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THE RELATIONSHIP BETWEEN SELF-DETERMINATION AND QUALITY OF LIFE AMONG INDIVIDUALS WITH DISABILITIES INVOLVED WITH A CENTER FOR INDEPENDENT LIVING

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Karsten Bekemeier

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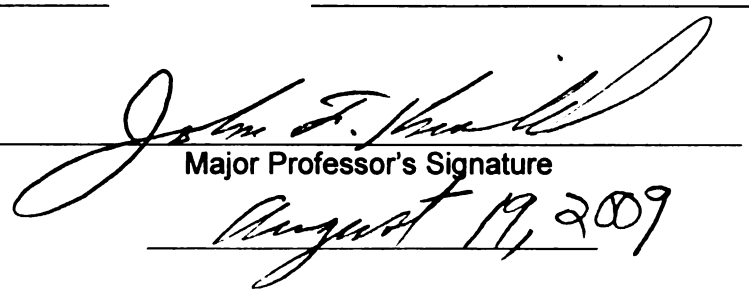

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By

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ABSTRACT

THE RELATIONSHIP BETWEEN SELF-DETERMINATION AND QUALITY OF LIFE AMONG INDIVIDUALS WITH DISABILITIES INVOLVED WITH A CENTER FOR INDEPENDENT LIVING

By

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Individuals with disabilities have historically been compromised in their ability to assert independence with respect to concepts of independent living and self-determination. In turn this may potentially impact an individual's overall quality of life. Community integration and availability of a full quality of life and to be self-determined has served as an indication of a positive outcome within research. This can result from a process in which individual self-determination results in an improved quality of life.

Research has focused on self-determination and QOL as both outcome variables and mediator variables in planning outcomes such as employment (Wehmeyer & Schwartz, 1998, Wehmeyer, 1996, Wehmeyer & Bolding, 1999). Although research has been conducted into specific population groups, the independent living setting provides an opportunity to evaluate self-determination and quality of life from a perspective of a setting that is specifically structured to promote and practice the independent living philosophy.

The purpose of the current study was to examine the relationship between self-determination and quality of life among individuals with disabilities. Participants included individuals with disabilities that were involved with a local Center for Independent Living and had received services (n = 43). *The Arc's Self-Determination*

Scale (Wehmeyer, 1995) and the *World Health Organization Quality of Life - BREF* (WHOQOL Group, 1998) were used to operationally define variables. Canonical correlation analysis was used to investigate the primary research question.

Tests of dimensionality for the canonical correlation analysis, indicated that two of the four canonical dimensions emerged as significant at the .05 level. Dimension one had a canonical correlation of 0.875. As such, 77% of the variance between self-determination and quality of life was explained by the first canonical variate. The first canonical correlation was determined to be interpretable and suggests that a moderate relationship exists between the self-determination and quality of life variable sets.

Within the first canonical score, the criterion variables of Quality of Life, Physical Health and Environment had a greater ratio of importance in calculating the canonical variate. Within the predictor variables of Self-determination, the greatest importance in calculating the canonical variate was Autonomy.

The result of the current study contributes to a growing body of literature which suggests that the first and perhaps most important steps towards promoting self-determination and quality of life is to support individuals towards acting on personal beliefs, assisting towards promotion of ones physical health, and the promotion of ones personal environment such as access to resources and the community. As such those who have obtained related services through the CIL may have a greater potential for emphasis and connection with community and belonging that may positively influence an individuals participation and self-determination and possibly overall quality of life.

To Sara.

It was with your continued support, words of encouragement, and love that this has been accomplished.

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Lastly, I have to give a very special thank you to my wife Sara. You laugh at most of my jokes, make me feel like I can accomplish anything; encourage me to try new things, and to look to the future as much as we also enjoy today. I have been in love with you for half my life and look forward to the rest of our life together. You are my Honey-Bunny and I love you with all of my heart.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter 1

Introduction

Rehabilitation policy, rehabilitation counselors and related professionals in the field, are closely linked to the application of core legislation including the 1973 Rehabilitation Act and the 1990 Americans with Disability Act (ADA). The intent of this legislation is to improve overall independence, integration, and achievement potential of individuals with disabilities. Research and practice has evolved to incorporate these ideals through development of methods of interaction and goal formation utilized by professionals in the field.

A primary objective of disability policy is to improve the circumstances of people with disabilities by empowering them to participate in the mainstream of society (Batavia & Schriner, 2001). The individual, political and legislative movement to increase the assistance for individuals with disabilities has evolved to a present understanding that those with disabilities are their own best stewards for successful rehabilitation, integration, or other services to assist towards independence in the community. This is an evolution that can be traced through legislation and political activity (McDonald & Oxford, 2007).

Individuals with disabilities have historically been compromised in their ability to assert independence with respect to concepts of independent living and self-determination. In turn such a situation may potentially impact an individual's overall quality of life. Professional organizations, state rehabilitation agencies and legislative initiatives have attempted to remove some of the challenges and barriers individuals with disabilities face.

The Center for Independent Living programs represents a clear example of a professional organization structured to work with individuals with disabilities to reduce and eliminate barriers to independence. The objective of a Center for Independent Living program is to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities and to integrate these individuals into the mainstream of American society (U.S. Department of Education, 2005). The first CIL was founded in Berkeley, Ca. as part of the independent living movement of the 1960's. The original Physically Disabled Students Program (PDSP) was formed by a group of students with disabilities at the University of California-Berkeley who joined forces to make the full academic and social life of the campus more accessible to themselves and others. In 1972 the CIL was formally incorporated and established the philosophies and goals that (Center for Independent Living, 2007):

- Comprehensive programs with a wide variety of services most effectively meet the needs of people with disabilities.
- People with disabilities know best how to meet the needs of others with disabilities.
- The strongest and most vibrant communities are those that include and embrace all people.

The independent living movement is based on what has been referred to as the "independent living model" (Batavia, DeJong, & McKnew, 1991). It recognizes disability as a complex phenomenon involving the interaction between impairments, "functional limitations" associated with the impairments, and "disabilities" (i.e., social disadvantages, "handicaps") associated with the limitations. Under this model, disabilities are not

inherent in individuals, but rather result from the interaction between individuals and their environments. Therefore, the appropriate intervention is to modify the environment to accommodate the needs of people with disabilities.

Statement of the Problem

The core services and principles of the CIL combine to establish criteria for both individual expectations along with service expectations for an individual with a disability. However, it is difficult to fully measure the impact of the independent living movement with respect to the individual needs and accommodations. Employment may serve as one indication of successful integration into the community and overall independence. However, such emphasis may also serve to alienate a population of citizens that either do not seek employment services or do not require employment services yet do request services towards independent living and community integration.

Community integration and availability of a full quality of life (QOL) and to be self-determined has served as an indication of a positive outcome within research. The rehabilitation process is philosophically structured to promote full integration and optimal self-sufficiency of individuals with disabilities into society. This can result from a process in which individual self-determination results in an improved quality of life. Research has focused on self-determination and QOL as both outcome variables and mediator variables in planning outcomes such as employment (Wehmeyer & Schwartz, 1998, Wehmeyer, 1996, Wehmeyer & Bolding, 1999). Although research has been conducted into specific population groups, the independent living setting provides an opportunity to evaluate self-determination and quality of life from a perspective of a

setting that is specifically structured to promote and practice the independent living philosophy of:

a. Consumer control of the center regarding decision making, service delivery, management, and establishment of the policy and direction of the center
b. Self-help and self-advocacy;
c. Development of peer relationships and peer role models; and
d. Equal access of individuals with significant disabilities to society and to all services, programs, activities, resources, and facilities, whether public or private and regardless of the funding source (Rehabilitation Act Amendment, 1998).

Ongoing research into the relationship of self-determination and quality of life serves to establish and reinforce the link between hat of rehabilitation programs, legislation, and program development. Wehmeyer and Schwartz (1998) concluded from research on self-determination and quality of life of individuals with mental retardation, that although individuals with disabilities have emphasized and researchers and practitioners have presumed connections between self-determination and quality of life, there remains an ongoing need for additional research into program development to achieve this outcome. Additional evidence is necessary to support the hypothesis that individuals who take greater control in their lives are more likely to have a higher quality of life.

The need exists to examine the relationship between self-determination and quality of life among consumers of independent living services. The impact of disability policies and rehabilitation services must ultimately be measured by the degree to which they contribute to the improved QOL of people with disabilities. Thus, QOL should be a focus of theory development and research in rehabilitation. In addition, due to the

potentially major role that rehabilitation services play in contributing to or even determining individual lifestyles (Felce & Perry, 1996), QOL has a central position in the development and evaluation of services for people with disabilities (Kosciulek, 2004).

Purpose of the Study

The purpose of this study is to study to relationship between self-determination and quality of life among individuals with disabilities. This research effort focuses on the common factors that are indicative of an individuals' level of self-determination with that of rated quality of life indicators. Within the field of rehabilitation, specific to independent living, focus is placed on working with consumers in a manner that supports self-determination in effort to increase their quality of life.

Research into self-determination as well as quality of life is based on the assumption that the extent of self-determination exhibited from a consumer who is a participant in independent living services is correlated with the perception of the impact of such services on his/her quality of life.

This investigation has a core purpose of examining the relationship between self-determination and quality of life among participants in Centers for Independent Living. Further studying the relationship between self-determination and quality of life may yield information useful for agencies such as CIL's and rehabilitation facilities to assess internal processes and barriers that may lead to more successful outcomes for the individuals served. The research question of interest in relation to the purpose of this study is as follows:

Research Question

The research question of interest in the proposed study is as follows: What is the relationship between self-determination and quality of life?

In a study of the relationship of indicated levels of self-determination with a measure of quality of life, the ultimate goal is to identify and develop strategies that are effective in facilitating, increasing, and improving individual outcomes for individuals with disabilities based on their goals towards rehabilitation.

Theoretical Framework

Self-Determination

To investigate self-determination there is a need for a conceptual framework to direct research. Within behavioral science, researchers are dealing with complex systems from which observed behavior is a result of many different, and often interacting, causal factors (Kosciulek, 2004). Theoretical models are essential to the analysis of such complex systems. The self-determination theory (SDT) (Ryan; Deci, 2000), and the consumer-directed theory of empowerment (Kosciulek, 2005), are used in this context to guide this research.

Self-Determination Theory (SDT) is specifically framed in terms of social and environmental factors that *facilitate* versus *undermine* intrinsic motivation. This language reflects the assumption that intrinsic motivation, being an inherent organismic propensity, is catalyzed (rather than *caused*) when individuals are in conditions that conduce toward its expression (Ryan, Deci, 2000). SDT is an approach to human motivation that highlights the importance of three fundamental psychological needs – autonomy,

competence, and relatedness. Combined these fundamental psychological needs combine to form an understanding of optimal functioning (Ryan, Deci, 2000).

Central to the theory of self-determination is that intrinsic goal pursuits have positive effects on well-being because they promote satisfaction of the basic psychological needs (autonomy, competence, and relatedness), that is, they promote people's natural growth tendencies (Vansteenkiste et al., 2004). Similarly, personal control or self-efficacy represents the person's belief that he or she is able to control events and thereby secure positive life outcomes. Thus low levels of control contribute to learned helplessness and possible task focused coping (Roessler, 2004).

Quality of life

Quality of life within the field of rehabilitation counseling is typically addressed as a global outcome category (Livneh, 2001). As a broad and multidimensional construct it incorporates both subjective and objective features. Livneh (2001) indicated QOL as an ultimate rehabilitation goal for people with chronic illness and disability. Individuals with disabilities who are referred to or seek rehabilitation services are inherently attempting to achieve what may be construed as a better quality of life (QOL). The varied concepts of self-determination, empowerment, consumer directed services, and choice are focused on assisting individuals with disabilities with increase of quality of life. Enhancing the QOL of people with disabilities is the inherent, overarching goal of disability policy and rehabilitation processes (Kosciulek, 2004).

Kosciulek (2004) summarized QOL as an overall general well-being comprised of objective and subjective evaluations of physical, material, social, and emotional well-being. Quality of life is determined by an individual's satisfaction with the extent of his

or her personal development and purposeful activity, which are appraised by a personal set of values. Objective evaluation refers to the description of life conditions under which people live, such as health, income, housing quality, friendship network, and social roles. Subjective evaluation refers to personal satisfaction with such life conditions. The significance of both objective and subjective QOL is interpretable in relation to the value or importance the individual places on each area in question (Felce & Perry, 1996). Well-being stems from the degree of fit between an individual's perception of his or her objective situation and his or her needs, aspirations, or values (Kosciulek 2005).

From subjective and objective evaluation, quality of life can be maximized based on loosely integrated domains including: a) intrapersonal functioning (e.g., health, psychological or subjective well-being, life satisfaction, self-concept or self-esteem); (b) interpersonal functioning (e.g., family life, marriage, friendships and peer relations, social activities); and (c) extrapersonal functioning (e.g., work activities, recreational pursuits, learning or schooling, housing, finances) (Livneh 2001).

QOL is directly related to having individual needs met, control over one's environment, and opportunities to make choices. The Consumer-Directed Theory of Empowerment (CDTE) provides a guide for evaluating the impact of CIL programming on self-determination and quality of life. CDTE asserts that: consumers are experts on their needs whereby an informed consumer is the best authority of what ones service needs are, that choice can be introduced into all service delivery environments, and that consumer direction should be available to all regardless of payer.

Overview of the Study

This research study will utilize past research to first define the components of both self-determination and quality of life as related to the accepted theoretical framework of each concept. This study will then investigate self-determination and quality life within a specific population of individuals with disabilities who are active members within a specific Center for Independent Living. One objective is to gain greater understanding of the impact of self-determination towards that of quality of life. A related objective is to gain greater insight as to the contribution of specific components of both self-determination and quality of life to determine what potentially has greater influence towards increased levels of both self-determination and subsequent quality of life.

Individuals who are members of a center for independent living have a shared objective of gaining services that are structured to assist in living independently with an emphasis placed on increasing personal control and overall quality of life. Of question is having a greater understanding of what services best contribute towards an increased quality of life. This study incorporates the conceptual understanding of self-determination and quality of life and will investigate how each concept is influenced by the other.

Definition of Terms

Center of Independent Living: independent living programs are funded to provide, expand, and improve independent living services; develop and support statewide networks of centers for independent living; and improve working relationships among relevant federal and non-federal programs (U.S. Department of Education, 2005).

The National Council on Independent Living (U.S. Department of Education, 2005) describes four core services of independent living:

- Individual and Systems Advocacy: CILs carry out their mission in a wide variety of ways, according to the priorities of local communities. Centers can provide disability awareness training, advocate for improved accessibility, or assist people transitioning from a nursing home to independent living in their community. Center staff advocate on an individual and system-wide basis to ensure the civil and human rights of people with disabilities.
- Information and Referral: The Independent Living community provides disability-specific information and referral to ensure people with disabilities have access to information needed to achieve or maintain independence in their community.
- Peer Support: To preserve their integrity as grassroots organizations, CILs implement peer support to achieve objectives set by the disability community itself. The value placed on peer support in the Independent Living Movement is paramount and unique, and the significance of a system that values the peer-to-peer relationship is often overlooked by a society that is accustomed to valuing the opinion of professionals and "experts" over the goals and needs of consumers.

- Independent Living Skills Training: CILs implement peer support to provide training on the very specific set of skills needed to achieve independent living, ensuring that people with disabilities achieve and maintain their independence.

Additionally, there are ten principles of independent living:

1. Civil Rights - equal rights and opportunities for all; no segregation by disability type or stereotype.
2. Consumerism - a person ("consumer" or "customer") using or buying a service or product decides what is best for him/herself.
3. De-institutionalization - no person should be institutionalized (formally by a building, program, or family) on the basis of a disability.
4. De-medicalization - individuals with disabilities are not "sick", as prescribed by the assumptions of the medical model and do not require help from certified medical professionals for daily living.
5. Self-help - people learn and grow from discussing their needs, concerns, and issues with people who have had similar experiences; "professionals" are not the source of help provided.
6. Advocacy - systemic, systematic, long-term, and community-wide change activities are needed to ensure that people with disabilities benefit from all that society has to offer.
7. Barrier-removal - in order for civil rights, consumerism, de-institutionalization, de-medicalization, and self-help to occur, architectural, communication and attitudinal barriers must be removed.

8. Consumer control - the organizations best suited to support and assist individuals with disabilities are governed, managed, staffed and operated by individuals with disabilities.
9. Peer role models - leadership for independent living and disability rights is vested in individuals with disabilities (not parents, service providers or other representatives).
10. Cross-disability - activities designed to achieve the first five principles must be cross-disability in approach, meaning that the work to be done must be carried out by people with different types of disabilities for the benefit of all persons with disabilities (U.S. Department of Education, 2005).

Self-determination: refers to individuals making life choices based on their personal preferences (Leff et al., 2003). There are a number of personality attributes, skills, types of knowledge, and attitudes that have been postulated to predispose or enable persons to be self-determining (Wehmeyer, 1999). These include self-knowledge, choice making skills, self-observation skills, problem solving skills, positive attributions of efficacy and outcome expectancy, decision making skills, goal-setting skills, self-instruction skills, internal locus of control, and self awareness. Self-determination can be defined as an individual who has the capacity of "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer & Kelchner, 1996).

Self determined behavior: refers to actions that are identified by four essential characteristics based on the function (purpose) of the behavior: (a) the person acted

autonomously, (b) the behavior(s) are self-regulated, (c) the person initiated and responded to event(s) in a psychologically empowered manner, and (d) the person acted in a self-realizing manner (Wehmeyer & Kelchner, 1996).

Quality of Life: is defined as the subjective sense of overall well-being that results from an individual's evaluation of satisfaction with an aggregate of personally or clinically important domains, or areas of life (Bishop, 2005). Among the most frequently identified domains are physical health, psychological or emotional health, social support, employment or other productive activity, and economic or material well being (Bishop & Allen, 2003).

Chapter 2

Literature Review

The purpose of the current study is to explore the relationship between self-determination and quality of life. To provide a comprehensive review of self-determination and quality of life, the literature review addresses three areas. First, a framework for investigating and analyzing self-determination will be discussed. Second, a model for organizing the conceptual understanding and outcome of quality of life will be presented. Finally, the major variables of interest in this study will be describes including the independent living program setting, and philosophy as applied to this study.

The current need within rehabilitation is to structure programming and services to what is known about the concepts of self-determination and quality of life for consumers who seek services. The 1992 and 1998 Rehabilitation Act (P.L. 102-569) state that "disability is a natural part of the human experience and in no way diminishes the right of individuals to: live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, or to enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream (Field, & Hoffman, 1994).

The concept of self-determination was found to best encompass the necessary components needed within the rehabilitation process to fully detail the expectation of services for an individual with a disability within the rehabilitation process. Similarly the concept of quality of life best summarizes the outcome of the rehabilitation process from the perspective of the consumer being served.

Self-determination

To investigate self-determination there is a need for a conceptual framework to direct research. Within behavioral science, researchers are dealing with complex systems from which observed behavior is a result of many different, and often interacting, causal factors (Kosciulek, 2004). Theoretical models are essential to the analysis of such complex systems. The self-determination theory (SDT) (Ryan; Deci, 2000) is used in this context to guide this research.

Self-Determination Theory (SDT) is specifically framed in terms of social and environmental factors that *facilitate* versus *undermine* intrinsic motivation. This language reflects the assumption that intrinsic motivation, being an inherent organismic propensity, is catalyzed (rather than *caused*) when individuals are in conditions that conduce toward its expression (Ryan, Deci, 2000). SDT is an approach to human motivation that highlights the importance of three fundamental psychological needs – autonomy, competence, and relatedness. The three fundamental psychological needs combine to the understanding of optimal functioning (Ryan, Deci, 2000).

Self-determination theory hinges on the concept of motivation. Within research motivation is often defined by the amount exhibited rather than the specific source or kind. Many factors may contribute to motivation, but it has inherently been represented a single variable within research. Within SDT the focus is placed on the strength of autonomous versus controlled motivation rather than the total amount of motivation.

Autonomous motivation (autonomy) centers on acting with a sense of volition and having the experience of choice (intrinsic motivation is an example of autonomous motivation). By contrast, controlled motivation involves acting with a sense of necessity,

or pressure (Gagne, Deci, 2005). Thus behaviors can be characterized in terms of the degree to which they are autonomous vs. controlled. Both sources of motivation are also intentional and are in contrast to amotivational, which involves a lack of intention and motivation (Gagne, Deci, 2005).

Research from Koestner and Losier (2002), found that intrinsic motivation yielded better performance on tasks that are interesting but that autonomous extrinsic motivation yielded better performance on tasks that are not in themselves interesting but that are important and require discipline or determination. Controlled motivation would potentially detract from such outcomes, particularly if the activity requires creativity, cognitive flexibility, or deep processing of information (Gagne, Deci, 2005).

Satisfaction of needs is tied to overall motivation and the self-determination theory. Within organizational theories, needs have typically been treated as individual differences; people are viewed as differing in the strength of particular needs. SDT defines needs as universal necessities. Something is a need only to the extent that its satisfaction promotes psychological health and its thwarting undermines psychological health (Gagne, Deci, 2005). Within SDT the three fundamental psychological needs for competence, autonomy, and relatedness are considered critical.

Within the model of SDT the consequences of the extent to which individuals are able to satisfy the needs within social environments are focused on. Addressing individual differences in peoples orientation towards the initiation and regulation of behavior, referred to as general causality orientations, index the degree to which people are autonomy orientated, control orientated, and interpersonally orientated (Gagne, Deci, 2005).

- Autonomy orientation reflects a general tendency to experience social contexts as autonomy supportive and to be self-determined. (positively related to self actualization, self-esteem, ego development, integration in personality, and satisfying interpersonal relationships)
- Control orientation reflects a general tendency to experience social contexts as controlling and to be controlled (associated with public self-consciousness, the Type A behavior pattern, defensive functioning, and placing a high importance on pay and other extrinsic motivators)
- Interpersonal orientation reflects the general tendency to be amotivated. (related to external locus of control (not controlling outcomes) and to self derogation and depression)

The self-determination continuum (Figure 1.) shows a range of self-determination from amotivation (a complete lacking of self-determination), to the types of extrinsic motivation with variation of degrees that increase in levels of self-determination, to intrinsic motivation (meaning invariantly self-determined).

Figure 1. Gagne, Deci(2005) SDT: Self –Determination Theory

Amotivation	Extrinsic Motivation				Intrinsic Motivation
	External Regulation	Introjected Regulation	Identified Regulation	Integrated Regulation	
Absence of intentional regulation	Contingencies of reward and punishment	self-worth contingent on performance ego-involvement	Importance of goals, values, and regulations	Coherence among goals values and regulations	Interest and enjoyment of the task
Lack of Motivation	Controlled Motivation	Moderately Controlled Motivation	Moderately Autonomous Motivation	Autonomous Motivation	Inherently Autonomous Motivation

The conceptual framework for the present study was adopted from the field of clinical and social psychology and the study of work motivation. Self-determination theory is a broad theory based off of cognitive evaluation theory. Self-determination theory is formulated as a theory of work motivation and is relevant to theories of organizational behavior.

Gagne and Deci (2005) developed the self-determination theory (SDT) based on the distinction between autonomous motivation and controlled motivation. SDT's assumption is that motivations differ in terms of their underlying regulatory processes and their accompanying experiences. It further suggests that behaviors can be characterized in terms of the degree to which they are autonomous versus controlled (together each is in contrast to amotivation, which involves a lack of intention and motivation)

An important aspect of SDT is the proposition that extrinsic motivation can vary in the degree to which it is autonomous versus controlled and that inherently autonomous motivation is based on intrinsic motivation. Within extrinsic motivation there is a presumed continuum based on the perception of a contingency between the behavior and a desired consequence. SDT proposes a continuum of four levels of extrinsic motivation:

1. External Regulation: Initiated and maintained by contingencies external to the person. A person acts with the intention of obtaining a desired consequence or avoiding an undesired one, so they are energized into action only when the action is instrumental to those ends.

2. Introjected Regulation: A regulation that has been taken in by the person but has not been accepted as his or her own is said to be introjected. (e.g., I work because it makes me feel like a worthy person).
3. Identified Regulation: People feel greater freedom and volition because the behavior is more congruent with their personal goals and identities. The activity may not be inherently of interest, but there does exist an internal locus of control with respect to the position.
4. Integrated Regulation: People have a full sense that the behavior is an integral part of who they are, that it emanates from their sense of self and is thus self-determined.

Not structured as a stage theory, SDT describes each type of regulation in order to index the extent to which people have integrated the regulation of a behavior or class of behaviors. SDT proposes that, under optimal conditions, people can, at any time, fully integrate a new regulation, or can integrate an existing regulation that had been only partially internalized Gagne and Deci (2005). Thus, SDT ranges from amotivation, which is wholly lacking in self-determination, to intrinsic motivation, which is invariantly self-determined. Between amotivation and intrinsic motivation, along this descriptive continuum, are the four types of extrinsic motivation, with external being the most controlled (and thus the least self determined) type of extrinsic motivation, and introjected, identified, and integrated being progressively more self-determined Gagne and Deci (2005).

Central to the theory of self-determination is that intrinsic goal pursuits have positive effects on well-being because they promote satisfaction of the basic psychological needs

for autonomy, competence, and relatedness; that is, they promote people's natural growth tendencies (Vansteenkiste, et al., 2004). Similarly, personal control or self-efficacy represents the person's belief that he or she is able to control events and thereby secure positive life outcomes. Thus low levels of control contribute to learned helplessness and possible task focused coping.

Research on self-determination and the rehabilitation process has focused overall within the field of youth transition services and individual education planning. Self-determination has broadly been defined as the capacity to chose, and to have those choices be determinants of one's own actions, and as a right of individuals to have full power over their own lives. Self-determination is realized when individuals are free to exercise control and experience the outcomes of their choices without coercion, obligation, or artificial constraints (O'Brien, Revell, & West, 2003). Within research and practice choice has been a term utilized to describe what is often one aspect or element of self-determination.

Of concern is the definition of self-determination with respect to this field of study. Martin and Marshall summarized the evolving definition within special education literature as describing individuals who: know how to choose - they know what they want and how to get it. From an awareness of personal needs, self-determined individuals choose goals, and pursue them. This involves asserting an individual's presence, making his or her needs known, evaluating progress toward meeting goals, adjusting performance and creating unique approaches to solve problems (Wehmeyer, Sands, Doll, & Palmer, 1996)

Further conceptualized, Field (1996) summarized that self-determination focused on an individual's attitudes, abilities and skills that lead one to define goals for them and to take the initiative to reach these goals. Deci and Ryan (1985) defined self-determination as the capacity to choose and to have those choices be the determinants of one's actions. Within definitional framework an act or event is self-determined if:

a. The person acted *autonomously;*

b. The behaviors were *self-regulated;*

c. The person initiated and responded to events in a *psychologically empowered* manner;

d. The person acted in a *self-realizing* manner.

Although there are various definitions in place, they tend to have an overall consistency and are complementary to each other. Field, Martin, Miller, Ward, & Wehmeyer (1998) summarized the definitions by stating, Self-determination is a combination of skills, knowledge and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society (Field, Sharver, & Shaw, 2003).

Research by Sigafoos and colleagues identified four behavioral categories contributing to autonomous (self-determined) functioning (Wehmeyer, Sands, Doll, & Palmer, 1996);

1. Self-/family-care activities: include routine personal care and family-oriented functions like meal preparation, care of possessions, performing household chores, shopping, home repairs, and other activities of daily living.
2. Management activities: refer to the degree to which a person independently handles interactions with the environment. These activities involve the use of community resources and the fulfillment of personal obligations and responsibilities.
3. Recreational activities reflecting behavioral autonomy are not specific actions but the degree to which an individual uses personal preferences and interests to choose to engage in such activities.
4. Social and vocational activities include social involvement, vocational activities, and the degree to which personal preference and interests are applied in these areas.

Within the definition of self-determination the field of rehabilitation and CIL's have historically placed emphasis on providing greater opportunities of choice and self-direction and on providing people with disabilities information that that an informed choice can be made. Within self-determination the goal of expressing self-determination from within an individual there is a focus on four principles:

1. Freedom- the ability for individuals, with freely chosen family and friends, to dream and plan a life with necessary support rather than to purchase a preplanned program from the system;

2. Authority- the ability for a person with a disability, with a social or support network if necessary, to control a certain sum of dollars in order to purchase supports;
3. Support--the arranging of resources and personnel, both formal and informal, that will assist an individual in everyday living; and
4. Responsibility--the acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development, and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing (Pennell, 2001).

The essential characteristics that define self-determined behavior emerge through the development and acquisition of multiple, interrelated component elements (Wehmeyer, Sands, Doll, & Palmer, 1996). Inherently self-determined behavior is a life-long process which may be continuously reinforced, or counteracted by the events and perceptions within individual occurrences. Each component has individually been utilized to define consumer involvement and the foundational concepts utilized to define practice within rehabilitation counseling.

Interrelated components of self-determination consist of:

a. Choice making – Highlighting the need to promote a conceptual understanding greater than the basic level of informed choice. Choice as an effective self-determined strategy may be considered one component associated with self-determination, but not necessarily the most important one (Storey, 2005). The skills necessary to produce an informed choice may not

be known to an individual. Thus providing informed choice and an individual attesting to being informed, may not follow that the ability to make an informed choice exists.

b. Decision making – This component of self-determination stems from gaining information leading to formation of a plan. Including the process of setting goals, identifying action steps to meet goals, anticipating results, and visually and orally rehearsing potentially stressful events such as job interviews (Kosciulek, 2004). (Wehmeyer, Sands, Doll, Palmer, 1996). Beyth-Marom, Fischhoff, Jacobs Quadrel, and Furby (1991) suggested that most models of decision-making incorporate the following steps:

    1. listing relevant action alternatives,
    2. identifying possible consequences of those actions,
    3. assessing the probability of each consequence occurring (if the action were undertaken),
    4. establishing the relative importance (value or utility) of each consequence, and
    5. integrating these values and probabilities to identify the most attractive course of action.

c. Problem-solving – As a component of self-determination, problem solving is "a task whose solution is not immediately perceived" (Wehmeyer, et al, 1996). Dixon (2000) focused research on individuals diagnosed with depression and found that in an untreated population, the self-appraised effective problem

solvers are much more likely to recover from a depressive episode than the ineffective problem solvers are.

d. Goal setting and attainment - While consumers direct the focus of goal setting, the setting will influence the final structure of goals. Goal attainment is typically a function of two related aspects of goals: content and intensity. As a component of self-determination, goal content refers to the topic of the goal whereas goal intensity reflects that goal's priority in the person's hierarchy of goals.

e. Self-observation, evaluation, instruction, and reinforcement skills - As a component of self-determination information utilized is often the result of assumptions and expectations of what is thought to be best for the person, rather than what is factual, realistic, and appropriate. Through increased self-determination an individual evaluates information that is provided to assess if it is factual, realistic, or appropriate and to not tolerate subjective decision making by professionals that are working with them.

f. Self-advocacy and leadership skills - Another component of self-determination, advocacy means to speak up or defend a cause or person. By definition, then, instruction to promote self-advocacy will focus on two common threads, how to advocate and what to advocate (Wehmeyer, Sands, Doll, Palmer, 1996). Within rehabilitation counseling practice emphasis is placed on consumer rights and responsibilities within that system. The CIL framework itself has evolved to become a support network, giving people the knowledge and the tools to assert their civil rights.

g. Internal locus of control - If a person is to act in or upon a given situation, it is important to believe that one has control over outcomes that are important to one's life. People who hold such beliefs have been described as having an internal locus of control (Wehmeyer, Sands, Doll, & Palmer, 1996). Strauser, Ketz, & Keim, (2002), found that higher levels of work personality did predict more internalized locus of control and higher levels of job-readiness self-efficacy. Internal locus of control, suggests reinforcement as primarily the consequences of one's own actions; whereas, if a person is characterized as having an external locus of control, reinforcement is viewed as the result of outside forces, e.g., luck, fate, chance and/or powerful others (Wehmeyer, Sands, Doll, & Palmer, 1996).

h. Positive attributions of efficacy and expectancy - As a component of self-determination, self-efficacy focuses on perception of ability to act competently/ effectively (Strauser, Ketz, Keim, 2002). Wehmeyer, Sands, Doll, and Palmer, (1996) summarized that belief that a specific behavior be performed in order to lead to the anticipated outcome are individually necessary, but not sufficient, for behavior like goal-directed and self-determined actions. A person has to believe that: (a) she/he can perform a specific behavior needed to achieve a desired outcome, and (b) if that behavior is performed, it will result in the desired outcome. Roessler (2004) indicated that personal control of self-efficacy represents the person's belief that he or she is able to control events and thereby secure positive life

outcomes. Thus low levels of control contribute to learned helplessness and possible task focused coping.

i. Self-awareness and self-knowledge - In order for one to act in a self-realizing manner, one must possess a basic understanding of one's strengths, weaknesses, abilities, and limitations as well as knowledge about how to utilize these unique attributions to beneficially influence one's quality of life (Wehmeyer, Sands, Doll, & Palmer, 1996). Jones, Crank, and Loe (2006) found that students in the special educational program were often left to their own devices to create some meaning behind their disability label and the education services they received. The notion is that through assistance in learning to identify strengths and needs individuals are able to mover forward in goal attainment and generalized belief that an obstacle can be overcome through self-instruction and awareness.

In general, self-determination is a concept and process that has emerged from the fields of rehabilitation counseling, special education, and disability studies. Self-determination represents a strength based approach to counseling clients with disabilities, with focus on goals related to the optimization of functioning.

Field and Hoffman,(1994) have defined self-determination as a multidimensional concept that includes:

- Attitudes, abilities, and skills that lead people with disabilities to define goals for themselves and to take the initiative to reach these goals,
- The capacity to choose and to have those choices be the determinant's of one's actions,

- Determination of one's own fate or course of action without compulsion, and
- The ability to define and achieve goals based on a foundation of knowing and valuing oneself.

As discussed in Chapter 1, CIL's are structured to incorporate a person centered-civil right approach to advocacy, independence and rehabilitation efforts through the principals of self empowerment and self-determination. The process encourages individuals with disabilities towards a goal of increased self sufficiency and greater quality of life. As a result the belief is that individuals will be able to pursue goals and follow through with plans that are developed based on their choice and ownership of the process of rehabilitation.

Within an individual the difference of engaging in an pursuit of a goal that they feel empowered to complete and within their control can be contrasted with the notion of engaging in an pursuit that seems controlled or completed with as sense of having to engage in such a direction. Inherently this is the difference between that of autonomous and controlled motivation.

Researchers have drawn similar conclusions to the concept and importance of self-determination within the rehabilitation process. The general consensus in the field is that a clients self-determination can be enhanced by helping to develop the knowledge, skills, and beliefs that will allow them to exercise greater control during the counseling process by providing opportunities to develop greater self-awareness and by teaching decision-making, goal setting, and negotiation skills (Kosciulek, 2004). The steps in the self-determination development process include clients knowing and valuing themselves, client planning, client action, experiencing outcomes and learning, and making

adjustments. The question considered is the impact of self-determination and its contribution to a more positive quality of life.

Quality of Life

Rubin and Chan (2003) identified the objective of the rehabilitation process as the process of promoting the full integration of individuals with disabilities into society, and ideally into a state of optimal economic self-sufficiency. This outcome would be expected to result from a process in which deficiencies in life skills are accurately diagnosed and reduced or removed via targeted rehabilitation services, that the recipient of rehabilitation services should experience improvement in his/her quality of life, and that changes in the life skills and quality of life of the individual with a disability from pre to post rehabilitation services can be considered as a valid index of the level of effectiveness of those services.

As an outcome to rehabilitation services, enhancing the QOL of people with disabilities is the inherent and overarching goal of disability policy and of rehabilitation programs (Fabian, 1991; Roessler, 2002). The degree to which services contribute to the improved QOL of people with disabilities is ultimately what needs to be measured in order to effect verification of the worth of services. Due to the potentially major role that rehabilitation services play in contributing to or even determining individual lifestyles (Felce & Perry, 1996), QOL has a central position in the development and evaluation of services for people with disabilities.

As a central position on the development and evaluation of services importance is placed on demonstrating the effectiveness of services rendered for individuals with disabilities and determination of the achievement of outcomes that are designated via

program structuring, funding sources, or that of legislation. There is qualitative significance with respect to focusing on quality of life on a consumer assessment of service outcomes. This is based on the assumption that that the extent of consumer motivation to participate in rehabilitation services is determined by the anticipated effect of those serves as perceived by the consumer on his/her quality of life (Rubin, Chan, 2003).

Rubin and Chan (2003) concluded that in the designing of an outcome assessment system for rehabilitation service, one must be able to not only see the connection between the specific design of services and specific gains in life skills (e.g. Maintain good grooming, Dress appropriately for work), but also the relationship between gains in life skills and positive changes in the perceived quality of life of the individual (e.g. Other people react toward me in a positive way).

As a component towards further defining quality of life (QOL), Livneh (2001) purports QOL as a broad and multidimensional construct that encompasses several life domains with both subjective and objective features. Quality of Life (QOL) has been defined as the subjective sense of overall well-being that results from an individual's evaluation of satisfaction with an aggregate of personally or clinically important domains, or areas of life (Bishop, 2005). Such identified domains include physical health, psychological or emotional health, social support, employment or other productive activity, and economic or material well-being.

Livneh (2001) observed that in the rehabilitation field, the QOL construct has taken on a more applied meaning, typically referring to (a) successful efforts to reestablish the psychosocial homeostasis disrupted by the advent of the disability and (b) attainment of

person-environment congruence. The better the fit between the person's subjective, psychosocial experiences and objective, external reality, the more successfully functional or "adjusted" the person is believed to be. Successful adaptation, then, is reflected in one's ability to effectively reestablish and manage both the external environment and one's inner experiences (cognitions, feelings, behaviors), and ultimately ensures the attainment of improved QOL (Livneh, 2001).

In a perceptive study of QOL related to cardiovascular research, Ferrans refers to five domains used by researchers in their operational definitions of QOL(in Pain, Dunn, 1998). These include:

b. social utility or the opportunity to fulfill valued social roles, including work.
c. happiness/affect using measures of internal affective or emotional states.
d. satisfaction with one's life condition.
e. achievement of personal goals, and
f. normal life measured by comparing current status to either perfect health or to pre-illness conditions.

McDaniel and Bach (1994), (in Pain, et. al., 1998) further propose four defining attributes of QOL:

a. the dynamic nature of QOL, in that it can change from day to day;
b. the multiple dimensions included in the concept, and the diversity of personal values for these different dimensions;
c. the interactive nature of the concept in that QOL is influenced by interchanges between the individual and the environment; and

d. congruence or agreement between one's hopes and expectations and actual conditions of life.

Quality of life is determined by an individual's satisfaction with the extent of his or her personal development and purposeful activity, which are appraised by a personal set of values (Kosciulek, 2004). The appraisal of personal values can be measured both objectively and subjectively. Objective evaluation refers to the description of life conditions under which people live, such as health, income, housing quality, friendship network, and social roles. Subjective evaluation refers to personal satisfaction with such life conditions. The significance of both objective and subjective QOL is interpretable in relation to the value or importance the individual places on each area in question (Felce & Perry, 1996).

QOL is also closely associated with the opportunity for personal growth, fulfillment, and self-esteem (Pain, Dunn, Anderson, Darrah, & Kratochvil, 1998). This may include the opportunity to establish social bonds with family, friends, and co-workers and to derive meaning from religious and civic activities. QOL is directly related to having individual needs met, control over one's environment, and opportunities to make choices. Increased control over disability in policy-making and service delivery would ensure that individuals with disabilities have opportunities to make choices and control their lives and, therefore, experience improved QOL (Kosciulek, 2004).

Since choice is such a central role within the measurement of success of rehabilitation counseling as well as within the structure of rehabilitation counseling practice, there is a need to further define choice within the concepts of self-determination and quality of life. As previously stated, choice-making, or informed choice as an effective self-determined

strategy may be considered one component associated with self-determination, but not necessarily the most important one (Storey, 2005).

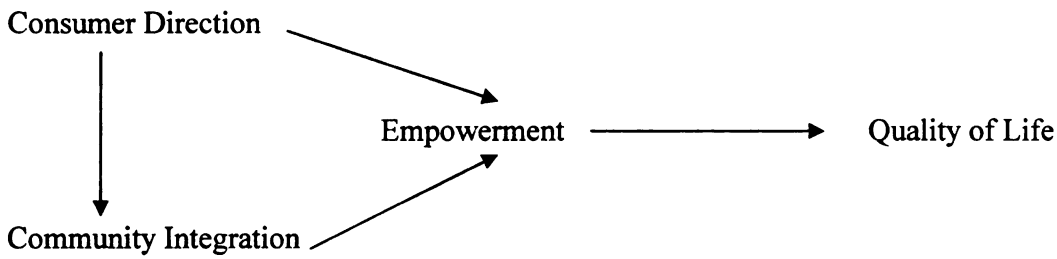
The skills necessary to proceed in a self-determined manner including the notion of informed choice may not be known to an individual. Thus providing informed choice and an individual attesting to being informed may not follow that the ability to make an informed choice exists. Consumer choice in vocational goals and services has emerged as an important component of VR and has consistently played a quintessential role in the modern rehabilitation field and within the measure of outcome and program effectiveness.

Empowerment through the increased utilization of choice and ideals of self-determination begins with the process of the consumer becoming active, informed individuals who learns and controls a planning process that they use for short and long-term goals such as career development or vocational rehabilitation. Within CDTE, consumer direction is the process by which people with disabilities take control of the lives and environment (Kosciulek, 2005).

Research has indicated support for the presence of paths between consumer direction and QOL and community integration and QOL (Kosciulek, 2005) (Figure 2.). It was further concluded that QOL is enhanced by increased control over all aspects of life including full integration into home and family environments, social and leisure activities, and productive experiences such as employment. The theoretical model of CDTE provides a foundation from which levels of self-determination can be compared

and contrasted to levels of quality of life.

Figure 2. (Kosciulek, 2005) Consumer-Directed Theory of Empowerment (CDTE)



As discussed, the center for independent living is structured to incorporate a person centered-civil right approach to advocacy, independence and rehabilitation efforts through the principals of self empowerment and self-determination. From the original students in Berkley who joined forces to make the full academic and social life of the campus more accessible to themselves and others, there has been a strong connection to the concept of quality of life.

The model utilized in conjunction with the model of self-determination theory (SDT), is Kosciulek's model of consumer-directed theory of empowerment (CDTE). This framework has been designed for the development and evaluation of disability policy and the outcomes of the processes in relation to empowerment and improved quality of life. Originating from the sociobehavioral discipline of rehabilitation counseling, the model argues for the relationship of the theoretical constructs between that of consumer direction, consumer integration, and empowerment as being related to the overall conceptual understanding of quality of life.

As defined in CDTE, consumer direction is the process by which people with disabilities take control of their lives and their environment. Within the CDTE model there are three theoretical assumptions of consumer direction.

1. Programming and disability policy should be based on a presumption that consumers are the experts on their needs and that an informed consumer is the best authority of what ones service needs are.
2. Choice and control can be introduced into all service delivery environments.
3. Consumer direction should be available to all regardless of payer.

Within the CDTE structural model there are four components consisting of consumer direction and community integration which both influence each other and in turn the third component of empowerment. The final component influence by all three is quality of life.

The first component of consumer direction consists of four primary components consisting of: a) the ability of consumers to control and direct the delivery of rehabilitation services, b) the ability of consumers to participate in the disability policy making process, c) the availability of a variety of service options, and d) the availability of appropriate information and long-term supports.

The second component, community integration, focuses on where and how people live. Community integrity focuses of the relationship of people who happen to have a disability with other members of their community. This refers to the level and quality of consumer integration into home and family environments, social and leisure activities, and productive activities.

The third component of CDTE is empowerment. CDTE conceptualizes empowerment as involving both internal psychological factors including; sense of control, competence, responsibility, participation, and future orientation, and situational-social aspects including; control over resources, interpersonal skills, work, organizational skills, and 'savvy' or the ability to 'get around' in society. The fourth and final component to CDTE is quality of life. This refers to an individuals perception of her or his well being as previously described by both objective and subjective evaluation of physical, material, social, and emotional well being.

Utilizing participants from a community rehabilitation program for consumers with disabilities (n=159), the relationship of consumer direction, empowerment, and quality of life were retained in the model, but community integration was not found to have a mediating relationship on empowerment. Community integration was instead found to have a direct relationship to quality of life.

Research involving quality of life and self-determination

The field of rehabilitation has yielded initial results with respect to the impact and relationship of self-determination and quality of life. Wehmeyer and Schwartz (1998) found that self-determination contributes to a more positive quality of life for people with mental retardation. In a study of 50 adults with mental retardation who resided in group homes, control was factored based on residence.

With a belief that increased self-determination will lead to an increased quality of life, the hypothesis was that self-determination scores should predict group membership where groups are formed based on high versus low quality of life scores, and that the scores would be positively correlated. Utilizing the Quality of Life Questionnaire, the

Arc's Self-Determination Scale (Wehmeyer, 1996), and the Life Choice Survey, results suggested that self-determination contributes to a more positive quality of life for people with mental retardation. However, it was acknowledged that the impact of self-determination on quality of life might have been unduly confounded by the living situation of individuals with mental retardation. The limited ability to generalize due to controlling for living situation was also viewed as a limitation of the study

In a related study Wehmeyer and Bolding (1999) studied 273 participants with mental retardation recruited based upon their current living or work situation. The result of this study demonstrated that people who lived or worked in community based settings were more self-determined, had higher autonomy, had more choices, and were more satisfied than were IQ and age-matched peers living or working in community-based congregate settings or non community based congregate settings.

Wehmeyer and Bolding (1999), suggest that it is unlikely that self-determination is taken into account in most placement decisions and those factors such as IQ and adaptive behavior levels have greater weight in such processes. Therefore, it would be suggested that people who are self determined will most likely strive to live and work in their communities. It is hypothesized that this would also contribute to a greater quality of life.

The primary message from the study is that the first and perhaps most important step in promoting self-determination is to support the live, work, play, and learning in ones community. In the present study the utilization of those who have obtained services through the CIL is that there is a greater emphasis and connection with community and

belonging that may positively influence an individuals participation and self-determination. In question is the level of correlation with that of quality of life.

Wehmeyer and Bolding (1999), theorize that a reciprocal relationship between experiences of control and choice making and the development of self-determination. If an individual is supported in making choices, participate in decisions, set goals, experience control in their life, and so forth, they will become more self determined. As they become more self determined they will then be more likely to assume greater control, make more choices and increase their overall skill such practices. It is suggested that this will then create a greater belief of ones ability to influence their own life (Wehmeyer and Bolding,1999). This greater capacity to influence their life should translate to realization of a better quality of life.

Chapter 3

Method

Participants

The population of interest for this study was persons with disabilities who have received CIL services. The sample for this study was drawn from the Jackson County Michigan CIL-DisAbility Connections. The Jackson CIL was selected because it expressed interest in development of a mechanism by which to assess both quality of life and self-determination for both individuals entering and receiving services through the CIL program. CIL's are non-residential, private, nonprofit, consumer controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities.

There was an initial interest of three CIL's that together covered a seven county radius. When organization of the study took place, it was decided that individual/small groups would be utilized to collect data. This was designed so that the research could be present to ensure that the longer surveys would be completed correctly and to respond to questions if necessary. Due to this rationale, along with the difficulty of coordination of multiple sites for data collection, one site was chosen for this initial research.

In this study, participant inclusion criteria consisted of consumers who had completed a core service component of the CIL during the 2007 and 2008 fiscal years of service. Individuals were either in process or had developed an independent living plan of service with core services having been initiated (ILPLAN). Participant inclusion criteria were those individuals who had utilized core CIL services (i.e., Employment Services, Independent Living Skills, Individual/System Advocacy, Informational & Referral, Peer

Counseling, Professional Counseling, Mobility Training services, Personal Assistance services, Preventive services, Prostheses services, Recreational services/Community Outings, Rehabilitation Technology services, Therapeutic Treatment, and/or Transportation services).

From November 2008 to January 2009, this investigator met five times with the Agency Director, the Associate Director, and CIL staff members. The intent of these meetings were to:

- Become orientated to the self-determination and quality of life concepts as they applied to this research.
- Reflect on the pool of participants and logistical considerations in conducting the surveys
- Discussion of the resources and procedures necessary for conducting the research.
- To review the survey tools being utilized.

There was an identified pool of 139 individuals who matched criteria for inclusion in this study. Of this number, two were identified as being under the minimum age of eighteen and were excluded from the study. During contact efforts five individuals were found to have died in the last year. Thus, a total potential available sample for this study was 132 individuals. A total of 43 individuals completed the study, representing 33% of the population available.

A *Participant Demographic Questionnaire*, which can be found in Appendix A, was used to collect demographic information from participants. The participants included 24 (55.8%) females and 19 (44.2%) males. A majority (90.7%) of the participants were Caucasian. The average age of participants was 43 years old (Range = 18-75).

Participants ranged in education from 18% indicating less than High School degrees, 37.2% a High School diploma, 32.5% some post High School education, and 11.6% a Bachelor degree or higher.

Of the participants, 25.6% indicated Multiple Disabilities with respect to nature of disability. The next two highest reported disabilities were Cognitive Impairments (14%) and Mental Illness (14%). A majority of individuals indicated onset of disability at over ten years ago (65.1%), were not employed (69.8%), and had Social Security Disability (SSI or SSDI) as their source of income (55.8%). With respect to time period of involvement with the CIL, a majority of individuals were involved for less than a three year period (30.2% were less than one year and 30.2% were 2-3 years). Regarding the services received from the CIL, a majority (60.5%) indicated Information and Referral services and 55% indicated Independent Living services. Three individuals indicated receiving only one service from the CIL, with a majority reporting receiving multiple services. Table 1 contains detailed information regarding participant demographic characteristics.

Table 1 Participant Demographic Characteristic

Variables	Freq	%
Gender		
Female	24	55.8
Male	19	44.2
Race		
Black/African American	2	4.7
Caucasian White	39	90.7
Education		
Less than High School	8	18.6
High School Graduate	16	37.2
Vocational/Technical School (2yr)	1	2.3
Some College	13	30.2
Bachelor's Degree or Higher	5	11.6
Disabilities		
Amputation	1	2.3
Autism	1	2.3
Blind/Visually Impaired	1	2.3
Bone/Joint Disease	4	9.3
Cerebral Palsy	3	7.0
Cognitive Impairments	6	14
Deaf/Hearing Impaired	1	2.3
Diabetes	1	2.3
Epilepsy/Seizure	2	4.7
Mental Illness	6	14
Muscular Dystrophy	1	2.3
Multiple Disabilities	11	25.6
Other	5	11.6
Onset of Disability		
Birth	6	14
Over 10 Years Ago	28	65.1
Over 5 Years Ago	2	4.7
Would Rather Not Say	2	4.7

Table 1. Continued Participant Demographic Characteristic

Variables	Freq	%	Mean	SD	Range
Age					
18-30	13	30			
31-40	6	14			
41-50	9	21			
51-65	9	21			
65 and older	6	14			
Total	43	100	43	17.36	18-75 (57 years)
Marital Status					
Divorced	9	20.9			
Married	6	14			
Single	26	60.5			
Widowed	2	4.7			
Employment Status					
Employed P/T	3	7			
Employed F/T	4	9.3			
Not Employed	30	69.8			
Student	6	14.0			
Source of Income					
Own Employment	4	9.3			
Social Security Income	24	55.8			
Retirement	5	11.6			
Family	8	18.6			
Other Public Assistance	1	2.3			
Would Rather Not Say	1	2.3			
Time Period Involved with CIL					
Less than one year	13	30.2			
2-3 Years	13	30.2			
4-5 Years	8	18.6			
Greater than 5 years	8	18.6			
Would Rather Not Say	1	2.3			
Payee Assistance					
Yes	6	14			
No	35	81.3			
Would Rather Not Say	2	4.7			

Variables and Measures

Self-determination. Conceptual writings about self-determination suggest there are five major aspects of self-determination. Two of these aspects relate to self-determination as an outcome: (1) self-regulated, autonomous behavior and (2) the attainment of preferences in selected life domains. A third is the combination of skills, knowledge, and beliefs that predispose and enable persons to engage in goal-directed, self-regulated, autonomous behavior. A fourth is the set of services and provider behaviors postulated to promote the outcome of self-determination. A fifth is the set of societal factors that promote self-determination (Leff, Conley, Campbell-Orde, 2003). In this study self-determination will be measured by the Arc Self-determination Scale (Wehmeyer, 1995).

The Arc's Self-Determination Scale (Wehmeyer, 1995; Wehmeyer, 1996; Wehmeyer & Kelchner, 1995), is a 72-item self-report scale that provides data on self-determination by measuring individual performance in four essential characteristics of self-determined actions: autonomy, self-regulation, psychological empowerment, and self realization. As a research tool, it can be used to assist in the identification of strengths and limitations in the area of self-determination, and to examine the relationship between self-determination and important outcomes such as QOL. The ARC Self-Determination Scale is presented in Appendix B.

The first subscale measures autonomy, including level of independence and the degree to which individuals act on the basis of personal beliefs, values, interests and abilities. For the first thirty-two questions, a likert-type format is used where individuals chose one of four alternative answers. There are 96 points possible in the Autonomy section. The second subscale measures self-regulation. This scale consists of two areas: (1)

interpersonal cognitive problem-solving and (2) goal setting and task performance. In the first area, respondents are presented a series of six, two to three sentence stories in which a beginning describing a problem and an outcome, respectively, is provided. Respondents identify the actions that best resolve the problem. Answers are evaluated along a scale of 0 to 2 with 0 being no means or completely irrelevant means and 2 being a relevant mean. A score of "2" does not represent an "optimal" answer, but simply an answer that would achieve the ending. To facilitate the scoring process each question is addressed individually in the scoring manual with suggestions as to what to look for and examples from the normative sample. Higher scores reflect more effective social problem solving abilities. This portion of the Self-Regulation domain has 12 points possible.

In the second section, respondents are asked to identify goals for the future in three questions (where they live, where they work and what transportation they use). If respondents identify a goal, they are asked to list 1 to 4 steps they should take to achieve this goal. Higher scores reflect more effective goal-oriented behaviors. Respondents who indicate that there is no plan in place are awarded 0 points. If there is a goal, but no steps there is 1 point awarded. If there are one or two steps indicated, a score of 2 is provided and students who provide three or four steps receive 3 points. Goals are not judged on the probability of achievement. However, steps to achieve the goals are judged based on whether they are viable steps in the process or unrelated to achieving the goal. The scoring manual provides components to look for from the norming sample examples. This portion of the Self-Regulation scale has 9 points possible.

The third subscale is an indicator of psychological empowerment. People who are self-determined take action based on the beliefs that (a) they have the capacity to perform

behaviors needed to influence outcomes in their environment and (b) if they perform such behaviors, anticipated outcomes will result. Respondents choose from sixteen items measuring psychological empowerment using a forced-choice method. Higher scores reflect positive perceptions of control and efficacy. A scoring key is provided to rate responses that reflect psychological empowerment and are scored with a 1. Answers that do not reflect psychological empowerment are scored with a 0. There are sixteen possible points in this section.

The final subscale measures self-realization. Respondents reply to a series of fifteen statements reflecting low or high self-realization by indicating that they agree or disagree with items. High scores reflect high levels of self-realization. Answers are scored with either 0 or 1 points based on the direction of the answer. Answers that reflect a positive self-awareness and self-knowledge are scored with a one and answers that do not are scored with a zero. There are a total of fifteen points available in this section.

There are a total of 148 points available on the scale and higher scores reflect a higher level of self-determination. *The Arc's Self-Determination Scale* was developed and normed with 500 adolescents with and without mental retardation. Information about this process is available in the procedural guidelines for the scale (Wehmeyer, 1995). Concurrent criterion related validity was established by showing relationships between *The Arc's Self-Determination Scale* and conceptually related measures, including multiple measures of locus of control, academic achievement attributions and self-efficacy. The scale has adequate construct validity, including factorial validity established by repeated factor analyses, and discriminative validity, as well as adequate internal consistency (Cronbach alpha = .90). The internal consistency reliability of the subscales indicates a

Cronbach's alpha of Autonomy (.90), Psychological Empowerment (.73), and Self-Realization (.62). The internal consistency reliability for the self-regulation subscale was not calculated due to the open ended answer format, which does not lend itself to such analysis. The adult version of this scale is identical to the student-version, with selected wording changes in questions to reflect adult outcomes (e.g., replace "school" with "work").

Quality of Life. Satisfaction with life, or improved quality of life (QOL) of people with disabilities, is the inherent, overarching goal of disability policy and rehabilitation programs (Fabian, 1991; Raphel, Brown & Renwick, 1996; Roessler, 1990). The impact of disability policies and rehabilitation services must ultimately be measured by the degree to which they contribute to the improved QOL of people with disabilities. Thus, QOL should be a focus of theory development and research in rehabilitation.

Rubin, Chan, and Thomas (2003) concluded that literature on QOL of persons with disabilities has emphasized three broad categories of measures of quality of life: (a) measures of one's satisfaction with life within multiple domains such as health, housing, social activities, and work, (b) measures of the level of functioning of the individual in his/her environment, and (c) social indicators (group statistics as a measure) such as unemployment rates, access to health care, and socioeconomic status (Bowling, 1995; Fabian, 1991).

The World Health Organization Quality of Life, (WHOQOL-100) assessment was developed in effort to establish a quality of life assessment that would be applicable cross-culturally. The World Health Organization (WHO) (O'Carroll, Smith, Couston, Cossar, & Hayes, 2000; Szabo, 1998) defines quality of life as "individuals' perception

of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL Group, 1995, p. 1405).

The WHOQOL-BREF was subsequently developed to provide a short form quality of life assessment that evaluates four life domains The WHOQOL-BREF (see Appendix C) contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the 24 facets contained in the WHOQOL-100 has been included. In addition, two items from the Overall Quality of Life and General Health facet have been included.

The WHOQOL-BREF produces a quality of life profile. It is possible to derive four domain scores. There are also two items that are examined separately: an individuals' overall perception of quality of life and an individuals overall perception of health. The four domain scores denote an individual's perception of quality of life in each particular domain. The WHOQOL-BREF four domains include:

1. Physical Health – including facets of activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity.
2. Psychological – including facets of bodily image, negative/positive feelings, self esteem, spirituality, and thinking/learning.
3. Social Relationships – including facets of personal relationships, social support, and sexual activity.

4. Environment – including facets of financial resources, freedom, physical safety/security, health and healthcare, home environment, opportunities for leisure activities, physical environment, and transportation.

The reported correlations between the WHOQOL-BREF and the domain scores of the WHOQOL-100 range from .89 (social relationships) to .95 (physical health). In terms of discriminative validity, the WHOQOL-BREF was found to be comparable to the WHOQOL-100 in discriminating between ill and healthy participants (WHOQOL Group, 1998). Cronbach's alpha values for the WHOQOL-BREF range from .66 (social relationships) to .84 (physical health). All four domain scores of the WHOQOL-BREF were found to contribute significantly to QOL scores, with physical health contributing the most and with social relationships contributing the least. WHOQOL researchers suggested that all four domains be considered when evaluating global QOL (WHOQOL Group, 1998).

Miller, Chan, Ferrin, Lin, and Chan (2008), concluded that the WHOQOL-BREF had strong psychometric validity in persons with disabilities and with individuals with spinal cord injury in particular. The WHOQOL-BREF was concluded to have the potential to contribute to comparative research on QOL in rehabilitation populations in different countries. In addition, given that the WHOQOL-BREF has such strong empirical support, rehabilitation researchers may find benefits in the use of this measure over its previous WHOQOL counterparts (Miller et al., 2008).

Procedure

An official request to conduct a research study was submitted to the DisAbility Connections - Center for Independent Living (Appendix D). The director of the agency

provided approval for conducting the study. Following receipt of a letter from the MSU Institutional Review Board indicating human subjects approval (see Appendix E), the researcher contacted the director of the DisAbility Connections CIL to arrange for a newsletter announcement of the study (Appendix F), to work with staff in generation a list of consumers and contact information, and to arrange for office use at the facility to conduct data collection.

All data collection and phone recruitment was conducted at the Disability Connections office location. A detailed script (Appendix G) was used to contact individuals to discuss possible inclusion in the study. The investigator spent two to six hours a day over a five week time period for a total of fifteen days, to both request participation and conduct data collection.

On the day of data collection the demographic questionnaire, World Health Organization Quality of Life (WHOQOL-BREF), and the Arc's Self-Determination Scale were administered to the CIL members in both individual and small groups of two to three individuals. A verbal description of the study and written letter of informed consent (Appendix H) were provided to each participant prior to completion of the study questionnaires.

Informed consent was implied for each participant who completed and returned the study questionnaire. At all times the researcher was present during administration of the study questionnaires. This procedure was designed to provide direct assistance such as physical completion, reading, or other accommodation as necessary. During data collection the researcher would directly review the surveys upon completion and review

for non-completed items. If items were not completed the individual was requested to complete missing responses.

For a total of five individuals the researcher assisted with filling out the surveys due to physical limitation that made writing difficult for the individual. For two individuals the surveys were read to them due to visual limitations. Direct assistance was provided based on approved methods provided by each survey. Items would be read without substitution of words and would be repeated if requested.

All study packets were sealed following completion and remained sealed until data entry. All demographic and questionnaire responses were entered into the *Statistical Package for Social Sciences 16.0 for Windows* (SPSS, 2007) for data analysis.

Data Analysis

Canonical correlation analysis was used to answer the primary research question of: What is the relationship between self-determination and quality of life? Canonical correlation was selected because it allows the researcher to investigate the relationship between two sets of variables (Tabachnick & Fidell, 2000; Hindle, 2004). With this analysis, the purpose was to evaluate the relationship between self-determination and quality of life. The quality of life criterion variables were measured through the *World Health Organization Quality of Life-BREF* subscales. The self-determination predictor variables were measured via subscales of the *Arc's Self-Determination Scale*. Figure 3 illustrates the predictor and criterion variables used in the canonical correlation analysis. Utilizing the guidelines developed by Cohen (1988) and the statistical power program developed by Dunlap, Xin, and Myers (2004) an a priori statistical power analysis when using canonical analysis (i.e., multiple correlation) indicated that under the conditions of

a fixed alpha level of 0.05, 4 predictor variables, and assuming an anticipated small to medium effect size, that a sample size of 43 was required to obtain a desired statistical power level of 0.82.

Predictor Variable	**Criterion Variable**
Self-determination	*Quality of Life*
Autonomy	Physical health
Self-regulation	Psychological
Psychological Empowerment	Social relationships
Self-realization	Environment

Figure (3): Variable Sets for Canonical Correlation

Chapter 4.

Results

The purpose of this investigation was to evaluate the relationship between self-determination and quality of life among individuals with disabilities. Prior to conducting the primary analysis related to the research question, descriptive statistics and correlation analyses were calculated to yield data to describe the variables in this study and their inter-relationships. Using the *Statistical Package for Social Sciences 16.0 for Windows* (SPSS, 2007), the primary research question: (i.e. the relationship between self-determination and quality of life) was addressed using canonical correlation analysis.

Descriptive Statistics and Correlation Analysis

Means, standard deviations, ranges, and internal consistency reliability estimates (i.e. Cronbach's alphas) for all study variables are presented in Table 2 and correlations among the variables are shown in Table 3. The alpha levels for the study variables, as indicated in Table 2, are similar to the alpha levels reported for both the *Arc's Self-determination Scale* (Wehmeyer, 1995) and the *World Health Organization Quality of Life BREF* (WHOQOL-BREF) (WHOQOL Group, 1998) subscales.

Within the *Arc's Self-determination Scale* (Wehmeyer, 1995) the lowest alpha reported was Self Realization (.62), and the highest was Autonomy (.90). However, the alphas reported for the study variables of this research study were reversed, with the lowest being for Autonomy (.76) and the highest for Self Regulation (.80). Within the *World Health Organization Quality of Life BREF* (WHOQOL-BREF) (WHOQOL Group, 1998) the lowest reported alpha level was .66 (Social Relationships) and the

highest was .84 (Physical Health). In slight contrast, the alphas reported for the study variables of this research study were all .80 or higher.

Table 2 Descriptive Statistics for study variables

Variables	M	SD	Range	(min-max)	alpha
Self-determination					
1. Autonomy	58.56	18.50	81	19-100	.76
2. Self Regulation	61.60	21.97	90	10-100	.80
3. Psychological Empowerment	83.67	16.87	75	25-100	.79
4. Self Realization	77.05	12.29	53	40-93	.78
Quality of Life					
1. Physical Health	12.32	2.00	9	8-17	.81
2. Psychological	13.77	2.29	9	5-17	.81
3. Social Relationships	12.40	3.61	13	5-19	.81
4. Environment	14.22	2.95	12	7-19	.80

Table 3 Correlations among Study Variables

Correlation Matrix								
	Physical Health	Psychological	Social Relationships	Environment	Autonomy	Self Regulation	Psychological Empowerment	Self Realization
Physical Health	--							
Psychological	.559**	--						
Social Relationships	.107	.312*	--					
Environment	.556**	.613**	.435**	--				
Autonomy	.646**	.502**	.533**	.763**	--			
Self Regulation	.425**	.414**	.397**	.435**	.477**	--		
Psychological Empowerment	.353*	.584**	.400**	.463**	.481**	.413**	--	
Self Realization	.330*	.569**	.167	.553**	.455**	.541**	.414**	--

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed)

The current study yields individual alpha levels that are different alpha as compared to previous investigations. One possible rationale may be the smaller sample size. Though item correlation may be relatively high, the coefficient is directly related to the number of items that make up the composite, such that the more items, the higher the alpha. The smaller sample size may account for this difference. Additionally, within each variable there are four cluster items which intercorrelate, the higher or lower alphas may possibly derive from every item on the scale correlating will with some of the other items, but not necessarily all of them. Thus the Cronbach's alpha indicated the relative absence of item error variance within the two surveys utilized. However, there does not exist a clear indication as to the difference in derived alpha's from this study as to previous investigations.

The correlation matrix presented in Table 3, indicates that there are multiple statistically significant correlations that are all positive. Within the Quality of Life subscales, the most significant relationship is noted between the Psychological and Environment variables (.613). This finding suggests that an individuals self image/self esteem is positively correlated with such factors as financial resources, health/healthcare, and opportunities for freedom/leisure activities. The lowest correlation was found between that of Physical Health and Social Relationships (.107). This finding suggests for the current sample, that there is not a significant relationship between such areas as activities of daily living, dependence of medicinal substances/medical aids, and mobility, compared to facets of personal relationships, social supports, and sexual activity.

Within the Self-determination subscales the most significant relationship was Self Realization and Self Regulation (.541). This finding suggested that there was a positive

relationship between an individual's self-awareness/self-knowledge, and that of interpersonal cognitive problem solving, goal setting, and that of task performance. The lowest correlation was found between Self Realization and Psychological Empowerment (.414). This result suggested that there was a modest relationship between that of an individual's self-awareness/self-knowledge, and the notion of taking actions based on beliefs, having the capacity to perform, and influence outcomes.

In analysis of the correlations between the subscales of Quality of Life and Self-determination it was found that the highest correlation was between Environment (Quality of Life) and Autonomy (Self-determination) at .763. This result suggests that there is a significant positive relationship of such factors as financial resources, health/healthcare, and opportunities for freedom/leisure activities, with that of an individuals level of perceived independence and the degree to which they can act on the basis of personal beliefs. The least significant relationship was noted between the subscales of Social Relationships including facets of personal relationships, social support, and sexual activity (Quality of Life), and Self Realization, or an individuals' self-awareness/self-knowledge (Self-determination). This result represented the smallest correlation of .167.

The primary research question of interest in this study was: What is the relationship between Self-determination and Quality of Life? The correlations and standardized canonical coefficients between self-determination and quality of life, as well as the overall canonical correlation results, are presented in Tables 4 and 5 respectfully.

Tests of dimensionality for the canonical correlation analysis, as shown in Table 4, indicates that two of the four canonical dimensions emerged as significant for

interpretation at the .05 level. Dimension 1 had a canonical correlation of 0.875 between the set of variables, while for dimension 2 the canonical correlation was lower at 0.597.

The squared canonical correlation of that canonical variate (R_c^2), which represented the variance shared by the linear combination of the two sets of variables, was .77 for the first canonical correlation and .36 for the second.

Table 4: Tests of Canonical Dimensions

Dimension	Canonical Corr.	Mult. F	df1	df2	p
1	.875	6.40	16	107.56	.000
2	.597	2.68	9	87.77	.008
3	.370	1.44	4	74.00	.231
4	.048	.088	1	38.00	.769

Table 5: Standardized Canonical Coefficients

Covariate	Correlation 1	Correlation 2	Canonical Coefficient 1	Canonical Coefficient 2
Self-determination Variables				
Autonomy	.97	.08	.83	.56
Self Regulation	.63	-.02	.18	.47
Psychological Empowerment	.60	-.45	.13	-.49
Self Realization	.53	-.72	.01	-1.03
Quality of Life Variables				
Physical Health	.75	.08	.46	.80
Psychological	.64	-.66	-.02	-1.12
Social Relationships	.64	.20	.40	.59
Environment	.88	-.27	.46	-.29

The standardized canonical coefficients demonstrate the importance of each of the original variables in relationship to calculation of the canonical score for each canonical

variate. The analysis is useful in determining how many dimensions are needed to account for that relationship. The objective is to find the linear combination of variables that produces the largest correlation with the second set of variables. This linear combination is extracted and the process is repeated for the residual data, with the constraint that the second linear combination of variables must not correlate with the first one.

Within the first canonical score, the criterion variables of Quality of Life, Physical Health and Environment had a greater ratio of importance in calculating the canonical variate. Within the predictor variables of Self-Determination, the greatest importance in calculating the canonical variate was Autonomy.

Within the second canonical score, the criterion variable of Quality of Life, Psychological (which was negatively correlated), and Physical Health had a greater ratio of importance in calculating the canonical variate. Within the predictor variables of Self-Determination, the greatest importance in calculating the canonical variate were both Self Realization and Psychological Empowerment, (both were negatively correlated).

The canonical (structure) coefficients are the bivariate product-moment correlation between the scores on a measured variable and scores on a latent variable for a given variable set (Humphries-Wadsworth, 1998). Structure coefficients inform of the contribution of each measured variable to the construction of the function. Absolute values of structure coefficients above .30 can be interpreted as important in defining the dimension of the canonical variate (Polit, 1996). In the present study, two canonical variates emerged for interpretation at a significant level.

The percentage of variance represents the amount of variance that each canonical variate extracts from the variables on its own side of the canonical equation. The variance explained by the criterion variables (Quality of Life) was 54.42% in the first and 13.99% in the second canonical variable. The variance explained by the predictor variables (Self-determination) was 38.13% in the first and 6.55% in the second canonical variable. Of other significance is the redundancy statistic. Redundancy is the percent of variance in one set of variables accounted for by the variate of the other set. Levine (1977) outlined that canonical correlation analysis responds to how much of the variance of a set, as contained in the variate, can be accounted for by a variate from the other set. The redundancy from the predictor variables in the variance of the criterion variable was .41 for the first and .05 for the second canonical correlation and the redundancy from the criterion variables in the variance of the predictor variables was .50 for the first and .18 for the second canonical correlation. Redundancy data thus indicate that a moderate amount of variance in each of the set of variables, as contained in one variate, is accounted for by the variate for the other set.

The canonical correlation for the first canonical variate was .875. The square of the canonical correlation represents the variance shared by the specific linear combination of the two sets of variables. Thus, the results in this study indicate that 76.56% of the variance between quality of life and self-determination is explained in the first canonical variate. The canonical correlation for the second canonical variate was .597. The variance shared by the second linear combination of the two sets of variables is 35.6%.

Chapter 5

Discussion

The self-determination theory (Deci & Ryan, 2000), outlines the motivational, self-regulatory, and perceived locus of causality bases of behaviors that vary in the degree to which they are self determined. The primary concern of self-determination theory is understanding the psychological process that promotes optimal functioning and health. Additionally self-determination theory has detailed the process through which extrinsic motivation can become autonomous, and suggests that intrinsic motivation (based on interest) and autonomous extrinsic motivation (based on importance) are both related to performance, satisfaction, trust, and well-being (Gagne & Deci, 2005).

When applied to an adult population of individuals with disabilities, Wehmeyer & Bolding (1999) suggested that people who live or work in community based settings were more self-determined, had higher autonomy, had more choices, and were more satisfied than were IQ or age matched peers living or working in community-based or non-community based settings.

Within the present study principle factors of self-determination theory were contrasted with components of quality of life indicators in effort to gain data useful towards better understanding the relationship of self-determination and quality of life. It was anticipated that research into self-determination as well as quality of life would demonstrate that the extent of self-determination exhibited from a consumer is correlated with the perception of his/her quality of life.

In a study of the relationship of indicated levels of self-determination with a measure of quality of life, the ultimate goal is to identify and develop strategies that are effective

in facilitating, increasing, and improving individual outcomes for individuals with disabilities based on their goals towards rehabilitation. The research question of interest was as follows: What is the relationship between self-determination and quality of life?

The potential value of this study is in providing data useful for better understanding individual factors that may promote overall quality of life as a direct relationship to self-determination. This chapter addresses the following topics: (a) limitations of the study; (b) narrative summary of results; (c) relation of findings to previous research; (d) theoretical and practice implications; and (e) suggestions for future research.

Limitations of the Study

Prior to discussion of the results and implications, several limitations should be noted within the current study. The first relates to the nature of the participant group. Although there was a high level of diversity with respect to many demographic factors, there was little diversification with respect to race, with 90.7% reporting Caucasian, and 90.7% not employed. There was also a large variety of disabilities reported along with 25.6% indicating multiple disabilities, thus limiting any generalizations that could be made towards specific disability groups within the study.

The sample population was drawn from individuals who are receiving services through an Independent Living program. Specific information regarding housing status was not collected. However, a majority of the individuals surveyed lived independently in the local community. Factors such as housing, ability to live independently, and involvement with a social entity such as the CIL, would affect any generalizations that might be made.

The study population resulted from a sample of convenience. All subjects were participants in a independent living program who have received services from the agency. This study had a primary focus on comparing and contrasting components of self-determination and quality of life. However each subject being a member of an independent living program might affect generalization of any outcomes. Individuals who attend a CIL may have a higher rating of self-determination, or as a result of services individuals may have an increased level of self-determination. However, as a potential tool to evaluate programming such analysis may lend itself to development of future programming options that can be evaluated for effectiveness based on factors of self-determination and quality of life.

Within pre-analysis statistical power was found to be adequate for calculating a multiple regression analysis that would yield interpretable results. The canonical correlations are sensitive to sample-specific covariation. To remove the sample specific covariation, the canonical analysis can be cross-validated. Randomly splitting the data into two sub-samples and for each sub-sample, canonical weights and canonical correlations are extracted. The canonical correlations are normalized and fitted to a running composite. The iterations are continued, until the composite stabilizes. At the termination of iterations, the running composite of the cross-validated canonical correlations is de-normalized, producing a k-fold cross-validated canonical correlation. With a larger sample size this additional procedure would be possible.

Narrative Summary of Results

The primary purpose of the current investigation, to study the relationship of self-determination and quality of life, was addressed through the application of canonical

correlation analysis. Two of four canonical dimensions emerged as significant. The first had a canonical correlation of 0.875, while the second canonical correlations were 0.597. Thus 77% of the variance between self-determination and quality of life variables is explained by the first canonical variate, and 36% of the variance in the second canonical variate. This finding suggests that a moderate relationship exists between self-determination and quality of life variable sets.

One aspect of the canonical variate interpretation that has potential reliability is the contribution of the variables to the canonical variate. The first canonical variate reflected within the criterion variable, Quality of Life, Environment and Physical Environment had the highest ratio of importance. Within the predictor variate of Self-determination, Autonomy had the greatest importance. Environment relates to facets such as financial resources, freedom, physical safety/security, health and healthcare, home environment, opportunities for leisure activities, physical environment, and transportation. Physical Health relates to facets of activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity. Autonomy relates to the level of independence and the degree to which individuals act on the basis of personal beliefs, values, interests and abilities.

Provided the importance of these variables to the canonical variate, it can be hypothesized that positive perception of ones environment, of physical health, and of an ability to act in an autonomous manner, strongly influences the relationship between self-determination and a positive perception of a quality of life. Additional studies that alleviate the potential limitations of the present study would be necessary to collaborate these findings.

The second canonical variate that emerged as interpretable reflected a distinct contribution of the individual variables. From the Quality of Life variables Psychological was negatively correlated with the outcome variate and Physical Health was positively associated. With the Self-Determination variables Self-Realization and Psychological Health were both negatively associated with the second canonical variate.

Although the first canonical variate retains the greatest significance within interpretation, the second canonical variate suggests that concepts such as bodily image, self esteem, and spirituality (Psychological); positive self-awareness, and self-knowledge (Self-Realization); and a conceptual understanding that taking actions based on beliefs and an ability to influence outcomes in their environment (Psychological Empowerment), were negatively associated with the combined canonical variate. However, the variable Psychological Health, which reflects having a positive outlook and ability within the areas of activities of daily living, medical aids, energy, mobility, sleep/rest, and work capacity, was positively associated with the second canonical variate.

The interpretation of the second canonical variate suggests that individual perception of such elements as bodily image, positive self-awareness, having an ability to influence the outcomes in ones environment are not necessarily critical in the attainment of a higher quality of life or perception of self-determination. However, having personal physical health and ability are of greater significance.

The nature of the sample and derived outcomes present a discussion point of interest. The overall response rate was low to moderate (33% response rate). Individuals who did attend the CIL to complete the survey had means/access to transportation and were active with the CIL. This level of independence also relates to the potential demographics of

those who did not participate. It can be derived that those who lacked access to transportation, had limited physical health, or limited financial means, where unable to attend the survey sessions. As a result, outcomes presented in this study represent a specific population of interest and generalization should be cautioned.

One observed outcome relates to the demographics of the population as related to the variables which contributed to the canonical correlation of both self-determination and quality of life. Of the sample population 90.7% were unemployed, of this 68.7% were on fixed incomes of Social Security Income and related benefit programs. However, the first canonical correlation retained the standard canonical coefficient derived from the quality of life variable of Environment. Environment pertains to a positive relationship to such factors as financial resources, opportunities for leisure and overall independence, which is in potential contrast to income status within this sample group. One possible conclusion is that involvement with the CIL and potential socialization and programming options may offset the contributing factor of financial resources within the Environment variable.

A second outcome of interest relates to the contributing variables of the second canonical correlation. Individuals who attend and are active in the CIL may reflect individuals who are engaged in a social environment and have relatively higher perceptions of quality of life and that of ability to be self determined as a result of their involvement. The second canonical variate indicated that the ability to influence ones environment, to reflect a positive self-awareness, or to have a positive reflection of bodily image, or self esteem, were not as critical as to the perception of physical health and the ability to function independently.

Relation of Findings to Previous Research

The findings of the current study can be associated with previous research and theory. With respect to quality of life, Environment was found to be highly related to the canonical variate, while Psychological and Social Relationships were least significant. Similarly, Stancliffe and Wehmeyer (1995) found that level of self-determination differed based on where a person lived (e.g., large congregate setting, group home, family home, independently) even when level of intelligence was entered as a covariate. Additionally, Schalock and Keith (1993) found that people who lived in supervised settings had lower quality of life scores than peers who lived in more independent settings.

In a study of 50 adults with mental retardation who resided in group homes, Wehmeyer and Schwartz (1998) found that self-determination contributes to a more positive quality of life for people with mental retardation. Utilizing the Quality of Life Questionnaire, the Arc's Self-Determination Scale (Wehmeyer, 1996), and the Life Choice Survey, results suggested that self-determination contributes to a more positive quality of life for people with mental retardation. In a related study Wehmeyer and Bolding (1999) studied 273 participants with mental retardation recruited based upon their current living or work situation. The result of this study demonstrated that people who lived or worked in community based settings were more self-determined, had higher autonomy, had more choices, and were more satisfied than were IQ and age-matched peers living or working in community-based congregate settings or non community based congregate settings. Related to these two findings, the current investigation suggests that the highest correlation between self-determination and quality of life was between the

components of Autonomy (self-determination) and Environment (quality of life), thus reinforcing previous results.

With respect to self-determination, Autonomy was found to be highly related to the canonical variate while Self Realization (reflecting a positive self-awareness and self-knowledge) and Psychological Empowerment (reflecting positive perceptions of control and efficacy) were not as significant. Autonomy, within the context of this study *(The Arc's Self-Determination Scale* (Wehmeyer, 1995; Wehmeyer, 1996; Wehmeyer & Kelchner, 1995)), centered on the level of independence and the degree to which individuals act on the basis of personal beliefs, values, interests and abilities. The general consensus in the field is that an individuals self-determination can be enhanced by helping them to develop the knowledge, skills, and beliefs that will allow them to exercise greater control during the counseling process by providing opportunities to develop greater self-awareness and by teaching decision-making, goal setting, and negotiation skills (Kosciulek, 2004).

Storey (2005) indicated that choice is such a central role within the measurement of success of rehabilitation counseling as well as within the structure of rehabilitation counseling practice, there is a need to further define choice within the concepts of self-determination and quality of life. Choice-making, or informed choice as an effective self-determined strategy may be considered one component associated with self-determination, but not necessarily the most important one (Storey, 2005). Within self-determination theory autonomous motivation (autonomy) centers on acting with a sense of volition and having the experience of choice (intrinsic motivation is an example of autonomous motivation). By contrast, controlled motivation involves acting with a sense

of necessity, or pressure (Gagne, Deci, 2005). The results of this study begin to suggest that components of independence and the degree to which individuals act on the basis of personal beliefs, values, interests and abilities (Autonomy) are of greater significance than reflecting a positive self-awareness and self-knowledge (Self Realization), or reflecting positive perceptions of control and efficacy (Psychological Empowerment).

Implications for Theory and Practice

The results of this investigation have implications for advancing self-determination theory in relationship to overall quality of life. Additionally there is potential benefit in program development and service delivery in agencies such as Independent Living Centers. Regarding self-determination theory, the findings of the present study, framed within an adult population of individuals with disabilities, can be used to further develop Gagne and Deci's (2005) theoretical model.

The primary message from the study is that the first and perhaps most important steps towards promoting self-determination and quality of life is to support individuals towards acting on personal beliefs, assisting towards promotion of ones physical health, and the promotion of ones personal environment such as access to resources and the community. In the present study the utilization of those who have obtained services through the CIL is that there is a greater potential for emphasis and connection with community and belonging that may positively influence an individuals participation and self-determination. In question is the level of correlation with that of quality of life.

Wehmeyer and Bolding (1999), theorize that a reciprocal relationship between experiences of control and choice making and the development of self-determination. If an individual is supported in making choices, participate in decisions, set goals,

experience control in their life, and so forth, they will become more self-determined. As they become more self-determined they will then be more likely to assume greater control, make more choices and increase their overall skill such practices. It is suggested that this will then create a greater belief of ones ability to influence ones own life (Wehmeyer and Bolding, 1999). This greater capacity to influence their life should translate to realization of a better quality of life.

Wehmeyer and Bolding (1999), proceed to also suggest that it is unlikely that self-determination is taken into account in most placement decisions and those factors such as IQ and adaptive behavior levels have greater weight in such processes. Therefore, it would be suggested that people who are self determined will most likely strive to live and work in their communities. It is hypothesized that this would also contribute to a greater quality of life. This study begins to address specific components of control and that of choice, providing potential areas of emphasis that may foster greater expressions of self-determination and quality of life.

Self-determination theory highlights the importance of three fundamental psychological needs – autonomy, competence, and relatedness. Primary emphasis is placed on the concept of motivation. In the present study the Self Realization (self-awareness and self-knowledge) was found to be less important in relation to self-determination then Autonomy. As put forth by Gagne and Deci (2005), Autonomous motivation (autonomy) centers on acting with a sense of volition and having the experience of choice (intrinsic motivation is an example of autonomous motivation). By contrast, controlled motivation involves acting with a sense of necessity, or pressure. Thus behaviors can be characterized in terms of the degree to which they are autonomous

vs. controlled. Future research may choose to focus more on specific elements of autonomy as they relate to intrinsic versus controlled motivation, and the impact on self-determination and the overall impact on quality of life.

The utility of the present study is also of importance in light of limiting fiscal constraints in the rehabilitation field and the continued emphasis on vocational outcomes as a measure of successful rehabilitation counseling services. With consideration to the limitations of this study, the implications of this study can be viewed as a direct tool by which to both structure program and services as well as a means by which to evaluate the impact of services provided.

Considerations for Future Research

Research within the concepts such as self-determination and quality of life challenge this field towards defining the basic constructs that define rehabilitation counseling practices. Within the context of this discussion, focus is placed on the CIL in relationship to the constructs of self-determination and quality of life.

First, by exploring the elements that compromise components of self-determination and quality of life, centers for independent living will be better able to structure programming and advocacy efforts that will successfully impact those with disabilities towards that of greater realized rehabilitation and community integration. As an example, if the CIL is able to initially target an individuals level of self-determination with an understanding of the overall impact on quality of life, advocacy and programming options would better be structured towards an outcome that would meet an individuals need and expectation.

A second use is through advocacy of individuals with disabilities in their own empowerment and control of service provision. The ultimate goal of vocational rehabilitation and legislative mandates is towards increased independence and ability for individuals to meet their own needs. Ultimately a programs success can be measured not simply by providing the designated service for an individual, but providing the ability to become more empowered and understanding of their needs in order to fulfill their own goals and objectives in life. A higher level of self-determination and a higher level of quality of life would necessarily be indicative of greater independence and control of ones life.

There are several considerations regarding future research with respect to the constructs of self-determination and quality of life within the CIL setting and in general. One consideration would be to select those individuals who are newly seeking services such as the CIL programs, or who are being contacted through outreach programs. These individuals may better represent a broader population comprised of those with/without transportation, income, housing or other limitations that may impact self-determination or quality of life indicators.

Another consideration for future research would consist of a pre/post evaluation of individuals within a CIL program. Of interest would be the generalized impact on quality of life and self-determination indicators based on being involved with the CIL, and possibly provide greater insight towards impact of specific programs, or trends within service provision. Additionally more emphasis will need to be placed on generating a sample of participants from various CIL centers in order to assist with greater generalizations.

Within this study Autonomy was of significance within the generated canonical analysis. However, greater understanding of autonomy in relationship to self-determination theory (Gagne, & Deci, 2005) is necessary. Individuals who have completed services through the CIL and who have indicated a higher degree of self-determination behaviors, would comprise of a select population where specific analysis of Autonomy in relationship to the self-determination range of Amotivation, Extrinsic Motivation, and Intrinsic Motivation could be further investigated.

APPENDICES

APPENDIX A

Demographic Questionnaire

The Relationship Between Self-Determination and

Quality Of Life Among Individuals With Disabilities

Demographic Questionnaire

What is your age? _____

What is your gender? Female Male Other

What is the highest level of education you have completed?

___ Less than High School Diploma ___ High School Diploma / GED

___ Vocational/technical school (2 year) ___ Some College

___ Bachelor's degree or higher

What is the nature of your disability? (check all that apply)

___ Amputation	___ Autism	___ Autoimmune Disorder	___ Blind/Visually Impaired	___ Bone/Joint Disease
___ Cardiovascular Disease	___ Cerebral Palsy	___ Cognitive Impairments	___ Deaf/Hearing Impaired	___ Developmental Disabled
___ Diabetes	___ Emotional Impairment	___ Epilepsy/ Seizure	___ Kidney Disease	___ Mental Illness
___ Multiple Sclerosis	___ Muscular Dystrophy	___ Pulmonary Disease	___ Spinal Cord Injury	___ Multiple Disabilities
___ Other				

When was the onset of your disability?

___ Birth	___ Over ten years ago	___ Over five years ago	___ In the last five years	___ Would Rather not say

Racial ethnic status? (check all that apply)

___Black/African American ___Caucasian/White ___Hispanic/Latino ___Asian

___Would rather not say ___Other

What is your current marital status

___ Divorced ___Married ___Separated ___Single

___Widowed ___Would rather not say

What is your employment status?

___Employed part time ___Employed full time ___Not employed ___Student

___Would rather not say

What is your primary source of income? (Check all that apply)

___Own employment ___Social Security Income ___Retirement ___Family

___Other public assistance ___Would rather not say

_____

APPENDIX B

Arc's Self-Determination Scale

The Arc's Self-Determination Scale

Adult Version

Name _____ Date _____
Agency _____ Facilitator's name _____

Section I

Directions: Check the answer on each question that BEST tells how you act in that situation. There are no right or wrong answers. (If your disability limits you from actually performing the activity, but you have control over the activity (such as a personal care attendant), answer like you performed the activity.)

1. I make my own meals or snacks.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

2. I care for my own clothes.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

3. I do chores in my home.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

4. I keep my own personal items together.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

5. I do simple first aid or medical care for myself.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

6. I keep good personal care and grooming.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

7. I make friends with others my age.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

8. I use the post office.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

9. I keep my appointments and meetings.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

10. I deal with salespeople at stores and restaurants.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

11. I do free time activities based on my interests.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

12. I plan weekend activities that I like to do.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

13. I am involved in community activities.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

14. My friends and I choose activities that we want to do.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

15. I write letters, notes or talk on the phone to friends and family.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

16. I listen to music that I like.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

17. I volunteer in things that I am interested in.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

18. I go to restaurants that I like.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

19. I go to movies, concerts, and dances.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

20. I go shopping or spend time at shopping centers or shopping malls.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

21. I take part in community groups (like YMCA/YWCA and church)

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

22. I do free time activities based on my career interests.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

23. I work on activities that will improve my career chances.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

24. I make long-range career plans.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

25. I work or have worked to earn money.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

26. I am in or have been in career or job classes or training.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

27. I have looked into job interests by visiting work sites or talking to people in that job.

I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

28. I choose my clothes and the personal items I use every day.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

29. I choose my own hair style.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

30. I choose gifts to give to family and friends.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

31. I decorate my own room.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

32. I choose how to spend my personal money.

☐	☐	☐	☐
I do not do even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

Section II

Directions: Each of the following questions tell the beginning of a story and how the story ends. Your job is to tell what happened in the middle of the story, to connect the beginning and the end. Read the beginning and ending for each question, then fill in the BEST answer for the middle of the story. There are no right or wrong answers. Remember, fill in the answer that you think BEST completes the story.

33. **Beginning** --You are sitting in a planning meeting with your boss. You want to learn to work the computer. Your boss want you to learn to work a cash register. You can only learn one of them.

Middle -- _____

_____

_____

_____

Ending -- The story ends with you learning to work a computer.

34. **Beginning** -- You hear a friend talking about a new job opening at the local book store. You love books and want a job. You decide you would like to work at the bookstore.
Middle -- _____
_____
_____
_____
Ending -- The story ends with you working at the bookstore.

35. **Beginning** -- Your friends are acting like they are mad at you. You are upset about this.
Middle -- _____
_____
_____
_____
Ending -- The story ends with you and your friends getting along just fine.

36. **Beginning** -- You go to your job one morning and discover you do not have some of the papers you need. You are upset because you need those papers to do your job.
Middle -- _____
_____
_____
_____
Ending -- The story ends with you using the papers to do your job.

37. **Beginning** -- You are in a committee at work. The committee chair announces that the members will need to elect new officers at the next meeting. You want to be the chair person of the committee.
Middle -- _____
_____
_____
_____
Ending -- The story ends with you being elected as the committee chair person.

38. **Beginning** -- You are at a new job and you don't know anyone. You want to have friends.
Middle -- _____
_____
_____
_____
Ending -- The story ends with you having many friends at the new job.

Section III
Directions: The next three questions ask about your plans for the future. Again, there are no right or wrong answers. For each question, tell if you have made plans for that outcome and, if so, what those plans are and how to meet them.

39. Where do you want to live in five years?

☐ I have not planned for that yet.

☐ I want to live _____
_____

List four things you should do to meet this goal:
1) _____
2) _____
3) _____
4) _____

40. Where do you want to work in five years?

☐ I have not planned for that yet.

☐ I want to work _____
_____

List four things you should do to meet this goal:
1) _____
2) _____
3) _____
4) _____

41. What type of transportation do you plan to use in five years?

☐ I have not planned for that yet.

☐ I plan to use _____
_____

List four things you should do to meet this goal:
1) _____
2) _____
3) _____
4) _____

Section IV
Directions: Check the answer that BEST describes you. There are no wrong answers.

42. ☐ I usually do what my friends want.	or	☐ I tell my friends if they are doing something I don't want to do.
43. ☐ I tell others when I have new or different ideas or opinions.	or	☐ I usually agree with other peoples' opinions or ideas.
44. ☐ I usually agree with people when they tell me I can't do something.	or	☐ I tell people when I think I can do something that they tell me I can't.
45. ☐ I tell people when they have hurt my feelings.	or	☐ I am afraid to tell people when they have hurt my feelings.
46.☐ I can make my own decisions.	or	☐ Other people make decisions for me.
47.☐ Trying hard at work doesn't do me much good.	or	☐ Trying hard at work will help me get a good job.
48.☐ I can get what I want by working hard.	or	☐ I need good luck to get what I want.
49.☐ It is no use to keep trying because that won't change things.	or	☐ I keep trying even after I get something wrong.
50.☐ I have the ability to do the job I want.	or	☐ I cannot do what it takes to do the job I want.
51.☐ I don't know how to make friends.	or	☐ I know how to make friends.
52.☐ I am able to work with others.	or	☐ I cannot work well with others.
53.☐ I do not make good choices.	or	☐ I can make good choices.
54.☐ If I have the ability, I will be able to get the job I want.	or	☐ I probably will not get the job I want even if I have the ability.
55.☐ I will have a hard time making new friends.	or	☐ I will be able to make friends in new situations.
56.☐ I will be able to work with others if I need to.	or	☐ I will not be able to work with others if I need to.

57. ☐ My choices will not be honored. or ☐ I will be able to make choices that are important to me.

Section V

Directions: Tell whether each of these questions describes you or not. There are no right or wrong answers. Choose the one that BEST fits you.

58. I do not feel ashamed of any of my emotions.	☐ Yes	☐ No
59. I feel free to be angry at people I care for.	☐ Yes	☐ No
60. I can show my feelings even when people might see me.	☐ Yes	☐ No
61. I can like people even if I don't agree with them.	☐ Yes	☐ No
62. I am afraid of doing things wrong.	☐ Yes	☐ No
63. It is better to be yourself than to be popular.	☐ Yes	☐ No
64. I am loved because I give love.	☐ Yes	☐ No
65. I know what I do best.	☐ Yes	☐ No
66. I don't accept my own limitations.	☐ Yes	☐ No
67. I feel I cannot do many things.	☐ Yes	☐ No
68. I like myself.	☐ Yes	☐ No
69. I am not an important person.	☐ Yes	☐ No
70. I know how to make up for my limitations.	☐ Yes	☐ No
71. Other people like me.	☐ Yes	☐ No
72. I am confident in my abilities.	☐ Yes	☐ No

APPENDIX C

The World Health Organization - Quality of Life (WHOQOL) BREF

The World Health Organization
Quality of Life (WHOQOL) - BREF

The World Health Organization Quality of Life (WHOQOL) - BREF

WHOQOL - BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

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

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

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

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in daily life?	1	2	3	4	5
9.	How healthy is your physical environment	1	2	3	4	5

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

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very Good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

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

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

_____

_____

APPENDIX D

Request to Conduct Research

The Relationship Between Self-Determination and

Quality Of Life Among Individuals With Disabilities

The purpose of this letter is to ask permission of disAbility Connections and its director and agency staff for researchers at Michigan State University to conduct a study. The study is entitled. "The Relationship Between Self Determination and Quality Of Life Among Individuals With Disabilities". The primary purpose of this study is to examine the relationship between individual levels of self-determination and levels of quality of life among individuals who are involved with Independent Living Plans. Further studying the relationship between self-determination and quality of life may yield information useful for agencies such as CIL's and rehabilitation facilities to assess internal processes and barriers that may lead to more successful outcomes for the individuals served.

Self determination can be described as the capacity to chose, and to have those choices be determinants of one's own actions, and as a right of individuals to have full ownership over their own lives. Self determination is realized when individuals are free to exercise control and experience the outcomes of their choices without coercion, obligation, or artificial constraints.
Quality of life is defined as a subjective sense of overall well-being resulting from evaluation of ones satisfaction with many domains of life. Domains include areas such as physical health, psychological or emotional health, social support, employment or other productive activity, and economic or material well-being.

DisAbility Connections is being asked to participate in this study because the agency serves as a Center for Independent Living program and the consumers served would represent a core sample group of interest in this study. Consumers would be invited to participate in the study. However, participation in this study is entirely voluntary. A consumer may refuse to participate, refuse to answer certain questions, or discontinue participation at any time without penalty. The study would include two study questionnaires which would be estimated to take 10-15 minutes each to complete.

Please be assured that any information provided will not allow the investigator to identify the consumers served. Even if this could be done, no attempt will be made to do so. If you choose to participate in the study, disAbility Connections would be able to utilize the results of the study for agency/program development. The results of this study may be published in professional journals and presented at conferences. However, no names of consumers or other identifying information will be used in any reports or publications that may result from this study. The consumer's privacy will be protected by the maximum extent allowable by law.

DisAbility Connections would be requested to assist in contacting consumers for invitation to participate in the study. The request for space to administer the surveys during the survey period is also requested. Additionally the request would be made to assist the researcher in remaining removed from identifying information of the participant

by allowing the use of staff time to assist in collecting necessary information during invitation to the study and actual survey time period.

If you have any questions concerning this study, please contact the investigator (Karsten Bekemeier, 625 Algonquin, Jackson, MI 49203 517-817-0413, bekemeie@msu.edu) or his faculty research advisor (Dr. John Kosciulek, 458 Erickson Hall, Michigan State university, East Lansing, MI 48824, 517-353-9443). If you have questions or concerns regarding the consumers rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact – anonymously, if you wish- the Michigan State University Director of Human Research Protection Program (Judy McMuillan, BS., CIP. by phone: (517) 355-2180, fax: (517) 432-4503, e-mail: , or regular mail: 202 Olds Hall, E Lansing, MI, 48824).

Your signature on this form indicates the willingness of disability Connections to participate in the study.

Monica Mosher
disAbility Connections
Agency Director

APPENDIX E

MSU Institutional Review Board (UCRIHS) Approval Letter

MICHIGAN STATE
UNIVERSITY

Initial IRB Application Approval

January 20, 2009

To: John KOSCIULEK
458 Erickson Hall

Re: **IRB# 08-1180** Category: EXPEDITED 2-7
Approval Date: January 17, 2009
Expiration Date: January 16, 2010

Title: The Relationship Between Self-Determination and Quality Of Life Among Individuals With Disabilities

The Institutional Review Board has completed their review of your project. I am pleased to advise you that **your project has been approved.**

The committee has found that your research project is appropriate in design, protects the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: IRB approval is valid until the expiration date listed above. If you are continuing your project, you must submit an ***Application for Renewal*** application at least one month before expiration. If the project is completed, please submit an ***Application for Permanent Closure.***

Revisions: The IRB must review any changes in the project, prior to initiation of the change. Please submit an ***Application for Revision*** to have your changes reviewed. If changes are made at the time of renewal, please include an ***Application for Revision*** with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify the IRB office promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

Sincerely,

Dan Ilgen, Ph.D.
SIRB Chair

c: Karsten Bekemeier
625 Algonquin
Jackson MI 49203

OFFICE OF REGULATORY AFFAIRS
Human Research Protection Programs

BIOMEDICAL & HEALTH INSTITUTIONAL REVIEW BOARD (BIRB)

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SOCIAL SCIENCE/ BEHAVIORAL / EDUCATION INSTITUTIONAL REVIEW BOARD (SIRB)

202 Olds Hall
East Lansing, Michigan
48824-1046
517-355-2180
Fax: 517-432-4503

www.humanresearch.msu.edu
IRB@msu.edu

APPENDIX F

Newsletter Announcement:

Newsletter Announcement:

DisAbility Connections along with researchers from Michigan State University, would like to request your involvement in a research study which will be taking place at disAbility Connections. This study will involve two survey questionnaires designed to evaluate and individuals self-determination and quality of life indication. As a consumer who has participated with disAbility Connections, your input would assist towards investigating potential benefits and area of growth for the field of rehabilitation as well as the services provided through disAbility Connections.

If you are interested in being involved in this study it is requested that you contact disAbility Connections at 517-782-6054 to arrange a time to come into disAbility Connections, to learn more of the study and to complete the questionnaires if you are interested.

During January and February 2009 individuals will be contacted to discuss their potential interest in this study and to request their involvement.

Karsten Bekemeier,
Michigan State University

APPENDIX G

Phone Conversation Script

Phone Script:

Hello, my name is Karsten Bekemeier and I am student from Michigan State University. I am working with Disability Connections to conduct a research study and wonder if I could speak with you for a moment to describe this project and to ask if you might be willing to take part.

The study is entitled "The Relationship Between Self-determination and Quality Of Life Among Individuals With Disabilities".

The purpose of this research study is to examine the relationship between self-determination and levels of quality of life among individuals who are involved with Independent Living Plans. The research is in effort to gain information useful for agencies such as the CIL to assess services that may lead to more successful outcomes for the individuals served.

You are being asked to participate in this study because you are a consumer in the Disability Connections program and have participated in an Independent Living Plan. Your participation in this study would be greatly appreciated. However, participation is entirely voluntary and you must be over the age of 18 to participate.

If willing to participate in this study, you would be invited to come down to Disability Connections on a future date to complete a demographic questionnaire that will take approximately 5-10 minutes. You will then complete two study questionnaires taking approximately 10-15 minutes each. At any time while completing the questionnaire, you can decide to stop and not continue.

The first questionnaire is on Self-determination and would ask questions about making choices and how making choices affects what you do. Self-determination is the notion that individuals are free to exercise control and experience the outcomes of their choices without coercion, or artificial constraints. The second questionnaire asks questions about ones Quality of Life. This is more so with respect to overall well-being based on ideas of physical health, psychological or emotional health, social support, employment or other productive activity, and economic or material well-being.

Although you will not directly benefit from your participation in this study, your assistance may contribute to greater understanding of agencies such as Disability Connections and other CIL?s to assess services that may lead to more successful outcomes for the individuals served. There are no foreseeable risks associated with participation in this study. You will be provided a nominal gift certificate of $10 for your assistance In this study.

If you are interested, could I offer you a time to come to Disability Connections to complete the questionnaires.

APPENDIX H

Letter of Informed Consent

The Relationship Between Self-Determination and
Quality Of Life Among Individuals With Disabilities

You are being asked to participate in a research study. Researchers are required to provide a consent form to inform you about the study, to convey that participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask the researchers any questions you may have.

This research study being conducted by researchers at Michigan State University as part of the Doctorate program for Rehabilitation Counseling and Education. The Research study is entitled "The Relationship Between Self-determination and Quality Of Life Among Individuals With Disabilities".

The purpose of this research study is to examine the relationship between self-determination and levels of quality of life among individuals who are involved with Independent Living Plans. Further studying the relationship between self-determination and quality of life may yield information useful for agencies such as the CIL to assess services that may lead to more successful outcomes for the individuals served.

Self-determination can be described as the capacity to chose, and to have those choices be determinants of one's own actions, and as a right to have full ownership over their own lives. Self-determination is realized when individuals are free to exercise control and experience the outcomes of their choices without coercion, or artificial constraints. Quality of life is defined as a subjective sense of overall well-being resulting based on the evaluation of ones satisfaction with many domains of life. Domains include physical health, psychological or emotional health, social support, employment or other productive activity, and economic or material well-being.

You are being asked to participate in this study because you are a consumer in the Disability Connections program and have participated in an Independent Living Plan. Your participation in this study would be greatly appreciated. However, participation is entirely voluntary and you must be over the age of 18 to participate. You may refuse to participate, to answer certain questions, or discontinue your participation at any time without penalty.

If willing to participate in this study, you will complete a demographic questionnaire that will take approximately 5-10 minutes. You will then complete two study questionnaires taking approximately 10-15 minutes each. At any time while completing the questionnaire, you can decide to stop and not continue.

Although you will not directly benefit from your participation in this study, your assistance may contribute to greater understanding of agencies such as Disability Connections and other CIL's to assess services that may lead to more successful outcomes for the individuals served. There are no foreseeable risks associated with participation in this study. You will be provided a nominal gift certificate of $10 for your

assistance in this study.

A copy of the completed research study will be provided to Disability Connections and will be available for your review. Individual scores will not be known or made available. The results of this study may be published in professional journals and presented at conferences. However, no names or other identifying information will be used in any reports or publications that may result from this study and your name will not be connected in any manner. Your privacy will be protected by the maximum extent allowable by law.

Please be assured that any information provided will not allow the investigator to identify you as an individual. Even if possible, no attempt will be made to do so. Participation in this research study is completely voluntary. You have the right to say no and may change your mind at any time and withdraw from the study. If you choose to participate or not to participate in the study, your status with Disability Connections will not be affected.

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or how to report an injury, please contact the researcher (Karsten Bekemeier, 625 Algonquin, Jackson MI 49203, 517-817-0413, bekemeier@yahoo.com) or his faculty research advisor (Dr. John Kosciulek, 458 Erickson Hall, MSU, East Lansing, MI 48824, 517-353-9443).

If you have any questions or concerns about your role and rights as a research participant, or would like to register a complaint about this study, you may contact, anonymously if you wish, the MSU's Human Research Protection Program at 517-355-2180, fax: (517) 432-4503, e-mail: irb@msu.edu, or regular mail: 202 Olds Hall, MSU, East Lansing, MI, 48824.

You may keep a copy of this letter for your reference and records. You indicate your voluntary agreement to participate by completing and returning the study questionnaires.

You can choose to sign this document if desired.

Thank You

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