, in a password protected file.

Pilot

Prior to data collection, the survey was piloted in both forms (paper and electronic) with several individuals to ascertain an estimated length of time that the survey will take, as well as gather feedback on clarity, readability, and ease of use of the instrument. A total of 13 individuals participated in the pilot, five using the paper/pencil version and eight accessing the electronic version. Alterations were made to the instrument according to suggestions, most notably selected instructions and formatting in an effort to increase clarity.

Dissemination

The survey was disseminated to the two samples in two different ways. For the university students, the survey was distributed via email. For the community sample, the survey was distributed both in person by the researcher, as well as via email to employees who do not work at the main building.

Response bias

Given the exploratory nature of the study, there was some expected response bias. The researcher made an effort to gather as large and varied a sample of participants as possible and will report limitations of the study given the kind of participants who completed the survey.

Ethical precautions

The sample was limited to adults over age 18. All potential participants received information about the purpose of the study, confidentiality, and how the data will be used and disseminated. Potential participants were informed that they could have skipped any questions they did not feel comfortable answering, and they could have voluntarily withdrawn their participation at any time prior to submission of data. Individuals were informed that they may request help with any part of the survey from any person of their choice and were provided with the researcher and the dissertation chair's contact information so they could express any concerns or ask questions. Resources were provided within each of the recruitment sites for assistance should any of the questions invoke a negative reaction in any potential participant.

Data analysis

Data analysis included several approaches to address the research questions. Prior to analysis, descriptive statistics were computed on the sample demographic characteristics for the following categorical variables: (a) gender; (b) age; (c) race; (d) educational experience; (e) marital status; (f) work status; (g) disability type; and (h) duration of disability or health condition. Data were also examined for relationships between and within factors. Q1: Are the hypothesized components of the ICF model (function, activity, participation, and environmental factors) supported empirically? To answer this question, items were centered around the sample mean and entered into an exploratory principal components analysis with oblique rotation. Standardized factor scores were generated for use in the other analyses. Q2: What is the relationship between disability-related factors, activities, participation, environmental and personal factors with QOL? Do these results vary by sampling group? To answer this question, QOL was regressed on personal factor variables (e.g., gender, age, race, marital status, education, disability type and duration), and the factor scores from the principal components. This analysis was also performed with using mean-centered variables to remove variance associated with sample as a large group (N = 346), and then using a within-groups analysis (with the original demographic variables) to answer the sub-question.

Q3: Do the components of the ICF model provide an improved way to measure QOL above typically derived outcomes of services (e.g., employment or independent living)? To answer this question, a block regression approach was used. The first entry was the demographic variables, the second was the component scores from the work and non-work activities (representing difficulty with work and independent living), and the third entry was the rest of the components representing the full ICF model. This analysis was also performed with using mean-centered variables to remove variance associated with sample as a large group, and then using a within-groups analysis to answer the sub-question.

Summary

To address these research questions, participants were presented with a 95-item survey with sections on demographic information; disability function, activity, and participation; environmental factors; and quality of life. Participants were recruited from a university setting and a community-based services setting. Data were analyzed to determine: whether the dimensions of the ICF model are independent when applied to QOL assessment, how individuals rate QOL within the context of this expanded, more theoretically driven model of QOL assessment, and whether the expanded model of QOL assessment provides increased information when compared with more typically utilized outcome measures of rehabilitation services.

Chapter 4

Results

The purpose of this study is to utilize a comprehensive framework (the ICF) to conceptualize and measure QOL in two samples of adults with disabilities representing a range of individuals receiving disability-related services. The results provide a basis of comparison for how well typical measures of employment and independent living predict the more comprehensive measure of QOL and if this relationship varies by the two different samples included in the study. Prior to addressing the research questions, the response rate and some basic characteristics of the samples are provided. All analyses were conducted using the Statistical Package for the Social Sciences 19 for Windows (IBM, 2010).

Participants

The target population for this study was adults with disabilities. To ensure inclusion of participants with a variety of life circumstances (or contextual factors), participants were recruited from two samples: (1) students from a large public university who utilized services from the Resource Center for Persons with Disabilities (RCPD); and (2) clients from a large community rehabilitation center. Although these samples were targeted due to the likelihood that there would be some differences between participants, individuals from both of these groups are among those who would likely to be seen by a rehabilitation counselor under similar conditions, and would likely be involved with similar types of services.

For the student sample, the survey was emailed by the director of RCPD to 1,022 current students. A total of 136 surveys (13.3%) were returned and 122 (11.9%) had sufficient data to be retained in the final sample. Two survey approaches were used for the CRP sample. During the in-person data collection, a total of 236 surveys were distributed. Of these, 200 were returned.

Surveys were also distributed online (to 300 people), and 40 were returned. Of the 240 total surveys returned (44.8%), 224 (41.7%) had sufficient data to be retained in the sample. The final samples included 122 students and 224 CRP clients, for a total of 346 participants (22.2% overall response rate). The procedures followed for data entry and missing data are outlined in the next section.

Data Entry and Missing data

Survey data from the electronic surveys were downloaded directly from the server and imported into SPSS. The paper surveys were entered by the researcher using a double entry check method. All paper surveys were entered twice, and then cross checked for inconsistencies between entries. Inconsistencies were resolved by verifying the data from the original survey. The researcher examined all survey responses for missing data, and immediately discarded individuals who did not meet the criteria or provided low quality responses (e.g., same answer for entire survey). Because of the length of the survey and typical response patterns of the intended audience, 28% of the CRP sample and 23% of the student sample had at least one missing data point. Participants who did not answer the question regarding their QOL were not included in the final sample. For the WHODAS 2.0 and Environmental sections of the survey, the researcher replaced missing values with a single imputation method (i.e., the median score for the sample) to maximize the number of participants who could be retained in the sample.

Participant Characteristics

A primary objective in the data collection process was obtaining a sample that represented individuals with a range of personal factors (e.g., race, age, disability type, education, etc.). Table 3 shows participant demographics.

	Students		CRP Clients		Total	
Variable	n	%	n	%	n	%
Gender						
Female	95	78.5%	126	57.0%	221	64.6%
Male	26	21.5%	95	43.0%	121	35.4%
Age						
25 and younger	89	74.8%	28	13.0%	117	35.0%
26-45	23	37.8%	83	38.6%	106	31.7%
46 and older	7	5.9%	104	48.4%	111	33.2%
Race/Ethnicity						
White	100	82.0%	126	57.0%	226	65.9%
Black/ African American	10	8.2%	53	24.0%	63	18.4%
Hispanic/Latino	3	2.5%	14	6.3%	17	5.0%
Asian/Pacific Islander	1	0.8%	10	4.5%	11	3.2%
Multiracial	5	4.1%	12	5.4%	17	5.0%
Other	3	2.5%	6	2.7%	9	2.6%
Marital Status						
Never married	99	81.1%	94	42.5%	193	56.3%
Co-habitating	8	6.6%	5	2.3%	13	3.8%
Married or partnered	9	7.4%	72	32.6%	81	23.6%
Separated	1	0.8%	10	4.5%	11	3.2%
Divorced	5	4.1%	31	14.0%	36	10.5%
Widowed	0		9	4.1%	9	2.6%
Disability Type						
Blind or visually impaired	4	3.3%	5	2.3%	9	2.6%
Deaf or hearing impaired	4	3.3%	5	2.3%	9	2.6%
Mobility impaired	8	6.6%	12	5.5%	20	5.9%
Brain injury	3	2.5%	9	4.1%	12	3.5%
LD/ADHD	31	25.4%	48	22.0%	79	23.2%
Psychiatric/mental health	30	24.6%	41	18.8%	71	20.9%
Chronic health condition	25	20.5%	39	17.9%	64	18.8%
Autism spectrum disorder	5	4.1%	5	0.3%	10	2.9%
Other*	12	9.8%	54	24.8%	66	19.4%

Table 3Participant Characteristics related to Personal and Disability Factors
Table 3 Cont'd

	<u>S</u>	tudents	С	RP Clients	Т	<u>otal</u>
Variable	n	%	n	%	n	%
Disability Duration						
Less than one year	1	0.8%	7	3.3%	8	2.4%
1-4 years	23	18.9%	11	5.2%	32	10.1%
5-9 years	30	24.6%	39	18.3%	69	20.6%
10 years or longer	39	32.0%	93	43.7%	132	39.4%
Since birth	29	23.8%	63	29.6%	92	27.5%
Level of Education						
Less than HS	0		23	10.5%	23	6.7%
Some HS	0		25	16.1%	25	7.3%
HS graduate/GED	15	12.3%	81	37.0%	96	28.2%
Some post-secondary	56	45.9%	57	26.0%	113	33.1%
Associate's degree	9	7.4%	15	6.8%	24	7.0%
Bachelor's degree	28	23.0%	13	5.9%	41	12.0%
Master's degree or higher	14	11.5%	5	2.3%	19	5.6%
Living Situation						
Own apt/home	70	57.4%	185	84.5%	255	74.8%
Other's apt/home	5	4.1%	20	9.1%	25	7.3%
Group living situation	2	1.6%	8	6.4%	10	2.9%
Homeless shelter	0		3	1.4%	3	0.9%
College/university housing	41	33.6%	0		41	12.0%
Other	4	3.3%	3	1.4%	7	2.1%
Occupational Status**						
Paid employment	56	45.9%	204	91.0%		
Self-employment	8	3.6%	2	1.6%		
Non-paid employment	17	11.5%	4	1.8%		
Student	113	92.6%	5	2.2%		
Retired	2	1.6%	3	1.3%		
Unemployed-seeking work	11	4.9%	4	3.3%		
Unemployed-not looking	4	3.3%	1	0.0%		
Other	2	1.6%	4	1.8%		

*Of individuals indicating "Other"- 8 students and 26 CRP clients indicated multiple disability types, and 10 CRP participants did not indicate a disability type.

** Participants could indicate more than one occupational status.

n.b.- Due to missing data, participant responses may not all add up to 346.

The participants in the two sample groups differed by personal characteristics. Chisquare analyses or independent sample t-tests were performed on each personal characteristic variable. Gender ratios were significantly different between samples ($\chi^2 = 15.807$; p < .001; df = 1). The student sample was very heavily female (78.5%) while the CRP sample had a higher proportion of females to males but was more evenly distributed by gender. Proportion of participants by race was also significantly different between samples ($\chi^2 = 24.141$; p < .001; df = 5). The student sample was mostly White (82%). The CRP sample showed more diversity, with 43% of participants coming from racial/ethnic minority groups. A more detailed breakdown is available in table 3. The students were younger than the CRP participants (students M = 25.23, SD = 8.91; CRP customers M = 42.89 SD = 13.45; t = 14.886; p < .001). Groups were also significantly different in terms of marital status ($\chi^2 = 61.513$; p < .001; df = 5). As might be expected, 86% of the student sample was non-married or partnered. About two-thirds of the CRP sample was not married or partnered, while one-third reported being married/partnered or living with a significant other. The student sample had levels of education ranging from high school graduate or equivalent to Master's degree or higher. The majority of students had completed some post secondary education, with another 23% completing a Bachelor's degree. The CRP sample had a wider distribution of educational levels, with the largest group earning a high school diploma or the equivalent, and another 26% with some post secondary education. The proportional difference in educational level was significant ($\chi^2 = 83.825$; p < .001; df = 6).

There were no differences in proportion of reported disability type between the two samples ($\chi^2 = 13.114$; p = .108; df = 8). The largest proportion of students reported learning disabilities or attention-deficit hyperactivity disorder as their primary disability type, psychiatric or mental health was second most common, and chronic health conditions as the third most common. Ten students reported "other" and the majority of these respondents (8) indicated multiple disabilities. In the CRP sample, the majority of respondents indicated learning disabilities or attention-deficit hyperactivity disorder as their primary disability type, with "other" (n=54; 24.8%) as second most common. Of those reporting "other," 26 individuals reported multiple disabilities and 10 chose not to indicate a disability type or indicated the kind of services they receive at the CRP. In each group, the largest proportion of participants reported having their disability or health condition for 10 years or longer. The second largest group in the student sample was "5-9 years." In the CRP sample, the second largest group was "Since birth." Differences in duration of disability between samples was significant ($\chi^2 = 21.427$; p <.001; df = 4). The differences observed between groups support looking at the groups separately as well as overall.

With respect to occupational status, respondents were asked to indicate as many of the options as applied to them. Considering the environment, it is not surprising that 91% of CRP respondents indicated that they are employed, with only a small number of respondents indicating a different occupational status. Also not surprising, 92% of students indicated "student" as an occupation status, with another 45% indicating some paid employment and 11% indicating non-paid employment. Five percent of students indicated that they were unemployed but seeking work.

Although data are not available to compare comprehensively the participants of each sample to their respective populations, some information is available to provide a general context. For the student sample, information on disability type and grade level was available. Compared with the population information, the student sample had a similar proportion of

individuals by disability type with the population, with the exception that the sample contained a lower proportion of individuals with LD/ADHD (46% in the population, 25% in the sample) than the population and a higher proportion of individuals reporting chronic illness (15% in the population, 20% in the sample). Although grade level does not directly correspond with age, 82% of the individuals who receive services from the resource center are undergraduates, which match up with the mean age and age range of participants in the student sample (University Resource Center for Persons with Disabilities, 2010). Looking at the broader university community, the proportions of individuals by race/ethnicity are similar to the individuals in the sample. However, the gender ratios are very heavily female in the student sample, which does not correspond well to the broader university population which is nearly half male and half female (University Report, 2011).

According to the National Center for Educational Statistics (NCES), approximately 11% of college students report having at least one disability (Snyder & Dillow, 2012). Among college students reporting a disability, approximately 57% are female, and 42% are male (Aud et al., 2012). This ratio is different than the gender ratios reported by the sample (78% female). With respect to age, NCES reported that 54% of college students with disabilities are between 15 and 23; 20% are between 24 and 29, and an additional 26% are thirty years of age and older (Snyder & Dillow, 2012). The present sample was a bit younger, with 62% aged 23 or younger, 16% between 24 and 29, and 20% aged thirty or older. Similar to the present sample, employment figures for college students range from 40-51% of full time students engaging in at least part time employment. For students attending school part time, employment estimates are as high as 73% of students who are also working (Aud et al., 2012).

For the CRP client group, the participants appear to be consistent in gender ratios and representation by race/ethnicity to the population from which they were recruited. Comparison of disability type is more difficult since the existing data from the CRP does not contain the same disability variables. The participants seem to match up well with the exception that the population of CRP clients has a higher proportion of individuals with mental illness and chronic illness. However, the participants in the sample had the option to select "other" for disability type, and many (25%) did so and indicated multiple disabilities. The data from the CRP does not have an "other" category, and no way for participants to indicate multiple disabilities. The participants in the study had a higher level of education on average than the CRP client population (Program Report, 2011).

Research Questions

Research Question One: Are the hypothesized components of the ICF model (function, activity, participation, and environmental factors) supported empirically?

Question one is intended to ascertain whether the data collected from these samples supported the components and structure of the ICF model. To answer this question, two exploratory analyses were required utilizing data from two separate parts of the instrument. Principal components analyses with eigenvalue extraction and an oblique rotation based on the domains derived from the WHODAS 2.0 (covers function, activity, and participation) and the environmental section (covers products/technology, support/relationships, attitudes, natural environment, and services) were conducted separately (See table 4). These analyses had to be conducted separately because the sections of the instrument used different scales so the items could not be combined into one analysis.

The exploratory Principal Components Analyses were conducted with all participants in an effort to extract a common set of components, which are required to compare results across samples. While it is recommended to ensure that samples are homogenous when conducting this analysis to enhance validity (Ho, 2006), the goal of the study is to evaluate a comprehensive model for assessing quality of life that would be more widely applicable than past efforts (e.g., quality of life studies that are specific to one disability group). Additionally, despite the demographic differences between samples, both groups represent individuals who pursue and are provided rehabilitation services related to education and work. To account for the demographic differences, a pooled within groups variance matrix approach was used where items were centered around the sample mean.

Table 4

ICF Model Components and Domains by Instrument Section

ICF Model Components (Instrument Section)	Domains
Personal Factors	N/A – ordinal or nominal variables
Environment (ICF Checklist- Environment)	Products and technology Support and relationships Attitudes Services and systems.
Function (WHODAS 2.0)	Cognitive Mobility Social Self-care
Activities (WHODAS 2.0)	Work-related activities Non-work activities
Participation (WHODAS 2.0)	Participation

Function, Activity, Participation

The ICF model hypothesized that function, activity, and participation are independent components. Using the items from the WHODAS 2.0, a 6 component solution explaining 67.85% of the variance was reached. Four items were dropped from the analysis due to cross loadings or low (< .4) item loadings (Ho, 2006). Table 5 below displays the variance explained and table 6 shows the rotated pattern matrix. Standardized component scores were generated using the regression score estimation method for each of the components for use in the additional analyses. The regression estimation method is computed by SPSS via standardizing the variable scores for each participant, and weighting by the factor loading coefficient (Tabaschnick & Fidell, 2007).

Compared with the original ICF model, which was the basis of the WHODAS 2.0 instrument, the components resulting from the analysis were similar but not an exact match. The first component contained four items from social and three from participation, specifically the items that indicated difficulty with feeling included in the community. One item from the original social domain, "difficulty with sexual activities," was dropped from the analysis because it cross-loaded with impact on self and family. The second component contained all five items from the mobility domain, and two from the self-care domain. The other two items from the original self-care domain, eating and staying alone, were removed from the analysis. "Difficulty eating" cross-loaded on both self-care and social, and "difficulty staying alone" had low item loadings. The third component contained the remaining four items from the original participation domain, and had an underlying theme of the impact of the disability or health condition on the person or their family (called "impact on self/others"). The fourth component contained all four items from the original "non-work activity" domain, and contained a theme of

attending to household responsibilities. The fifth component contained 5 of the 6 items from the original cognitive domain, the remaining item, "starting and maintaining a conversation," was dropped from the analysis because it cross-loaded on both the social and cognitive components. The shared variance in this item was an interesting observation, because it highlights the overlap between the cognitive and social elements of the task. The sixth and final domain included all four items from the original work-related activity domain. Figure 3 is a visual depiction of the items as they were organized with the WHODAS 2.0 and then how items grouped together to form components as a result of the analysis.

Table 5

Total Variance Explained by the Six-component Solution

	<u>Initial E</u>	Eignvalue	S	Extracti	on		Rotation
	Total-%	6Var-Cu	n %	Total -9	6Var-Cu	m %	Total
Social/inclusion	11.762	36.756	36.756	11.762	36.756	36.756	6.594
Mobility/self-care	2.762	8.630	45.386	2.762	8.630	45.386	6.383
Impact	2.263	7.073	52.459	2.263	7.073	52.459	4.706
Non-work	1.969	6.155	58.613	1.969	6.155	58.613	6.794
Cognitive	1.615	5.047	63.660	1.615	5.047	63.660	4.725
Work/School	1.342	4.194	67.854	1.342	4.194	67.854	6.303

Table 6Rotated Pattern Matrix of Components

			Compo	onents ¹		
Item (ICF Domain ²)	1	2	3	4	5	6
Concentrating (C)					.743	
Remembering (C)					.767	
Analyzing problems (C)					.738	
Learning new tasks (C)					.665	
Understanding others (C)					.499	
Standing for 30 minutes (M)		680				
Standing up from sitting (M)		829				
Moving inside home (M)		745				
Getting out of home (M)		687				
Walking long distances (M)		754				
Washing self (S-C)		547				
Getting dressed (S-C)		618				
Dealing with strangers (S)	.757					
Maintaining friendships (S)	.822					
Getting along with those close to you (S)	.607					
Making friends (S)	.806					
Taking care of household tasks (NW)				837		
Doing household chores well (NW)				827		
Getting all housework done (NW)				828		
Getting work done quickly (NW)				794		
Work/School Activities (W)						760
Doing tasks well (W)						745
Getting all tasks done (W)						786
Getting tasks done quickly (W)						772
Joining community activities (P)	.513					
Barriers/hindrances in world (P)	.481					
Living with dignity (P)	.569					
Time spent on condition (P)			.688			
Emotional consequences (P)			.683			
Drain on family resources (P)			.712			
Emotional consequences family (P)			.755			
Independent leisure (P)			.570			

¹ 1 = non-work activities; 2 = mobility/self-care; 3 = social relationships & inclusion; 4 = impact on self/family; 5 = cognitive; 6 = work/school activities.

² ICF Domains: C = Cognitive; S = Social; M = Mobility; S-C = Self-Care; W = WorkActivities; NW= Non-Work activities; P = Participation.

Table 6 cont'd

*removed items: (1) starting conversations (C) -social and cognitive; (2) eating (S-C)- self-care and social; (3) staying alone (S-C) -low loadings; and (4) sexual activities (S)- social & impact on self and family.

Figure 3

WHODAS 2.0 items and resulting components



Figure 3 cont'd



Note: * indicates that item dropped from the analysis due to low or cross-loadings.

Environment

The ICF checklist included four aspects of environment that are assessed separately: products and technology; support and relationships; attitudes; and services. When the items from the ICF checklist were entered into a Principal Components Analysis with an oblique rotation, three components were extracted that explained 57.85% of the variance. The components were a very close match to the original, the only exception was that the items regarding "support and relationships" and "attitudes" loaded on the same component, although "attitudes observed in the community" loaded on the services component. Table 7 below displays the variance explained and table 8 shows the rotated pattern matrix. Figure 4 is a visual depiction of the items as they were organized with the ICF checklist and then how items grouped together to form components as a result of the analysis. Standardized component scores were generated using the regression score estimation method for each of the components for use in the additional analyses. The regression estimation method is computed by SPSS via standardizing the variable scores for each participant, and weighting by the factor loading coefficient (Tabaschnick & Fidell, 2007).

Table 7

Total Variance Explained by the Three-component Solution

	<u>Initial I</u>	Eignvalue	S	Extraction S	SS Loadin	ngs R	otation SS Loading	gs
	Total-%	6Var-Cun	n %	Total -9	%Var-Cu	m %	Total	
Services	7.552	41.954	41.954	7.552	41.954	41.954	4 5.897	
Supp./Attitudes	1.536	8.531	50.486	1.536	8.531	50.480	5 5.575	
AT & access	1.330	7.390	57.875	1.330	7.390	57.875	5 4.806	

Table 8

Rotated Pattern Matrix of components

	Com	ponents ³	
Item (ICF Checklist domain ⁴)	1	2	3
Societal attitudes in the community (A)	.444		
Health Services (S)	.407		
Education and training (S)	.657		
Employment (S)	.609		
Accessible transportation (S)	.578		
Legal services (S)	.843		
Social Security (S)	.855		
Accessible housing (S)	.794		
Attitudes of family (A)		.843	
Attitudes of friends/acquaintances (A)		.705	
Attitudes of personal care staff/healthca	re workers (A)	.700	
Relationships with friends/acquaintance	s (S&R)	.534	
Relationships with immediate family (S	&R)	.707	
Relationships with personal care staff/			
healthcare workers (S&R)		.821	
Products for personal use (P&T)			.552
Products for mobility/transportation (P&	żΤ)		.826
Public and Private buildings (P&T)			.741
Products for communication (P&T)			.844

 $^{^{3}}$ 1 = services & community attitudes; 2 = relational support & attitudes; 3 = assistive technology & accessibility 4 P&T = Products and Technology; S&R = Support and Relationships; A = Attitudes; S =

Services

Figure 4 *ICF checklist items and resulting components*

ICF Checklist Items & Domains	Resulting Components
Products & Technology Personal products for use in daily living Products for mobility/transportation Products for communication Public and private buildings	Assistive Tech & Accessibility Products for use in daily living Products for mobility/transportation Products for communication Public and private buildings
Support & Relationships Relationships w friends and acquaintances Relationships w immediate family Relationships w personal care staff & healthcare workers	Relational Support & Attitudes Relationships w friends & acquaintances Relationships w immediate family
Attitudes Attitudes of friends & acquaintances	Attitudes of friends & acquaintances Attitudes of immediate family Attitudes of personal care staff, etc.
Attitudes of immediate family Attitudes of personal care staff/healthcare workers Attitudes I observe in my community	
Services	Services & Community Attitudes
Health services	Attitudes I observe in my community
Education and training	Health Services
Employment	Education & training
Accessible housing	Employment
Legal	Accessible housing
Social security & other support systems	Legal
	Social security & other support systems

Summary

Question one was intended to evaluate the dimensions of the ICF model, as measured by the WHODAS 2.0 and modified ICF checklist, and was addressed using an exploratory principal components analysis. While there were some differences between the components that emerged and the original domains, for the most part the data provided support for the ICF model. The differences between the components resulting from the analysis and the domains from the instruments show some areas of overlap that may need clarification if the ICF model continues to be utilized in research. Items from the instrument that were anticipated to match up with a particular aspect of the model did so, with the exception that the domains representing participation split into two components ("inclusion" and "impact on self or family") rather than the one that exists in the ICF model. The items pertaining to feelings of inclusion loaded with the social relationships items. Additionally, the self-care items (i.e., dressing and washing), loaded with the mobility items. The shared variance in the items from these domains is not surprising given the common themes associated with social relationships and feelings of inclusion, as well as the common functional abilities required for mobility and self-care activities.

In the analysis of the environmental section, the items in the separate domains related to products and technology and services grouped as they were originally intended and remained distinct, but items from the sections on attitudes of the persons family, friends, support workers loaded with items related to the supportive relationships with the persons family, friends, and support workers. The item regarding attitudes observed in the community loaded with items related to services. The shared variance between the items related to relationships with family, friends and support workers and the attitudes of these individuals was not surprising given the common underlying theme of the questions from these two domains.

Research Question Two: What is the relationship between disability-related factors, activities, participation, environmental and personal factors with QOL? Do these results vary by sampling group?

Question two examined the relationship between the predictor variables and quality of life. To answer this question, the quality of life scale was regressed on components from the principal components analyses along with personal factors (gender, age, race, education, marital status, disability type, and disability duration). This analysis was performed with all participants together with the variance related to sample removed by using pooled within groups variance based on sample mean. Answering this question with the combined samples allows us to consider a universally applicable model that would be relevant for a range of clients receiving rehabilitation services. However, because there were differences between sampling groups, an additional within-group analysis was also performed with the same components (predictor variables) so that comparisons could be drawn. The following is a description of the model preparation, followed by a presentation of results for the full equation, the student sample and then the CRP sample.

Model Preparation

The original scale for the outcome measure (QOL) was a 5-point scale; however, few respondents indicated very poor. Accordingly, responses of "1" and "2" were combined into a single score representing poor/very poor QOL. Additionally, some of the ordinal variables were collapsed into two categories (e.g., race was collapsed into White or minority, marital status was collapsed into married/ partnered/ cohabitating or single). Disability types were entered into the

model as a dummy (yes = 1; no = 0) variable. Living arrangement and occupational status had little variability so were omitted from the regression analyses.

For the full model with all participants, all variables were standardized using the group mean, using the pooled variance matrix approach. For the within-group analyses, the original demographic data were used, along with the common components.

The Equation

Yi = $\mu i + \beta 1$ gender + $\beta 2$ age + $\beta 3$ education + $\beta 4$ duration of disability + $\beta 5$ Race+ $\beta 6$ Marital + $\beta 7$ Blind/vision + $\beta 8$ Deaf/hearing + $\beta 9$ Mobility + $\beta 10$ TBI + $\beta 11$ LD/ADHD + $\beta 12$ MH + $\beta 13$ Chronic+ $\beta 14$ ASD + $\beta 15$ Factor Score- non work activities+ $\beta 16$ Factor Score-mobility/self care + $\beta 17$ Factor Score- social relationships/inclusion + $\beta 19$ Factor Score- impact on self/family + $\beta 20$ Factor Score- cognitive + $\beta 21$ Factor Score- work/school activities + $\beta 22$ Factor Score-Environment: services + $\beta 23$ Factor Score- Environment: attitudes and relationships + $\beta 24$ Factor Score: Environment: assistive technology and accessibility + vi

where Yi is Quality of life⁵

Outcome Measure

The outcome variable for this research question is self-reported quality of life. The question that participants responded to was, "how would you rate your quality of life?" Responses were on a 5-point likert scale ranging from "very poor" to very good" with a neutral option. Gil and Fiensten (1994) recommended the use of a subjective, single item global rating. This is thought to be a reliable way to ascertain information that reflects the values and preferences of the respondent that is not linked to any specific context. The single item global measure has been shown to match up well with other measures, be stable over time, and is not thought to be

⁵ The test of the significance of the intercept represents the test of significance for Other Disabilities.

vulnerable to social desirability (Noll, 2000). Table 9 below displays the response patterns for the participants in each group.

Table 9

Outcome measure responses by sample

	Student Sample	CRP Sample	Total
Response	n %	<u>n %</u>	<u>n %</u>
Very poor	1 (0.8%)	6 (2.7%)	7 (2.0%)
Poor	14 (11.5%)	19 (8.5%)	33 (9.5%)
Neither poor nor good	18 (14.8%)	46 (20.5%)	64 (18.5%)
Good	58 (47.5%)	106 (47.3%)	164 (47.4%)
Very good	31 (25.4%)	47 (21.0%)	78 (22.5%)

Full Model- All participants

Results.

The model accounted for 24.8% of the variance in quality of life. Level of education was the only personal factor to emerge as a significant predictor (B = .075; $\beta = .107$; p = .045). Four of the components extracted from the ICF model were significantly related to QOL: social relationships/inclusion (B = .152; $\beta = .165$; p = .006), mobility/self care (B = .135; $\beta = .145$; p = .022), impact on self/family (B = .323; $\beta = .348$; p < .001), and environmental support and attitudes (B = .169; $\beta = .182$; p = .004). The relationship between social relationships and inclusion and impact on self/family was negative, indicating that less difficulty in these areas was related to higher reported QOL. The relationship between the environment of supportive relationships and attitudes was positive, indicating that a more positive perception in this area related to a higher reported QOL. The relationship between difficulty with tasks related to mobility and self-care was also negatively associated with QOL; however, the negative factor loadings from the previous analysis resulted in a reversed scale for the factor score, meaning that

a higher difficulty score on the mobility and self-care scale would result in a lower factor score. Table 10 displays the means and standard deviations for all model variables, table 11 shows the correlations, and table 12 displays the non-standardized and standardized coefficients and pvalues for all of the predictor variables.

Table 10

Means and Standard Deviations for all Model Variables- combined samples

Variable	Μ	SD
Gender ($\mathbf{M} = 0$: $\mathbf{F} = 1$)	00	47
Age	08	12.01
Education ⁶	.02	1.30
Disability Duration ⁷	.00	1.02
Race (White = 0; minority= 1)	.00	.46
Marital Status (single = 0; partnered = 1)	01	.43
Disability type "Other" $(0 = no; 1 = yes)$	01	.38
Blind/Visual Impairment ($0 = no; 1 = yes$)	.00	.17
Deaf/Hearing Impairment $(0 = no; 1 = yes)$.00	.17
Mobility Impairment $(0 = no; 1 = yes)$.00	.24
TBI (0 = no; 1 = yes)	.00	.17
LD/ADHD (0 = no; 1 = yes)	.00	.42
Psychiatric/Mental health ($0 = no; 1 = yes$)	.01	.41
Chronic health condition $(0 = no; 1 = yes)$.01	.40
Autism spectrum disorder ($0 = no; 1 = yes$)	.00	.17
Factor Score- Non-work Activities	01	.99
Factor Score- Mobility/self-care	.01	.99
Factor Score- Social relationships/ inclusion	01	1.00
Factor Score- Impact on self/family	.02	.99
Factor Score- Cognitive	.00	.99
Factor Score- Work/school activities	01	1.00
Factor Score- Environment: Services	.00	.99
Factor Score- Environment: Attitudes		
& relationships	01	.99
Factor Score- AT & accessibility	02	.98
QOL Score ⁸	2.81	.92

*Note: n = 321 due to missing data in demographic characteristics.

⁶ Education Level: 1 = Less than HS; 2 = Some HS; 3 = HS graduate/GED; 4 = Some postsecondary; 5 = Associates; 6 = Bachelors; 7 = Masters or higher.

⁷ Duration: 1 = less than 1 year; 2 = 1-4 years; 3 = 5-9 years; 4 = 10 years or more; 5 = Since birth.

⁸ QOL Score: 1= poor; 2= neutral; 3= good; 4 = very good

 Table 11 Correlations for All Predictors and Outcome Measure – combined samples

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- -.02.04 -.09 **-.18**.10 1
- 7 .07 .03 -.04 .04 -.05 .07 1
- -.12.06 .06 .02 .03 .01 -.091
- -.08 .01 -.07 .02 -.01 .01 -.08 -.03 1
- .05 -.01 .03 .02 -.01 -.02 **-.12** -.04 -.04 1
- -.09.06 .09 -.03**.13** -.01 -.10 -.03 -.03 -.05 1
- **.**.**12 .**.**25 .**.**21 .25 .**.**03 .**.**03 .**.**03 .**.**27 .**.**09 .**.**09 .**.**14 .**.**10 1**
- **13** .04 .08 **.12 .15** .03 -.02 <u>**.24**</u> -.09 -.09 -.13 -.09 <u>**.28**</u> 1
- **14 .13 .15** .10 <u>-.20</u> -.00 .01 <u>-.24</u> -.08 -.08 -.12 -.09 <u>-.26</u> <u>-.25</u> 1
- -.07 **-.18** -.03 .06 -.10 -.08 -.08 -.03 -.03 -.04 -.03 -.10 -.09 -.08 1
- -.08 -.06 -.02 -.02 -.08 **.14** -.01 -.04 **.13** -.03 -.05 -.02 **.11** -.10 .10 1
- **17** -.06 -.16 .10 .01 .01 -.11 -.06 .01 -.04 <u>-.30</u> .01 .11 .18 -.11 .13 <u>-.29</u> 1
- **18** <u>.20</u> .17.13 -.12.06 -.07.09 -.10 -.07.04 -.00 <u>-.25</u>.16 .14 -.13.21 <u>-.23</u> 1
- -.08 -.18 -.10 -.02 -.02 .07 .03 .05 .09 -.02 .01 .05 -.03 -.11 .03 -.31 .33 -.28 1

Table 11 cont'd

Bold = p < .05; bold and underlined = p < .001

Correlation Table Key

1 = gender; 2 = age; 3 = education; 4 = duration of disability col Blind or visually impaired; 9 = Deaf or hard of hearing; 10 = Mobility impairment; 11= Traumatic Brain Injury; 12 = Learning disability or attention deficit hyperactivity disorder; 13 = Mental health disability; 14 = Chronic health condition; 15 = Autism spectrum disorder; 16 = Factor score: social relationships and inclusion; 17 = Factor score: mobility and self-care; 18 = Factor score: impact on self/family; 19 = Factor score: non-work activities; 20 = Factor score: cognitive; 21 = Factor score: work/school activities; 22 = Factor score: environment- services and community attitudes; 23 = Factor score: environment- relational support and attitudes; 24 = Factor score: Assistive technology and accessibility; 25 = QOL.

Predictor Variable	B(SE)	β	95% CI	p-value
Constant*	2.814 (.045)	-	[2.726, 2.902]	.000
Gender	.020 (.103)	.010	[016, .000]	.843
Age	008 (.004)	103	[039, .018]	.063
Education	.076 (.038)	.107	[.002, .150]	<u>.045</u>
Disability Duration	.053 (.049)	.059	[044, .150]	.281
Race (White or minority)	.006 (.105)	.003	[201, .214]	.951
Marital (single or partnered)	116 (.110)	054	[334, .101]	.293
Blind/Visual Impairment	147 (.297)	026	[731, .437]	.620
Deaf/Hearing Impairment	.296 (.300)	.053	[294, .887]	.324
Mobility Impairment	163 (.225)	042	[605, .280]	.470
TBI	.329 (.287)	.062	[236, .894]	.252
LD/ADHD	.115 (.164)	.052	[207, .437]	.482
Psychiatric/Mental health	107 (.154)	048	[410, .195]	.485
Chronic health condition	.006 (.152)	.002	[294, .305]	.971
Autism spectrum disorder	177 (.294)	033	[755, .401]	.548
Factor Score- Social relationships/				
Inclusion	152 (.055)	165	[261,043]	<u>.006</u>
Factor Score- Mobility/self-care	135 (.058)	145	[250,020]	.022
Factor Score- Impact on self/family	323 (.054)	348	[430,216]	<u><.001</u>
Factor Score- Cognitive	.050 (.055)	.054	[057, .158]	.356
Factor Score- Non-work Activities	009 (.054)	010	[116, .097]	.862
Factor Score- Work/school activities	.092 (.055)	.100	[016, .200]	.094
Factor Score- Environment: Services &				
Community attitudes	.014 (.058)	.015	[100, .127]	.812
Factor Score- Environment: Relational				
Support & Attitudes	.169 (.058)	.182	[.056, .282]	<u>.004</u>
Factor Score- Environment:				
AT & accessibility	.047 (.058)	.050	[067, .161]	.419

Table 12 Linear Regression Coefficients: Full Model- Combined samples

*Represents participants with "other" disabilities.

The outcome measure in this model is QOL Score.

Model $r^2 = .302$; Adjusted $r^2 = .248$ Student Sample

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Results.

When a within group analysis with students, the model accounted for 26.0% of the variance in quality of life. None of the personal factors were significant predictors; however, two of the

components extracted from the ICF model were significantly related to QOL: social relationships/inclusion (B = -.293; $\beta = -.263$; p = .012) and work/school activities (B = .435; $\beta = .368$; p = .007). The relationship between social relationships and inclusion in the equation was negative, indicating that a lower level of reported difficulty with social relationships and community inclusion was related to a higher reported quality of life. For the work and school activity component, the negative factor loadings from the previous analysis resulted in a reversed scale for the factor score, meaning that a higher difficulty score on the work/school activity scale would result in a lower factor score. The results indicate that lower reported difficulty with work or school tasks were related to a higher reported quality of life. Table 13 displays the means and standard deviations for all model variables, table 14 shows the correlations, and table 15 displays the non-standardized and standardized coefficients and p-values for all of the predictor variables.

Table 13

Means and Standard	Deviations for	all Model	Variables-	Student sample
				1

Variable	Μ	SD
Gender $(M - 0; E - 1)$	78	42
Age	25.26	.+2 8.94
Education ⁹	4.78	1.28
Disability Duration ¹⁰	3.59	1.07
Race (White = 0: minority= 1)	.18	.38
Marital Status (single = 0; partnered= 1)	.14	.35
Disability type "Other" $(0 = no; 1 = yes)$.10	.30
Blind/Visual Impairment ($0 = no; 1 = yes$)	.03	.18
Deaf/Hearing Impairment ($0 = no; 1 = yes$)	.03	.18
Mobility Impairment $(0 = no; 1 = yes)$.07	.25
TBI $(0 = \text{no}; 1 = \text{yes})$.03	.16
LD/ADHD (0 = no; 1 = yes)	.25	.44
Psychiatric/Mental health ($0 = no; 1 = yes$)	.25	.43
Chronic health condition $(0 = no; 1 = yes)$.21	.41
Autism spectrum disorder ($0 = no; 1 = yes$)	.04	.20
Factor Score- Social relationships/ inclusion	02	.84
Factor Score- Mobility/self-care	.00	.96
Factor Score- Impact on self/family	04	1.02
Factor Score- Cognitive	02	1.04
Factor Score- Non-work Activities	.00	.94
Factor Score- Work/school activities	.01	.79
Factor Score- Environment: Services &		
Community attitudes	.02	.88
Factor Score- Environment: relational support		
And attitudes	.01	.88
Factor Score- AT & accessibility	03	.77
QOL Score ¹¹	2.89	.93

*Note: n = 118 due to missing data in demographic characteristics.

⁹ Education Level: 1 = Less than HS; 2 = Some HS; 3 = HS graduate/GED; 4 = Some postsecondary; 5 = Associates; 6 = Bachelors; 7 = Masters or higher.

¹⁰ Duration: 1 = less than 1 year; 2 = 1-4 years; 3 = 5-9 years; 4 = 10 years or more; 5 = Since birth.

¹¹ QOL Score: 1= poor; 2= neutral; 3= good; 4 = very good

 Table 14 Correlations for All Predictors and Outcome Measure – Student Sample

9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 1 2 3 4 5 6 7 8 1 1 .13 1 2 .01 .58 1 3 -.14 -.06 .14 1 4 -.01 .16 -.01 -.06 1 5 -.08.24 <u>.38</u> .07 .18 1 6 .11 .14 .07 -.11 .13 -.05 1 7 **8** -.02 .20 .18 .20 .03 .06 -.06 1 9 -.02 .12 .07 .07 .03 -.07 -.06 -.03 1 -.02 -.06 -.08 -.05 .13 -.01 -.09 -.05 -.05 1 10 **11** -.05 **.30** .20 -.09 .06 **.24** -.05 -.03 -.03 -.04 1 **12 .**.**25** -.15 -.08 <u>.38</u> -.18 .04 **.**.**19** -.11 -.11 -.16 -.09 1 **13** .11 .00 .04 **-.19** -.12 -.01 **-.19** -.11 -.11 -.15 -.09 **-.33** 1 **14** .17 -.10 -.11 **-.26** .08 -.03 -.17 -.09 -.09 -.13 -.08 **-.30 -.30** 1 15 -.09 -.10 -.06 .16 .01 -.08 -.07 -.04 -.04 -.06 -.03 -.12 -.12 -.11 1 **16** -.02 -.03 -.11 .00 .04 -.05 -.12 -.08 .12 -.06 .05 -.07 .15 -.16 <u>.33</u> 1 **17** -.05 -.24 .15 .12 -.18 -.01 -.12 -.01 .04 -.38 -.25 .28 .21 -.18 .12 -.04 1 18 .30 .16 -.01 -.25 .17 .17 .08 -.12 -.14 .01 .02 -.25 .26 .10 -.12 .22 -.25 1 **19 .**21 - .17 - .12 .04 .11 - .07 .20 .03 .13 .12 - .02 - .01 **.**22 - .03 - .03 - .17 - .01 <u>-.41</u> 1 **20** .09.03 -.13.04 -.06 -.02 -.14 **-.18** -.11 **-.29**.02 **.40 .18 -.27**.08 **.25 .18** .17 **-.30** 1

Table 14 cont'd

 $1 \quad 2 \quad 3 \quad 4 \quad 5 \quad 6 \quad 7 \quad 8 \quad 9 \quad 10 \quad 11 \quad 12 \quad 13 \quad 14 \quad 15 \quad 16 \quad 17 \quad 18 \quad 19 \quad 20 \quad 21 \quad 22 \quad 23 \quad 24 \quad 25$ $21 \quad -.19 \quad .01 \quad -.01 \quad .10 \quad .10 \quad .03 \quad .03 \quad .16 \quad .12 \quad .21 \quad .11 \quad -.20 \quad -.20 \quad .10 \quad .01 \quad -.09 \quad -.210 \quad -.37 \quad .60 \quad -.57 \quad 1$ $22 \quad .14 \quad -.07 \quad .04 \quad .15 \quad .13 \quad -.05 \quad -.10 \quad -.02 \quad -.04 \quad .04 \quad -.10 \quad .09 \quad .15 \quad -.20 \quad .09 \quad -.02 \quad .27 \quad .01 \quad .04 \quad .04 \quad -.04 \quad 1$ $23 \quad .00 \quad -.09 \quad -.10 \quad -.10 \quad .11 \quad -.05 \quad -.14 \quad .05 \quad -.02 \quad .16 \quad -.03 \quad -.04 \quad .04 \quad -.01 \quad .04 \quad -.19 \quad .24 \quad -.15 \quad .26 \quad .33 \quad 1$ $24 \quad .02 \quad .07 \quad .01 \quad -.08 \quad .27 \quad .05 \quad .14 \quad .11 \quad -.04 \quad .16 \quad .01 \quad -.15 \quad -.01 \quad -.11 \quad .08 \quad -.01 \quad -.05 \quad .06 \quad .18 \quad -.17 \quad .16 \quad .36 \quad .26 \quad 1$ $25 \quad -.10 \quad -.15 \quad -.06 \quad .07 \quad -.07 \quad -.17 \quad -.07 \quad -.02 \quad .08 \quad -.03 \quad .02 \quad .15 \quad -.16 \quad .10 \quad -.10 \quad -.33 \quad .03 \quad -.44 \quad .31 \quad -.19 \quad .37 \quad .08 \quad .28 \quad -.03 \quad 1$

Bold = p < .05; bold and underlined = p < .001

Correlation Table Key

1 = gender; 2 = age; 3 = education; 4 = duration of disability condition; 5 = race; 6 = marital status; 7 = disability type- other; 8 = Blind or visually impaired; 9 = Deaf or hard of hearing; 10 = Mobility impairment; 11= Traumatic Brain Injury; 12 = Learning disability or attention deficit hyperactivity disorder; 13 = Mental health disability; 14 = Chronic health condition; 15 = Autism spectrum disorder; 16 = Factor score: social relationships and inclusion; 17 = Factor score: mobility and self-care; 18 = Factor score: impact on self/family; 19 = Factor score: non-work activities; 20 = Factor score: cognitive; 21 = Factor score: work/school activities; 22 = Factor score: environment- services and community attitudes; 23 = Factor score: environment- relational support and attitudes; 24 = Factor score: Assistive technology and accessibility; 25 = QOL.

Predictor Variable	B(SE)	β	95% CI	p-value
Constant*	2.990 (.577)	-	[1.844, 4.136]	.000
Gender	.120 (.210)	.054	[296, .537]	.567
Age	019 (.013)	180	[044, .007]	.146
Education	.080 (.088)	.109	[095, .255]	.368
Disability Duration	062 (.090)	071	[241 .117]	.492
Race (White or minority)	.009 (.222)	.004	[433, .451]	.968
Marital (single or partnered)	447 (.251)	169	[945, .052]	.078
Blind/Visual Impairment	258 (.514)	050	[-1.278, .762]	.616
Deaf/Hearing Impairment	.473 (.507)	.092	[535, 1.480]	.354
Mobility Impairment	455 (.420)	123	[-1.288, .379]	.281
TBI	.396 (.585)	.067	[766, 1.558]	.500
LD/ADHD	.494 (.382)	.232	[265, 1.253]	.200
Psychiatric/Mental health	.116 (.351)	.054	[580, .812]	.742
Chronic health condition	.149 (.322)	.066	[491, .789]	.645
Autism spectrum disorder	058 (.549)	012	[-1.147, 1.032]	.917
Factor Score- Social relationships/incl.	293 (.115)	263	[521,065]	<u>.012</u>
Factor Score- Mobility/self-care	118 (.116)	122	[349, .113]	.312
Factor Score- Impact on self/family	189 (.102)	207	[392, .014]	.068
Factor Score- Cognitive	.035 (.112)	.039	[187, .257]	.753
Factor Score- Non-work activities	052 (.112)	053	[275, .171]	.645
Factor Score- Work/school activities	.435 (.157)	.368	[.125, .746]	<u>.007</u>
Factor Score- Environment: Services &				
Community Attitudes	.036 (.112)	.034	[187, .259]	.748
Factor Score- Environment: relational				
Support and Attitudes	.095 (.109)	.089	[122, .311]	.368
Factor Score- Environment:				
AT & accessibility	010 (.117)	009	[243, .222]	.929

Table 15 Linear Regression Coefficients: Full Model- Student Sample

*Represents participants with "other" disabilities.

The outcome measure in this model is QOL Score.

Model $r^2 = .406$; Adjusted $r^2 = .260$

Community Rehabilitation Provider Client Sample

Results.

When a within-group analysis was performed with the CRP clients, the model accounted for

26.2% of the variance in quality of life. Two of the personal factors, level of education (B =

.141; $\beta = .204$; p = .003) and duration of disability (B = .035; $\beta = .147$; p = .037), and two of the components extracted from the ICF model social relationships/inclusion (B = ..147; $\beta = ..174$; p = .031), impact on self/family (B = ..345; $\beta = ..369$; p < .001) were significantly related to QOL. Results indicated that higher level of education, and having the disability or health condition for a longer time were positively related to quality of life. The relationship between social relationships and inclusion in the equation was negative, indicating that a lower level of reported difficulty with social relationships and community inclusion was related to a higher reported quality of life. The same relationship was found for the impact of the disability or health condition on the person or his or her family: a lower reported impact (i.e., financial drain, emotional strain, time spent managing condition) was related to a higher reported quality of life. Table 16 displays the means and standard deviations for all model variables, table 17 shows the correlations, and table 18 displays the non-standardized and standardized coefficients and p-values for all of the predictor variables.

Table 16

Means and Standard Deviations for all Model Variables- CRP Client sample

Variable	М	SD
Gender ($M = 0; F = 1$)	.58	.50
Age	42.74	13.50
Education ¹²	3.36	1.32
Disability Duration ¹³	3.89	1.00
Race (White = 0; minority= 1)	.40	.49
Marital Status (single = 0; partnered= 1)	.33	.47
Disability type "Other" $(0 = no; 1 = yes)$.25	.43
Blind/Visual Impairment ($0 = no; 1 = yes$)	.02	.16
Deaf/Hearing Impairment ($0 = no; 1 = yes$)	.02	.16
Mobility Impairment $(0 = no; 1 = yes)$.05	.23
TBI $(0 = no; 1 = yes)$.03	.18
LD/ADHD (0 = no; 1 = yes)	.21	.41
Psychiatric/Mental health ($0 = no; 1 = yes$)	.20	.40
Chronic health condition $(0 = no; 1 = yes)$.19	.39
Autism spectrum disorder ($0 = no; 1 = yes$)	.02	.16
Factor Score- Social relationships/ inclusion	.00	1.09
Factor Score- Mobility/self-care	.01	1.02
Factor Score- Impact on self/family	.05	.98
Factor Score- Non-work Activities	02	1.06
Factor Score- Cognitive	.01	.97
Factor Score- Work/school activities	02	1.11
Factor Score- Environment: Services &		
Community attitudes	01	1.05
Factor Score- Environment: Relational		
Support and attitudes	01	1.06
Factor Score- AT & accessibility	01	1.09
QOL Score ¹⁴	2.76	.92

*Note: n = 203 due to missing data in demographic items.

¹² Education Level: 1 = Less than HS; 2 = Some HS; 3 = HS graduate/GED; 4 = Some postsecondary; 5 = Associates; 6 = Bachelors; 7 = Masters or higher.

¹³ Duration: 1 = less than 1 year; 2 = 1-4 years; 3 = 5-9 years; 4 = 10 years or more; 5 = Since birth.

¹⁴ QOL Score: 1= poor; 2= neutral; 3= good; 4 = very good

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	.17	1																		
	.07	.13	1																	
	17	'17	'04	1																
	02	00. 2	13	24	1															
	.02	.12	11	12	.08	1														
	.06	.01	07	.11	.05	04	1													
	18	6.01-	.02	11	01	.02	09	1												
	11	03	.15	02	01	.02	09	02	1											
0	.09	.02	.09	.06	09	001	14	04	04	- 1										
L	10)01	.05	01	04	.09	12	03	03	05	51									
2	06	5 <u>29</u>	<u>28</u>	.16	.04	06	5 <u>31</u>	08	08	812	211	1								
3	.02	.11	.16	13	.03	.04	28	<u>07</u>	07	'11	10) <u>25</u>	<u>1</u>							
1	.11	.25	.22	15	02	2.01	27	<u>07</u>	07	'11	09	9 <u>2</u> 4	<u> </u> 22	21						
5	05	23	.02	02	13	611	09	02	02	204	03	808	807	707	71					
6	10)07	.02	03	.18	09	9.02	02	.13	02	209	0.01	.09	08	302	21				
7	06	513	8.08	06	08	8.01	04	.02	08	<u>25</u>	<u>.</u> 12	.03	.16	07	7 .14	<u>36</u>	<u>5</u> 1			
8	.15	.18	.21	03	18	6.01	.09	09	02	.06	02	2 <u>25</u>	<u>.10</u>	.17	14	.21	21	l 1		
9	03	18	809	06	.05	01	03	.05	.08	09	0.02	.09	.07	15	5.07	37	7 .49	21	l 1	

 Table 17 Correlations for All Predictors and Outcome Measure – CRP Sample

Table 17 cont'd

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 -.04 - .13 - .00 .13 -.11 .06 - .00 .11 - .45 .47 -.11 .37 - .19 1

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 -.06 .10 .07 - .02 - .07 - .10 .05 - .12 .05 - .12 - .01 - .08 .12 .58 1

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 -.01 .06 .07 - .05 .02 .10 - .05 - .09 .00 .12 - .02 .04 - .11 - .02 - .04 .22 .12 .13 - .06 .22 .51 .54 1

 25
 -.05 - .13 .03 .21 .06 - .02 .03 .04 .00 .06 .10 .10 - .15 - .15 .10 - .22 .08 - .41 .09 - .04 .16 .20 .28 .14 1

Bold = p < .05; bold and underlined = p < .001

Correlation Table Key

1 = gender; 2 = age; 3 = education; 4 = duration of disability col Blind or visually impaired; 9 = Deaf or hard of hearing; 10 = Mobility impairment; 11= Traumatic Brain Injury; 12 = Learning disability or attention deficit hyperactivity disorder; 13 = Mental health disability; 14 = Chronic health condition; 15 = Autism spectrum disorder; 16 = Factor score: social relationships and inclusion; 17 = Factor score: mobility and self-care; 18 = Factor score: impact on self/family; 19 = Factor score: non-work activities; 20 = Factor score: cognitive; 21 = Factor score: work/school activities; 22 = Factor score: environment- services and community attitudes; 23 = Factor score: environment- relational support and attitudes; 24 = Factor score: Assistive technology and accessibility; 25 = QOL.

Predictor Variable	B(SE)	β	95% CI	p-value
Constant*	1.798 (.427)	•		.000
Gender	.030 (.122)	.016	[211, .271]	.804
Age	002 (.005)	024	[011, .008]	.732
Education	.141 (.047)	.204	[.048, .235]	<u>.003</u>
Disability Duration	.135 (.064)	.147	[.008, .262]	<u>.037</u>
Race (White or minority)	.122 (.128)	.065	[131, .374]	.342
Marital (single or partnered)	007 (.126)	003	[254, .241]	.959
Blind/Visual Impairment	.233 (.395)	.040	[546, 1.013]	.556
Deaf/Hearing Impairment	.431 (.395)	.073	[349, 1.211]	.277
Mobility Impairment	.019 (.277)	.005	[528, .565]	.946
TBI	.369 (.334)	.074	[291, 1.029]	.271
LD/ADHD	.125 (.189)	.056	[249, .499]	.511
Psychiatric/Mental health	231 (.182)	101	[589, .128]	.206
Chronic health condition	187 (.182)	081	[546, .172]	.306
Autism spectrum disorder	.430 (.399)	.073	[359, 1.218]	.284
Factor Score- Social Rel. & Incl.	147 (.067)	174	[280,014]	<u>.031</u>
Factor Score- Mobility/self-care	107 (.078)	119	[260, .046]	.170
Factor Score- Impact on self/family	345 (.069)	369	[481,209]	<u><.001</u>
Factor Score- Non-work activities	017 (.067)	019	[148, .115]	.804
Factor Score- Cognitive	.088 (.069)	.092	[049, .224]	.207
Factor Score- Work/school activities	.046 (.063)	.056	[079, .171]	.466
Factor Score- Environment: Services				
& community attitudes	005 (.070)	006	[143, .132]	.939
Factor Score- Environment: Relational				
Support and attitudes	.130 (.071)	.150	[011, .270]	.071
Factor Score- Environment:	.107 (.069)	.127	[030, .244]	.125
AT & accessibility				

 Table 18 Linear Regression Coefficients: Full Model- CRP Sample

*Represents participants with "other" disabilities.

The outcome measure in this model is QOL Score.

Model $r^2 = .346$; Adjusted $r^2 = .262$

Summary

Research question two was intended to identify significant predictors from the ICF model

(personal factors, function, activities, participation, and environment) on QOL. The analysis was

conducted with the pooled sample and standardized variables to remove the variance associated

with the two groups. Results indicated that using the demographic variables and the components extracted from the ICF, 24.8% of the variance in QOL was explained. The significant predictors included level of education, social relationships and inclusion, mobility/self-care, impact of the disability on self and family, and relational support and attitudes of family members, friends and acquaintances. These results provide initial support for the notion that QOL is a multi-dimensional construct that is explained by a variety of person-level and environmental factors.

Since there were differences observed between the two samples, within-group analyses were also performed. For each group, the set of common factors extracted from the ICF (standardized to remove variance associated with sample) was used so that the groups could be compared, but the original demographic data were used. For students, 26% of the variance of QOL was explained by the model, and the significant predictors were social relationships and inclusion and work/school activities. For the CRP clients, 26.2% of the variance in QOL was explained, with level of education, duration of disability, social relationships and inclusion, and impact on self/family emerging as significant predictors. These differences in the within-groups analysis provides some support for the idea that even considering the same factors, there are differences in importance based on some life-factors (e.g., age, student status, etc.).

Research Question Three: Do the components of the ICF model provide an improved way to measure QOL above typically derived outcomes of services (e.g., employment or independent living)?

To answer this question, a block entry regression was used, with QOL as the outcome variable and the independent variables entered as follows: Block one- personal factors (demographic characteristics), Block two- work/school and non work activities (work and independent living), and Block three- the remaining ICF components. This analysis was meant to compare the variance explained in QOL by the information that is typically available to counselors when providing rehabilitation services (personal factors, disability information, and difficulties with work or life activities) with the full ICF model (block 3). As in the previous question, the analysis was carried out first with the entire sample using the mean-centered predictors based on pooled within groups variance. An additional within-group analysis was also conducted, using the pooled variance component scores, but the original demographic data. The results are presented below, first the entire sample, then student sample, and then CRP client sample.

Model Equation

 $Yi = \mu i + \beta 1 \text{gender} + \beta 2 \text{age} + \beta 3 \text{education} + \beta 4 \text{duration of disability} + \beta 5 \text{race} + \beta 6 \text{marital} + \beta 7$ Blind/vision + \beta 8 Deaf/hearing + \beta 9 Mobility + \beta 10 TBI + \beta 11 LD/ADHD + \beta 12 MH +

 β 13Chronic+ β 14ASD + β 15 Factor Score- Non-work activities + β 16 Factor Score-

Work/school activities + vi

where Yi is Quality of life¹⁵

Combined Sample

When the demographic variables only were regressed on QOL, the variance explained was 3.7%. When the demographic variables plus the work/school and non work activities factor scores were regressed on QOL, 7.8% of the variance was explained. The full model, (block 3) explained 24.8% of the variance in QOL. This represented a substantial improvement in variance accounted for with the additional information obtained in other life areas beyond simply personal factors, work/school, and non-work activities. Table 19 shows the model summaries.

¹⁵ The test of the significance of the intercept represents the test of significance for Other Disabilities.

Table 19

Model Summaries for the Block Regression- combined samples

Model	R ²	Adjusted R ²	ΔR^2	Std. Error
Demographics only (age, gender, race, marital education, duration, disability)	.079)	.037		.904842
Demographics + Activities (work/school and non-work)	.124	.078	4.1%	.885352
Demographics + Activities+ All components from ICF (social relationships/inclusion, mobility/self-care, cognitive, impact on self/family, service & community attitudes relation support & attitudes AT & acc	.302 s nal	.248	17.0%	.799470

Student Sample

When the demographic variables only were regressed on QOL, the variance explained was 1.4%. When the demographic variables plus the work/school and non work activities factor scores were regressed on QOL, 17.8% of the variance was explained. The full model, (block 3) explained 26.0% of the variance in QOL. For students, it seems that there is a substantial gain in ability to predict QOL by adding the work/school and non-work activities, with an additional improvement by adding the rest of the components from the ICF model. Table 20 shows the model summaries.
Table 20

Model Summaries for the Block Regression- Student Sample

Model	R ²	Adjusted R ²	ΔR^2	Std. Error
Demographics only (age, gender, race, marital education, duration, disability)	.132	.014		.925061
Demographics + Activities (work/school and non-work)	.290	.178	16.4%	.844733
Demographics + Activities+ All components from ICF (social relationships/inclusion, mobility/self-care, cognitive, impact on self/family, services & community attitudes relation support & attitudes, AT & acco	.406 al essibility)	.260	8.2%	.801413

CRP Client Sample

When the demographic variables only were regressed on QOL, the variance explained was 7.9%. When the demographic variables plus the work/school and non work activities factor scores were regressed on QOL, 9.4% of the variance was explained. The full model, (block 3) explained 26.2% of the variance in QOL. For the CRP clients, it seems that there is a substantially greater ability to predict QOL by using the more comprehensive ICF model above what can be accounted for by simply taking work/school and non-work activities and demographic characteristics into account. Table 21 shows the model summaries.

Table 21

Model Summaries for the Block Regression- CRP Sample

Model	R ²	Adjusted R ²	ΔR^2	Std. Error
Demographics only (age, gender, race, marital education, duration, disability)	.143	.079		.878014
Demographics + Activities (work/school and non-work)	.166	.094	1.5%	.871131
Demographics + Activities+ All components from ICF (social relationships/inclusion, mobility/self-care, cognitive, impact on self/family, services & community attitudes relation support & attitudes, AT & acco	.346 al essibility)	.262	16.8%	.786379

Summary

To answer research question three, which was intended to ascertain whether the full ICF model components provided an improved way to predict QOL over more typical outcomes related to rehabilitation services (e.g., work and independent living), a block entry regression was used. When both samples were analyzed together using standardized variables, the additional variance accounted for in QOL between block 2 (demographic characteristics and work/school and non-work activities) and the full ICF model was 16.8%. The results of the within-groups analysis provided more information specific to each sample. For students, the work/school and non-work activities added a more substantial portion of variance explained than in the CRP client sample, but for both groups, the full model explained a greater portion of the outcome (QOL) than the more restricted models.

Chapter 5

Discussion

The intent of the present study was to explore the use of the ICF as a framework of conceptualizing and measuring QOL among two samples of adults receiving disability-related services. To accomplish this, the WHODAS 2.0 was selected to measure function, activity, and participation, as it is the only instrument that was developed directly from the ICF model itself. A separate tool, the ICF checklist, was selected to represent the environmental domain, and it included several different aspects of environment to be considered. The domains of these instruments were analyzed in an exploratory principal components analysis to see if the aspects of the ICF model remained distinct. The study also compared how well typical measures of employment and independent living predict the more comprehensive measure of QOL and how this relationship varied by the two different samples included in the study.

The ICF Model

Data collected from the samples provided some support for the components of the ICF model as measured with the WHODAS 2.0, although some of the items did not load with the domain they were intended to measure, showing that there may be a need to further clarify some aspects of the instrument. For example, some items from the participation domain shared variance with items from the social relationships domain and items from the self-care domain shared variance with the items from the mobility domain. This is likely due to some of the same functional limitations that would impact both mobility and self-care. Some items from the instrument were dropped from the analysis because they either showed low loadings or cross-loaded onto two components. In the analysis of the environmental section, the items in the

separate domains related to products and technology and services grouped as they were originally intended and remained distinct, but items from the sections on attitudes of the persons family, friends, and support workers loaded with items related to the supportive relationships with the persons family, friends, and support workers. The item related to attitudes perceived from the community loaded with the items related to services. These results indicate that the domains from the ICF, as measured using the WHODAS 2.0 and ICF checklist, may have some areas of overlap, particularly in the distinctions made between "attitudes" and "supportive relationships" as well as how "participation" is defined and operationalized. Further work clarifying these points will allow us to evaluate the more theoretical hypothesized dimensions of the model itself with more confidence.

The finding that there is some level of overlap in the components of the ICF model, as currently assessed, is consistent with previous discussions of concerns in applying the model to research and practice (Whiteneck & Dijkers, 2009). One area, participation, has been identified as particularly difficult to define and measure. Garin et al. (2010) completed a large scale study attempting to confirm the dimensions of the WHODAS 2.0 (36-item version) in a sample of adults with various disabilities. They found, similar to the present study, that items from the participation domain loaded with other domains, in particular the social relationships items. Specifically, the items related to the impact of the condition on the individual or their family remained together and as a separate component. Garin et al. (2010) suggested retaining the components of the model although possibly relocating some of the participation items.

The environmental aspects of the ICF model have been cited as the area that is least often the focus of research (Whiteneck & Dijkers, 2009). While no earlier analyses of the ICF checklist were located in a literature search, there is a clear need for continued thought on what makes up "environment" and how it should be conceptualized. The ICF checklist as modified for the present study had distinct questions on products and technology, attitudes, support and relationships, and services. Shared variance was observed between attitudes and support and relationships and these items became one component. This finding of overlap between attitudes and supportive relationships is consistent with the large body of work on attitudes towards disability and how they impact how people are treated by others in their lives, including close friends and family and professionals (e.g., Cook, 1998; Smart, 2001). It may not be possible to distinguish these two parts of environment.

QOL Studies

When the samples were assessed together, education, difficulty with social relationships and inclusion, the impact of the disability or health condition on the person or their family, difficulty with tasks associated with mobility and self-care, and relational support and attitudes from friends, family, and acquaintances had the strongest relationships with QOL. These results are consistent with the idea that QOL is, as has been discussed previously, a multi-dimensional construct that depends on several factors at both the person and environment levels. Within the student sample, social relationships and inclusion and difficulty with work/school activities had the strongest relationships with QOL. Within the CRP client sample, level of education, duration of the disability or health condition, social relationships and inclusion, and the impact of condition on self and family had the strongest relationship with QOL. The differences that emerged between the samples may be interpreted to mean that even when common factors are considered, different things may seem more important to an individual's conception of their QOL based on life-factors (such as age, or being a student).

Findings from this study join a body of literature related to measuring QOL among persons with disabilities as part of an effort to determine how individuals with disabilities construct their QOL perceptions. This study was focused on factors that support well-being where the emphasis is not limited to aspects of the person, but includes information that demonstrates their relationship with their surrounding environment (e.g., activities, participation, environment; cf., Albrech & Devlieger, 1999; Levine, 1987). Results from this study indicated that some personal characteristics (e.g., education, disability duration) were related to quality of life, however, additional factors such as difficulty in social relationships and inclusion, activity, impact of the condition on self and family, and perception of environmental social supports were also shown to be related to how individuals rate their QOL. These results are consistent with several other studies that note a relationship between a variety of non-disability factors (e.g., environment, participation, social support, opportunities for desired activity) and QOL (Crewe, 1980; Fuhrer et al., 1992; Fuhrer, 1994; Heinemann & Whiteneck, 1995; Kennedy, Lude, & Taylor, 2006; Kinney & Coyle, 1992; Whiteneck et al., 2004) However, the majority of the studies listed here were focused on a sample of individuals with a particular type of disability, while the present study was purposely cross-disability. Also, some of these previous studies relied on secondary data analysis, while the current study used a prospective data collection method. This study provides an expansion of previous research and initial support that these results are not due to focusing on a single group of individuals who may experience relatively similar functional limitations or disability-related issues along a continuum of severity. The cross-disability sample allows for broader application of the findings.

The result that the majority of individuals from these samples rated their quality of life as good or very good is more consistent with QOL ratings from the general population (Cummins,

2003; Skevington et al., 2004) and also studies of people with disabilities who rate their QOL as relatively high despite experiencing limitations due to disability (Albrech & Devlieger, 1999). Albrech & Devlieger explained these findings by suggesting a framework that differentiated the impact of disability from the interaction between the person, their internal sense of balance, their social context, and their environment. Using the ICF as a comprehensive framework accomplishes something similar in that it provides a model of disability that is inclusive of personal and environmental factors. The findings that only one of the personal factors was a significant predictor of quality of life in the combined sample analysis differed from a number of other studies where a number of demographic factors were significantly related to QOL (e.g., Chen & Crewe, 2009; Deiner, 1984; Heinemann & Whiteneck, 1995; Herman, 2008). The present study also did not include some psychological dimensions (e.g., hope, spirituality, wellbeing, acceptance) that have been demonstrated to relate to QOL in previous work (e.g., Chen & Crewe, 2009; Cummins, 1996), instead taking a more functional approach that lines up more closely with the focus of rehabilitation services.

QOL and typical outcome measures

When the typical measures of rehabilitation services (e.g., employment and independent living) were compared with the full ICF model as a way to predict QOL, results indicated that the additional information associated with other life areas and environment provided a substantially better way to account for reported QOL than just the demographic information and information related to work/school and life activities. This result obtained when the samples were considered together was also consistent in the analyses performed by sample, although a greater portion of the QOL was explained by the work/school and life activities model for the students than the CRP clients.

The findings from the present study were also consistent with previous efforts to connect levels of function in different life areas to measures of subjective well being. Cardoso et al. (2004) connected life skills (e.g., employability skills, self-care, communication, etc.) with measures of subjective well-being (e.g., physical, psychological, social, and environmental). Findings indicated a moderate correlation between life skills and well-being. Authors concluded that rehabilitation services aimed at improving life skills would lead to an improvement in subjective QOL. However, the level of skill that seems to be required for work did not seem to significantly correlate with psychological well-being. Authors suggested that other factors may be at play, including stress, family support, and interference in activities. Heinemann and Whiteneck (1995) used an earlier version of the ICF (the ICIDH) to compare aspects of function, disability, and handicap to subjective well-being and found that social and productive activities were the strongest predictors. The model only explained 13% of the variance in QOL, and environmental factors were not included. In an earlier study, Furher et al. (1992) also found an indirect negative relationship between level of perceived "handicap" and life satisfaction; however, in the predictive model of life satisfaction the significant predictors were self-assed health, perceived control, and social support indicating that these other factors were more prominent.

Results showing the relationships between life satisfaction, various types of life skills, and perception of handicap provide us with a nice comparison to the present study. Instead of "life skills" or perceived "handicap," the focus here was on broader dimensions of functioning as well as including environmental supports. The common theme is that it appears that function does play a role in QOL, but the greater picture is a combination of other elements that are an aspect of the interaction of the person in their environment. This is particularly evident in that

even the full model explained only about 26% of the variance in QOL, meaning that there is much left unaccounted for.

Study Limitations

Although this study has several strengths, some limitations must be noted before discussing the implications of the findings. First, the two samples recruited for this study were samples of convenience and are not adequate to generalize to all people with disabilities, or even all CRP clients and university students with disabilities. The combination of an incentive offered and the low response rate in the student sample makes it likely that some response bias is observed in this group of participants. However, the samples were at least somewhat comparable to the populations from which they were drawn. The student sample was compared with national data on college students, and while many of the demographics (e.g., gender, age) were different than the current sample, the proportion reporting also having a job was similar. A larger overall sample size would have been desirable for generalizablity, as would confirmation that the individuals who chose to participate did not differ from individuals who did not. Given these sample limitations, as well as the smaller representation by students in the combined sample, additional care should be taken when considering the implications of the findings for college students with disabilities in particular. Replication of these results in a larger student sample would provide more confidence in the applicability of the findings. It may be that additional factors not included in the study also have a relationship with quality of life. In other samples, different relationships between personal, environmental, and disability-related characteristics and quality of life might be revealed.

Another limitation is related to the self-report methodology, particularly in the areas of collecting information on function or difficulty with particular tasks. While other researchers have argued for the usefulness of what are referred to as "subjective health assessments" in ascertaining information about health and function (e.g., Albrect, 1996), there is no way to confirm validity of all responses given that there is no guarantee that all respondents had a concrete understanding of the concepts involved. Alternative methods of gathering information that have some aspect of verification or cross-validation should be considered in future research. Additionally, the cross-sectional nature of the study is a limitation given that quality of life is known to have intra-individual variability over time despite being relatively stable (Gadermann & Zumbo, 2007). Another method to consider is a longitudinal design where data would be collected on each individual over a period of time to ensure that QOL perception was not simply a reflection of how the person felt that day. Another limitation is the reduction of broad dimensions (e.g., social function) to selected aspects of the variables measured (e.g., getting along with others), which may not capture the full picture of the individual.

The grouping of several variables (e.g., race/ethnicity, marital status) also served as a limitation as the depth of the analysis was constrained. The researcher chose to collapse these variables due to small numbers of individuals in specific groups (i.e., racial and ethnic minorities, individuals who rated their quality of life as poor). Another decision made during analysis that might have impacted the results and thus serves as a study limitation was the decision to extract common factors and analyze the samples together with efforts to remove variance associated with the samples by standardizing the variables. The commonalities among participants (all persons with disabilities receiving disability-related work and educational services) and the small student sample size were the reasons that common principal components

were extracted. Different components may have emerged if the two samples were analyzed separately, however, comparisons would not have been able to be made between groups. The theoretical aspects of the ICF model and the analysis of the dimensions in the present study are considered exploratory and would benefit from additional follow up with a confirmatory analysis. Despite these limitations, the findings have some interesting implications for rehabilitation counseling policy, practice, and future research.

Study Implications

While agreement exists that quality of life is the underlying goal of rehabilitation (Crewe, 1980), we still lack a comprehensive way to conceptualize and measure QOL among adults with disabilities. Despite some overlap observed between domains as measured by the WHODAS 2.0, the ICF lends itself as a conceptual framework for QOL assessment due to its basis in the biopsychosocial model of disability and emphasis on the interaction between the person in their environment when considering the impact of disability (Peterson & Rosenthal, 2005a). Growing momentum to expand outcome measurement beyond more traditional measures such as shortterm employment provides motivation to re-visit the logistics of using QOL as a potential method of gathering information on the results of services (Bishop et al., 2008; Frisch, 2004). QOL assessment is client-centered and focuses on changes that are clinically significant to the client (Frisch, 2004), and thus is considered a useful indicator of the impact of a practice or service. Results of this study indicate that while for at least some participants, more traditional measures of service success, specifically factors related to education and employment, are significantly related to QOL, other areas of life are also important and provide a clearer picture. For the individuals in these samples, the social and relational aspects of their lives and how their disability or health condition impacts them and their family were significant predictors of QOL.

It is worth noting, but not surprising, that in a sample of adults with disabilities who have much higher than typical levels of engagement with school and work that the social and relational aspects of disability in QOL emerged in the findings as opposed to issues related employment or independent living. This lends support to the claim that individuals with disabilities in our society continue to experience attitudes, bias, and discrimination that negatively impacts their daily lives (Smart, 2012), even when they are engaged in activities and roles that are typical based on age and culture. In the principal component analysis, I found that the dimensions of "attitudes" and "supportive relationships" shared common variance based on data collected from these samples. This finding closely relates to ongoing discussions of how family, friends, and rehabilitation professionals can influence how an individual with a disability feels about themselves and what they are capable of (Chan et al., 2009; Chubon, 1992; Kosciulek, 1999; Smart, 2012) and become barriers to achieving personal goals. The finding that items related to difficulty with "social relationships" and "community inclusion" shared variance indicates that the experience of difficulty getting along with others on an individual level and gaining access to typical community activities might feel similar to the individuals in the sample. We know that individuals with different kinds of disabilities experience different kinds of stigma and discrimination (e.g., related to visibility, onset, characteristics), but the impact may be analogous in terms of QOL. The implications of these findings for policy and practice, rehabilitation education, and research are discussed separately.

Implications for Rehabilitation Administrators and Counselors.

As is emphasized in seminal rehabilitation counseling text, "rehabilitation is a facilitative process enabling a person with a [*sic*] handicap to attain usefulness and satisfaction with life" (Wright, 1980, p. 3). Wright goes on to explain that handicap results from a combination of

disability itself, as well as cultural, financial, or educational disadvantage and the goal of rehabilitation is not limited to employment, but is expanded to include activity that is considered personally useful and satisfying. For a variety of reasons, including historical roots and legislative mandates, the outcome measurements of rehabilitation (particularly in the public sector) have largely been limited to employment and to a lesser extent independent living. However, in the literature we find frequent suggestions that this narrow focus leaves us with a misleading impression of the results of rehabilitation services (Bishop et al., 2008; Chapin Miller, Ferrin, Chan, & Rubin, 2004) and a broader measure including components of QOL would be more useful (Bishop & Fiest-Price, 2001; Chapin et al., 2004). Results from the present study indicate that employment and independent living are not sufficient to capture the broader picture of QOL.

A potential strategy to capitalize on these and previous findings that connect functional skills, environmental supports, and opportunities for activity and participation to QOL in practice is to adopt the ICF as a model or framework of assessment for clients at the beginning and the end of service provision. This along with a brief assessment of quality of life (e.g., "how would you rate your quality of life?") could provide practitioners with self-reported and subjective information about how the person is doing when first introduced to the agency, and thus provide some structure and direction for service plan development that includes areas of life that are connected to QOL, while still relevant to the goal of services. This more holistic model is consistent with the philosophical underpinnings of rehabilitation (Wright, 1980), and ensures that attention is paid to environmental supports as well as person-level factors. Additionally, the information at both intake and exit could provide the agency with data that reflects not only changes in life areas such as employment or independent living, but also functional ability,

environmental support, and perceived quality of life. At a time where accountability has only become more critical to program funding (Leahy et al., 2009), powerful information of this nature on the impact of services can only help agencies prove their merit or worth (Frisch, 2004).

Implications for Rehabilitation Counselor Educators.

A second area where this study has implications is in rehabilitation counselor education. While traditionally, counselors were prepared with the intent to work in the state-federal vocational rehabilitation system, graduates are increasingly pursuing work in other settings (Bishop et al., 2008; Bishop, Crystal, & Sheppard-Jones, 2003). This does not detract from the importance of the typical measures of rehabilitation service success (e.g., employment and independent living), but does create an expanded scope of services and outcomes that counselors will need to understand and be able to communicate across health-related professions. The ICF model of disability and QOL as a general outcome of focus provide rehabilitation counselors and related professionals with a common framework despite areas of difference in focus across service areas. Adopting theoretically-driven and evidenced-based methods of assessment, intervention, and research has been suggested as critical to advancing the discipline (Chan et al., 2009).

Additionally, the components of the ICF model represent important life areas that students should become attuned to when they work with future clients. In particular, the areas of social relationships and inclusion and impact of the disability or health condition on self and family appear to be critical aspects of a person's life that a rehabilitation counselor should be ready to discuss. Results of the present study showing relationships between these components as well as for students the work and school activities component, and for the CRP clients the level of

education and the environmental attitudes and supportive relationships provide some initial evidence of the importance of these life areas to QOL. While many students and counselors already understand the importance of inquiring about these areas of life, the data from this sample provide us with reinforcement that areas of life beyond our primary focus have an impact on the subjective well-being of clients.

Implications for Disability Advocates and Policy Makers.

The findings related to the importance of social relationships and inclusion, attitudes and supportive relationships, and the impact of the disability or health condition on self and family in QOL point to critical issues for the disability community and policy makers. Even though the original domain "participation" split into two other components, the collective issues (inclusion and impact of the disability on self and family) are at the heart of the disability rights movement and government policies to reduce discrimination against individuals with disabilities. The environmental oriented social support and attitudes facets continue to be important because of the long history of how persons with disabilities are perceived and treated by others and the pervasive experiences of bias and discrimination (Smart, 2001). As long as negative attitudes persist, the full acceptance and inclusion of persons with disabilities is unlikely (Antonak & Livneh, 2000). At the individual level, both of these areas provide information on where to target interventions in ones environment that may have great impact on the ability to take part in desired activities and fill social roles as well as improve QOL (Whiteneck & Dijkers, 2009). At the policy and advocacy level, findings support the importance of addressing attitudes toward disability for QOL.

Implications for Rehabilitation Researchers.

A final area where the present study has implications is for future research. As one of the few examples of cross-disability quality of life research with practical connections to rehabilitation services, the results would be strengthened with replication in various settings with samples that are representative of the general population of clients of rehabilitation services. Additionally, a longitudinal methodology might also reveal different findings related to the temporal aspect of quality of life perception. An effort to cross-validate self-reported functional limitations might also serve to improve the measurement of the constructs included in the ICF model. Additionally, alternative methods of data collection might enhance the ability of people with lower reading and language comprehension levels to more fully participate in a study of this nature.

Aside from these recommendations, additional directions in QOL assessment and application of the ICF model to rehabilitation research could also serve to advance knowledge and strengthen practice. Results indicated that the dimensions of the ICF, as measured by the WHODAS 2.0, were largely supported by the data from this sample, with the exception of some areas of overlap. In particular, some clarification of "participation" and its relationship with social relationships and inclusion seems necessary. Despite some underlying commonality observed among domains, results of the study support the utility of the ICF model and its potential for broader application in rehabilitation research. It would be useful to understand the connection between the areas of the ICF model of health and disability and effective service planning and provision. QOL is one outcome measure to consider, but others that are more relevant to individual service providers might also reveal interesting findings related to implementing the ICF as a comprehensive model of assessment. For example, when the ICF

model is used as a framework for assessment and service planning, are outcomes such as employment or customer satisfaction improved? A study of this nature could serve to influence the development of evidence-based practice. Another area of future research could be to assess changes in personal perception in multiple life areas (e.g., those included in the ICF) as a method of determining the impact of services. It is possible that even if the focus of services is narrow (e.g., employment or education), that the carryover of services impact other areas as well and as a result have a greater impact than originally realized.

Finally, there were several variables in this study that were related to QOL that deserve more attention, particularly participation as this has and continues to represent a measurement challenge (Whiteneck, Bogner, & Heinemann, 2011). This concept in the ICF model has been particularly difficult for practical application as it is a complex construct with subjective dimensions that make it difficult to characterize what "ideal" participation means. Several large scale research studies have resulted in improved measurement tools that might be utilized in future research that includes this construct (Whiteneck et al., 2011). Measuring environmental characteristics and activity are also challenging and future efforts might include alternate methods of gathering this information (Whiteneck & Dijkers, 2009). Additionally, continued investigation into the reported quality of life of individuals with disabilities, particularly compared with the general population, is important information for disability advocates and the disability community.

Conclusions

The findings of this study support and expand upon previous research regarding contributors of quality of life for adults with disabilities. Results show that the ICF model

dimensions, as measured by the WHODAS 2.0, were largely supported but have a few areas of overlap that may require further clarification. Additionally, findings indicate that quality of life is a complex construct where a portion can be explained by function, difficulty with work and daily living activities, community participation, and environmental support. When just the demographic characteristics and variables related to work and independent living were included, much less QOL was explained by the data. Additionally, the sample from the present study reported quality of life levels that are more typically observed in the general population (i.e., most people reported satisfaction), which lends support to the notion that reports of lower levels of QOL in individuals with disabilities is not universal, and may not be due to disability itself. Finally, the role of social and relational aspects of individuals' experiences emerged as an important part of their perceived QOL. As we continue to hold quality of life as the underlying goal of rehabilitation services, a shift in how we consider individuals, plan interventions, and measure outcomes may be beneficial at both the individual and agency level in targeting resources to areas that are personally meaningful as well as providing more complete information on the value of service interventions. The present study provides us with initial results to that support the utility of the ICF for conceptualizing disability and its impact in a way that is inclusive of both personal and environmental factors, and providing a more comprehensive picture of QOL.

APPENDICES

APPENDIX A: SURVEY INSTRUMENT

As an adult with a disability or chronic health condition, you are being asked to take part in a research study about the relationship between activities, community factors, and community participation and how people feel about their quality of life.

I anticipate that the survey will take approximately 20 minutes to complete.

Risks and benefits: A potential benefit is that the information gathered from you could be helpful in community advocacy efforts to ensure that people with disabilities have increased opportunities to take part in activities and have full access to their communities. I do not expect any risks to you if you participate in this study. However, if you do experience stress, please contact your vocational case services representative at [The CRP]. [Student instrument made reference the University Counseling center instead]

Compensation: As a token of thanks for completing the survey, you will receive a \$10 Meijer gift card. [Student compensation was to be entered in a lottery to win one of five \$50 gift cards].

Confidentiality: All information collected through this survey will remain confidential, meaning that only the researcher will have access to the information. I will never ask for your name or other personal information (like a social security number, address, or phone number), so you will not be able to be identified through your survey. Information collected through the survey may be used to fulfill an educational requirement and/or result in published professional journal articles and/or presented at professional meetings.

Taking part is voluntary: Please note that your participation in this research study is voluntary and you can skip any question(s) that you do not want to answer. You can also discontinue the survey at any time. After you hand in the survey you will not be able to withdraw your responses because I will be unable to identify your answers.

If you choose to participate and continue, you will be presented with a few sets of questions. The first questions are designed to get some information about you. This will include things about where you live and your community, your disability and how it impacts your activities and participation in your community. Then I will ask some questions about how you feel about your life at this point. There are no right or wrong answers to these questions, and often your first reaction to the question will be your best answer. I am truly interested in your opinions and feelings.

If you would like assistance completing this survey, or if you would like to do it in an alternate format (say, on a paper copy, or telling me your answers over the phone), please contact me at either: flemi112@msu.edu or 617-413-6378. I would be happy to accommodate any requests.

If you have any other questions about the study, please contact Michael Leahy (517-432-0605; leahym@msu.edu ; 463 Erickson Hall, Michigan State University, East Lansing, MI 48824) or Allison Fleming (617-413-6378; flemi112@msu.edu). Thank you!

Information about you:

1. What city and state do you live in?

2. Gender?

- a. Male
- b. Female

3. Age? _____ (enter in years)

- 4. What is your race/ethnicity?
- a. White/Caucasian
- b. African American or Black
- c. Hispanic/Latino
- d. Asian or Pacific Islander
- e. Multiracial
- f. Other (Please specify)
- 5. Years of formal education? (select one)
- a. Less than HS
- b. Some HS
- c. HS graduate or GED
- d. Some post-secondary
- e. Associates degree
- f. Bachelors degree
- g. Masters or higher
- 6. Current marital status (select one)
- a. Never married
- b. co-habitating
- c. Married
- d. Separated
- e. Divorced
- f. Widowed
- 7. Current occupation (select one)
- a. Paid employment
- b. Self-employment
- c. Non-paid work such as volunteer/charity
- d. Student
- e. Keeping house/home-maker

f. Retired

- g. Unemployed- seeking work
- h. Unemployed- not seeking work
- i. Other- please specify
- 8. Disability Type: (select all that apply)
- a. Blind or visually impaired
- b. Deaf or hard of hearing
- c. Mobility impaired (e.g., spinal cord injury)
- d. Brain injury
- e. Learning disability or Attention-deficit Hyperactivity Disorder (ADHD)
- f. Psychiatric or mental health (e.g., depression, anxiety, mental illness)
- g. Chronic health condition (e.g., lupus, chronic pain, neurological disorder, Crohn's Disease)
- h. Autism spectrum disorder (e.g., Autism, Asperger's)
- i. Other: _____

9. How long have you had this disability or health condition? (select one)

- a. Since birth
- b. 10 years or longer
- c. 5 years or longer
- d. 1 year or more
- e. less than one year

10. What is your current living situation? (select one)

a. In my own apartment or house alone or with family or friends

- b. In someone else's apartment or house with them
- c. In a group living situation (e.g., group home)
- d. In a homeless shelter
- e. In college/university housing
- f. Other (please specify)

This part of the questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the past 30 days, how much difficulty did you have in: Understanding and communicating

11. Concentrating on doing something for ten minutes?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

12. Remembering to do important things?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

13. Analyzing and finding solutions to problems in day-to-day life?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

14. Learning a new task, for example, learning how to get to a new place?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

15. Generally understanding what people say?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

16. Starting and maintaining a conversation?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

Getting around

- 17. Standing for long periods such as 30 minutes?
- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

18. Standing up from a sitting position?

a. None

- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

19. Moving around inside your home?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

20. Getting out of your home?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

21. Walking a long distance such as a mile?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

In the past 30 days, how much difficulty did you have in Self-care:

22. Washing your whole body?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

23. Getting dressed?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do
- 24. Eating?
- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

25. Staying by yourself for a few days?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

Getting along with people 26. Dealing with people you do not know?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

27. Maintaining a friendship?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

28. Getting along with people who are close to you?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

29. Making new friends?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

30. Sexual activities?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

Life activities

31. Taking care of your household responsibilities?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

32. Doing most important household tasks well?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

33. Getting all the household work done that you needed to do?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

34. Getting your household work done as quickly as needed?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

Because of your health condition, in the past 30 days, how much difficulty did you have in:

35. Your day-to-day work/school?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

36. Doing your most important work/school tasks well?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

37. Getting all the work done that you need to do?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

38. Getting your work done as quickly as needed?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

Participation in society

39. How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

40. How much of a problem did you have because of barriers or hindrances in the world around you?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

41. How much of a problem did you have living with dignity because of the attitudes and actions of others?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

42. How much time did you spend on your health condition, or its consequences?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

43. How much have you been emotionally affected by your health condition?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

44. How much has your health been a drain on the financial resources of you or your family?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

45. How much of a problem did your family have because of your health problems?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

46. How much of a problem did you have in doing things by yourself for relaxation or pleasure?

- a. None
- b. Mild
- c. Moderate
- d. Severe
- e. Extreme
- f. Cannot do

For these next questions, please think back and give an estimate.

47. Overall, in the past 30 days, how many days were these difficulties present? Number of days: _____

48. In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition? Number of days: _____

49. In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition? Number of day: s _____

This part of the questionnaire asks about your environment and the community you live in. Please consider how each of the following either helps you participate (a facilitator) in the community, or makes it more difficult for you (presents a barrier).

I am interested in your perception of how much people and things in your environment help you or make things more difficult for you.

Please use the following scale:

Severe barrier = Presents significant difficulty to you in participating in the community

Moderate barrier = Presents moderate difficulty to you in participating in the community.

Mild barrier = Presents some difficulty to you in participating in the community.

Neither a barrier nor a help (facilitator) = You feel neutral- it does not help nor present difficulty to you.

Mild facilitator = Provides some assistance in participating in the community.

Moderate facilitator = Provides moderate assistance to you in participating in the community

Substantial facilitator = Provides significant assistance to you in participating in the community

For example, if you do not have adequate means of mobility or transportation, you might consider that a barrier. You would then tell me the degree to which this is a problem for you by using the scale. On the other hand, if you do have access to transportation, you might consider this a facilitator, and then you would tell me the degree to which this helps you participate in the community using the scale.

Products and Technology: Please consider how much technology and / or available products help or hinder your ability to participate in your community.

50. Products for personal use in daily living (e.g., assistive devices, food, medicine, etc.)

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

51. Products for mobility and transportation (e.g., wheelchair, walker, or other assistive mobility device)

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator
- 52. Products for communication (e.g., telephones, assistive devices)
- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

53. Public and private buildings in the community (e.g., government buildings, stores, restaurants, movie theatres, malls, etc.)

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

Natural Environment

54. To what extent does the climate where you live (for example- heat, snow, rain, altitude) help or hinder your ability to participate in your community?

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

Support and Relationships: please consider how much support from and relationships with people in your life help or hinder your ability to participate in your community.

- 55. Your immediate family
- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

56. Friends and acquaintances

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

57. Personal care staff and other healthcare workers

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

Attitudes: please consider how much the attitudes of people around you help or hinder your ability to participate in your community.

58. The attitudes of my immediate family members

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

59. The attitudes of my friends and acquaintances

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

60. The attitudes of my personal care staff and other healthcare workers

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

61. The societal attitudes that I observe in my community

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator
Services, systems, and policies: please consider how much the availability of services and opportunities help or hinder your ability to participate in your community.

62. Available and accessible housing

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator
- 63. Communication (for example, access to a phone, TTY, or video conference)
- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator
- 64. Available and accessible transportation (e.g., public or private)
- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator
- 65. Available and accessible legal services
- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

- 66. Social security and other support systems
- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

67. Health services

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

68. Educational training and opportunities

- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator
- 69. Employment services
- a. Severe barrier
- b. Moderate barrier
- c. Mild barrier
- d. Neither a barrier nor a facilitator
- e. Mild facilitator
- f. Moderate facilitator
- g. Substantial facilitator

The following questions ask how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last 4 weeks.

- 70. How would you rate your quality of life?
- a. Very poor
- b. Poor
- c. Neither poor nor good
- d. Good
- e. Very good

71. How satisfied are you with your health?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

The following questions ask about how much you have experienced certain things in the last 4 weeks.

72. To what extent do you feel that physical pain prevents you from doing what you need to do?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

73. How much do you need any medical treatment to function in your daily life?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

74. How much do you enjoy life?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount
- 75. To what extent do you feel your life to be meaningful?
- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount
- 76. How well are you able to concentrate?
- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount
- 77. How safe do you feel in your daily life?
- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

78. How healthy is your physical environment?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

The following questions ask about how completely you experienced or were able to do certain things in the last four weeks.

79. Do you have enough energy for every day life?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

80. Are you able to accept your bodily appearance?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount
- 81. Have you enough money to meet your daily needs?
- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

82. How available to you is the information that you need in your day-to-day life?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

83. To what extent do you have the opportunity for leisure activities?

- a. Not at all
- b. A little
- c. A moderate amount
- d. Very much
- e. An extreme amount

- 84. How well are you able to get around?
- a. Very poor
- b. Poor
- c. Neither poor nor good
- d. Good
- e. Very good

85. How satisfied are you with your sleep?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

86. How satisfied are you with your ability to perform your daily living activities?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

87. How satisfied are you with your capacity to work?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

88. How satisfied are you with yourself?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

89. How satisfied are you with your personal relationships?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

90. How satisfied are you with your sex life?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

91. How satisfied are you with the support you get from your friends?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

92. How satisfied are you with the conditions of your living place?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

93. How satisfied are you with your access to health services?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

94. How satisfied are you with your transport?

- a. Very dissatisfied
- b. Dissatisfied
- c. Neither satisfied nor dissatisfied
- d. Satisfied
- e. Very satisfied

The following question refers to how often you have felt or experienced certain things in the last 4 weeks.

95. How often have you had negative feelings such as blue mood, despair, anxiety, or depression?

Never Seldom Quite often Very often Always

Thank you for your participation!

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