SELF-DETERMINATION AND END-OF-LIFE PLANNING FOR PERSONS WITH DISABILITIES

By

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ABSTRACT

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For nearly a half century, self-determination has been a prominent topic for discussion within the field of disability, and prevalent within the research literature (Bekemeier, 2009). Disability literature is clear regarding the value on the voice of the people with disabilities (PWD) to guide and direct their own lives as they see fit (Moye, Wood, Edelstein, Arnesto, Harrison & Wood, 2007). Despite this high value, many PWD continue to experience interventions, in the form of legal maneuvering, that seek to strip them of legal rights and responsibilities for their own decision making (Black, 2008). Guardianship and conservatorship are the most common methods used to take control of another's life, and leave PWD voiceless to control the events in their lives (Black, 2008). Often, these decisions are made in response to a crisis, at a time when PWD may be unable to carefully consider and communicate their preferences (Black, 2008). Concerns regarding the use of guardianship and conservatorship have been increasingly reported in the media, practices and ethics have come under intensive scrutiny (Paillaud, Ferrand, Lejonc, Henry, Boullianne, & Montagne, 2007). The ability to appoint proxies to serve in times when an individual is unable to relay their desires has been codified with the

introduction of the Patient Self Determination Act and expanded with the Uniform Healthcare Decisions Act (Galambos, 1998).

The study proposed seeks to determine the relationship between constructs of self determination and engagement in the creation of a durable power of attorney for healthcare among persons with disabilities served by Centers for Independent Living in Lansing, Michigan and Lubbock, Texas. The study will utilize a well developed survey to measure the presence of self-determined behaviors and a created survey regarding the creation of a durable powers of attorney document. The created 'Participant Planning Questionnaire' will additionally seek information regarding the interest of respondents in learning more about the durable powers of attorney creation process. Demographic information will be gathered to allow for description of the respondent population.

DEDICATION

To Kris – who never paused in her belief!

ACKNOWLEDGEMENTS

I wanted to write this today, because it's a Wednesday. Not my favorite day of the week, per se, but clearly one of the most reflective. As I sit thinking about this task, I am terrified that I will forget someone – someone important – and that is something I wouldn't want to do – so to cover my lapses, if you are reading this, it is likely because you love me – and therefore I thank you for sharing my journey…

No. That's not enough. Some people have to be named! Some honored with titles! It's required! So, here goes: First and foremost I acknowledge my family – all of them – living and dead. If not for you, I could not have gone down this long path. You believed in me, challenged me, held me when I wanted to cry (or did), and for that I owe you everything. My family includes my partner Kris, and children (Julie, Ryan, Ren & Dan); my parents (deceased) Bill, Mary & Audrey; My siblings: Dean (dcd), Pat (& Joyce), Julia (& Dale), Gary, Bert (& Kathleen); Nieces & Nephews: Sherry, Randy, Ralph, Derek (Christin), Nikki, Robbie, J. Mike, Joseph & Christopher; and my Julia M. Also my myriad of Aunts, Uncles, Cousins – you know who you are! And I need to include the family of my heart – Frank & Sharon, Dorothy, Jan, Mary, Jim & Elaine, Pati & J., Dennis & DeLane, Deb & Chris, Sharon and many more. This journey could never have begun without the clearing of space, so some credit goes to my men's group (Robert, David, Bill, Dave); my recovery group (David, Lawrence, Mary Ann), and the skills of David L. Lowe. Some of you are far away, others only a flit of an eyelid.

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I know that this can never be complete, and I live in terror that I will forget you. If I have, please know that it was unintentional, and that I do remember….

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CHAPTER 1

INTRODUCTION

For nearly a half century, self-determination has been a prominent topic for discussion within the field of disability, and prevalent within the research literature (Bekemeier, 2009). Disability literature is clear regarding the value on the voice of the people with disabilities (PWD) to guide and direct their own lives as they see fit (Moye, Wood, Edelstein, Arnesto, Harrison et al, 2007). Despite this high value, many PWD continue to experience interventions, in the form of legal maneuvering, that seek to strip them of legal rights and responsibilities for their own decision making (Black, 2008). Guardianship and conservatorship are the most common methods used to take control of another's life, and leave PWD voiceless to control the events in their lives (Black, 2008). Often, these decisions are made in response to a crisis, at a time when PWD may be unable to carefully consider and communicate their preferences (Black, 2008). Concerns regarding the use of guardianship and conservatorship have been increasingly reported in the media, practices and ethics have come under intensive scrutiny (Paillaud, Ferrand, Lejonc, Henry, Boullianne, & Montagne, 2007).

Statement of Problem

Importance of Self-determination. Built on patriarchal and protective value systems, most PWD have encountered resistance to self-direction as they encounter the service systems designed to provide services they require (Wilber &

Reynolds, 1995). Although references to personal control and self-determination have been present in disability literature for nearly a century, the concept has only recently come to be viewed as the 'gold standard' of services (Owen, 2009). First relayed as a fully developed theory by Wehmeyer (2003), self-determination theory has been adopted as a guide for policy across many public and private service structures (Owen, 2009, Wehmeyer, 1999). Self-Determination Theory is based on the measurement of motivation as it interacts with factors of promotion or extinction (Gagne & Deci, 2005). As individuals move along the continuum from amotivation to intrinsic motivation, varying types of regulation intercede as the individual seeks coherence and autonomy (Gagne & Deci, 2005). In brief, self-determination theory calls for both the 'right and capacity' of PWD to control their lives (Wehmeyer, 1999; Gagne & Deci, 2005). Further extension of self-determination work has built both structure and methods of measurement that further define the self-determination construct (Owen, 2009). Using the structure and measures, supportive studies have been published advocating for self-determination in the appointments of proxies by PWD (MacGuire, Rao, Anderson & Ford, 2007).

Proxy Appointment. Appointment of proxy agents occurs primarily in two ways in the State of Michigan, each with many distinct implications and capacities (Geller, 2000). For PWD, the most common proxy appointment occurs within the realm of the Probate or Family Court, and occurs as either a guardianship or conservatorship (Geller, 2000). Guardianship typically has two prescriptive levels, plenary and partial, and proxies may be appointed to decide on issues involving the person and estate (Geller, 2000). Plenary guardianships grant power for substitute decision making across wide domains, and often are considered to strip the 'ward' of most of their adult rights and responsibilities (Geller, 2000). Partial guardianship is more common, and often limits powers to specific decision making tasks – like medical care (Geller, 2000). Conservatorship is typically applied only to control access to one's assets or estate (Geller, 2000). Although persons with disabilities are often consulted during the appointment process used by the courts to create these proxy relationships, if differences of opinion exist between the person with a disability and other persons without a disability familiar with their lives, it is often difficult to ascertain which parties most commonly prevail in the court system (Geller, 2000).

Under scrutiny for issues of overuse and abuse, questions have been posed regarding the necessity of guardianship (Moye et al, 2007). Advocates point to other options, including use of proxy decision making arrangements commonly used with other population groups such as the elderly (McCarthy et al, 2007). Proxy arrangements, commonly referred to as 'Durable Power of Attorney for Healthcare', exist in nearly all states. Some states allow for 'Living Wills', which are a very similar document that extends to cover decision making regarding assets and living arrangements (Paillaud, et al, 2007). While creation of a Durable Power of Attorney for Healthcare or a Living Will does not prohibit a court from appointing a guardian, many states are guided in their decision making by their presence, using the creation of such documents as evidence of the capacity to engage in informed consent (Sith, 2006). Common among persons without disabilities, use of proxies has been slow to catch on in use for PWD (Lingler et al, 2008). Changes in legal interpretations have increasingly held that a person is presumed competent to act on their own behalf until adjudicated incompetent (Sith, 2006; Gregory, Roked, Jones, & Patel, 2007).

Conflict. At first glance, it would appear that an insurmountable chasm would exist between the implementation of self-determination theory and proxy appointment practices. This would be particularly true with traditional methods of appointment. However, when we embrace the idea of self-appointment of proxies as methods of extending the ability to self govern, we begin to see convergence. Although courts have held that PWD are assumed to have the capacity to enter into such arrangements, little information is reported in the literature regarding the prevalence of such activities.

Self-determination theory (SDT), a model of decision making that has been increasingly adopted for use with PWD, has adapted from an initial state of conflict to embrace the self-appointment of proxies as a method of living a self-determined life (Owen, 2009). Self-determination theory reflects a continuum of interaction between motivation and sources of regulation to measure the level of autonomy experienced by PWD (Gagne & Deci, 2005). As the individual experiences integration of regulation, their autonomy increases (Gagne, Deci, 2005). Appointment of a guardian would be a strong reflection of external regulation, and thus is not desirable to persons seeking to live self-determined lives (Dore, 2008). Appointing a proxy with limited powers to act only in compliance with the explicit wishes of the PWD and only during periods of incapacity would represent fully integrated regulation, and would thus increase self-determination for the PWD (Gagne & Deci, 2005).

Despite increased acknowledgement of the congruence of self-appointment of healthcare proxies with extension of recovery, empowerment and self-determination, little has been documented regarding the frequency of utilization (Castle & Mor, 1998). It is clear that guardianship is neither necessary nor preferred in many of the instances in which it is invoked (Hommel, 1996). A review of the literature finds increasing support for consumer-driven healthcare decision making, although little reporting is present regarding the frequency of use, or levels of adherence to the wishes of the consumer arising from such arrangements (Owen, 2009).

Purpose of the Study

This study sought to develop an understanding of the frequency of use of documents such as Durable Power of Attorney for Healthcare or Living Wills by persons with disabilities. While studies have demonstrated that appointment of guardians, particularly public or non-related guardians, for PWD is decreasingly nationally, alternatives allowing for self-appointment of advocates have met with resistance in legal and jurisdictional locales (Wilber & Reynolds, 1995). The discourse regarding issues of competency to create Durable Powers of Attorney for Healthcare or Living Wills has been extensive, and appears to generally have been solved by assuming competence until incompetence has been adjudicated (Gregory et al, 2007; Sith, 2006). Coupling this assumption with the increased call for the development of proxy arrangements amongst the general public, it would appear a prudent time to measure the occurrence of self-appointment of proxy within the disability community (Pozzuolo, Lassoff & Valentine, 2005).

Prevalence. Frequency of use of advanced planning practices that are inclusive of health care proxy appointment was the primary focus of this study. As advocates for persons with disabilities have increasingly voiced support for such arrangements, little literature is available to indicate growth in adoption by PWD (McGuire et al, 2007). Of the literature available regarding use of Durable Power of Attorney for Healthcare appointment by PWD, the majority places focus on two specific populations: those with life-long cognitive impairments and those with acquired cognitive impairments (Allen & Hilgeman, 2009; Gregory et al, 2007; Heller, Factor, Sterns & Sutton, 1996; Johns, 2004; McGuire, et al, 2007; Stratling et al, 2004). Furthermore, the majority of the studies have limited their focus to end of life issues, and have not been inclusive of planning for short term health incapacities or psychiatric health interventions (Pape, Jaffe, Savage, Collins & Warden, 2004). If we develop an understanding of the frequency of usage of proxy appointment by PWD, we can then attempt to identify barriers to selection and usage.

Knowledge regarding usage of proxy appointments to extend decision making for PWD also appears to be under-represented in the research literature. Although limited information is available regarding proxy appointment for persons with Dementia, Alzheimer's Disease, Mental Retardation and Traumatic Brain Injury has been located, virtually no information has been presented regarding use of proxy arrangements for persons with other health impairments or disabilities (Allen & Hilgeman, 2009; Gregory, et al, 2007; Heller, et al, 1996; Johns 2004; McGuire, et al, 2007; Stratling, et al, 2004). Only one specific outcome report of a training exercise regarding development of proxy arrangements for PWD is reported, and that report is dated (Heller, et al, 1996). Furthermore, that study was limited in participation to a specific disability (Heller, et al, 1996). The result is a dearth of information regarding the practice and preparation Durable Powers of Attorney for Healthcare by PWD.

Research Questions

To address this research vacuum, this study sought to gather information regarding both current practice and level of education regarding use of Durable Powers of Attorney for Healthcare across a more diverse population of PWD. To gain understanding of the relationships between two important social constructs within the field of disability (self-determination, life planning), this study posed two research questions, used two assessment instruments that will be offered to a diverse grouping of PWD in service settings at two locations. Research Question One poses the following: "What is the relationship between the presence of SD behaviors and the creation of Durable Powers of Attorney for Healthcare?" This was measured by self-report during completion of a voluntary questionnaire offered to program participants. Data collection compared answers to three questions for each construct (SD & proxy appointment), and analysis explored the relationship between responses. A positive relationship was expected to occur between these two constructs. Research Question Two poses the following: "What is the frequency of creation of Durable Powers of Attorney for Healthcare documents for persons with disabilities?" Data collection occurred in voluntary reporting utilizing a questionnaire created by the study author. There does not appear to be adequate existing data to predict the nature of this relationship.

Results of Prior Study

Both proxy planning and self-determination theory benefit from a wealth of study establishing their efficacy (Gregory, et al, 2007). Little information, however, is available to examine the relationship between the constructs of Self Determination, and creation of Durable Powers of Attorney for Healthcare. Studies measuring the creation of Durable Powers of Attorney by persons with disabilities have typically focused on a small, precise segment of the population (Lingler, et al, 1998). A brief review of current literature regarding each construct and studied applications will follow to grant insight into the building of the questions for this study.

Proxy Appointment Planning is often studied in context with healthcare and aging, estate planning, and memorial funding (Allen, et al, 2009; Asche, 2005; Black, 2008; Galambos, 1998; O'Neill, 2001). Although options for proxy appointment have been legally available for decades, such activities are increasingly in popularity among the general population (Palliuard, et al, 2007). Increasingly studied in relation to changes in cognition related to disease process, researchers have consistently established that such an illness has little effect on the individual's ability to engage in meaningful planning processes (McGuire, et al, 2007).

Self-determination has been measured as a construct for many life domains: Housing, Employment, Education, and Relationships (Gagne' & Deci, 2005; Hardy, 2008; Hellar, et al, 1996; Kosciulek, 2005). In nearly all studies, high levels of SD have been found congruent with higher levels of quality of life and satisfaction with decision making (Gagne' & Deci, 2005; Hardy, 2008; Hellar, et al, 1996; Kosciulek, 2005).

Overview of the Study

Definition of Terms

Self Determination. Self Determination as a rehabilitation construct refers to using one's values, preferences and experiences as a guide to the decision making processes (Wehmeyer, 1999). Self-determined behavior and treatment arises from self-knowledge, and focuses on skill building to transfer that knowledge to action.

Empowerment. Disability literature has struggled with the definitions of empowerment, despite it being heralded as the desired outcome of services for decades (Dempsey & Forman, 1997). The most commonly accepted definition of empowerment is not a true definition – moreover, it is the collection of components that signify the presence of empowerment (Dempsey & Forman, 1997). Current models call for the presence of seven components: self-efficacy, participation and collaboration, a sense of control, the meeting of personal needs, and an understanding of the environment, the taking of personal action, and the access to resources (Dempsey & Forman, 1997).

Durable Power of Attorney for Healthcare. A legal document, accepted by law nationally, that allows an individual to formalize the appointment of a decision making role to another person if they are either unavailable or incapacitated to make medical decisions regarding their care (McGuire, et al, 2007)

Guardianship. Guardianship is the appointment, by a state agency, of an alternate entity to make decisions for an individual based upon two criteria: 1) court determined incapacity; and 2) the need to protect the person's well-being (Wright, 2010).

Proxy Appointment. Proxy Appointment is generally expected to make crucial life decisions by "applying the person's prior statements and personal values to determine what the patient would want to have done under the circumstances" (Bellard, 2001).

CHAPTER 2

LITERATURE REVIEW

The purpose of the current study was to examine the relationships between two elements that are central to the rehabilitation process: self-determination and life planning. To provide a comprehensive review of each of the variables and their intersections, the literature review will be organized into four sections. First, the construct of self-determination was examined from theoretical underpinnings to contribution to the rehabilitation process. Secondly, the current status of life planning activities for persons with disabilities was examined. Third, the related legal precedents were reviewed to provide a platform for the study at hand. Finally, the areas of convergence and interplay between each of these constructs were investigated with an eye towards current practices, service modification, and policy development.

Rehabilitation policy continues to evolve in efforts to build programs and interventions to embrace the concept of self-determination. Engagement in life planning is addressed distinctly and separately in the 1992 and 1998 Rehabilitation Act Amendments (P.L. 102-569), although discussion of this engagement as a desirable outcome requiring measurement is not clearly specified in these documents (Field & Hoffman, 2002). Moreover, the true success found in these legislative actions is commonly linked to their strong voice in the areas of social justice. Disability is described as a "natural part of the human experience…that 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 fill inclusion and integration in the economic, political, social, cultural, and educational mainstream…" (Field & Hoffman, 2002, p 113). These legislative mandates influenced the direction of service provision and outcome measurement in rehabilitation for nearly two decades.

During the assessment process for persons entering rehabilitation services, tools and techniques are often used to measure the presence of self-determined behaviors and the ability to engage in services planning activities. Self-determined behaviors are seen as an indicator that the person with a disability will identify the desired outcomes of the rehabilitation process. The final construct, Life Planning, refers to the engagement of the person with a disability in the processes of completing life directing planning activities (such as wills, durable powers of attorney) that extend their self-determination practices and quality of life desires beyond their ability to effectively communicate these concerns directly. It is the ability to create such documents that allows individuals to appoint proxies to carry out detailed plans for their lives in the absence of their ability to engage in the process. Measurement of presence and engagement of the constructs of self-determination and life planning is at the core of this study.

Self-Determination

Self-determination is a behavioral construct that attempts to measure the level of self-direction in an individual's life. Since people are often inaccurate reporters of intricate concepts like self-determination, measures are often gleaned or inferred from observations of complex and interacting factors in human life (Kosciulek, 2004). To study these complex ideas, researchers often develop and rely on theoretical models to allow for comparison across complex systems (Kosciulek, 2004). For this study, the Self-determination Theory (SDT) first postulated by Deci and Ryan in 2000 will guide the research.

Self-determination Theory (SDT) looks to the interaction between person and environment, and how this interaction impacts the level of motivation for the individual (Deci & Ryan, 2000). SDT postulates that environmental factors serve to either facilitate or undermine intrinsic motivation (Ryan & Deci, 2000). The theory is built on the idea that intrinsic motivation, which occurs naturally in people, will be encouraged when individuals are in the presence of conditions that nurture expression of motivation (Ryan & Deci, 2000). Autonomy, Competence, and Relatedness are identified in SDT as the three psychological needs that combine to create a theory of optimal functioning (Ryan & Deci, 2000).

Motivation is at the core of Self-determination theory. Traditional research models have conceptualized motivation by measuring the amount of motivation presented, rather than motivation as a prime source or entity. The strength of autonomous versus controlled motivation is the focus in SDT, and is viewed as more important than the overall levels of motivation (Deci & Ryan, 2000).

Volition and choice are seen as measures of autonomous motivation, and higher autonomous motivation is viewed as being more self-determined (Gagne & Deci, 2005). Actions that occur due to imposition of external variables (requests, pressure, rewards) are considered to be controlled, and are viewed as being less self-determined (Gagne & Deci, 2005). SDT also looks to determine the intentionality of decision making, recognizing actions that are intentional to be more reflective of self-determination (Gagne & Deci, 2005).

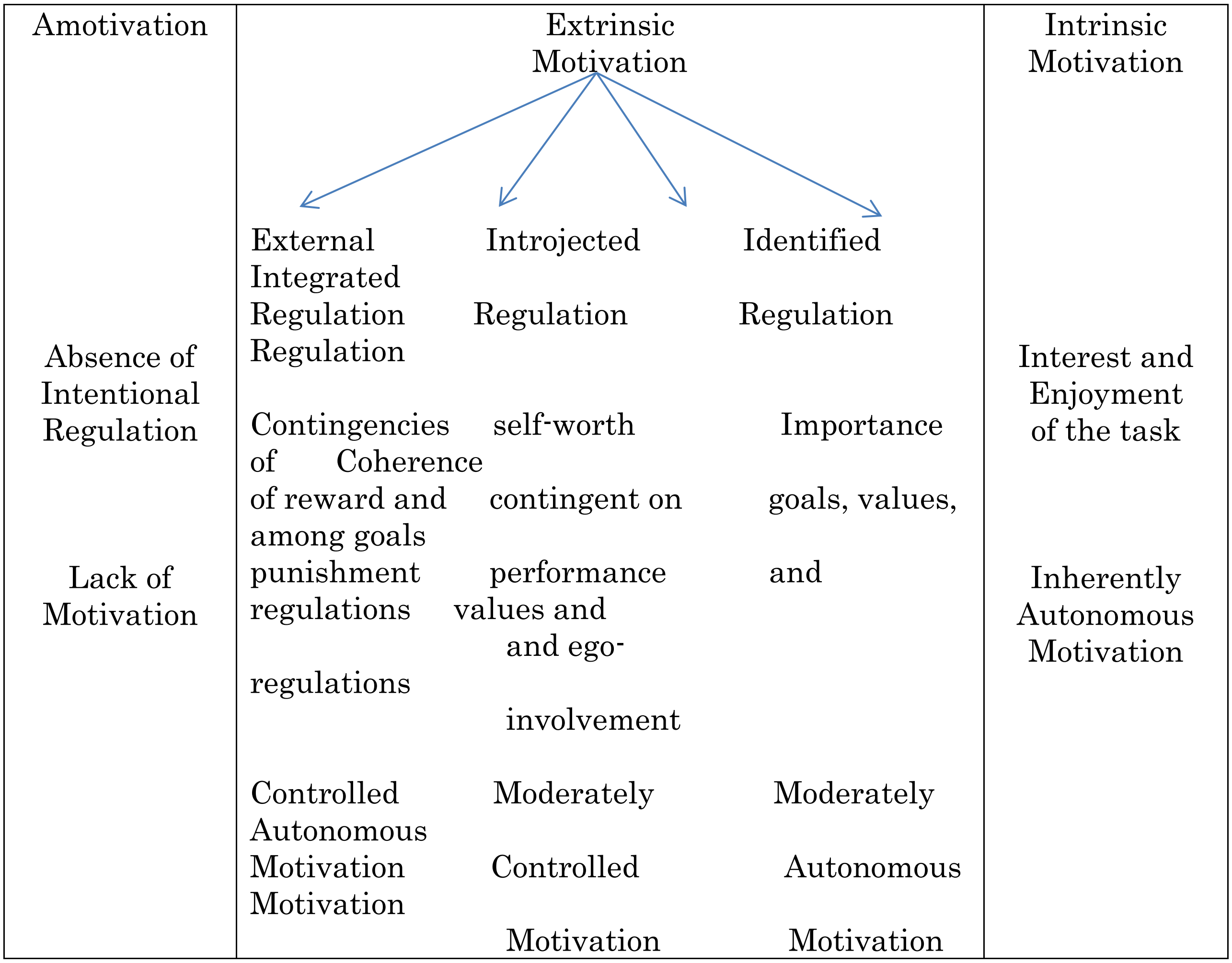
SDT terms motivation from within as intrinsic motivation, while motivation that comes from other stimuli as being extrinsic (Gagne & Deci, 2005). While both have roles, researchers have noted intrinsic motivation works well for some activities, but activities requiring discipline or determination may yield better performance with autonomous extrinsic motivation (Koestner & Losier, 2002). Autonomous extrinsic motivation differs from controlled motivation in that the locus of control remains with the individual (Gagne & Deci, 2005). For activities that require the deep processing of information, creativity, or cognitive flexibility, concern exists that controlled motivation could possibly detract from the outcomes (Gagne & Deci, 2005).

Within SDT, overall motivation is strongly allied with the satisfaction of individual needs. SDT differs from other theories in that it defines needs as universal necessities, while other organizational theories treat them as simple differences and look to measure their strength (Bekemeier, 2009). Psychological health is improved by the meeting of needs, and negatively impacted by factors that impede the meeting of the identified needs. SDT identifies three primary psychological needs as competence, autonomy and relatedness (Gagne & Deci, 2005).

SDT focuses on the ability of individuals to meet these critical needs within the social context. The theory further recognizes causality orientation, which reflects the degree to which individuals are autonomy oriented, control oriented, and interpersonally oriented (Gagne & Deci, 2005). Autonomy orientation refers to an experiential tendency for social contexts to be autonomy supportive and to be self-determined. The positive attributes of self-actualization, self-esteem, ego development, integration in personality, and satisfying interpersonal relationships are strongly positively related to having an autonomy orientation (Bekemeier, 2009). A general tendency to experience social contexts as controlling or being controlled is congruent with Control Orientation. Individuals with control orientations may exhibit behaviors such as defensive functioning, type A behaviors, and place a strong value on pay or other extrinsic motivators (Bekemeier, 2009). In contrast, persons with an Interpersonal Orientation tend to have externalized locus of control and are likely to experience social contexts as being amotivational (Bekemeier, 2009).

The range of self-determination (from highly self-determined to completely amotivated), degrees of extrinsic motivation (external regulation – integrated regulation) present in levels of self-determination, and levels of intrinsic motivation (being completely self-determined), are reflected in the Self-Determination continuum in figure 1.

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



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

For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this dissertation.

The study of motivation in this context has been reframed to provide insight into motivation at an individual level. Motivation study was first ascribed as an attribute of study within the realms of social and clinical psychology, but was typically only applied to work settings. By including aspects of cognitive evolution therapy, SDT applies organizational techniques to provide us with a platform for understanding the implications at an individual level. Focusing on the interaction of the individual and environment, SDT allows us to explore the impact of motivation in decision making activities.

In the SDT model, Gagne and Deci (2005) proposed a model that recognizes the interactions with the environment that prove important to the levels of motivation for an individual. Identifying innate motivation as “Autonomous Motivation” and motivation inspired by reward or consequence as “Controlled Motivation”, SDT allows for study of the interaction between the types of motivation and the individual’s perception of the outcomes (Gagne & Deci, 2005). Moreover, it provides the structure for understanding how some experiences are socially constructed and perceived in ways that either increase or decrease motivation.

At the core of SDT is the belief that inherently autonomous motivation is a reflection of intrinsic motivation, and that extrinsic motivation can vary widely based upon the level of controlled behaviors involved. It is the perception of the contingency between the behavior and a desired consequence that can be observed across an extrinsic continuum (Bekemeier, 2009). SDT identifies the continuum of extrinsic behaviors with four, progressive markers. External Regulation refers to behaviors that are initiated by contingencies external to the person. Actions at this level occur obtain a reward or avoid a consequence, with the sole motivation instrumental to meeting that need. Behavior that occurs due to external stimuli that has been accepted but not fully integrated to the person is referred to as Introjected Regulation. As we move closer to acceptance, we begin to develop volition and desire to complete an activity, even if not of our desire, because the behavior meets our needs and satisfies our locus of control. Gagne and Deci label such behaviors as occurring due to Identified Regulation. Finally reaching a level of behavior that is fully congruent with values and identity, the individual begins to be truly self-determined by engaging Integrated Regulation.

Using the index of behavioral integration allows SDT to develop measures of self-determined behaviors. SDT allows for behaviors to be measured individually, meaning that people can utilize different types of regulation simultaneously, depending on the level of integration (Gagne & Deci, 2005). Also present on this continuum is the SDT range from intrinsic motivation (completely self-determined) to amotivation (totally lacking the ability to engage in self-determined behaviors). As one progresses from amotivation to intrinsic motivation, the four levels of regulation serve as a guide to the overall level of self-determined behavior (Gagne & Deci, 2005).

SDT postulates the increases in self-determined behavior and intrinsic goal pursuits will have a positive effect on the individual (Bekemeier, 2009). These positive effects are directly related to the satisfying of the psychological needs for autonomy, competence, and relatedness, and that this supports the individual's natural growth processes (Vansteenkiste, etal, 2004). Success with autonomous actions feeds the individual in their locus of control and increasingly fosters a sense of social competence (Vansteenkiste etal, 2004). Lack of success with autonomous behaviors fosters a sense of learned helplessness and may decrease the presence of self-determined behaviors.

Within the field of rehabilitation, the majority of research regarding self-determination has been aimed at engagement of transition aged students in the development of individual education plans (Bekemeier, 2009). In these contexts, self-determination is typically measured by examining three criteria:

a) Choice: That the individual has the capacity to choose;
b) Reflection: That the choices made by the individual are fully reflected in the developed service plan;
c) Full Power: That the individual has full power over their own lives.

Self-determined behavior is recognized to occur when individuals are "free to exercise control and experience the outcomes of their choices with coercion, obligation, or artificial constraints" (O'Brien, Revell, & West, 2003). In review of the research, the criteria of choice is most commonly measured, with the assumption being that if choice is communicated in any manner, the later criteria applies.

It is this ability to make and communicate choices that serves as the hallmark of the definition of self-determination within the field of disability. Researchers identify the steps of self-determination as 1) knowing how to make choices; 2) understanding what the outcomes the individual desires; and 3) the individual knowing how to accomplish their goals (Wehmeyer & Kelchner, 1996). In other writings with other co-authors Wehmeyer is more expansive, identifying five steps to the demonstration of self-determined behavior:

1) Asserting the individual's presence

2) Making his or her needs known
3) Evaluating process toward meeting goals
4) Adjusting performance
5) Creating unique approaches to solve problems

(Wehmeyer, Sands, Doll & Palmer, 1996)

Building on earlier works regarding self-determination and transition aged youth, Field (1996) focused her study of development for an individual of the attitudes, abilities and skills that guide one to develop and strive to meet goals. The capacity to choose and have those choices be the determinant of an individual's actions is the core definition of self-determination (Deci & Ryan, 1985). Within this definitional framework, actions are self-determined if they meet four criteria: 1) Autonomous Action; 2) Self-regulation; 3) Psychological Empowerment; and 4) Self-realization. The collection of a multitude of individual self-determined acts is seen as a reflection of living in a self-determined manner (Field, 1996).

A variety of definitions of self-determined behavior have been proffered by researchers in recent decades, sharing common characteristics. Prominent researchers in the field have reached consensus that self-determination is engagement in goal-directed, self-regulated, autonomous behaviors as the result of a combination of skills, knowledge and beliefs that underpin the activity (Field, Martin, Ward, & Wehmeyer, 1998). Accurate self-assessment of both personal strengths and challenges, coupled with a strong sense of self-efficacy are essential to act in a self-determined manner (Bekemeier, 2009). Individuals who are able to act upon this knowledge, skills, and attitudes have a greater ability to assume the role of successful adults in control of their lives (Field, Sharver, & Shaw, 2003).

As part of the continued effort to determine factors that contribute to the presence of self-determined functioning, researchers have attributed four realms of activity (freedom, authority, support, and responsibility) that appear to be consistently present (Pennell, 2001). Freedom identifies the individual's ability to freely choose relationships and activities without having to select from a preplanned menu. Authority speaks to the degree an individual handles interactions with others and the environment, as well as their fulfillment of obligations. Support refers to one's ability to utilize and benefit from an array of services and supports that assist them in meeting their goals. Responsibility involves the fulfillment of a role in society inclusive of employment, affiliations, and participation in economic affairs.

Self-determined behaviors are best characterized as the acquisition of a number of interrelated elements that must be developed by an individual to act in a self-determined manner (Wehmeyer, et al, 1996). As an overarching developmental process, self-determined behaviors interact with the experiences in one's life, and therefore are subject to influence by the environment (Bekemeier, 2009). The list of interrelated components of self-determination is lengthy and includes: choicemaking, decision making, problem-solving, goal setting, self-management, self –advocacy, an internalized locus of control, positive self-efficacy, and self-knowledge (Wehmeyer, et al, 1996).

Choice making refers to one's ability to develop an enhanced ability to engage in informed choice, which involves far greater skills than simple decision making. Choice making in the context of self-determination refers to having the skills and self-knowledge to elect an option that meets with one's goals, values, and desires (Storey, 2005). Traditional informed choice requires only that the individual be informed of a choice option, and communicate an election, not that the individual demonstrate the skills necessary for electing a choice that is in their best interests (Storey, 2005).

Conversely, Decision making refers to the practice of gathering information sufficient to the formation of plans and goals. This often includes intermediary steps that include learning and practicing techniques to assist with potentially stressful situations (Wehmeyer, etal, 1996). Within the field of rehabilitation and education, decision making skills are often taught as multi-step processes that include the identification of alternatives, identification of potential consequences (for action or inaction); assessing the likelihood of each consequence, determining the utility of each consequence, and integrating that information into the determination of the outcome (Beyth-Marom, Fischoff, Jacobs-Quadrel, & Furby, 1991).

Problem-solving within the context of self-determination looks to the integration of both choice-making and problem-solving skills to resolve concerns that are where the action path is unclear (Bekemeier, 2009). These are the circumstances in which the interplay between elements is so complex and interwoven, that it is challenging to determine the core of the issue, and thus multiple factors must be considered.

In SDT, the outcome is less important that the ability of the individual to direct the process. Despite a strongly recognized impact of the setting upon both the structure and outcome of the goals, the role of the client in identification and prioritization of the goals for their lives takes priority. This portion of SDT is commonly referred to as Self-management.

The component of Self-management refers to the development and use of skills of self-observation, instruction, and reinforcement skills and allowing them to appropriately replace the perceptions of others of what is best with factual information (Bekemeier, 2009). This skill set often intermingles with self-knowledge and self-efficacy to support the individual in their rejection of the subjective perceptions of those around them (Bekemeier, 2009).

Equally important for self-determined behaviors to occur is the development of self-advocacy skills. Self-determined individuals have the ability to advocate for themselves and others, and may use these skills to assume leadership in the advocacy for causes they determine to be important (Bekemeier, 2009). Treated differently between service systems, self-advocacy skills have been given priority in legislation involving persons with disabilities in the past three decades (Wehmeyer & Fields, 2003).

For self-determined behaviors to occur consistently, the individual must have an internalized locus of control. This has been described as having control over the outcomes that are important to an individual (Wehmeyer etal, 1996). Positive outcomes linked to higher levels of internalized control have been demonstrated within the rehabilitation context (Strauser, Ketz, & Keim, 2002). Internalized locus of control is believed to be built through reinforcement created as the consequence of one's actions, whereas consequences controlled by others create a more externalized locus of control (Wehmeyer, etal, 1996).

Strauser, Ketz and Kein (2002), found that the ability to act competently and effectively in a self-determined manner was directly related to the positive attributions of efficacy and expectancy. Other researchers concluded that the belief that a behavior is goal-directed and self-determined may be sufficient for self-determination (Wehmeyer, etal, 1996). Moreover, it is the confidence that not only is the individual able to complete the task, but that task completion will result in the desired outcome (Wehmeyer, etal, 1996). This belief by the individual in having personal control of self-efficacy has been attributed with allowing them to control events and have positive outcomes, whereas lacking in this attribute can lead to learned helplessness (Roessler, 2004).

The final component of self-determination skills comes from a strong sense of self-awareness and self-knowledge (Bekemeier, 2009). Wehmeyer, et al (1996) indicated that a basic understanding of one strengths, weaknesses, abilities, limitations, and knowledge of how to use these attributes is essential to act in a self-realizing manner. Through the process of discovery of capacity along these lines, individuals begin the determination process of the outcomes they desire, and can begin to move in the direction of their desired outcomes (Bekemeier, 2009).

Emerging from the fields of rehabilitation counseling, special education, and disabilities studies, self-determination represents a strength based approach to service provision to persons with disabilities focused on attaining their optimal functioning (Bekemeier, 2009). The conceptualization of self-determination as 'multidimensional' was confirmed by researchers Field and Hoffman (1994), who concluded the concept of self-determination 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.

The difference between autonomous and controlled motivation has been reported as a reflection between the willful pursuits of a goal of one's choosing contrasted with feeling compelled to act in a specific manner (Bekemeier, 2009). Within the field of rehabilitation, much focus has been placed on enhancing individual, autonomous decision making and striving to support those decisions. A strong link has been established between the provision of assistance in the development of knowledge, skills, and beliefs and the fostering of greater control during the counseling process (Bekemeier, 2009). It has also been found that these skills can be enhanced during service provision by the teaching of decision-making, goal setting, and negotiation skills which assist in the development of greater self-awareness (Kosciulek, 2004). Therefore it can be argued that the process of acting in a self-determined manner is a self-actualization process, one which allows the client to integrate their values and experiences in the planning processes.

Life Planning

Life planning is a term that has been used in a variety of contexts that often overlap, but have markedly different meanings and measures to the individual. For the purposes of this study, the focus is on the life planning activities involving legal activities that are often considered to be related to end of life. Specifically, this study will address the creation of wills, living wills, and durable powers of attorney for healthcare. Since the study will occur within the state of Michigan, the study will rely on the practices allowed by law in that jurisdiction. Regulations regarding the creation of wills and durable powers of attorney for healthcare have undergone a continuous revision process, and this study will review the important changes and interpretations as they apply to persons with disabilities. Wills and durable powers of attorney documents will be studies across three domains: business, medicine, and social justice. Finally, exploration in this section will conclude with a convergence of interpretation among these concepts and their linkage to other social phenomenon.

Planning and Disability. The extension of life planning activities to PWD is a relatively newly applied concept that has not occurred without some controversy. In this section, I will explore the various psycho-social barriers that play a role in the acceptance of autonomy for this segment of the population. To complete this task, I will split the review into four areas of exploration: important intersections; core concepts; approaches; and application to PWD. Important intersections will explore research findings regarding correlates of autonomy and quality of life. In the core concepts section, we will review the literature regarding advanced planning, application of guardianship practices and review both the language and impacts of three key pieces of healthcare reform legislation. Looking to approaches, we will explore the literature regarding current practices and beliefs, best practices, and impact on life outcomes. In the final section, we will tackle research that has looked to the usage of the legislation and prior learning to the application of life planning activities with PWD.

Important Intersections. Subjective well-being has been at the forefront of rehabilitation research for much of the last century. The overriding goal of the rehabilitation profession has been the support of PWD in their pursuit of a full and meaningful life. While many factors have been identified as important in the facilitation of these goals, two of these principles provide important intersections for the present study. Among the indicators of subjective well-being identified by researchers include issues of autonomy (which is also often attributed as empowerment and self-determination) and quality of life (Plagnol, 2010). To fully explore their contributions to the argument at hand, we will look first to establish the foundation of autonomy, and follow with an exploration of the intersection between quality of life and pre-planning.

Role of Autonomy. Autonomy in the rehabilitation research has a varied history, having been studied using a multitude of methodologies and for a myriad of purposes. It is often used as a measure of service outcome, a view of well-being, a reflection of assertion of culture, from a standpoint of competence, a clarification of culture, and a measure of impact of personal values. The paragraphs that follow will explore these presentations and attempt to forge an argument regarding the importance of this variable.

Researchers Frain, Bishop & Tschopp (2009) established clearly the positive relationship between issues of autonomy and service outcomes. Providing a meta-analysis of the research literature regarding empowerment, these authors established the link between rehabilitation service outcomes and work status, adjustment to disability, functional ability, and quality of life (Frain, et al, 2009). Concluding their works with a recommendation for practitioners to work in the direction of development of empowerment skills, the authors identify the role of autonomy in the overall well-being of PWD.

Extending the thoughts regarding subjective well-being, Plagnol (2010) studied the levels of subjective well-being across the lifespan. Recognizing the fluctuating nature of subjective well-being, the author explores many life events deemed to have impact on this construct (Plagnol, 2010). Health was found to have a significant impact on one's subjective well-being, with unexpected health changes having the strongest and most long-lasting impact (Plagnol, 2010). Despite these initial reactions, the adaptation process is seen as resilient, with persons incorporating their altered health status into their subjective well-being.

The concept of subjective well-being has been linked in the research not only to issues of autonomy, but also to the construct of competence. Researchers at Rochester University utilized a diary study of 60 college students reporting daily measures of well-being, activity, and feelings of competence to establish the linkage between these constructs and autonomy (Sheldon, Ryan, & Reiss, 1996). Using a hierarchical linear model, the researcher identified the psychological needs for autonomy and competence improved functioning both globally and on a daily basis (Sheldon, etal, 1996).

The relationship between competency and quality of life has also come under scrutiny in relationship to appointment of guardians for persons with disabling conditions adjudicated as unable to act on their own behalf. Using a focus group model including both elder law attorneys and public guardians, the respondents consistently identified choice as central to the experience of subjective well-being (Svare & Anngela-Cole, 2010). Focused on issues of faith and religion, the authors point strongly to expression of one's desires and beliefs as being a critical factor in their happiness (Svare & Anngela-Cole, 2010). Furthermore, these researched pointed to the engagement of the individual in relationships and activities they chose as a method of increasing hope, purpose, and meaning in life (Svare & Anngela-Cole, 2010).

It is the inclusion not only of choice, but the reflection of one's values and history that has demonstrated a strong tie with issues of autonomy. In looking specifically to the development of advanced directives for healthcare, researchers Peters & Chiverton (2003) recommend the use of an approach that utilizes a 'values history', in which lifelong patterns are used to guide development of medical advanced directives.

The intersection of concepts of quality of life and the development of advanced directives is often framed in a context of competing forces. Studied from a variety of perspectives, many practitioners are hesitant to engage their clients in conversations that approach this intersection (Cagle & Kovacs, 2009). For those willing to engage, such conversations typically focus on information gathering, and offer little to the client in the manner of information or guidance in decision making (Carr & Khodyakov, 2007). This intersection is also approached from a descriptive perspective, attempting to learn common definitions and activities (Bowling, etal, 2003). Finally, attempts to measure this intersection are commonly framed in the context of faith and spirituality, where we typically see increased divergence (Idler, McLaughlin, & Kasl, 2009).

Researchers Cagle and Kovacs (2009) advocate strongly for the provision of educational services regarding quality of life and advanced directives to persons approaching the end of life. Coming from the perspective of social work, these practitioners argue that provision of such services allows for the clients to be empowered and supported in making increasingly complex decisions (Cagle & Kovacs, 2009). Supporting their premise with contributions from a number of theoretical perspectives (Ego psychology, Cognitive Behavioral, Empowerment, and Crisis), the authors establish a clear mandate for the extension of human service interventions into this domain (Cagle & Kovacs, 2009). Putting the discussion of advanced directives into the context of empowerment substantiates the importance across populations.

Looking to the planning practices of the general population, information appears to support the idea that despite receipt of education, the majority of persons do not engage in planning processes. Researchers Carr and Khodyakov (2007) found that less than 50% of adults over the age of 50 have completed advanced directives for healthcare. Using data from two waves of the Wisconsin Longitudinal Study (WLS), the authors attempted to discern reasons for the planning activity practices, specifically targeting three criteria: 1) recent hospital admissions; 2) the presence of two beliefs: death avoidance and control over healthcare decisions; and 3) one's prior experiences with end of life issues (Carr & Khodyakov, 2007). The findings were significant in that they highlighted familiarity with both the concept and practices of planning, but reflected that slightly over 50% actually completed the documents for their lives (Carr & Khodyakov, 2007). Moreover, approximately 75% of all respondents reported informal discussions with family members, demonstrating that planning events were on their mind (Carr & Khodyakov, 2007).

The results of the above study would largely appear to mirror the experiences of researchers in other developed nations. In a study of nearly 1000 recipients over the age of 65 years in Britain, researchers found that worries about declining health and decision making were at the forefront for this group (Bowling, etal, 2003). Moreover, their perspectives on quality of life were greatly influenced by their continued 'functionality'. The loss of functionality and worry regarding issues of care were paramount, raised by 38% of respondents (Bowling, et al, 2003). Many tied decision making and worry to issues of faith, specifically wanting decision making to be made in concordance with their expression of faith (Bowling, etal, 2003).

The impact of faith on decision making at the end of life has also been an area of study. Focusing on reports of quality of life, researchers found that patterns of faith tend to be resilient – tracking with those practices developed over a lifetime (Idler, et al, 2009). Observances of faith based practices were shown to have a positive relationship with subjective quality of life, and anchored the perception respondents that retaining control of activity was pivotal (Idler etal, 2009). In an interesting note, those individuals participating in this study via proxy (designated responder) were found to report comparable levels of quality of life as those self-reporting (Idler, etal 2009).

Importance of Planning. The act of planning, or 'getting one's affairs in order', has been present in the media in various forms for generations. Much of the literature focuses on the financial aspects of planning, including the creation of wills (Pozzuolo, Lassoff, & Valentine, 2005). However, in recent decade both legislation and research has branched into the exploration of creation of advanced directives for healthcare (Slamond & David, 2005). While the availability of these tools has soared, usage and development has stagnated, a factor attributed by some to their complexity (Vogel, 2011). Despite this apparent complexity concern, other researchers continue to advocate for extending the practice of planning in alternate directions to eliminate the need for substituted judgment (Kemp & Kopp, 2010).

Guardianship. Among the most common of substituted judgment, especially among persons with disabilities, is the imposition of guardianship. Guardianship involves the appointment of a proxy by a court of law to make decisions regarding virtually all aspects of an individual's life (Hommel, 1996). Although some jurisdictions make allowances for limited proxy appointment, the appointment requires a finding of incapacity, essentially stripping an individual of the rights of self-advocacy. Furthermore, few courts impose any restrictions on guardianship requiring the proxy to act in congruence with the values and desires of the ward (Teaster, 2002). Although this process has been incorporated into civil law in virtually every jurisdiction in the United States, it is often viewed as wholly inadequate and a 'last resort' for many of the people for whom it is imposed (Hommel, 1996). Courts have traditionally had great latitude in the appointment of guardians, with options to appoint family members or ‘public’ guardians to fulfill these roles. Public guardians are members of the community who receive compensation for serving in this capacity, and although few laws require a legal education, most of these roles are held by attorneys.

The global reasoning behind the appointment of a guardian as proxy for decision making is the theory that the individual lacks the capacity to act on their own behalf (Wright, 2010). Tradition has called for the appointment of guardians when the question is raised – that is, someone has questioned an individual’s capacity in court. Beginning with the immediate appointment of a “Guardian Ad Litem”, the court process begins the activities of gathering evidence to support the need for substitute judgment (Geller, 2000). It what ratio of petitions result in appointment, and the criteria for such appointment appears rife with vagaries (Geller, 2000). Moreover, it is clear that the criteria for appointment has variance across geographic areas, and often, across judges within those districts.

Researchers studying the phenomenon of guardianship have voiced concerns regarding the impingement on the rights of individuals created by the practice. Specifically, some authors have noted that the appointment of public guardians should occur only as a last resort – that should proxy appointment be necessary, every effort should be made to locate a familiar person who would be willing to serve (Hommel, 1996). Additionally, those represented by proxy should have regular access to their representatives, as should the persons close to them (Wright, 2010). For those with public guardians, scholars advocate for the cooperative development of life planning that involves as many advocates for the individual as possible (Teaster, 2002). Despite this wealth of knowledge and recommendations, researchers have continued to find major inadequacies in the current system, often calling for sweeping changes to requirement of need guardianship (Moye, Wood, Edelstein, Amesto, Harrison & Wood, 2007).

Dore (2008) identifies "Ten reasons people get railroaded into guardianship" as a method of educating persons regarding the imposition and impact of guardianship on the person. The first observation offered is that guardianship is often misconceived, a seemingly benign action to protect individuals instead of the stripping of all of their rights (Dore, 2008). She points to changes in statute in many states substituting the word "incapacity" for "incompetency", and therefore lowering the subjective burden of proof required for appointment (Dore, 2008). Acknowledging petitions for guardianship are often filed capriciously in response to financial concerns, Dore goes on to raise concerns of professional ethics regarding the activities of potential public guardians (Dore, 2008). Citing ageism (although offering proofs involving younger persons and persons with potential disabilities), Dore paints a clear picture of incidences of inappropriate guardian appointment (Dore, 2008). The balance of concerns raised reflects consideration of the mutual roles and relationships within the legal community that may challenge the impartiality required under the law (Dore, 2008). In the end, proposals for reform are offered that include the separation of roles and conflicts of interests amongst the participants, and a call for insistence on the presentation of 'clear and convincing' evidence (Dore, 2008).

When looking at the use of guardianship for younger persons in the State of Michigan, researchers Millar and Renzaglia (2002) found that 100% of all petitions for guardianship from 1995 examined in her study were granted for either partial or plenary status. Moreover, findings conveyed that guardianship was most commonly granted over both the person and estate, essentially stripping the individual of the capacity to make major decisions regarding their activities or assets (Millar & Renzaglia, 2002). Moreover, of the 221 cases reviewed, none represented appointment solely over assets – all involved control of the person (Millar & Renzaglia, 2002). While the majority of the petitioners were granted the powers sought in their petitions, evidence of deviance from the request was found in nearly 25% of all cases, with 3% being appointed with powers greater than requested in the petition (Millar & Renzaglia, 2002).

In part due to the abuses of the guardianship system as a whole, and in part due to an increasing call for self-determination, many advocates have begun laying the groundwork for exploration of alternatives to the appointment of guardians (Gellar, 2000; Wilber & Reynolds, 1995). Citing the ready availability of power of attorney arrangements, authors look to the answer of prior planning to resolve some of the potentialities (Wilber & Reynolds, 1995). Applying reasoning solely to Michigan Law, the Michigan Long Term Care Ombudsman Program prepares pamphlets discussing the advantages of Durable Power of Attorney for Healthcare implementation, urging citizenry to plan ahead by appointing proxies of their choosing (Geller, 2000). The issue of fair representation to persons lacking capacity to act in their best interests garnered attention in the U.S. by the early 1990's, sparking a series of legislative attempts to resolve concerns of abuse (Alston, 1997).

Healthcare Reform. Although healthcare reform remains a major subject of political interest within the U.S., it has been a subject of constant scrutiny for decades. By the early 1990's many Americans were calling for reforms to healthcare laws that were viewed as paternalistic and controlling (Alston, 1997). With cases like the Cruzan decision filling the news, many voiced opposition that decisions regarding end of life activities would be made by persons not invested in the event (McCloskey, 1991). Advocacy spread quickly, and legislation providing some structure to decision making and appointment of proxy decision makers was addressed with the passage of the Patient Self-Determination (PSDA) act in late 1990 (McCloskey, 1991). The PSDA, known officially as part of the Omnibus Budget Reconciliation Act of 1990 (OBRA, 1990), federalizes what many state statutes had already codified: that Americans must be free to determine for themselves when to artificially extend life or treatment (McCloskey, 1991). Furthermore, the bill codifies at the federal level the ability of individuals to appoint proxies to carry out instructions regarding such care when necessary (McCloskey, 1991). With the passage of the PSDA, medical facilities were charged with gathering information secondary to the patient's desires (Mezey & Latimer, 1993). Quickly three themes emerged representing the actions by providers:

advocacy, assignment of duties, and centrality (Mezey & Latimer, 1993). Advocacy occurred in the form of encouragement of execution of advanced directives among patients (Mezey & Latimer, 1993). Other providers focused on creating a line of responsibility for discussion of advanced directives through the assignment of these duties to specific staff (Mezey & Latimer, 1993). Finally, energy turned to the recording and storage of advanced directive materials, to insure that documents would be readily available and known to providers in the time of need (Mezey & Latimer, 1993).

Designed to unify and standardize provisions throughout the U.S., the PSDA was met with minor resistance, but significant fragmentation in implementation across the country (Galambos, 1998). The Uniform Health-Care Decision Act (UHCDA) was proposed and accepted by the National Conference of Commissioners on Uniform State Law during their annual conference in 1993 (UHCDA 2006). Having much in common with the PSDA, the UHCDA was built around six precepts:

1) Acknowledgement of the right of individuals to decide all aspects of his or her healthcare in all circumstances, including the right to decline health care to direct that health care be discontinued.
2) The act was considered comprehensive, replacing existing legislation and allows for health-care decisions to be made by an agent who is designated to decide when an individual cannot or does not wish to make the decisions.

3) The act is designed to simplify and facilitate the making of advance health-care directives, allowing for either oral or written instructions.
4) The act seeks to insure to the extent possible that decisions about an individual's health care will be governed by the individual's own desires concerning the issues to be resolved.
5) The act addressed compliance by health-care providers and institutions by mandating complains with the instructions of the patient or designee and provision of sanctions for failure to comply.
6) The act provides a procedure for the resolution of disputes. (UHCDA, 2006).

Many scholars of health care and end-of-life decision making heralded the passage of UHCDA, and advocated for universal acceptance (Galambos, 1998). Noting the strong measures of the UHCDA towards the preservation of autonomy, author Colleen Galambos (1998) offered the view that "…the UHCDA advances autonomous decision making thought its specific attempts to preserve an individual's known values, desires, and directives…" However, some in the legal community expressed concerns regarding universal enactment of this act, citing concerns that the act may actually impede the experience of autonomy (Stith, 2006). Moreover, Stith (2006) builds a case in which persons with disabilities may be marginalized under the provisions of the act, and that any evolutionary thoughts on their part regarding quality of life might be overlooked. Critics also raise concerns that the act allows for appointment of surrogates that may not share values or may have adverse interests (Stith, 2006). The struggle to define capacity in the context of making end-of-life decisions has international considerations.

In Britain, the issue of has reached increased clarity with the passage of the Mental Capacity Act of 2005. This act provides for five basic principles to guide the discussion of capacity:

1) Every adult is presumed to have capacity unless is proved otherwise;
2) People must be supported in making their own decisions, before anyone can decide they are unable to make a decision;
3) People have a right to make eccentric or unwise decisions;
4) Anything done on behalf of someone must be done in their best interests;
5) Any intervention should be the least restrictive (Brammer, 2005).

The original doctrine provides for the determination of incapacity, as well as provision for sanctions for the failure to comply (Irons, 2007). While viewed as imperfect legislation, the act was widely heralded by advocates of personal liberty in the U.K. (Chapman & Hayes, 2007). The principles of this decision have been widely adopted, especially in the United States. By 2007, with 23 states having modified their guardianship statutes, all had accepted the need for a 'comprehensive' evaluation prior to the ruling of incapacity by any of their courts (Moye, Butz, Marson, and Wood, 2007). Adoption of language requiring assessment across six domains of functioning actuated the principles of the Mental Capacity Act in the United States. The six domains requiring assessment include:

1) Medical Condition
2) Cognition
3) Functional Abilities
4) Values
5) Risk of harm and level of supervision needed
6) Means to enhance capacity.

While each of these aspects receives considerable treatment in the press regarding applicability, the essence is very similar. Of particular importance is the 'means to enhance capacity' domain, as it is the first to include language of supported decision making via the use of proxy designation (Moye, etal, 2007).

Approaches to Planning. In contemporary medicine patient autonomy is often construed as the right to self-determination as measured in the ability to give or withhold consent (Struhkamp, 2005). Advancing beyond issues of consent is often identified as engaging advanced directives, which may on a stand-alone basis be inadequate (Teno, Nelson, & Lynn, 2004). Moreover, a Living Will or such document may be overruled unless accompanied by the creation of a Durable Power of Attorney for Healthcare (DPOAH) (Teno, etal, 2004). In reviewing the criteria for the state of Michigan, although both a Living Will and Durable Power of Attorney for Healthcare are considered reliable expressions of a patient's values, only the DPOAH actually appoints a proxy with legal decision making capacity (Slocum, Cheever, & Geller, 2006).

Critics of the current DPOAH laws and regulations note many concerns regarding the implementation. First and foremost, while the law allows for any competent person to create a DPOAH, the actual laws is mute on the issue of competency – allowing for the potential of conflict (Kuczewski, 2004). In furthering the murkiness of substituted judgment, the critics often point to inconsistencies in the actual documents themselves – or to situations unseen by the authors (Kuczewski, 2004).

Regardless of the critics, DPOAH remains the law in many states, and continues to allow for proxy appointment. To address many of the concerns of critics, advocates quickly point to the easiness with which changes can be accomplished, as well as the ability to establish multiple, sequential proxies to insure plans are followed (Slocum, etal, 2006). Even the advocates, however, recommend engagement in a serious planning process for the development of these documents (Slocum, et al, 2006).

Call for Planning. Since the advent of advanced planning activities such as the creation of DPOAH's, society has taken a mixed view regarding their implementation at the end-of-life (O'Neill, 2001). Researchers have repeatedly found the role of proxy to be rife with stress, and decisions made to be more reflective of the proxy than the patient (O'Neill, 2001). Advocates quickly remind critics that the creation of a proxy healthcare arrangement is not intended to be a one-time conversation, but a "process of communication among patients, their health-care providers, and their families…" (Martin, Emanuel, and Singer, 2000).

Martin, et al (2006) detailed a process in which all parties explore the factors and options for the patient. In recognition that many lack the ability and language to discuss matters such as artificial life sustainment directly, authors Simon, Murray and Ruffin (2008) advocate for the use of 'facilitated advance care planning'. Noting that facilitated advanced care planning (ACP) has been present since the mid-1990's, the concept embraces a series of conversations that occur while the individual has the capacity to effectively express their desires (Simon, etal, 2008). To that end, researchers have advocated for the creation of planning documents that provide a thorough review of the issues at hand and have been reviewed by all interested parties (Hickman, Hammes, Moss, & Tolle, 2005). Acknowledging the need for thoroughness, researchers Giger, Davidhizar, & Forham (2006) articulate a strong need for advanced directives that are culturally relevant, and reflect the values of the patient. In the case of facilitated ACP, other researchers point not only to cultural relevance, but to issues of professional disclosure (Carlisle & Neurlicht, 2010).

Planning and the Elderly. Much of the research regarding the development and usage of DPOAH documents and advanced healthcare planning in general has been focused on the elderly or persons in frail health. In a study of the use of ACP's among residents of long term care facilities, researchers Joeng, Higgins, & McMillan (2010) found that although virtually all residents had created such documents, few were actually used. This contrasts starkly with reports that show completion of ACP's among the general population to range from 13 – 51% of the population (Castle & Mor, 1998). Studies of community-dwelling elders found that although the discussion of ACP's was recommended when the patient was healthy, they often did not get created until a major health concern was identified (McCarthy, Pencina, Kelly-Hayes, Evans, Oberacker, D'Agostino, Byrns and Murabito, 2007). Because of the lateness of planning, the potential for abuse to the patient was noted McCarthy etal 2008). Black (2008) identifies such abuse as common, finding that many elders are failed by the laws designed to protect them. To that end, many question the process of directive development, particularly where issues of capacity may already be present (Johns, 2004).

Application to Persons with Disability. Much of literature regarding issues of advanced planning and persons with disabilities focuses on four areas: Social Justice, Planning and cognition, planning and mental illness, and planning at the end-of-life for persons with acquired disabilities. Opinions range wildly in sentiment, but few studies offer information about frequency of use, nor the questioning of capacity.

Planning Practices for Persons with Disability. Advocacy and ideas of self-determination have been present in the rehabilitation literature since the beginning of the profession (Blanck, 2008). Although focused frequently on issues of ability and capacity, the goal of the rehabilitation process became dubbed 'integrationalism' – ensuring the rights of persons with disabilities to 'live in the world' (Blanck, 2008). While specifically focusing on the demands of life and the receipt of care, the works were the first demand for self-determination that would take years to enter public policy and practice (Blanck, 2008).

Despite years of advocacy and demands for autonomy, persons with disabilities were often last to the table for autonomy regarding healthcare decisions at the end of life (Bellard, 2001). Issues of capacity were frequently raised, looking for obstacles to place as a barricade to the wishes of persons with disabilities – despite the individual having lived their lives in a largely autonomous manner. Tying this activity to issues of paternalism, Bellard (2001) makes a strong case for engagement in planning process, regardless of level of impairment. Even persons with significant dementia have been found capable of engaging in the planning process, and research has demonstrated outcomes consistent with long-held beliefs and values, when the planning occurs in conference with concerned others (Allen & Hilgeman, 2009). Using change models, participants are able to effectively manage their stress and provide input into the decision making process, including the appointment of proxies (Rizzo, Engelhard, Tobin, Penna, Feigenbaum, Sisselman, Nicholson, Niemeyer, Albert and Lombardo, 2010).

Planning and Cognition. The advance care planning experiences of persons with impaired cognition has received some attention in the literature. Researchers have looked to measure the impact of other avenues of training (person centered planning, self-determination training), as well as the impact of communication strategies for persons with severe disabilities. Others have focused their research to looking at the intersection of cognition and planning, while others have looked to measure the presence of advanced directive planning activities among persons with impaired cognition.

In studying the impact of person centered planning activities for older adults, researchers were able to substantiate that individuals with cognitive impairments were able to engage both in the training process, but also in the decision making that followed (Hellar, Factor, Sterns, & Sutton, 1996). This result was surprising in that prior to the training, family members voiced hesitancy in that discussions of life planning activities (living arrangements, healthcare, etc.) would create too much anxiety on the parts of the patient with the cognitive impairment (Hellar, etal, 1996). Furthermore, with the implementation of a structured training activity, participants not only engaged in decision making process with greater frequency, they also engaged in the decided upon activity with more frequency (Hellar, etal, 1996). Olney (2001) opines that even the most severely impaired have the capacity to voice preferences and become involved in decision making activities.

A British study found that although the level of cognitive impairment was significantly related to the capacity to create advance directives, the majority of the population studied was able to engage in a planning process with support of family and friends (Gregory, et al, 2007). Furthermore, when looking at a national survey of 325 persons diagnosed with cognitive impairments, 60.8% of respondents were able to complete advanced directives (McGuire, Rao, Anderson & Ford (2007). This is congruent with related research that demonstrated a DPOAH completion rate of

65% for persons with cognitive impairments (Lingler, Kirschman, Garand, Dew, Becker, Schultz, and DeKosky, 2007).

Planning and Mental Illness. When we alter our scope to reflect the use of advanced directives among persons with severe and persistent mental illness, we see some very similar correlates. For use with this population, ACP activities have been studied in the context of a service model, as well as from the impact on service providers. In addition, ACP has been reflected in relation to recovery oriented care, as well as a reflection of quality of life. Finally, the use of ACP to address specific symptoms across the lifespan has been measured in the presence of severe and persistent mental illness.

In a study of 228 individuals with severe and persistent mental illness regarding the engagement in effective decision making and planning, researchers in MA were able to demonstrate marked improvement in quality of life ratings and locus of control ratings for participants (Shen, Smyer, Mahoney, Simon-Russinwitz, Shinogle, et al, 2007). Building upon this research, the issue of preparation of Psychiatric Advanced Directives (PAD's) was studied from the perspective of the service providers. Findings of that study support not only did the use of PAD's assist the clients in feeling empowered regarding their options for care during psychiatric emergencies, but that the empowerment carried over and enhanced overall feelings of control and life satisfaction, increasing compliance with treatment regimens (Van Dorn, Scheyett, Swanson & Swartz, 2010). Furthermore, secondary studies have established that when available, over two-thirds of treatment decisions were consistent with the instructions provided (Swartz & Swanson, 2007). Using a qualitative method including 28 open-ended questions, researchers confirmed the utility of PAD's with the identification of three themes: 1) PAD's were seen as tools of empowerment; 2) Concern existed regarding the knowledge of PAD's among clinical staff; and 3) PAD's were not easily communicated to inpatient staff during crises (Kim, Van Dorn, Scheyett, Elbogen, Swanson et al, 2007). Perhaps on the most interesting findings was that PAD's were well understood and accepted by persons with severe and persistent mental illness (Kim, etal, 2007).

Planning at the End-Of-Life. Having affirmed the required knowledge, policies, and laws to support persons with disability in planning activities throughout their life, the next reasonable step would appear to support their decision making near the end-of-life. Several authors have tackled the subject from both practical and philosophical perspectives. The philosophical side, authors discuss the issue of life affirmation in the time of death, while the pragmatists talk of specific decision making practices and herald the practices of self-determination as preparation for such important decision making.

In looking to the intersection of disability and cessation of life supports, author Asch (2005) looks to contemporary film for insight into the American psyche regarding life with disability. Engaging the argument further by presenting views from the disability rights organization ADAPT, the author points to the constant tension that fuels this debate in our society. Asch argues for thoughtful consideration, not only of what is, but what might be by society.

In looking to measure the end-of-life preferences for persons with severe mental illness, researchers Foti, Bartels, Van Citters, Merriman and Flecther (2005) studied 150 community-residing persons using the Health Care Preferences Questionnaire. The results of this study indicate that even in the presence of disabling mental illness, individuals are able to indicate preferences for treatment at the end-of-life. Furthermore, the authors identify a core belief that creation of proxies will enhance communication with family and healthcare providers (Foti, etal, 2005). At a minimum, the findings support creation of the documents as written guidance should their designated proxy not be upheld (Foti, etal, 2005). This view is supported by updated works of researchers Baez and Avery (2010), who found that persons with terminal illness and Schizophrenia tended to be ignored in their communications.

Despite the tendency to be ignored, the creation of the documents involved in advanced planning at the end-of-life demonstrates a level of self-determination to make preferences known. With changes to the Rehabilitation Act, IDEA, and ADA, persons with disabilities are being encouraged throughout life to engage in self-determined behavior (Havranek, 1999). If we look to the plenitude of self-determination and Person-centered Planning opportunities and training provided to persons with disabilities in our society, the engagement in self-determined behavior at the end-of-life appears reasonable.

CHAPTER 3

METHODS

Participants

The population of interest in this study was persons with disabilities. The sample for this study was drawn from two sources: the Lansing, Michigan based Capital Area Center for Independent Living (CACIL) and the Lubbock, Texas based LIFE/RUN Center for Independent Living. These providers were selected because they expressed ongoing interest in issues of self-determination, quality of life and planning for persons served in their myriad of programs. CACIL is a large Center for Independent Living serving primarily a four county area in central Michigan. Encompassing multiple service programs and domains, CACIL services extend to persons with a wide array of disabling conditions. Services include information & referral; peer support; independent living; assistive technology; rehabilitation nursing; nursing facility transitions; and community awareness & advocacy. LIFE/RUN is also a large, Center for Independent Living serving multiple counties in northwestern Texas. Serving a slightly larger geographic area than CACIL, LIFE/RUN offers the same array of core services as CACIL, but supplements unmet community needs with eight additional specialty services including: job readiness training; payee services; dignity U wear; ASL interpreting; energy assistance, youth transition, and social & recreational Services.

For this study, inclusion criteria required that the participants be involved in active services with one of the sponsor agencies during the data collection period in the fall of 2012. Active service involvement would be self-reported by the participants, and would not be verified by any means. Since data collection occurred at sponsor agency locations during program service and activity hours, it is likely that the majority of respondents are currently enrolled for services. Participants of all of the service programs of the selected agencies were provided with the opportunity to participate in the study process.

The potential pool of participants fluctuates daily. During the two day data collection period at CACIL, 28 persons were available for survey. Of these, 19 completed the survey for a completion rate of 67.9%. Of the non-responders, 2 identified a desire to report but could not consent due to guardianship issues. The remaining 7 non-responders offered no reason but declined to participate. During the days of data collection at the sites, a total of 94 program participants attended services at LIFE/RUN generating 72 completed surveys for a completion ratio of 76.6%. Of 22 non-responders in this setting, only one identified language as a barrier for completion. Joining the two settings, an overall response rate of 74.6% was attained of available participants. The *Participant Demographic Questionnaire*, which can be found in Appendix A, was used to collect demographic information from participants. The *Participant Demographic Questionnaire* poses twelve demographic questions seeking information on legal status, age, gender, educational level, racial/ethnic status, marital status, habitation status, employment status and primary source of income. Information was collected via circling the correct answer or range on the checklist, or collected verbally from individuals unable to communicate graphically.

Between the two sites on the days of data collection, a total of 92 individuals were present and expressed an interest in participating in the survey activity. One person was excluded from data collection following disclosure that he believed he had an appointed guardian (but was unsure). He received the stipend but did not complete the survey.

Data was collected at CACIL in Lansing, Michigan on Wednesday, September 19, 2012 and Thursday, September 20, 2012 during regularly scheduled program activities at the center. Data was collected at LIFE/RUN in Lubbock, Texas on Wednesday, September 12, 2012 and Thursday, September 13, 2012 during regularly scheduled program activities at the center. This setting was a little more challenging for data collection in that many programs were occurring simultaneously and it was difficult to divide attention. In total, 92 individuals completed the survey process and provided responses to some or all of the questions of the *Participant Demographic Questionnaire.* For reporting purposes, the results from the *Participant Demographic Questionnaire* was divided into five sections: 1) Basic demographic information of age, gender, and race/ethnicity identification; 2) Educational experience reporting including special education service and global attainment; 3) Disability Information including disability status, identification of disabling conditions, and presence of disability over the lifespan; 4) Social status questions inclusive of marital status, living arrangement, and duration of U.S. living; and 5) Economic factors including work status and income source.

Basic demographic information netted the most comprehensive results, with virtually all respondents providing information regarding gender and race/ethnicity. In reporting age, 9 individuals elected to not disclose their age, with the remaining 82 respondents reporting an age range of 23 to 79 years of age, with the mean being 50.8 years. The identified gender of survey respondents was positively skewed towards female, with 62 (68.1%) indicating female, 28 (30.8%) identifying as male, and 1 (1.1%) electing not to disclose. Racial/ethnic identity responses found just over half (*n=48; 52.8%)* of respondents identifying as 'white', followed by 'Latino' with 22 (24.2%) and 'black' with 20 (22.0%). Native American was the identity selected by 6 (6.6%) of individuals, with 2 (2.2%) identifying as 'Asian'. No individuals identified as being 'pacific islanders' and 1 individual (1.1%) declined to identify any racial or ethnic labels.

Looking to education components, the majority of respondents (*n=56, 61.5%)* denied receipt of special education services, while 26 (28.6%) individuals reported having received such services and 9 (9.9%) elected not to answer. With regards to educational attainment, only 6 (6.7%) reported attaining less than high school equivalency. High school graduates (*n=30, 33.7%)* and those completing the G.E.D. (*n=14; 15.7%)* comprised the next largest groups. College attendance included 10 (11.2%) with some coursework, 10 (11.2%) completing two years of study, and 10

(11.1%) completing a four year degree. Six (6.6%) individuals elected not to report educational attainment.

Disability information provided perhaps the most puzzling information in the survey. Although receipt of services from a disability-centric agency was a required part of the informed consent, only 75 (82.4%) identify their status as having a disability. Another 10 (11.0%) denied status as a person with a disability, and 6 (6.6%) indicated no answer. However, when queried regarding the nature of their disability, 11 (12.1%) individuals elected not to disclose by reporting no answer, and another 34 (37.4%) indicated that their disabling conditions did not fall within the list of provided. Among the individuals electing to disclose the nature of their disability, 18 (19.8%) reported joint or bone disorders; 12 (13.2%) reporting hearing loss; 10 (11.0%) indicated psychiatric disorders; 8 (8.8%) each reported cognitive impairments and epilepsy; 6 (6.6%) each reported visual impairments and heart/cardiac impairments. The smallest subset of individuals reporting their disabling conditions was for cerebral palsy, where 4 (4.4%) identified this as their primary disorder.

Reporting on social factors was also robust, with only three respondents electing not to answer some of the questions. Looking to marital status, over one-third (*n=38; 41.8%)* reported their status as single; trailed by 22 (24.2%) of individuals reporting being currently married. Those previously married included groups of 10 (11.0%) each who identified as divorced or widowed. Those identifying as being partnered (*n = 8, 8.8%)* came next, no persons (0.0%) reported being legally separated, and 3 (3.3%) declined to report their marital status. As individuals were able to select more than one answer, some category percentages exceed 100%.

Living arrangement reporting showed that 34 (37.4%) of individuals reporting living alone, while 30 (33.0%) reported living with family members. Of those living with non-relatives, 18 (19.8%) reported living with a partner; 4 (4.4%) reported living with roommates; and 2 (2.2%) reported living in some form of group home. Three (3.3) individuals elected not to provide information regarding their living status. When queried regarding length of time living in the United States, the majority (*n=78, 85.7%)* reporting living here their entire lifetimes, 10 (11.0%) reported longer than 10 years; 2 (2.2%) reported less than ten years. Only one (1.1%) elected no answer to this question.

Moving to economic status questions, half (*n=46; 50.6%)* of respondents indicated that they were not currently in the labor force. However, nearly half reported some type of employment: 14 (15.4%) reported part-time employment and 30 (33.0%) reported full time employment. Only one (1.1%) respondent elected no answer for this question. Disability was identified as the primary source of income for 50 (55.0%) of individuals reporting, followed by 26 (28.6%) who identified wages. Family provided the most support for 6 (6.6%) individuals, while 4 (4.4%) identified either pensions or welfare as the primary source of income. One (1.1%) individual elected no answer in response to this question. As individuals were able to select more than one answer, some category percentages exceed 100%. In sum, 91 *Participant Demographic Questionnaires* were collected during the data collection period, although one individual recorded no answers. Not all participants responded to each question, and therefore the number of responses varies by question.

Table 1 Overall Demographic Characteristics

Variables	Frequency	%
AGE REPORTING		
Non-reported	*n = 9*	
Youngest	23 years	
Eldest	79 years	
Mean	50.8 years	
GENDER IDENTIFIED		
Female	*n = 62*	68.1
Male	*n = 28*	*30.8*
No Answer	*n = 1*	*1.1*
RACE/ETHNICITY IDENTIFIED*		
White	*n = 48*	*52.8*
Black	*n = 20*	*22*
Asian	*n = 2*	*2.2*
Latino	*n = 22*	*24.2*
Native American	*n = 6*	*6.6*
Pacific Islander	*n = 0*	*0*
Other	*n = 1*	*1.1*
SPECIAL EDUCATION ATTENDANCE		
Yes	*n = 26*	*28.6*
No	*n = 56*	*61.5*
No Answer	*n = 9*	*9.9*
EDUCATION LEVEL ATTAINED*		
Less than High School Graduate	*n = 6*	*6.7*
High School Graduate	*n = 30*	*33.7*
General Equivalency Degree	*n = 14*	*15.7*
Some College	*n = 10*	*11.2*
2 yr. Degree Completed	*n = 10*	*11.2*
4 yr. Degree Completed	*n = 10*	*11.2*
No Answer	*n = 17*	*19.1*

Table 1 (cont'd)

DISABILITY STATUS REPORTED		
Yes	*n = 75*	*82.4*
No	*n = 10*	*11*
No Answer	*n = 6*	*6.6*
NATURE OF DISABILITY IDENTIFIED*		
Cognitive Impairment	*n = 8*	*8.8*
Psychiatric Impairment	*n = 10*	*11*
Epilepsy	*n = 8*	*8.8*
Visual Impairment	*n = 6*	*6.6*
Joint/Bone Disorder	*n = 18*	*19.8*
Hearing Impairment	*n = 12*	*13.2*
Cerebral Palsy	*n = 4*	*4.4*
Heart/Cardiac Impairment	*n = 6*	*6.6*
Other Disabling Condition	*n = 34*	*37.4*
No Answer	*n = 11*	*12.1*
DISABILITY OVER LIFETIME		
Yes	*n = 44*	*48.4*
No	*n = 36*	*39.6*
No Answer	*n = 11*	*12.1*
MARITAL STATUS		
Single	*n = 38*	*41.8*
Married	*n = 22*	*24.2*
Separated	*n = 0*	*0*
Divorced	*n = 10*	*11*
Widowed	*n = 10*	*11*
Partnered	*n = 8*	*8.8*
No Answer	*n = 3*	*3.3*

Table 1 (cont'd)

CURRENT LIVING ARRANGEMENT		
Alone	*n = 34*	*37.4*
Roommates	*n = 4*	*4.4*
Partner	*n = 18*	*19.8*
Family	*n = 30*	*33*
Group Home	*n = 2*	*2.2*
No Answer	*n = 3*	*3.3*
HOW LONG IN UNITED STATES		
Lifetime	*n = 78*	*85.7*
Greater than 10 years	*n = 10*	*11*
Less than 10 years	*n = 2*	*2.2*
No Answer	*n = 1*	*1.1*
WORK STATUS		
Full Time	*n = 30*	*33*
Part Time	*n = 14*	*15.4*
Not in Labor Force	*n = 46*	*50.6*
No Answer	*n = 2*	*2.2*
INCOME SOURCES		
Wages	*n = 26*	*28.6*
Disability	*n = 50*	*55*
Pension	*n = 4*	*4.4*
Welfare	*n = 4*	*4.4*
Family	*n = 6*	*6.6*
No Answer	*n = 5*	*5.5*

**numbers and percentages may vary due to multiple responses*

Variables and Measures

Self-Determination. Present within the literature for rehabilitation for over 30 years, Self Determination Theory builds from a foundation of intrinsic motivation (Deci & Ryan, 1985). Motivation, however, does not fully explain self-determined behaviors. Self-determined behaviors come about via the interaction of motivation with knowledge, supports and environmental factors that allow such characteristics to develop (Ryan & Deci, 2000). In this study, Self Determination will be measured by the Self Determination Scale (Sheldon & Deci, 1995).

The *Self Determination Scale (*Deci & Ryan, 1995, Sheldon, Ryan & Reiss, 1996, Ryan & Deci, 2000, Thrash & Elliott, 2002) is a 10-item self-report scale that provides measures for two domains: awareness of self and perceived choice. These subscales can be used separately or together to provide an overall measure of self-determined behavior. As a research tool, the *Self Determination* Checklist provides a brief measure of core characteristics identified with self-determination. The *Self-Determination Scale* is presented in Appendix B.

The *Self Determination Scale* provides ten pairs of contrasting statements, labeled A & B, with the respondent requested to identify which statement they feel to be the 'most true' at this point in their lives. Responses are measured on a five-point likert type scale, with 1 = only "A" feels true and 5 = only "B" feels true. If both statements feel equally true, the appropriate response would be "3". For scoring, odd numbered items have their scores reversed (the author suggests subtracting item score from 6 to obtain reversed score). Scores are then added, with a higher score reflecting the presence of more self-determined behaviors. If desired, the global score can be divided to obtain two sub-scores, with even number questions (2,4,6,8,10) reflecting awareness of self and odd number responses (1,3,5,7,9) reflecting the perceived choice.

The *Self Determination Scale* was developed at the University of Rochester by Deci and Ryan and is in the public domain for private research. Used extensively in private research, the measure has reported good internal consistency (ratings .85 - .93 in multiple studies) and adequate reliability ($r = .77$).

Participant Planning The primary focus of the current study was to explore the levels of knowledge and engagement in pre-planning activities by the population of interest. Having completed an extensive review of the literature, no formalized data collection instruments were readily available to assess current practice. In the absence of a published instrument, the *Participant Planning Questionnaire* was created for use in this study. The *Participant Planning Questionnaire* is presented in Appendix D.

The *Participant Planning Questionnaire* was developed for use in this study and provides information on participant's current status affecting advance planning and participant's desires/interests in engaging in advanced planning activities. Formatted with 14 YES/NO response questions, participants will have the option to omit responses or indicate no preference for each question. Questions 1 – 4; 6 – 8; and 10 - 13 focus on their current level of activity and status, while questions 5, 9 & 14 focus on their desire to engage in the process. Of the 91 persons engaging the study, 89 (97.8%) completed the *Participant Planning Questionnaire*, although 2 (2.2%) omitted answers for question eight. All other responses were complete for this measure. Scoring for the *Participant Planning Questionnaire* was accomplished by coding all responses of Yes = 1; No, No Answer = 0. An individually summed score was then used in the correlational analysis with the *Self-Determination Scale.* Data collected in response to questions 5, 9, & 14 was summarized and provided to the sponsor agencies (CACIL and LIFE/RUN) for program planning services.

Procedure

Following receipt of the approval letter from the MSU Human Subjects Review Board (Appendix E), an official request for participation was forwarded to the Executive Directors of each of the sponsor agencies. Upon receipt of a signed affiliation agreement (Appendix E), the agencies were supplied with recruitment posters (Appendix F). The recruitment posters were placed in public break areas of each of the sites where data was collected. The researcher and representatives of the sponsor agency worked together to determine appropriate dates for data collection and to arrange for appropriate facilities.

All data collection occurred at locations operated by the sponsor agencies in their service to individuals with disabilities. Data was collected using a detailed script (Appendix G), and following instructions, participants were offered the option to complete the questionnaire on their own or to have assistance completing the questionnaire. The primary investigator was available to assist individuals in instrument completion at their request.

During the data collection process, participants were gathered into small groups and provided a verbal overview of the study. The informed consent document (Appendix H) was read verbatim as part of this overview, and participants completing the survey were deemed to have given implied consent by their actions. The researcher was present throughout the data collection activity and provided interpretation or assistance as requested. The researcher collecting data reviewed the questionnaire upon submission to insure that the survey has been fully completed. If multiple questions or pages were left unanswered, the researcher queried the respondent to determine if the void was intentional. If the questions/pages were overlooked, the respondent was given the opportunity to complete the missing data. Individuals requesting personal assistance during the data collection period were offered the following options: a) a scribe to record data for individuals unable to physically record their responses, b) a reader to read the survey documents verbatim to allow the individual to record their own answers; or c) a combination reader/scribe. All requests for interpretation of the survey instruments were provided using the scripted interpretations of terms found in Appendix I.

Upon completion, all survey instruments were sealed in manila envelopes recording the date, location, time, and surveyor collecting the data. All demographic and questionnaire responses were entered into the *Statistical Package for Social Sciences 20.0 for Windows* (SPSS, 2011) for data analysis.

Data Analysis

At the close of data collection, a total of 91 responses had been obtained. A cursory review of the data revealed that a total of five of the responses had significant gaps in the data for the measures *Self-Determination Scale* and *Participant Planning Questionnaire.* In this review, it was determined that five (5.5%) of the responses had sufficient missing data to damage the potential outcome analysis. These responses were discarded from the calculations used for data analysis, leaving us a clean data response of 86 participants.

For the 86 clean data responses, the total scores recorded for the *Self-Determination Scale* and *Participant Planning Questionnaire* were compared for correlation using the *Statistical Package for Social Sciences 20.0 for Windows* (SPSS, 2011). Using both the clean data set for the entire *Self-Determination Checklist* and *Participant Planning Questionnaire* found that no significant relationship (.139) existed between the two variables using a two-tailed test. Dividing the *Self-Determination Checklist* into the two proscribed subsets and running a correlation between these variables netted a relationship significant (.249) at the .05 level using a two-tailed test. Based on these findings, it was decided to run each of the subscales of the *Self-Determination Checklist* against the entire *Participant Planning Questionnaire.*

Subscale A of the *Self-Determination Checklist* has been established as a measure of an individual's awareness of self (Deci & Ryan, 1995). This subscale is composed of all even numbered questions (2,4,6,8,10) summed. No significant correlation (.047) was found between subscale awareness of self and the *Participant Planning Questionnaire.*

Subscale B of the *Self-Determination Checklist* has been established in prior works as a measure of an individual's perceived choice (Deci & Ryan, 1995). Subscale B is comprised of all odd numbered (1,3,5,7,9) questions, reverse scored and then summed. On correlation, a statistically significant relationship (.222) at the .05 level was established between subset perceived choice and the *Participant Planning Questionnaire* using a two-tailed measure.

CHAPTER 4

RESULTS

The purpose of this investigation was to evaluate the relationship between self-determination and quality of life among persons with disabilities. Prior to conducting the primary analysis related to the research questions, descriptive statistics and a correlation analysis was completed to yield data to describe the variables in this study and their inter-relationships. Using the *Statistical Package for Social Sciences 20.0 for Windows* (SPSS, 2012), the first research question (i.e. the relationship between the presence of SD Behaviors and the creation of Durable Powers of Attorney for Healthcare) was addressed using a simple correlation.

Results Related to Research Question 1

Research Question One poses the following: "What is the relationship between the presence of SD behaviors and the creation of Durable Powers of Attorney for Healthcare?" The relationship between the presence of SD behaviors and the creation of Durable Powers of Attorney for Healthcare was measured by correlation between the outcomes of the *Self-Determination Scale* and the sum of the *Participant Planning Questionnaire.*

Descriptive Statistics and Correlation Analysis

Means, standard deviations, and ranges for all study variables utilizing raw data are presented in Table 2 and correlations among the variables are shown in Table 3.

Table 2 Descriptive Statistics for study variables (RAW)

Variables	*n*	M	SD	Range (min-max)
Self Determination	91	29.40	9.74	0 – 46.00
Participant Planning	91	7.23	3.63	0 – 14.00

Table 3 Correlations among Study Variables (RAW)

Correlations

		SDS All	PPQ All
PPQ All	Pearson Correlation	1	.131
	Sig. (2 tailed)		.215
	N	91	91
SDS All	Pearson Correlation	.131	1
	Sig. (2 tailed)	.215	
	N	91	91

As noted in the correlation boxes above, no statistical significance was found using the raw data results for the entire population. Since a number of responses appeared questionable (either one or both data sheets were not completed or were missing), it was suggested that the data be cleaned by removing these responses from the sample. In all, five responses were deemed to provide inadequate information for inclusion in the analysis and were discarded. Once discarded, the samples were analyzed a second time and the descriptive statistics (mean, standard deviations, and ranges) were generated for the clean data and are presented in Table 4, while the correlations measured are reported in Table 5.

Table 4 Descriptive Statistics for study variables (CLEAN)

Variables	*n*	M	SD	Range (min-max)
Self Determination	86	29.40	9.32	10 – 46.00
Participant Planning	86	7.65	3.27	1 – 14.00

Table 5 Correlations among Study Variables (CLEAN)

Correlations

		SDS All	PPQ All
PPQ All Clean	Pearson Correlation	1	.140
	Sig. (2 tailed)		.198
	N	86	86
SDS All Clean	Pearson Correlation	.140	1
	Sig. (2 tailed)	.198	
	N	86	86

Although no previous studies have been accomplished using the Participant Planning Questionnaire (PPQ), the Self-Determination Scale (SDS) has been used in a myriad of other study situations against other constructs. Scoring for the SDS is often divided into two subscales, odd numbered questions deemed reflective of Perceived Choice; while even numbered questions are deemed reflective of Awareness of Self. As both are seen as key indicators of self-determination, the scale allows for them to be scored as one or separated and used independently. Since no clear statistical relationships were established using the entire scale, each subscale analyzed separately. The descriptive statistics (means, standard deviations, and range) for Subscale Perceived Choice in correlation with Subscale Awareness of Self are presented in Table 6, and the correlation measures follow in Table 7. It should be noted that these statistics were run using the clean data set.

Table 6 Descriptive Statistics SDS Subsets (CLEAN)

Variables	*n*	M	SD	Range (min-max)
Perceived Choice	86	13.05	5.30	5 – 23.00
Awareness of Self	86	16.36	6.50	5 – 25.00

Table 7 Correlations among SDS Subsets (CLEAN)

Correlations

		SDS All	PPQ All
Awareness of Self	Pearson Correlation	1	.241*
	Sig. (2 tailed)		.025
	N	86	.86
Perceived Choice	Pearson Correlation	.241*	1
	Sig. (2 tailed)	.025	
	N	86	86

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

Having achieved a statistically significant correlation between the SDS subscales, it was decided to study each of the SDS subscales individually with the PPQ total (there are no PPQ Subscales). Table 8 provides the descriptive statistics (mean, standard deviation, and range) for the Perceived Choice and the Participant Planning Questionnaire (total). Table 9 examines the statistical relationship between these two constructs as measured in this survey.

Table 8 Descriptive Statistics Perceived Choice and PPQ (CLEAN)

Variables	M	SD	Range (min-max)
Perceived Choice	13.05	5.30	5 – 23.00
PPQ Total	7.65	3.27	1 – 14.00

Table 9 Correlations among Perceived Choice and PPQ (CLEAN)

Correlations

		SDS-A	PPQ All
Perceived Choice	Pearson Correlation	1	.221*
	Sig. (2 tailed)		.041
	N	86	86
PPQ Total	Pearson Correlation	.221*	1
	Sig. (2 tailed)	.041	
	N	86	.86

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

Finding a statistically significant positive relationship between the variable subscale of perceived choice and the PPQ Total, it was decided to examine independently the relationship between the subscale Awareness of Self and the PPQ Total. Table 10 presents the descriptive statistics (mean, standard deviation, and range) for this measure, and Table 11 presents the correlations between these subsets.

Table 10 Descriptive Statistics Awareness of Self and PPQ (CLEAN)

Variables	*n*	M	SD	Range (min-max)
Awareness of Self	86	16.36	6.50	5 – 25.00
PPQ Total	86	7.65	3.27	1 – 14.00

Table 11 Correlations among Awareness of Self and PPQ (CLEAN)

Correlations

		SDS-B	PPQ All
Awareness of Self	Pearson Correlation	1	.047
	Sig. (2 tailed)		.665
	N	86	86
PPQ Total	Pearson Correlation	.047	1
	Sig. (2 tailed)	.665	
	N	86	.86

In examining the data for this relationship, it becomes clear that no statistically significant relationship exists between the SDS Awareness of Self and the Participant Planning Questionnaire.

Having confirmed this statistical relationship, the data demonstrates a variation in pattern that was not anticipated. While the overall data renders research hypothesis #1 to be null, test instrument and subsets of the population reflect a positive statistical relationship. Analysis of the relationship between the subsets Perceived Choice and Awareness of Self, the SDS demonstrated a statistically significant positive relationship (.241 two-tailed) where measured against each other. Only the subset SDS Perceived Choice demonstrated a positive statistical relationship (.221 two-tailed) measured against cleaned population PPQ scores. Overall it should be noted that all relationships reported within this data analyses were positive, but that the majority lacked statistical significance.

Results Related to Research Question 2

Research Question Two poses the following: "What is the frequency of creation of Durable Powers of Attorney for Healthcare documents for persons with disabilities?" It was agreed in the proposal that this would be measured descriptively by counting the positive responses to questions 4, 8 and 13 from the *Participant Planning Questionnaire.* Question 4 is the most pertinent, asking: "Have you ever talked with a lawyer to make legal plans for your health decisions?" Question 8 asks: "Have you ever talked with a lawyer to make legal plans for your estate decisions?" Finally, question 13 asks: "Have you ever talked with a lawyer to make legal plans for your funeral decisions?" Descriptive data for these measures is reported below in Table 12.

Table 12 Descriptive Statistics Participant Planning Questionnaire

Variables	*n*	Yes	No	No Answer
Question #4	86	18(20.1%)	68(79.1%)	0(0.0%)
Question #8	84	22(26.2%)	60(71.4%)	6(7.1%)
Question #13	86	12(13.9%)	74(86.0%)	0(0.0%)

No statistical analysis was completed with Research Question Two. In looking at response numbers, it is clear that the majority of respondents have not engaged in creation of Durable Powers of Attorney for Healthcare.

However, perhaps the most significant outcome is can be reflected by the reporting of outcomes for the entire *Participant Planning Questionnaire.* Table 13 reports outcomes for each of the questions.

Table 13 Descriptive Statistics for Participant Planning Questionnaire

Questions	*n*	Yes	No	No Answer
Question 1	89	32(35.96%)	54(60.67%)	3(3.37%)
Question 2	89	62(69.66%)	16(17.98%)	11(12.36%)
Question 3	89	46(51.69%)	40(44.94%)	3(3.37%)
Question 4	89	18(20.22%)	70(78.65%)	1(1.12%)
Question 5	89	50(56.18%)	30(33.71%)	9(10.11%)
Question 6	89	62(69.66%)	20(22.47%)	7(7.87%)
Question 7	89	46(51.69%)	36(40.45%)	5(5.62%)
Question 8	87	22(25.29%)	62(71.26%)	7(8.05%)
Question 9	89	70(78.65%)	10(11.24%)	9(10.11%)
Question 10	89	66(74.16%)	18(20.22%)	5(5.62%)
Question 11	89	64(71.91%)	22(24.82%)	3(3.37%)
Question 12	89	46(51.69%)	42(47.19%)	1(1.12%)
Question 13	89	12(13.48%)	76(85.39%)	1(1.12%)
Question 14	89	62(69.66%)	22(24.72%)	5(5.62%)

While questions 4, 8, & 13 answer research question 2 the most clearly, questions 5,9, & 14 posed questions regarding the interest of the respondent in learning more about the details of planning activities. For question #5, which posed 'If a lawyer were available to you ….would you want to create a DPOA, over half of all respondent indicated an interest. For question #9, which queried interest in creating a will, nearly 80% of respondents indicated a desire to meet with an attorney. Finally, for question #14 addressing creation of funeral or memorial plan, nearly 2/3 of respondents indicated a desire to learn more.

In a similar vein, while most participants were readily able to identify the persons who they believed would make decisions on their behalf (as reflected in questions 2 & 11), consistently low numbers of individuals had engaged in discussions with these individuals regarding the decisions that might be made (as reflected in questions 3, 7 & 12).

While not tied specifically to research questions of this study, this information reflects two interesting dynamics: 1) individuals with disabilities desire an opportunity to learn about the options available to them for planning; and 2) individuals with disabilities do not often engage in discussions with significant others regarding their desires for end of life care.

CHAPTER 5

DISCUSSION

Self-Determination Theory (Deci & Ryan, 2000) places focus on the psychological motivations involving concepts of awareness of self and perceived control as avenues of measure in determining an overall sense of one's level of self-determination. Prior research has established a relationship between levels of self-determination and autonomy, choice-making, community living or employment and higher levels of life satisfaction (Wehmeyer & Bolding, 1999). The Self-Determination Scale (Deci & Ryan, 1995) was developed to provide a brief measure of the global level of self-determination, but provided for independent measures of key concepts of awareness of self and perceived control.

The present study sought to develop an understanding of the frequency of use of documents such as Durable Power of Attorney for Healthcare or Living Wills by persons with disabilities. This was accomplished using a global measure of self-determination against a fourteen question survey of engagement in planning activities for the end of life. The survey document, 'Participant Planning Questionnaire' sought information regarding engagement in a series of planning activities projected to measure autonomy in the planning for end of life. This document was developed by the researcher, and was piloted with a composite grouping of five individuals from the survey population group before being implemented. It was anticipated that the results from the administration of the standardized *Self-Determination Scale* would correlate positively with total scores from the non-standardized *Participant Planning Questionnaire*.

The importance of this relationship is that it relates to the planning of services for persons with disabilities in the development of aspects of control over their lives. To that end, the first research question of interest in this study was: What is the relationship between self-determination and end of life planning? The second research question of interests was: How many people with disabilities have completed Durable Powers of Attorney for Healthcare? These planning activities are increasing in frequency among the general population and in the future can be expected to be of increasing importance to persons with disabilities.

The potential for value of this study is four-fold. First, it provides a measure of the numbers of persons with disabilities currently engaging in planning activities for the end of life, as well as the depth of those activities. Secondly, the results provided a measure of the interest of the participants in learning about their options for using these planning tools to impact decisions made at the end of their lives. A third benefit of this study is reflections of a significant lack of engagement by PWD and their significant others in discussions regarding end of life planning. Finally, the study will provide a snapshot of the relationship between self-determination and engagement in planning activities. This chapter examines five aspects of the study: (a) the limitations of the study; (b) a narrative summary of the results; (c) the relation of the findings to previous research; (d) the theoretical and practice implications; and (e) suggestions for future research.

Limitations of the Study

Prior to any discussion of the results and implications of this study, a review of a few of the limitations should be noted. The limitations include the nature of the participant group, sample convenience, and relationships established between the constructs of interest.

A wide variety of participant information was collected via the *Participant Demographic Questionnaire.* Although issues of age and race appeared congruent with census data (U.S.C.B., 2012a; U.S.C.B., 2012b) gender was heavily skewed towards female participants. . Neither program site collects data regarding program attendance that offers an explanation for this skew. Reporting regarding disability status also reflects inconsistency, with 16 individuals denying or opting not to disclose disability status, and 11 failing to identify a disabling condition. The remainder of the data collected on this form reflected comparable data to annual reporting for both agencies.

The sample was drawn from persons accessing services at independent living centers in both Texas and Michigan. The information collected regarding living arrangements appeared to be congruent with data supplied in annual reporting for the agencies. It is possible that due to the timing of data collection some participants who receive services who were not present during the collection period. Factors such as employment, transportation and involvement in other social activities would likely affect any generalizations that might be made. As such, the study sample may not be representative of the overall populations of the two agencies at which data were collected.

The study populations resulted from a sample of convenience. Data was collected from participants during a visit to the independent living center during the data collection period. Therefore, the outcomes of this study cannot be generalized to all persons with disabilities.

Finally, while pre-analysis statistical power was found to be adequate for the correlational measure used, the results failed to demonstrate the relationship established in similar studies. However, splitting the groups into geographic sub-sets revealed a statistically significant relationship between one of the sub-sets and sub-scores of the *Self-Determination Scale*. With this variation in the scoring, results cannot be generalized to other sample or populations. It should be noted that while limited statistical relationships were established between some constructs, the strength of these relationships may not rise to a practical level.

Narrative Summary of the Results

The purposes of this study were two-fold: (1) to study the relationship between self-determination and end-of-life planning and (2) to evaluate the extent of engagement in end-of-life planning activity. Research question one was explored using a correlational measure, while research question two was measured by simple descriptive statistics.

Research question one asked “What is the relationship between Self-Determination and End-of-life Planning activities?” Studied by correlation, the measure failed to establish a statistically significant relationship when using a two-tailed test. Using data cleaned of incomplete answers, a total of 86 responses demonstrated a statistically insignificant positive relationship of .140. Descriptive statistics for this relationship were based on 86 responses on the *Self-Determination Scale* netting a mean response of 29.40 with a standard deviation of 9.32 and a range of 10-46. For the *Participant Planning Questionnaire* descriptive statistics confirmed 86 responses with a mean of 7.65, a standard deviation of 3.27, and a range of 1-14.

Research question two asked: “What is the occurrence of completion of Durable Powers of Attorney for Healthcare?” This question was answered via descriptive statistics, with responses to questions 4, 8, and 13 representing the measure of this activity. Question 4 asked “Have you ever talked with a lawyer to make legal plans for your health decisions?” This question was deemed most significant to the question at hand, and all 86 respondents in the clean data set answered, with 18 (20.1%) indicating that they had spoken with a lawyer; 68 (79.1%) indicating they had not. Question 8 asked: “Have you ever talked with a lawyer to make legal plans of your estate decisions?” Question 8 was answered the least, with only 84 respondents supplying an answer. Of those responding, 22 (26.2%) indicated they had conferred, with 60 (71.4%) indicated they had not conferred, and 6 (7.1%) indicated no answer. The final related question, #13, asked:

"Have you ever talked with a lawyer to make legal plans for your funeral decisions?" The full 86 individuals represented in the clean data set provided answers, with 12 (13.9%) indicating they had conferred, 74 (86.0%) indicating they had not conferred. While no statistical analyses were conducted on the responses to the three questions related to research question #2, it is clear that the majority of respondents had not completed Durable Powers of Attorney for Healthcare documents.

Despite the original goals of this study, the perhaps most significant outcome is in the form of demonstration that PWD wish to be involved in decision making activities and that they wish to have factual information upon which to base their decisions. Their willingness to engage in learning upon which to base decisions implies an active engagement, and is congruent with central constructs of autonomy and sense of self.

Relation of Findings to Prior Research

The findings of the current study add to previous research and theory. No prior research had posed a question regarding relationship between self-determination and planning for end-of-life, although substantial work had established a positive relationship between choice-making and self-determination; perceived control and self-determination; end-of-life planning and satisfaction; and engagement in planning and retention of life control.

The relationship between choice-making and self-determination has been established in multiple settings with varied groups of individuals (Havranek, 1998).

Fields, etal.(1998) identified the process of both having choice and learning how to make choices as a key ingredient in the development of self-determination. Training in choice-making skills was established as critical for older adults (Heller, etal, 1996); those with dementia (Allen and Hilgeman, 2009), as well as for those with severe disabilities (Olney, 2001). Validated several times in research, the role of choice was established as a predictor of empowerment in rehabilitation (Frain, etal, 2009).

Perceived control or locus of control has been long established as an area of research within the field of rehabilitation, as well as a primary indicator of self-determination (Field, etal, 2003). Wehmeyer and Shalock (2001) solidify the linkage between locus of control and self-determination, and extend the relationship to provide a reflection of quality of life. Other researchers in the field (Wehman, etal, 2003; Wappett, 2002; Plagnol, 2010; Palmer, 2010; Mcclimans, 2010) have established positive relationships between the exercise of control in a multitude of settings across the lifespan as being essential component of both self-determination and quality of life measures.

The relationship between end-of-life planning and self-determination has received less examination in the research, especially focused on persons with disabilities. End-of-life planning is studied commonly among aged persons (Bowling, et al, 2003; Carr, et al, 2007; Castle & Mor, 1998; Martin, et al, 2000; Pozzoulo, et al, 2005; Teno, et al, 1994), especially among persons receiving medical care for potentially life threatening illnesses. Planning has also been studied in the context of specific disability populations, especially those with mental illness (Cook & Jonikas, 2002; Geller, 2000; Peters & Chiverton, 2003; Ryerson, 2007; Sheldon, et al, 1996; Sith, 2006; Swartz & Swanson, 2007).

Locus of control over one's life has been at the core of much research regarding end of life planning. From a global perspective, research has focused on establishing the outcomes of a myriad of legislation created to establish the ability to designate plans for end-of-life (Alston, 1997; Black, 2008; Brammer, 2005; Dore, 2008; Hickman, et al, 2005; Irons, 2007; Kemp & Kopp, 2010; Kim, et al, 2007; O'Neill, 2001; Sith, 2006). Lesser research has explored perceptions and completion rates (Black, 2008; Blanck, 2008; Carr & Khodyakov, 2007; Galambos, 1998; Salmond & David, 2005). The concept has been studied in the context of guardianship and avoidance of guardianship (Bellard, 2001; Black, 2008; Dore, 2008; Hommel, 1996; Moye, et al, 2007; O'Neill, 2001; Teaster, 2002; Wright, 2010). As a subset of the guardianship consideration, the question of substituted judgment and proxy decision making has also been studied numerous times (Allen & Hilgeman, 2009; Asch, 2005; Gregory, et al, 2007; Giger, et al, 2006; McGuire, et al, 2007; Slocum, et al, 2011).

Theoretical Implications

From a theoretical perspective, this works supports prior research findings across three domains: the importance of decision making skills; the fundamental value of autonomy; and the interest in attaining relevant knowledge by persons with disabilities. Decision-making skills have been the subject of trainings for persons with disabilities since the introduction of the concepts of self-determination and person-centered planning (Wehmeyer and Schwartz, 1998). Identified as a basic building tool towards controlling one's future, training in decision-making has been in the forefront of curricula since the mid-1990's (Wehmeyer, etal, 1999). Beginning with adolescents, researchers have established that training in decision-making skills can enhance nearly all aspects of one's lives (Field & Hoffman, 1994). The ability to make decisions that control one's lives is also tied heavily to the concept of autonomy (Havranek, 1999). The results from questions 5, 9 & 14 would appear to support the idea that PWD want information upon which to base these decisions.

Autonomy is one of the essential components of rehabilitation counseling philosophy, and has been codified into policy for nearly 40 years (Parker, etal, 2005). Within research, autonomy is identified as a frequent contributor to concepts of quality of life (Pain, etal, 1998) as well as psycho-social adaptation to chronic illness (Bishop, etal, 2008). Using the adaptation model, autonomy is often addressed in the context of understanding complexity of the options (Gregory, et al, 2007).

A wealth of literature is available that suggests that individuals with disabilities seek information upon which to base decision making (Allen & Hilgeman, 2009; Bishop, et al, 2008; Bowling, et al, 2003; Carr & Khodyakov, 2007; Geller, 2000; Kuczewski, 2004; McCarthy, et al, 2007; Paillaud, et al, 2007; Peters &

Chiverton, 2003; Sheldon, et al, 1996; Sith, 2006; Swartz & Swanson, 2007). The findings of this study clarify that individuals with disabilities would like information from professional sources regarding creation of Durable Powers of Attorney for Healthcare, as well as creation of wills and funeral or memorial planning.

Practice Implications

Perhaps one of the greatest findings of this study is that individuals with disabilities desire information regarding planning activities as well as options to maintain their autonomy. These findings are consistent with prior research that identifies locus of control as a primary player in measures of quality of life (Bishop, etal, 2008). Buttressing the arguments for autonomy, research has concluded training may be necessary to facilitate independent decision making for persons with disabilities (Allen & Hilgeman, 2009; Fields & Hoffman, 1994; Fields, et al, 1998; Fields, et al, 2003; Havranek, 1998; Wehmeyer, et al, 1999). Applying this research, it becomes a mandate for ethical practice to engage in techniques that enhance individual empowerment for persons with disabilities across rehabilitation settings (Aldridge, 2010; Alston, 1997; Betcher, 2008; Bowling, et al, 2003; Breeding, 2008; Dempsey & Foreman, 1997; Geller, 2000; Hein, et al, 2005; Leff, et al, 2003; Smart, 2009; Swartz & Swanson, 2007).

Considerations for Future Research

Research on the relationship between self-determination and end-of-life planning has been scarce in the rehabilitation literature, despite seemingly similar goals: increased autonomy and improved locus of control. Centers for independent living have a primary goal advocacy on behalf of persons with disabilities. Taking an advocacy perspective, this study establishes clearly with the results related to research question two that many individuals in this sample are not currently creating durable powers of attorney for healthcare. Moreover, the responses to question #5, 9 and 14 on the *Participant Planning Questionnaire* establish a desire for information on planning activities by these individuals. Question 5 asked about interest in creating a Durable Power of Attorney for Healthcare, were 62 individuals (72.1%) indicated a desire to consult with an attorney. Question 9 asked about creating a will, and 70 persons (81.4%) responded affirmatively. Offered the opportunity to learn about creating a memorial plan, 62 (72.1%) of respondents reported an interest in this activity. As such, additional research is needed to explore the relationship between self-determination and various aspects of end of life planning. The finding that PWD seek information and desire to be involved in decision making tasks may be the strongest outcome from this study.

Each of the programs involved in the current study have received information regarding their respondents answers to the study questions, increasing the potential for the development of education and training processes to occur in each setting.

The results of this study lend support to previously established constructs regarding the need to train individuals in choice-making skills and self-advocacy (Field et al, 1998), setting the stage for research into application among a variety of rehabilitation settings. Since application of these planning activities has been held evidence of competence (Galambos, 1998), research focusing on substitution of Durable Powers of Attorney for Healthcare in place of guardianship should be conducted.

Research into the myriad of cultural considerations that impact issues of end-of-life planning, such as prohibitions of faith and hierarchy of personal preferences is largely missing the research literature Development of cultural competency in the discussion of directives should be explored more thoroughly (Giger, etal, 2006). Moreover, a shift from contextualizing culture and social values from a group level to an individual level would support an individualization of all attempts to discuss end of life issues (Cartwright, et al, 2009; Nadal, 2011; Sue, etal, 2008; Sue, etal, 2007).

Finally, methods utilizing more active participation by the subjects of the study should be considered in future research. Utilizing peer group members for the collection of data has been shown to increase response rates in survey research (Smith & O'Flynn, 2000). While no respondents reported discomfort at discussing these topics with persons outside of their peer groups, it is possible that different results would be obtained in discussion with peers; or with the use of other methods of data collection.

APPENDICES

APPENDIX A

PARTICIPANT DEMOGRAPHIC QUESTIONNAIRE

Table 14 Participant Demographic Questionnaire

Self-Determination and End of Life Planning for Persons with Disabilities

PARTICIPANT DEMOGRAPHIC QUESTIONNAIRE			
QUESTIONS	RESPONSES		
1. What is your age?			
2. How do you identify your gender?	Female	Male	Other/ No Answer
3. How do you identify your race or ethnicity? (Please circle all that apply)	White	Black	Asian
	Latino	Native Amer	Pac. Islndr.
	Other:		
4. Did you attend Special Education?	YES	NO	No Answer
5. What is your highest level of education?	Less than HS Grad	High School Grad	GED
	College	2 yr Degree	4 yr Degree
6. Do you have a disability?	YES	NO	No Answer
7. If yes, what is the nature of your disability? (Please circle all that apply)	Cognitive	Psychiatric	Epilepsy
	Visual	Bone/Joint	Hearing
	C.P.	Heart	Other
8. Has your disability been present for your whole life?	YES	NO	No Answer
9. What best describes you marital status today?	Single	Married	Separated
	Divorced	Widowed	Partnered
10. Which best describes your living arrangement?	Alone	Roommates	Partner
	Family	Group	No Answer
11. How long have you lived in the U.S.?	Entire Life	10 or more years	Less than 10 years
12. Which best describes how much you work?	Full Time (everyday)	Part Time (Some days)	Do Not Work
13. Which of the following best describes your primary (largest) source of income?	Wages	Disability	Pension
	Welfare	Family	No Answer

APPENDIX B:

SELF-DETERMINATION SCALE

Table 15: Self-Determination Scale

Self-Determination Scale

Instructions: Please read the pairs of statements, one pair at a time, and think about which statement within the pair seems more true to you at this point in your life. Indicate the degree to which Statement A feels true, relative to the degree that Statement B feels true, on the 5-point scale shown after each pair of statements. If statement A feels completely true and statement B feels completely untrue, the appropriate response would be 1. If the two statements are equally true, the appropriate response would be a 3. If only statement B feels true and so on.

STATEMENT “A”						STATEMENT “B”
1. I always feel like I choose the things I do.	1	2	3	4	5	1. I sometimes feel like it isn’t really me choosing the things I do.
2. My emotions sometimes feel alien to me.	1	2	3	4	5	2. My emotions always seem to belong to me.
3. I choose what I have to do.	1	2	3	4	5	3. I do what I have to, but I don’t feel like it is really my choice.
4. I feel that I am rarely myself.	1	2	3	4	5	4. I feel like I am always completely myself.
5. I do what I do because it interests me.	1	2	3	4	5	5. I do what I do because I have to.
6. When I accomplish something, I often feel it wasn’t really me who did it.	1	2	3	4	5	6. When I accomplish something I always feel it’s me who did it.
7. I am free to do whatever I decide to do.	1	2	3	4	5	7. What I do is often not what I’d choose to do.
8. My body sometimes feels like a stranger to me.	1	2	3	4	5	8. My body always feels like me.
9. I feel pretty free to do whatever I choose to.	1	2	3	4	5	9. I often do things I don’t choose to do.
10. Sometimes I look in the mirror and see a stranger.	1	2	3	4	5	10. When I look in the mirror I see myself.

APPENDIX C:

PARTICIPANT PLANNING QUESTIONNAIRE

Table 17: Participant Planning Questionnaire

PARTICIPANT PLANNING QUESTIONNAIRE			
QUESTIONS	RESPONSES		
1. Have you ever completed any life planning activities (like a person centered plan, created a will, or power of attorney)?	YES	NO	UNSURE
2. Do you know who would make medical or legal decisions for you if you could not?	YES	NO	UNSURE
3. Have you talked with that person about what decisions they should make?	YES	NO	UNSURE
4. Have you ever talked with a lawyer to make legal plans for your health decisions?	YES	NO	UNSURE
A ‘Durable Power of Attorney for Healthcare” allows another person to make medical decision for you IF YOU BECOME UNABLE.			
5. If a lawyer were available to you (for free or at a very low cost) would you want to create a Durable Power of Attorney for Healthcare?	YES	NO	UNSURE
6. Do you know who would inherit your things (clothes, furniture, car, home) if you were to die?	YES	NO	UNSURE
7. Have you talked with that person about what decisions they should make?	YES	NO	UNSURE
8. Have you ever talked with a lawyer to make legal plans for your estate decisions?	YES	NO	UNSURE
A “WILL” allows you to legally specify what will happen with everything you own should you die.			
9. If a lawyer were available to you (for free or at a very low cost) would you want to create a WILL?	YES	NO	UNSURE
10. Do you have strong beliefs or feelings about the type of funeral / Cremation / Memorial you would want held if you died?	YES	NO	UNSURE
11. Do you know who would make funeral or memorial service arrangements if you were to die?	YES	NO	UNSURE
12. Have you talked with that person about what decisions they should make?	YES	NO	UNSURE
13. Have you ever talked with a lawyer to make legal plans for you funeral decisions?	YES	NO	UNSURE
A “FUNERAL PLAN” allows you to tell others what activities you would like to occur when you die.			
14. If assistance were available to you (for free or at a very low cost) would you want to create a plan for your funeral decisions?	YES	NO	UNSURE

APPENDIX D:

REQUESTS TO CONDUCT RESEARCH

Self-Determination and End of Life Planning for Persons with Disabilities

The purpose of this letter is to ask permission of the Capital Area Center for Independent Living (CACIL) and its director and agency staff for researchers at Michigan State University to conduct a study. The study is entitled: "Self-Determination and End of Life Planning for Persons with Disabilities". The primary purpose of this study is to examine the relationship between individual levels of self-determination and end of life planning activities for persons with disabilities. Further study of the relationship between self-determination and end of life planning 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 choose, and to have those choices be determinants of one's own actions, and as a right of individuals to have full ownership over their lives. Self-determination is realized when individuals are free to exercise control and experience outcomes of their choices without coercion, obligation, or artificial restraints. End of life planning looks long into the future and your involvement in activities to help you plan for future care decisions including medical care and funeral planning.

CACIL is being asked to participate in this study because the agency serves as a Center for Independent Living program and 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 the study is entirely voluntary. A consumer may refuse to participate, refuse to answer questions, or discontinue participation at any time without penalty. The study would include three study questionnaires which would be estimated to take 10-15 minutes 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 this study, CACIL 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.

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

If you have any questions concerning this study, please contact the investigator (Dave Schroeder, 4729 2nd Street, Lubbock, TX 79416; telephone 517.897.2736; e-mail: schro111@msu.edu) or his faculty research advisor (Dr. John Kosciulek, 458 Erickson Hall, East Lansing, MI 48824; telephone 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 McMullan, BS, CIP by telephone: 517.355.2180; Fax: 517.432.4503; e-mail: MCMILL12@ORA.MSU.EDU; or postal: 408 W. Circle Drive, Rm. 205A, East Lansing, MI 48824.

Your signature on this form indicates the willingness of the Capital Area Center for Independent Living to participate in this study.

Ellen Weaver CRRN

Ellen Weaver, Executive Director
Capital Area Center for Independent Living

Self-Determination and End of Life Planning for Persons with Disabilities

The purpose of this letter is to ask permission of the LIFE/RUN Center for Independent Living and its director and agency staff for researchers at Michigan State University to conduct a study. The study is entitled: "Self-Determination and End of Life Planning for Persons with Disabilities". The primary purpose of this study is to examine the relationship between individual levels of self-determination and end of life planning activities for persons with disabilities. Further study of the relationship between self-determination and end of life planning 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 choose, and to have those choices be determinants of one's own actions, and as a right of individuals to have full ownership over their lives. Self-determination is realized when individuals are free to exercise control and experience outcomes of their choices without coercion, obligation, or artificial restraints. End of life planning looks long into the future and your involvement in activities to help you plan for future care decisions including medical care and funeral planning.

LIFE/RUN is being asked to participate in this study because the agency serves as a Center for Independent Living program and 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 the study is entirely voluntary. A consumer may refuse to participate, refuse to answer questions, or discontinue participation at any time without penalty. The study would include three study questionnaires which would be estimated to take 10-15 minutes 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 this study, LIFE/RUN 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.

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

If you have any questions concerning this study, please contact the investigator (Dave Schroeder, 4729 2nd Street, Lubbock, TX 79416; telephone 517.897.2736; e-mail: schro111@msu.edu) or his faculty research advisor (Dr. John Kosciulek, 458 Erickson Hall, East Lansing, MI 48824; telephone 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 McMullan, BS, CIP by telephone: 517.355.2180; Fax: 517.432.4503; e-mail: MCMILL12@ORA.MSU.EDU; or postal: 408 W. Circle Drive, Rm. 205A, East Lansing, MI 48824.

Your signature on this form indicates the willingness of the LIFE/RUN Center for Independent Living to participate in this study.

Michelle Crain, Executive Director
Capital Area Center for Independent Living

APPENDIX E:

ANNOUNCEMENT/INVITATION POSTER

You Are Invited!

To

Participate in a Research Study!

What: CACIL, Inc. & LIFE/RUN, Inc., along with researchers from Michigan State University, would like to request your involvement in a research study which will be taking place at CACIL, Inc. & LIFE/RUN, Inc. This study will involve a survey questionnaires designed to evaluate an individual's self-determination and advance planning practices. As an individual who participates in services with either CACIL, Inc. & LIFE/RUN, Inc., your input would assist towards investigating potential benefits and area of growth for the field of rehabilitation as well as the services provided through either CACIL, Inc. & LIFE/RUN, Inc.

Where: CACIL, Inc. & LIFE/RUN, Inc. locations including sites in Lansing, Michigan and Lubbock, Texas.

When: September, 2012. Various dates – watch this location for specific dates!

Who: Participation is limited to ADULT program participants.

If you are interested in participating in this research activity, researchers will be visiting CACIL, Inc. & LIFE/RUN, Inc. service locations during the month of September, 2012. Watch this location for posting of exact dates!

Dave Schroeder ∞ Michigan State University

APPENDIX F:

LETTER OF INFORMED CONSENT

Table 18: Letter of Informed Consent

Self-Determination and End of Life Planning for Persons 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.

Consent to Participate

This research study is being conducted by researchers at Michigan State University as part of the Doctorate program in Rehabilitation Counseling and Education. The research study is entitled "Self-Determination and End of Life Planning for Persons with Disabilities".

The purpose of this study is to examine the relationship between self-determination, and end of life planning issues for persons with disabilities. Further study of the relationship between self-determination and end of life planning activities may yield information useful to organizations providing services in planning to improve outcomes for the individuals served. This study seeks information about two things: Self-determination and End of Life Planning Practices. Self-determination can best be described as a pattern of acting in one's best interest, according to their wishes, and for the purposes they desire. End of Life Planning looks long into the future and your involvement in activities to help you plan for future care decisions including medical care and funeral planning.

You are being asked to participate in this survey due to your relationship with a sponsor agency. Your participation in this survey will be greatly appreciated, however, it is completely voluntary. You must be at least 18 years of age and have no legally appointed guardian to participate. You may refuse to participate, refuse to answer certain questions, or stop participation at any time without penalty.

If you are willing to participate in this study, you will answer a brief demographic (descriptive) questionnaire that will take about 5 minutes to complete. You will then be asked to complete two study questionnaires that will take less than 10 minutes each. If at any time during participation you decide to stop, you may stop and not continue with no penalty.

Table 18 (cont'd)

Although you may not benefit directly from participating in this study, your assistance may contribute to greater understanding of the relationships involved, which may allow agencies to develop programs to improve the outcomes for the people they serve. There are no foreseeable risks associated with participation in this study. As consideration for your time, you will receive $5.00. If you agree to participate, please turn the page and begin the questionnaires. When you are finished, please teach off the front page and give the remainder to the person giving you this survey.

If you have any concerns or questions about this survey, including the survey outcomes, please contact:
Investigator: Dave Schroeder Telephone: 517.897.2736 or 806.416.2738 E-mail: schro111@msu.edu
Faculty Sponsor: John Kosciulek Telephone: 517.353.9443 E-mail: jkosciul@msu.edu
Written Correspondence: 455 Erickson Hall, East Lansing, MI 48824

APPENDIX G:

SCRIPTED DEFINITIONS

GUARDIAN:	A court appointed individual who makes decisions for you. No one is your guardian unless a judge has appointed them.
WILL:	A will is a document created by you (usually with a lawyer) to determine who gets your belongings when you die.
DURABLE POWER OF ATTORNEY FOR HEALTHCARE:	Sometimes called at DPOA, this person is appointed by YOU to make MEDICAL decisions if you are unable (You must be unable to communicate). This person has access to ALL of your medical records if ENACTED.
PRE-PLANNING:	Planning for something before you need it – an example would be to plan your funeral.
PERSON CENTERED PLANNING ACTIVITY:	A meeting, usually with you present, in which you discuss what you want in your life and how it can be arranged.
END OF LIFE CARE:	Arrangements for meeting your needs towards the end of your life if you are not able to meet these needs yourself.
FUNERAL PLANNING:	Planning, in advance, your desires for services (or none) that should occur after you die.
ATTORNEY:	An individual trained in law to assist you in writing your legal documents.
HEALTH CARE ADVOCATE:	Someone who knows your desires, values, and wishes and will assist you in getting your way.

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