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Quality of Life of People with Profound Developmental Disabilities Based Upon Residential Settings

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Walden University
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Abstract

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MS, Nova University, 1991

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

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Abstract

The level of support of people with severe to profound intellectual and developmental disabilities who resided in the community or in an institution as measured by the *Supports Intensity Scale® (SIS)* was assessed. There is much research literature on quality of life with people with varying mild to moderate levels of developmental and intellectual disabilities. A gap remained in the current literature regarding differences between the severe to profound levels of intellectual and developmental disability across residential settings. The purpose of this study was to assess the level of support of people with severe to profound levels of developmental disabilities who resided and received services either in an institution and those who receive services within the community. The theoretical foundation for this study was Maslow's theory of humanism along with the contemporary theory of quality of life. Using a quantitative research design, the SIS was administered to a convenience sample of 60 adults who receive supports while residing in the community and 60 adults who receive supports and reside in an institution in the southeast U.S. The data was analyzed using one-way analyses of variance (ANOVA) on the SIS subtest scores. Although the levels of support for the basic needs were not statistically different between the two residential settings, there was a significant difference in the need for medical and/or behavioral needs. The findings of this study promoted social change as these differences can be presented as part of the individualized needs assessment to prevent *Reinstitutionalization* of these stakeholders.

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Dedication

My dedication is three-fold. First, I dedicate this body of work to my family. In honor of my mother, Ms. Carol Molnar, and my Grandfather, Mr. Stephen Molnar, I thank you both for instilling in me a strong work ethic and empathy toward others. To my Great Uncles, Mr. Charles Kennedy and Mr. Lee Mosher, I thank you for always supporting me and encouraging me to laugh when life presents those opportunities for both humor and patience. Second, I dedicate this study to my extended family. Mr. Jason Plyler, Mr. Joshua Plyler, and Ms. Savannah Plyler—your love and support have enriched my life in so many ways. For that, I am truly thankful. Finally, I dedicate the outreach and applicability of my research to all stakeholders and their families. One special dedication I would like to extend is to my nephew, Mr. Quinton Shawn Plyler. It is with you in mind that I truly hope that my study makes a small yet helpful contribution in support of what levels of support are truly needed for people with special needs.

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This has been both a rewarding and arduous process. Along the way toward completion of my life-long goal, I have had the pleasure of meeting several stakeholders, and contributory professionals in this field. First, I would like to thank God for seeing me through to the end of this journey and pointing me toward my new one.

First, I would like to thank my Chairperson, Dr. Elizabeth Matthews, for her steadfast guidance and support. I also thank Dr. Jay Greiner for his expertise in reviewing and challenging my direction. I also would like to thank Dr. David Bauer who served as my initial Advisor in my Doctoral journey for his wisdom and guidance.

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Chapter 1: Introduction to the study

Introduction

In the psychological paradigm of humanism, the prevailing belief is that all human beings are in pursuit of satisfying healthy goals of life (Maslow, 1970). These goals of life can be hierarchical in nature. In theory, one is said to be satisfied with one's life as these goals or needs once presented are met. A person progresses through the hierarchy to achieve their fullest potential that Maslow (1970) referred to as *self-actualization* (p.279). Identification of impediments to self-actualization occurs when these needs go unmet. Maslow continued to hypothesize that a person will communicate these needs to others by appearing "sick and withered" (p. 279). Thus, it is believed that a sense of wellness or quality of life will be achieved once these identified needs are met.

Another way of operationally defining the pursuit of self-actualization is identifying and maintaining a level of satisfaction or quality with one's life. According to several prominent researchers on the topic, the concept of *quality of life* varies in its definition (Schalock et al, 2002). Within the scope of this research project, quality of life is defined as how satisfied one is with his or her current life situation. This concept appears frequently in the research literature with a variety of populations. Among the variety, these research groups of interest have included patients with dementia (Friedman & Brown, 2001) and children with chronic health conditions (Farmer, Clark, & Marien, 2003).

Background of the study

A third population, and the population of focus for this study, of which quality of life has been investigated is people with developmental disabilities. These disabilities include intellectual disabilities (often referred to as mental retardation), (Schalock, 2007) cerebral palsy, epilepsy, and autism.(Schalock, 2007). In pursuit of what Wolfensberger (1972) referred to as *normalization* (p. ii), a person with developmental disabilities can make functional choices that not only meet basic needs but also parallel the needs of society at large. According to Schalock et al (2007), the description of a person with a developmental disability is not stagnant but fluid. It is “no longer considered entirely an absolute, invariant trait of the person” (Schalock et al, p. 117). Among the traits that were listed as those that a person with an intellectual/developmental disability could possess include self-worth and subjective well-being (Maslow, 1970). These two concepts arguably may form the foundation for the pursuit of one’s quality of life.

One such basic need is the need for shelter. In Conroy's (1996) analysis of the small intermediate care facility for the mentally retarded (ICF/MR) or people with developmental disabilities as well as his review of the Hissom (a state institution in Oklahoma) closure (Conroy et al, 2003), he posed this question—“Is there a difference in the quality of life and supports provided in the institution versus community-based group homes*?”* (p. 264). Although several well-respected researchers have questioned Conroy’s research, this question triggered research into the area of quality of life as a rehabilitation and residential goal (Cooper & Picton, 2000; Cummins & Lau, 2003; Gilner & Sample, 1996; Holburn, 1992; Holburn et al, 2000; Janssen et al, 1999). That is, was a mere relocation from an institution to the community sufficient in enhancing a person's quality of life? There appears to be contrasting empirical evidence in the literature. Bird and Luiselli (2000), who found that there were deficits not met in the community plan, challenged the earlier hypothesis. Furthermore, Stancliffe and Keane (2000) stated that social satisfaction and loneliness were identified as barriers to a high quality of life for those people with developmental disabilities who reside in the community. Although additional research regarding the transition from an institution to the community was reported as favorable for people with mild to moderate levels of disabilities, it remained unclear in the literature as to how people with severe to profound levels of disabilities faired in the transition (Cooper & Picton, 2000; Cummins & Lau, 2003; Felce et al, 2000; Gutshall, 2005; Hardy & Gill, 2004; Lancioni et al, 2005; Mansell, 2006). According to Thompson et al. (2004), there have been five trends that have helped to shape the need for assessment of quality of life. The first trend asserts that "positive expectations for the life experiences of people with disabilities" have prompted the "need for practical tools to accurately identify individualized supports." (p.2). It can be argued that these positive expectations are those goals (to be happy, for example) that are set to meet the needs as identified through the implementation of such tools (i.e., the level of support that is needed to achieve the *goals t*hat address the needs). Herein lies the connection between the level of support and quality of life—the support is the "means" that each person uses to achieve the end or a quality life.

Statement of the problem.

A gap in the current literature exists with regard to the manner in which people with severe to profound developmental and intellectual disabilities measure their own quality of life. Is it possible to achieve personal outcomes within the framework of quality of life in an institution and/or in the community with the levels of support currently provided? The population of focus is growing in both prevalence and longevity. The subcategory of people with these levels of disabilities is approximately 11.5% of the total population of people with a disability (U. S. Census Bureau, 2002). This figure is an increase over the previous census in 1990 of 1%. The prevalence of people with severe to profound developmental disabilities is not only growing in number but also in age (U. S. Census Bureau, 2002). Approximately 12.6% of people in the 45 to 54 years-of-age category had a severe disability, and about 25.4% of people in the 65 to 69 years-of-age category had a severe disability. Due to the growing number of people living longer in the community with one or more developmental disabilities, one needs to plan a strategy for how to meet the ongoing needs of this population. One step in the planning process is to assess what each person finds important to oneself. That is, an analysis of quality of life is warranted due to the importance of the identification of needs (or levels of support) in planning and providing for this population.

Purpose of the Study

The purpose of this study is to assess the levels of support necessary to provide a quality life of people with severe to profound levels of developmental disabilities (including health and behavioral needs) who reside and receive services in an institution (i.e., Intermediate Care Facility for the Developmentally Disabled/ ICF/DD) and those who receive services within the community (under the Home and Community Based Medicaid Waiver program (HCBS)). The actual operational definition of developmental disability will be defined in a later section.

Research Questions and hypothesis

The research questions and hypotheses were derived from existing literature reviewed on quality of life, level of support, deinstitutionalization, and intellectual and developmental disability.

In sum, the primary research question and hypotheses are as follows:

Research Question 1: Is there a relationship between the residential setting (Institution or Community) and level of support/quality of life of people with severe to profound intellectual/developmental disabilities

Null Hypothesis 1: Level of support/quality of life is independent of residential setting given a consistent level of severity (severe to profound) of intellectual/developmental disability.

Alternative Hypothesis 1: Level of support/quality of life is not independent of residential setting given a consistent level of severity (severe to profound) of intellectual/developmental disability.

Theoretical Background

According to Abraham Maslow's theory of humanism (1970), the human being is goal-directed. That is, Maslow postulated that each person creates, reviews, and revises his or her own goals and motives (Maslow, 1970). This evolving process is not time-limited, nor is it bound by level of functioning or cognizance of environment. Maslow further suggested that the concept of normality is both “achievable and is available to each of us” (p. 279). Hierarchy of needs and self-actualization can be likened to the concept measured in this study, quality of life. Maslow's theory of human motivation is a series of presented needs that is incrementally achieved through a person's desire to satisfy each one. This process involves a person acting to reduce the needs through negative-feedback loops until self-actualization is apparent. The motive for reaching self-actualization intensifies as one expresses it--a positive-feedback loop completes the hierarchy. This implies that fulfillment does not feed back to diminish the activity of the system but rather to strengthen it. Maslow stated that the withered state of being ill persists until the apparent need or needs is/are met.

In Maslow’s work *Toward a Psychology of Being*, (1962), he describes a state of sickness that merely “disappears” when “deficiencies were eliminated.” (p. 19). That is, it might be stated that when the needs are met, the sickness is resolved. However, Maslow did not directly link intellectual and/or developmental disabilities to this deficiency definition. Kreuger, van Exel, and Nieboer (2008) cited the connection between Maslow’s need hierarchy and the

Social Production Function theory (p. 467). Maslow’s theory focuses upon physical needs while the Social Production theory focuses upon social needs. It added that differential quality to the status of having needs met rather than merely just applying an all-or-none condition. That is, the latter theory applied the *quality* to the status of *life*.

Researchers can say that quality of life may be an application or extension of Maslow's self-actualization process. Schalock, Gardner, & Bradley (2007) offer a definition of quality of life that has been widely researched and recently updated. The main premise of this definition has three principles; these include *conceptualization, measurement, and application*. The conceptualization principle of the definition states that quality of life is *multidimensional* that includes “positive values and life experiences; has the same concepts for all people; has both subjective and objective components; and is enhanced by self-determination, resources, purpose in life, and a sense of belonging” (p. 3).

According to Schalock, Gardner, & Bradley (2007), the conceptualization component provided the foundation of quality of life; it is the measurement principle offers a quantitative method of evaluation. This principle includes assessing the “degree to which people have life experiences that are valued” (p. 3). The process of measuring a person’s quality of life also takes into account the domains that are often contributory to a person’s life, the environmental contexts (including physical, social, and cultural), and both common and unique experiential occurrences (p. 3).

Finally, the application component to quality of life is a set of guidelines for not only the people with disabilities but also for all providers of services and families with children/adult children with disabilities. This component includes enhancing well-being across cultural contexts; forming the basis for interventions and supports; supporting evidence-based findings; and mandating its inclusion into all professional education and training protocols (Schalock, Gardner, & Bradley, 2007).

In sum, the theory behind the concept of striving for quality of life is indeed motivation and the meeting of needs. Maslow's humanistic paradigm embraced all human beings including those with diverse needs such as people with developmental disabilities. These needs have often been operationally defined within the social context of the time period. Examining the history through the application of this theory for this population lends support for social change.

Definition of terms

Autism is a disorder that can begin at birth or manifest within the first 2 1/2 years of life (National Institute of Neurological Disorders and Stroke, 2008). A person who has autism exhibits impairments in three areas--these are social interaction impairments (i.e., lack of eye contact, peer relations, and emotional reciprocity), communication impairments (i.e., lack of spoken expressive language to be replaced with repetitive speech as in echolalia), and stereotypic patterns of behaviors (i.e., finger flicking and body rocking) (National Institute of Neurological disorders and Stroke, 2008).

Cerebral Palsy is a group of chronic conditions that affect body movement and muscle coordination due to abnormalities in the brain. They may include ataxia (lack of muscle coordination), spasticity (involuntary and uncontrollable movements of the extremities) and/or extreme rigidity or flaccidity of the extremities (National Institute of Neurological Disorders and Stroke, 2008).

Community residential facilities include those settings in which the person served lives freely in an apartment or a home not directly licensed by an agency that serves people with developmental disabilities (APD, 2008).

Developmental disabilities include four primary disabilities. These include mental retardation/intellectual disability, cerebral palsy, autism, and epilepsy. Although cerebral palsy and epilepsy are physiological in orientation, data suggests that these two disabilities can occur concurrently with intellectual disability and autism (National Institute of Neurological Disorders & Strokes, 2008; Epilepsy Foundation, 2008).

Epilepsy is a condition of the brain that is manifested by seizures (brief, strong surges of electrical activity that can affect all or part of the brain) that occur more or less regularly throughout a person's lifetime (Epilepsy Foundation, 2008).

Institutional residential facilities include the following residential settings. These include Intermediate Care Facilities for people with Developmental Disabilities (ICF/DD), in-patient institutions, and psychiatric hospitals (ICF/DD, 1977).

Mental Retardation/Intellectual disabilities are defined as "substantial limitations in present functioning" (AAIDD, 2008). It is characterized by significantly sub-average intellectual functioning existing concurrently with related limitations in two or more of the following areas: communication, home living, community use, health and safety, leisure, self-care, social skills, self-direction, functional academics, and work. (AAIDD, 2008). The degrees of severity of mental retardation/intellectual disability that are highlighted in this study are those people who fall within the categories of *severe* indicative of intelligence quotients that fall between 20-35 and *profound* with intelligence quotients that fall below 20 points (American Psychiatric Association, 2000, p. 40).

Quality of life (QOL) is defined as how one's needs are met through the necessary levels of support. Within the scope of this study, quality of life will be assessed through objective and subjective means (i.e., levels of support ratings) (Schalock, Gardner, & Bradley, 2007, p. 3).

The *traditional Medicaid* service delivery system involves a person with developmental disabilities receiving mandated services through an institutional manner. As the person resides in an institution he or she receives continuous active treatment (training protocols in activities of daily living) with respect to addressing barriers to independent living (APD, 2008; ICF/DD, 1977).

The *Medicaid Home and Community Based Waiver program (HCBS)* provides those individuals and their families with access to services to meet all identified needs as specified in the person's individual support plan. The support plan along with an estimated cost plan for services is submitted to the district's developmental disabilities office for approval and allocation of the funding. Each service identified in the support plan is then offered to the person and his or her family through an interview process of local service providers. The person and his/her family then decide upon whom to hire to provide the services. The providers are independent and work as long as the person requires the service and retains their service (Department of Health & Human Services, 1989; Delmarva Foundation, 2001).

Assumptions and Limitations

This proposed study confined itself to interviewing people with severe to profound developmental and intellectual disabilities as defined by AAIDD (2008) (that is, those individuals who have an identified IQ that is between these two ranges (below 20-34) who reside in an institution (ICF/DD) and those who reside in the community. The study took place in various regions in Florida. The purposive sampling procedure decreased the generalizability of the findings. Limiting information gathered from residents also decreased the generalizability of the findings to occurrences in all states.

It is assumed that the intellectual and medical impairment degree was a fixed variable. Although some medical conditions such as chronic aspiration secondary to swallowing difficulties may have exacerbated and resolved during the research process, one continues to be predisposed for these conditions. The intellectual level at the time of the initial screening for eligibility is what dictated whether or not this participant was included in this study. How behavior functions in the environment may change due to contingency adduction (or “rapid learning”) (Cooper, Heron, & Heward, 2007, p. 622). It is also to be assumed that the participants in this study had an accompanying significant other (proxy) through which information was requested.

Some additional limitations that were possible within this study included that the participant may not have cooperated, engaged in maladaptive behaviors, or did not fully comprehend the interview process. There were steps listed in the eligibility criteria as well as in the exclusionary criteria that addressed these limitations (i.e., giving frequent breaks, excluding the participant should the maladaptive behavior continue after given one warning, and prompting the proxy-respondent to communicate the information is a manner that is typical for the participant). How each participant was treated by his or her own caretakers (i.e., differences in the two residential environments) was not a focus of this study but perhaps could be evaluated in a subsequent data analysis and review. The standardized method of administration of the single questionnaire implemented in this study minimized this potential variable.

Significance of the study

The purpose of this study was to determine the level of support for people with severe to profound developmental disabilities as they resided in institutions or the community at large. This study also compared the perceived quality of service delivery as these beneficiaries chose to shift systems from traditional Medicaid to the Medicaid Home and Community-based waiver program.

First, to address the reasons as to how this study will add to the scholarly research and literature in the field, one must be cognizant of the current challenges facing people with developmental disabilities. Wolfensberger (1972) promoted the concept of "normalization" which espoused the notion of equal opportunities for all people regardless of disability status. This idea rapidly caught on as a challenge for service providers as well the people for which the services were designed. Community-based living as an alternative to institutionalization seemed logical to some yet difficult to achieve by others. This transition occurred in other fields (i.e., depopulation of psychiatric institutions) with both positive and negative results. Measuring the quality of life provides an empirical measurement as to how one with developmental disabilities functions in life.

Second, the study aimed to improve the practice or service delivery system for people with developmental disabilities in that it will give rise to the actual necessary levels of support that might not have otherwise been recognized. Schalock, Gardner, and Bradley (2007) discussed how measuring the quality of life will add credibility to these actions promoted by policy makers and legislators. It also provided an outlet for those people with developmental disabilities needing, desiring, but not receiving true quality services under the Home and Community based Medicaid Waiver program. It also enabled service providers to utilize yet another tool in the process of planning true and achievable outcomes for those people served.

Finally, the study may improve policy as it can identify for policy makers whether they indeed made the prudent decision in depopulating people previously served in ICF/DD facilities while relocating these people into the community. Current policy favors shifting service delivery to the community in the face of less favorable empirical data. Schalock, Gardner, and Bradley (2007) discussed how the current movement is reminiscent of the depopulation of people with chronic mental illness which correlated with the increase of homelessness in several rural communities that experienced a closing of a psychiatric hospital. This study will strive to support those people with developmental disabilities who indeed live within a higher quality of life in the community rather than in the ICF/DD.

Summary

Quality of life as measured through the level of support is an integral component in evaluating how one appraises his or her life experiences, challenges, and needs. This concept has been applied to various populations including the one of focus for this study (Accordino et al, 2000; Baker et al, 2005; Bowman, 2001; Boyd et al, 2005; Crews & Campbell, 2004; Friedman & Brown, 2001). As the population of people with developmental disabilities increases by density and longevity, the social concern becomes one of inclusion in planning. This act of planning results from identifying needs and methods of meeting those needs.

The next chapter identifies current research in the areas of quality of life and developmental disabilities. The research review will be presented in a historical manner. That is, the field of improving the lives of those people with developmental disabilities has evolved over the past several decades. The dark beginnings that were so eloquently illustrated in works like *Christmas in Purgatory* (Taylor, 2006) prompted society to change several policies that have resulted in governing and auditing agencies like the Delmarva Foundation. It is through this historical journey that this writer has arrived at the testable conclusions discussed in chapter III. The actual interview and results will be detailed in chapter IV. Chapter V will offer the conclusions and suggestions for further research and policy changes.

Chapter 2: Literature Review

Introduction

This chapter includes a comprehensive review of the research literature on quality of life with people who have developmental disabilities, the historical perspective of treatment of that population that called for quality of life standards, and the quantitative methods used to measure and determine quality of life. The strategy used for gathering the literature included a computer-generated search of all of the published literature regarding the key terms of *quality of life, developmental disabilities,* and *residential locations*. Research data was obtained through searches on Medline, PsycInfo, Psych Abstracts, Sociological Abstracts, and Dissertation Abstracts. Research data was also obtained through the Florida State University and Indiana University library direct loan systems.

Historical review of institutionalization

Much has been documented in history regarding the inadequate and often deplorable treatment of people with developmental disabilities. The notion that institutions are not appropriate for most people with developmental disabilities dates back to the writings of Howe (1874) and Seguin (1846). Howe operated an institution that was called "Massachusetts Asylum for the Blind" (Trent, 1994, p. 13). The residents were referred to as "idiots" and "lunatics who were condemned to hopeless idiocy." (p.13). Seguin believed that there was hope, and that the "attributes of intelligence and will are dormant and underdeveloped." (as quoted in Trent, 1994, p. 17). This belief led to his method of educating the "feeble-minded" to exhibit functional skills. These functional skills included *self-dining, self-dressing, and hygiene*. All of these skills were once thought impossible to achieve were occurring frequently under Seguin's supervision. According to Trent (1994), Seguin was one of the first superintendents of state –run institutions. However, the conditions were less than favorable due to a lack of financial resources and available facilities. At present, these institutions have been mostly abandoned because the environments were similar to jail cells rather than homes. The work of several pioneering advocates such as Blatt and Kaplan (1966) exposed these conditions. The conditions were filthy, primitive, and overcrowded. The pictures displayed a hole in the floor to be used as a commode; six to seven children in separate cribs; and a bowl of food appeared more like "slop" (Blatt and Kaplan, 1966). These conditions lead to the public outcry for closure of the institutions such as Willowbrook (in New York) and Sunland (in *Florida*). The institutions that were once headed by educators interested in the promotion of skill development became warehouses for people with mental retardation and other developmental (and physical) disabilities headed by superintendents interested in fiscal responsibility. (Gutshall, 2005). Once these facilities began to feel the pressure of financial strain and lack of resources, closure became inevitable. But, then the issue at hand became what environment *is* suitable for people with intellectual deficits/developmental disabilities after closure of their current residences? What level of care or support is needed for these stakeholders? Is it possible to receive the necessary services like physical therapy, occupational therapy, and medical care outside of an institution? Recent literature still reflects the controversy over what Taylor (2006) refers to as the "continuum of care" (p. 15). Taylor's belief is that the traditional mode of service delivery is "antiquated," "sanctions infringement on basic human rights," (p. 20) and "directs attention to physical settings rather than to the services and supports for these people" (p. 21). It should also be noted that mortality rates are of great concern (Bird & Luiselli, 2000).

The De-institutionalization movement

According to Emerson (2000), there has been a significant increase in depopulating the larger state institutions. The pursuit of what Wolfensberger referred to as *normalization* began in the late 1960's (Wolfensberger, 1972). Though there appeared to be a brief historical moment when institutions were theoretically viewed as being the sole answer to the problem of developmental disabilities, the idea was quickly abandoned as both "unwise and impractical" and contributed to the overall attribution of devaluing people with developmental disabilities. (Nibert, 1995, p. 59). Community-based care loomed on the horizon due to the enlightenment of society at large. With the onset of the civil rights movement in the 1960s, community-based care was pushed into the forefront by President Kennedy. In 1961, President Kennedy appointed a panel on mental retardation that included representatives from both the professional community and the consumer advocate population. The professional representatives were from the National Institute on Mental Health (NIMH) as well as the American Association on Mental Deficiency. A parent-advocate, Ms. Elizabeth Boggs, was selected from a local ARC (Association for Retarded Citizens) as a member. (Gutshall, 2005; Trent, 1994). The goal of this panel was to shift the focus away from the state-run superintendent frame of thinking to the actual consumer and professional model of thought. This shift in focus paved the way for active treatment and behavior modification procedures. Active treatment is the process through which a person is trained to perform those daily and essential tasks. These include tooth brushing, toileting, and self-dressing. (ICF/DD, 1997). Behavior modification is implemented in order to reduce maladaptive behaviors while teaching methods to replace those targeted behaviors with adaptive or healthy behaviors. (Cooper, Heron, and Heward, 2007).

The Intermediate Care Facility for the Developmentally Disabled

The Intermediate Care Facility for the Mentally Retarded/Developmentally Disabled (ICF/MR or ICF/DD) was created with the inception and promulgation of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P. L. 88-164). Although the federal funding program provided over $67 million dollars for the development of these smaller facilities in the community, there appeared to be a bigger cost. The community services system was overwhelmed with medical model legislation and regulations (Guttshall, 2005). That is, the medical model was recreated in smaller community-based settings.

The Reintegration Movement

Because the demand for services increased, there needed to be a set of criteria established for serving those with more significant needs in one or more areas. This need gave rise to the concepts of *continuum of care* and *least restrictive environments (LRE)* (Guttshall, 2005; Taylor, 2001, 1988). Although the medical model was still prevalent in regulating the facilities, the least restrictive environment policy intended to provide the consumers with needed interventions while safeguarding his/her human and civil rights. Taylor (2001) rates the residential continuum beginning with public institutions viewed as most restrictive to independent living viewed as least restrictive (Taylor, 2001, p. 17). The most restrictive facilities are also defined as being the least integrated, the least normalized, but the most intensive in service provision (Taylor, 2001). Although the intent was to preserve human rights, Taylor postulates four major flaws in the least restrictive/continuum of care concept. First, he stated that “any health-related, education, or habilitative service that can theoretically be provided in a segregated setting can be provided in an integrated setting” (Taylor, 2001, p. 19). Although replication of an institution out in the community is not recommended, he did believe that most services are available and portable. Second, he affirmed that “the least restrictive environment continuum does restrict rights but to varying extents (p.20).” Each person with varying levels of disability has corresponding varying needs. The least restrictive environment concept does restrict rights. For example, a person with a developmental disability may have direct access to a doctor in the institution on a 24-hour basis. When that person relocates into the community, the search for a physician willing to treat this person may be difficult. It is challenging primarily because of the disproportionate balance between supply (the access to health care providers who accept Medicaid) and demand (the growing number of Medicaid recipients). According to the Florida Attorney General’s report on Medicaid Fraud (1996), Florida has 1.6 million Medicaid recipients which claim approximately $6.7 billion dollars in health care services each year (McCollum, 1996). At present, this figure is significantly lower than as predicted by medical experts such as Seals (2006). In his review of the Florida Medicaid bill, he predicts that Medicaid recipients will “consume about 58 percent of Florida’s total budget by 2015” (Seals, 2006, p. 2). Both authors offered a rather gloomy picture of what is to come for Florida’s citizens with disabilities who rely on Medicaid for service provision.

Third, living in an institution is different from living in the community. Cummins and Lau (2003) also affirm that people with developmental disabilities are not fully integrated merely by geographical location. They state that this mere physical integration falls short for people with developmental disabilities (Cummins and Lau, 2003). Both sources agree that exposure occurs more frequently than actual integration. Finally, Taylor believed that the focus should not be on the actual physical setting but rather the necessary services and supports. This echoes the statement made in the previous point in that integration and exposure should be mutually exclusive and not thought as synonymous. *Reintegration* includes exposure and support for integration into the community. However, there exists a difference in this process between people with and without disabilities (Taylor, 2001, p.22).

When a person relocates, there is a period of adjustment with respect to a new home, a new job, and new social group. When a person with complex physical and developmental disabilities desires to relocate, the challenges for adjustment increases. Moving back into the community (after placement at an institution has ended) is what Cummins and Lau (2003) refer to as “reintegration” (p. 147). One need that one must also include for successful reintegration is a transition plan that includes follow-up services for health and well-being as well as maintenance of care (Dagnan, Trout, Jones, and McEvoy, 1996; Emerson, 2004; Kim, Larson, & Lakin, 2001; Mansell, 2006; O’Brien, Thesing, Tuck, & Capie, 2001; Ouellette-Kuntz, 2005; Young, 2006;). Dagnan et al. (1996) investigated how a group of people with developmental disabilities and "challenging" behaviors relocated from a hospital ward to a small community unit. The results were indicative of a need for close supervision and monitoring on the part of the professionals so as to ensure that appropriate health and psychiatric care were "offered and used" by the consumer (Dagnan et al., 1996). These results were supported by subsequent research conducted by Ouellette-Kuntz (2005) who affirmed that there were several factors that contributed to better health conditions in the community rather than in an institution. The factors that were highly prevalent in the institution more so than in the community included life expectancy and morbidity issues, more sedentary lifestyles, obesity, poor dental care, and poor prophylactic care such as immunizations, annual gynecological exams, and other screenings (Ouellette-Kuntz, 2005. p. 116). A study conducted by O’Brien et al. (2001) focused on the perceptions of change of those residents with developmental disabilities between life in an institution and life out in the community. The major finding was that all of the informants regarded the relocation as a “positive” change (O’Brien et al, 2001). This “positive life changing event” finding was also supported by research conducted by Young (2006). Mansell (2006) stated in his research that there needed to be more support for those people with severe to profound developmental disabilities. “Hands-on” active support and frequent opportunities for choice were two “pivotal” issues that contributed to residential success. (Mansell, 2006, p. 70). According to Felce and Perry (1995) and Felce (2006), both articles supported a plausible explanation for a function of maladaptive behaviors. A person (with or without a disability) strives to achieve what is preferred in life. This act of pursuit may be to fulfill what is referred to as “life conditions, subjective well-being, personal values and aspirations, and personal satisfaction” (Felce & Perry, 1995, p. 127). The journey may be different not “aberrant” (Felce, 2006). That is, these behaviors that deviate from what society deems as appropriate might indeed be functional for those people with varying degrees of disability. Several studies have supported the belief that this deviation is what has lead to multiple placement failures in the community (Baker & Blancher, 2002; Becker-Cottrill et al, 2003; Cooper & Picton, 2000; Cummins & Lau, 2003; Felce et al., 2000; Fujiura, 2006; Janssen et al., 1999; Kim et al., 2001; Kravetz et al., 2002; Mansell, 2006; Mazzelli et al., 2000; O’Brien et al., 2001; Parish & Lutwick, 2005).

At the core of the debate on the appropriateness of institutions is the contrast to life inside of an institution with what is perceived as "normal" on the outside of it. It appeared that this beginning step toward the community was better than the institution; however some situations remained disturbingly similar. The types of facilities traditionally recognized as "public residential facilities (PRFs)" or "intermediate care facilities (ICFs)" (Scheerenberger, 1981, p. 5) were the initial residences created to meet the need of inclusion. However, when one resident was surveyed to obtain her satisfaction level with this placement, she stated the following:

> Living here includes such conditions as schedules of daily living set by an interdisciplinary team-not me, the food delivered of varying texture has no taste at all and my living conditions resemble a jail

rather than someone's house. (Client, personal communication, May 1, 2009).

Also included in this service delivery system was a high cost for the services provided. Conroy (1996) graphically illustrates the growing costs for intermediate care facilities allocated by the federal government from 1982-1996. The figures range from approximately 3.8 billion dollars in 1982 to 9.7 billion dollars in 1993 (Conroy, 1996). In Florida, the rate has increased over time. During the 2005-06 fiscal years, the state of Florida’s allocated amount for a total of 2,068 licensed (ICF/DD) beds was 136 million dollars (APD, 2008).

With poor living conditions at an apparent exorbitant rate (the rate for the year 2000 was 19.5 billion dollars nationally for both HCBS waiver and ICF/DD services), some observers within the developmental disabilities arena began to suggest a need for a new way of thinking about services and supports for people with developmental disabilities (Smith, Prouty, & Lakin, 2001, p. 490). This "new way of thinking" gave way to the movement known as "community integration or Community Residential Facilities (CRFs)." (Conroy, 1996, p. 15). In contrast to public residential facilities which were viewed as idyllic settings for care and habilitation, community residential facilities or "apartments" intended to deliver what the PRFs failed to create--a "home-like environment." (Stumpf, 1990, p. 7).

The Home and Community-based Medicaid Waiver program (HCBS)

The Home and Community-based Medicaid Waiver program (HCBS) was a program that was initiated under Section 1915 (c) of the federal Social Security Act of

1981 (APD, n.d.; P.L. 97-35, Section 2176-the Social Security Act, Section 1915 (c)-Home and Community Based Services). This program provides people with developmental disabilities the necessary services in home or in a community-based office. That is, the person can "waive" their right to access an institution while receiving the typical institutional services at home. There are a number of different services such as physical therapy, behavior analysis, and respite care. In theory, a person would relocate out of an institution and back home *with* the services required.

This program was arriving at the same time with two other pieces of landmark litigation. The Americans with Disabilities Act (ADA) was promulgated in 1990. It served as the foundation upon which advances in integrated lifestyles for people with disabilities were etched (P.L. 101-336). The second legal contribution to the plight of integration came in June, 1999. The Supreme Court rejected the state of Georgia's appeal to enforce institutionalization of people with disabilities in the case *Olmstead v. L. C. and E. W.* (1999). This case was spearheaded by two women with mental disabilities who desired to live in a non-restrictive environment while receiving the necessary care. Much has been expounded upon to include varying categories of disabilities—including people with developmental disabilities (Gutshall, 2005). Although the majority of the literature revealed successful outcomes in community integration and inclusion for people with mild to moderate levels of developmental disabilities, Jordan (2004) postulated in her dissertation that there still existed a void in the literature for inclusion for people with severe to profound levels of developmental disabilities. This need was also asserted by Persinger (2000) in her earlier dissertation as well. The difference in focus between these two studies is the level of support needed for success.

There needed to be a method through which the quality of service delivery could be ascertained. This data needed to be collected as it had in the past in order to determine how satisfied the consumers were with the services delivered. Thus, the systematic assessment of quality of life was applied to this setting.

Quality of life Assessment

The term *quality of life* can be operationally defined as how satisfied one is with his or her life (Schalock & Verdugo, 2002) and through what levels of support are necessary (Thompson et al, 2004). One of the most frequently cited authors in the field of quality of life and outcome measurement with people who have developmental disabilities is Robert Schalock. (Schalock et al, 2008). Schalock and Verdugo (2002) published a meta-analysis on quality of life entitled *Handbook on quality of life for human service practitioners*. In this analysis, Schalock and Verdugo have broken down quality of life into several pertinent components. This work was then expanded upon in the subsequent publication by Schalock, Gardner, and Bradley (2007). First, the authors stated that quality of life is conceptually *multi-dimensional* in that it encompasses a number of different concepts that are indicative of *positive values and life experiences* (Schalock, Gardner, & Bradley, 2007). Second, these indicators (or *outcomes* as referred to in more recent literature) are shared among *all* people—not merely those with developmental or intellectual disabilities. Third, the assessments of quality of life for people have both *subjective* and *objective components* (Schalock, Gardner, & Bradley, 2007). Finally, quality of life is improved through acts that can be labeled as acts of *self-determination. accessing resources, finding a purpose in life, and a sense of belonging* (Schalock, Gardner, & Bradley, 2007). In order for one to fully appreciate the current benchmark from which much of the quality of life work is launched, a historical review of the evolution of the quality of life is necessary at this time.

According to Schalock, Gardner, and Bradley (2007), quality of life references date as far back to the days of Plato and Aristotle's quest for well-being. However, the authors are quick to highlight the work that has been conducted primarily over the past three decades. The body of literature not only seems to parallel the paradigm shifts in legislation and regulation of services for people with developmental/intellectual disabilities, but many articles also reinforce the continuing evolution of service delivery and outcome measurement.

Quality of Life Assessment with People with Developmental Disabilities

According to Brown (1989), quality of life is a construct that is indicative of a *discrepancy between achieved and unmet needs and desires* (Brown, 1989). Although the initial focus of his research appeared to be negative, Brown offered an initial glimpse into a different manner in which to view people with developmental/intellectual disabilities. He postulated that the 'disabled are people first*"* meaning that service professionals should refrain from categorizing for treatment simplicity and focus on the individual person. Brown also advocated that disabilities are not diseases but rather "processes that can be controlled environmentally*" (*Brown, 1989,

p. 557). This optimistic view was also echoed by Crocker (1990) in his editorial regarding meeting the medical needs of persons with mental retardation living in the community. Schalock, Gardner, and Bradley (2007) asserted four main explanations for the acceptance of the quality of life movement at this time. First, the movement embraced the notion that people with developmental/intellectual disabilities can be empowered, included in the community, and viewed as equal. *Self-determination* makes this happen (Schalock, Gardner, & Bradley, 2007, p. 4). Second, the demeaning jargon or labels such as *retarded* can be replaced with goal-directed language as *normalization, deinstitutionalization, and mainstreaming.* Third, the zeitgeist of the time was the focus on quality in every aspect of customer service. This also applied to how service providers worked with people with developmental/intellectual disabilities to achieve these quality outcomes (Council on Quality and Leadership, 2005). Finally, the clients/customers/stakeholders/service recipients would now come to expect and demand significant changes in how their services were provided and improve or enhance his or her lifestyle (Schalock, Gardner, & Bradley, 2007; Schalock, 2004; Schalock & Verdugo, 2002; Schalock, 1996; Schalock, 1990; Brown, 1989).

After the promulgation of several key pieces of legislation including the Americans with Disabilities Act of 1990, the continuation of the Individuals with Disabilities Education Act of 1991 (IDEA), and the Rehabilitation Act Amendments of 1992, people with intellectual/developmental disabilities were thrust upon the community at large with the realization that they too could join in the pursuit of happiness (Americans with Disabilities Act, 1990; Individuals with Disabilities Act, 1990;

Rehabilitation Act, 1992; 1973). However, it was not enough to simply offer choices but to also assess the value of these choices for each person.

According to Heal and Sigelman (1996, p. 91), "the understanding of quality of life vary considerably." Measures can be objective or subjective. Objective methods involve the analysis of the circumstances of people's lives (i.e., income level, housing, patterns of behavior, etc.) while subjective methods focus on "attitudinal phenomena” (Heal & Sigelman, 1996, p.91). In 1993, the Council on Quality and Leadership (formerly known as the Accreditation Council on Services for People with Disabilities) published a guideline of principles that would be known as “outcome measures” (Council on Quality and Leadership, 1993, p.11). Although the original set of outcomes included thirty, the list was revised in 2005. The list was revised and now contains twenty-one actual measures. These measures are listed in Table 1 (see Table 1). These outcomes not only are measured by objective means (for example, one can count how many friends the person has in order to measure outcome “People have friends.”) but also by subjective means (for example, outcome - “People are satisfied with services” is subjective, that is it is personal to that individual) (Council on Quality and Leadership, 2005).

Table 1

Outcome Measures for People

People are connected to natural support networks
People have intimate relationships
People are safe
People have the best possible health

People exercise rights
People are treated fairly
People are free from abuse and neglect
People experience continuity and security
People decide when to share personal information
People choose where and with whom they live
People choose where they work
People use their environments
People live in integrated environments
People interact with other members of the community
People perform different social roles
People choose services
People choose personal goals
People realize personal goals
People participate in the life of the community
People have friends
People are respected

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To effectively plan for the outcomes listed in Table 1 to be present, one must complete a survey of the person's current landscape. This survey is conducted through various assessment strategies. There have been several researchers in the field of quality of life who have contributed to this growing body of tools (Brown, Schalock, & Brown, 2009; Cummins, 2004; Schalock & Verdugo, 2002; Verdugo, Schalock, Keith, & Stancliffe, 2005). These researchers have created and implemented assessment tools that primarily focused upon gathering objective information about people with intellectual and developmental disabilities. Schalock, Gardner, and Bradley (2007) postulate a paradoxical six-point mental model of how the field of quality of life assessment has evolved. They state that each point exists as a *duality* (Schalock, Gardner, and Bradley, 2007). The first model is *Reductionism versus Systems Theory*. The focus is a shift from examination of each isolated part to the connection among each part. The second model is *Mechanistic versus Organic Theory* whose focus is a shift from rules and regulations to decentralization/person-centered theory. The third model is *Analysis versus Synthesis Theory* which highlights the shift from an examination of small components to the combination and evaluation of all components. The fourth model is *Planned versus Self-Organizing Emergent System* which postulates a shift from an emphasis on data analysis and predictions to a system of networking. The fifth model is *Thinking versus Doing Theory*. This theory challenges traditional patterns of thought and shifts the focus to the application of the theory. Finally, the sixth model is *Tacit versus Explicit Knowledge*. This marks the shift from "soft" information which is defined as "values acquired over the years" to a focus of shared and easily-transferred data. (Schalock et al, 2007, pp. 154-155). This multi-step model summarizes how the researchers have shifted their focus to three emerging influences. (Schalock, Gardner, & Bradley, 2007). These three concepts include "social capital, community life context, and managing for personal outcomes." (p. 158).

According to Schalock, Gardner, and Bradley (2007), "social capital" not only refers to the connections among individuals but also stresses "reciprocity" among stakeholders/consumers and actual hands-on application of scientific theories. The notion of "reciprocity" embraces the cooperative effort that often is seen anecdotally between parents of children/adults with intellectual/developmental disabilities. Each parent communicates how effective one treatment or often one therapist may have been helpful (or not in some cases) with their son/daughter's clinical issues. It also may widen the gap between those traditional professionals who hold steadfast to antiquated views of intervention and those professionals who choose to venture off to more non-traditional methods of treatment. Research into social capital is growing. Several authors including Bates and Davis (2004) and McClimens and Gordon (2010) assert that social capital is dependent upon the presence of reciprocity and social inclusion.

Moving into the context of "community life" has also evolved. There has been an exhaustive history of the de-institutionalization movement and community inclusion movement previously in this chapter. In addition, a recent Harris poll (2000) found that "64% of people with more severe disabilities are particularly likely to feel that community organizations have not encouraged or invited them." (National Organization on Disability & Harris Interactive, Inc. [NOD/Harris], 2000). One program in particular that emphasizes the need for people with intellectual and developmental disabilities to participate in their communities is the program entitled "The Community Life LENS." (Council on Quality and Leadership, 2008). "LENS" blends the concepts of learning, exploring and experiencing, networking, and strategizing and sharing. These concepts together with social relationships between people with and without disabilities have been intended to demonstrate an enhancement of quality of life. (Council on Quality and Leadership, 2008). However, there is no published outcome research on the LENS program.

Managing for personal outcomes is the third component to Schalock, Gardner, and Bradley's concept of social capital and inclusion. The early instruments that were administered to assess for quality of life included the "Quality of Life Questionnaire," (Schalock & Keith, 1993); the "Ask me!" project (Bonham, Basehart, &

Marchand, 2000); and the "Personal Life Quality Protocol (PLQ)" (Conroy, 2000). The domains that were the focus in all three of these instruments included overall satisfaction, integration, independence, productivity, and dignity (Guttshall, 2005). Expanding upon the need for outcome measurement created the tool known as the *Supports Intensity Scale* (Thompson et al, 2004). In order to understand the void that this tool provides, it is important to also recognize how it differs from previous outcome and quality of life assessment tools.

The *Quality of Life Questionnaire* was created Schalock and Keith (1993). It contains 40 questions that can be directly answered by the consumer or by a proxy using a 3 or 5-point Likert scale. The test items contain questions that are both subjective and objective indicators of the following domains: Satisfaction, Work, Independence, and Integration (Schalock et al, 1994, p. 63). The scores are summed and the outcome is an Index measure of Quality of Life. Although there have been several studies that have evaluated the statistical reliability, validity, and factor structure of the questionnaire (Schalock et al., 1994; Kober & Eggleton, 2002; Schalock et al., 2007), the main criticism of this instrument is that the scores that measure satisfaction were less reliable (Gutshall, 2005).

The *Ask Me* project was initiated in Maryland (Bonham, Basehart, & Marchand, 2000). It differs from the previous assessment tool in that it is administered by people with intellectual and developmental disabilities. Also, the actual questions can be operationally simplified by coding facial expressions as responses. The domains of focus included Satisfaction, Work, Independence, Integration, and Dignity. The main contribution of this questionnaire is the provision of the mindset that any person with any level of disability can and should answer questions regarding what one considers important and necessary in one’s own life.

The *Personal Life Quality Protocol* (Conroy, 2000) was created out of outcome measures that were used to assess the effects of deinstitutionalization. It is similar in administration to the two aforementioned instruments as the questions can be presented and answered by both the consumer and the proxy. One glowing difference is that it requires specialized training to administer and to score the test. It also adds several focus domains to the growing body of interest in quality of life. These include the previously mentioned independence, integration, productivity, and satisfaction while adding choice-making, individual planning, relationships, adaptive/challenging behavior, and overall quality of life (Conroy, 2000). The main criticism of this assessment tool is that it has lacked extensive reliability studies. Gutshall (2005) attempted to conduct a reliability study as part of her dissertation study; however she shifted her focus to content validity studies and advised that reliability studies should be *interpreted cautiously*. (Gutshall, 2005, p. 172).

The *Supports Intensity Scale (SIS)* (Thompson et al, 2004) evolved from a 5-year evaluation of the changes in society’s perception of people with disabilities (p. 1). The *SIS* is comprised of three sections—the Supports Needs Scale, the Protection and Advocacy Activities supplemental section, and the Exceptional Medical and Behavioral Support Needs supplemental subsection. Although the details of this particular instrument will be presented in chapter 3, it is necessary to highlight the strengths of this tool at this point. First, the SIS embraces all of the positive contributory factors that the previously-detailed tools offer. As in all three of the assessment tools, it includes sections for consumer and proxy responses. It also surveys a wide variety of elements that contribute to a person's overall measure of quality of life. Second, it provides a shift that is consistent with the most current models of thought that embrace the theories of systems, organic, synthesis, self-organization, doing, and explicit knowledge. That is, it measures outcomes and not policy. Third, it offers a new world vision for assessing the person *in context.* It focuses on the functional ability and level of support that is necessary to help that person achieve success. Finally, it captures the social capital and community-at large concepts by providing an opportunity for networking (Bates & Davis, 2004; Thompson et al, 2004).   An in-depth analysis of the *Supports Intensity Scale* will be presented in Chapter 3.

Quality of Life Assessment issues

Factors affecting responses in survey research while examining the quality of life question include task variables, (DeMaio, 1984), interview variables, (Sudman & Bradburn, 1974), respondent variables, (Schuman & Converse, 1971), and inter-rater reliability between informants and factual records (Sigelman et al., 1983). DeMaio (1984) and Rugg (1941) suggest that responses can be systematically biased by question wording and question format or structure. Comparisons of closed-ended and open-ended questions revealed similar response effects associated with question format. An interview variable known as *acquiescence* (Cronbach, 1942, p. 413), or the *tendency to answer a question affirmatively regardless of content*, was examined by Matikka and

Vesala (1997, p. 75). They suggested that this might occur when the interviewer is perceived by the participant as desiring a positive response. Acquiescence also appears to be a respondent variable as well as an interview variable. Inter-rater reliability factors arise when two or more interviewers' attention is drawn to different variables within an interview. This reliability may also be called into question when verbal reports do not appear to match documented factual reports.

According to Schalock, Gardner, and Bradley (2007), *quality services should begin with the person*. This process known as *individualization* (p. 1) is a key consideration in assessing the quality of life with people with developmental disabilities. Recent literature has focused upon the relationship between individual traits, especially those that are psychologically related, and community adjustment (or quality of life in the community) as a *little understood phenomenon rather than as a predictor* (Levine, 1985, p. 30). According to Kernan et al (1978, p. 56), *beliefs based in fear about people with developmental disabilities spurred individual-focused research*. Some of these beliefs include a *high prevalence of personality disorders*, (Hutt & Gibby, 1965, p. 45); concomitant *personality disorders such as anxiety*, (Hirsch, 1959, p. 642); and *predicative personality traits in success and post-institutional failure* (Windle, 1962, p. 201). A shift in focus occurred in the research on quality of life from "person" to "environment" due to the recurring failures of placement. Holburn (1992) reviewed nine published studies comparing ICF/DD programs to non-ICF/DD programs. He found that only three dealt with comparisons within community programs; the other six involved comparisons within institutions or institution-community comparisons. (p. 140). Of the three studies, all three studies yielded findings that validated the notion of a higher quality of life in community living arrangements in ten (10) out of thirty-five (35) indicators. (Lutfiyya et al., 1987, p. 134; Schalock, Keith, Hoffman, & Karan, 1989, p.30; O'Neill et al., 1990, p. 187).

In examining quality of life assessment with people with intellectual and/or developmental disabilities, the focus of the most recent literature is based upon evaluation of outcomes rather than process (Schalock et al, 2007). Self-report data collection has been referred to as the *fundamental form of participation* (Stancliffe, 2000, p. 89). Another method of assisting in data collection is through use of proxies. A proxy is defined as a person, typically a family member or caregiver, who knows the consumer well and is asked to provide reliable and accurate information (Stancliffe, 2000; Perry & Felce, 2002; Gutshall, 2005). These studies support the use of proxies in quality of life research by demonstrating moderate agreement between self-report and proxy reports on observable indicators rather than subjective ones. Fisher et al (2009) continues to support the use of proxies in healthcare decision-making circumstances, however they caution that the single data-set of information from the proxy respondent should be taken into consideration in cooperation with what is in the best interest of the person as well as the medical input from appropriate personnel (Fisher et al, 2009, p. 409).

Other research into the quality of life question that supports the need for gathering corroborating information was conducted by the Washington State Department of Social and Health Services (DSHS) (Lucenko et al, 2010). In this study, the information that was also included as part of the outcome research was not only the *Supports Intensity*

Scale scores but also a coded system of information based upon a qualitative review of the records. Such information severe maladaptive behaviors that might not have otherwise been captured as part of the standardized tool (i.e., “self-harm,” “feeling/bolting,” and “requires 1+:1 staffing or single-household”) (Lucenko et al, 2010, p. 13). The study supports replication in another state to provide supportive research toward the use of the *Supports Intensity Scale* (Thompson et al., 2004) as well as a preliminary step toward a future level-of-care predictive model. This would be helpful in planning for discharge from the institutions and/or relocation from one place in the community to another. The focus of this study is to provide this support. There will be more detail as to the process in chapter 3.

Summary

In summarizing the literature highlighted in this chapter, the focus of this study is to contribute to the ground-breaking work in the field of quality of life with people with Intellectual/Developmental Disabilities. Historically, the focus appeared to be primarily on custodial care behind closed doors away from the general public view. Once litigation was brought to light regarding human rights violations by several states, the paradigm shifted. Assumptions once held regarding a lack of involvement in the planning of a person’s care changed to upholding the importance and essential presence of that person in one’s planning. Clearly, there was a need for such institutional placements for those people requiring intensive supports. However, the actual placement environment has changed as a result of the changing contexts (Butinx & Schalock, 2010). According to Butinx and Schalock (2010), the conceptual framework for human functioning is dependent upon the provision of the necessary level of supports in the areas of intellectual abilities, adaptive behavior, health, participation (in community), and (environmental or social) context. Although there have been difficulties in assessing this population, the overall synthesis of all acquired information on the consumer is the goal. This synthesis or outcome measurement summary will be viewed in context of the person. This study will add to the process of bridging the gap between service and support delivery and one’s achievement of optimal human functioning.

Chapter 3: Research Method

Introduction

The two previous chapters have presented the foundation upon which this study is predicated. First, it is imperative for the reader to understand the history of the treatment of this population as well as the research challenges they present. Second, the literature review supports the continuing search for the necessary level of supports to achieve optimal human functioning or quality of life. This chapter will outline the plan to include the purpose, the research design, the setting and sample, the instrumentation, the data collection procedure, the data analysis process, and any ethical considerations.

Purpose of the study

This study employed a quantitative approach using a one-way analysis of variance (ANOVA) design to assess for the differences in the means of the scaled scores. It was followed by a one-way analysis of variance (ANOVA) with pairwise comparisons (t-tests) if the means were found to be statistically significant. The dependent variable was the level of support as measured on each scale within the *Supports Intensity Scale* (Thompson et al., 2004) *and* the Support Needs Index standard score between the two groups. The independent variable was the current residential status of each participant (institution or community). It was assumed that all participants will be assessed only once, and that each participant's residential status was continuously in place for a minimum of 1 calendar year from the date of the assessment. The level of severity of disability was also a consistent variable. This was consistent in the assessment process.

The research design addressed the problem statement in that it quantified the statistical significance of variance between the two participant groups.

Setting & Sample

The target population in this study was people with severe to profound intellectual and/or developmental disabilities. The operational definition of participants will meet the following criteria as defined by Schalock and colleagues at the American Association for Intellectual and Developmental Disabilities (AAIDD) (2007). Intellectual disability is characterized by “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.” (Schalock et al, 2007, p. 118).

These disabilities may include autism, cerebral palsy, and epilepsy. However, the clinical eligibility indicator is the Intellectual Quotient (IQ) score that falls within the range of severe to profound Intellectual Disability/Mental Retardation (ranging from an IQ score of 34 or below). The target population might have also had existing co-morbid medical conditions such as gastrostomy tubes, and aspiration precautions. The people targeted for this survey were limited to adults (ranging in age 18 years and above). The participants included not only the person living with a disability but also his or her legal guardian who participated on a voluntary basis solicited from the target population within the state of Florida. The legal guardian had the choice to elect to appoint an alternate caretaker to respond to the questions and serve as a participant. The alternate caretaker must have known the person with the disability for at least one calendar year. The legal guardians of those potential participants who resided within an institution (ICF/DD) were given an announcement on the study within their facility. The legal guardians of individuals who resided within the community were given an announcement on the study through their Support Coordinators. Each site had a research liaison appointed to perform six tasks. These tasks included identification of potential eligible participants (per agency), provision of the contact information, compilation of the direct mail/email notifications, distribution of the notifications, and provision of the eligibility inclusion data. Liaison training by the researcher was conducted in order to ensure proper dissemination of information regarding the study. The legal guardians of people with Intellectual/Developmental Disabilities from at least two regions of Florida received these announcements and chose whether or not to participate. The legal guardians of the person of interest then contacted the researcher in order to determine eligibility. Appointments were made, and the primary researcher travelled to the participant's location. The participants were confirmed for selection once the eligibility criteria for the study had been reviewed and approved.

Research Design

The legal guardians of the individual consumers who voluntarily accepted participation in this study were from one of two residential environments. First, the consumer participant either resided in an Intermediate Care Facility for people with Developmental Disabilities (ICF/DD) or a community-based apartment or dwelling that does not house more than 5 individuals with Intellectual and/or Developmental Disabilities. A single-family home is an acceptable residential environment so long as the participant resided with his or her own family. Second, the consumer met the defined criteria of Developmental and/or Intellectual Disability (severe to profound range of Intellectual Disability as measured by an IQ of 34 or below) as stated in a previous section. This information was verified during the interview process (by obtaining written documentation of habilitation plan, support plan, and/or psychological evaluation report with the IQ clearly noted). Third, the participant's residential status was verified so that he or she must have resided in the current environment continuously for a minimum of one calendar year from the date of assessment. The intake notes reflected if there was a prior history of institutionalization and/or community placement. This information was gathered and the results were significant for a post hoc analysis evaluating previous placements' level of support service provision. Fourth, the participant was an adult (18 years of age or older). Finally, the participant was one part of the interview team. The team included at least the legal guardian as the primary respondent who provided the intake information and assessment interview responses. If the legal guardian opted out of the direct participation, the team included the alternate caretaker who was named by the legal guardian. The caretaker had at least one calendar year of experience with the participant in order to provide sound responses to the assessment process. Therefore, the response team included the consumer, the legal guardian or an alternative caretaker designed by the legal guardian as appropriate to participate in the interview. Exclusion from the study was determined if any of the above criteria are not met at the time of assessment.

An a priori power analysis revealed that for a two-tailed test at $p< 0.5$, to detect a medium effect size of .40 with a power of at least .80, the study requires a sample of at least 52 participants regarding the possible relationship between level of support and residential status. Therefore, a minimum sample size of 60 participants was necessary to account for possible attrition and/or unforeseen exclusion. This was met in that 60 participants from each sample group were included in this study. No treatment was implemented during the course of the assessment process.

Instrumentation & Materials

There was one formal instrument utilized during this study. The *Supports Intensity Scale* (Thompson et al, 2004) was administered to assess the current level of support. This form was used on all of the targeted participants. The use of collaborative data through a record review (i.e., central file to verify IQ scores, primary diagnoses) and significant others (proxy respondent) was also be necessary and included as part of the process. This tool has been statistically reviewed for all types of validity and reliability. This tool has also been subjected to norming procedures for the target population.

The *Supports Intensity Scale* (*SIS*) (Thompson et al, 2004) is a standardized interview instrument that was designed to measure the "pattern and intensity of supports an adult with ID/DD needs to be successful*"* (AAIDD, 2008, p.5; see Appendix I). According to the authors, the *SIS* is a tool that addresses three consistent areas of debate in the assessment of quality of life with people with ID/DD. First, the focus of the tool is upon what support one needs to be successful rather than the level of deficit. Second, the tool itself is comprehensive in that it not only addresses all of the major life domains common to all people but also specific domains that are vital in the pursuit of optimal human functioning for people with ID/DD. Finally, the focus of importance has shifted from team consensus to the person's viewpoint (AAIDD, 2008, p. 8). The *SIS* includes three major sections. First, the "Supports Needs Scale" includes six domains that are measured by forty-nine items in the areas of home living, community living, lifelong learning activities, employment activities, and health and safety activities. The items in each domain require a rating that is three-fold. First, the "Frequency" rating is prompted by asking the person how frequently would the person need the support doing (the task highlighted in the item) if they were going to be doing this activity over the next several months? (AAIDD, 2008, p. 8). The frequency scale ranges from a "*0=none or less than monthly* to *4=hourly or more frequently*." Next, the "Type" of support rating is prompted by asking what help does the person need to complete (task highlighted in item) on your own or by yourself? (p. 9). The scale ranges from a *"*0=none or no support to 4=full physical support*."* Third, the "Daily Support Time" rating is prompted by asking how much total time would be needed to provide this support in a typical 24-hour day (p.9). The scale ranges from a "0=none to a 4=4 hours or more*"* (p. 10).

> Examples of the tasks in each part include "Home Living-using the toilet, preparing food, dressing, and bathing; Community Living- shopping, interacting with friends and family, and using public services in the community; Lifelong Learning Activities-using technology for learning and learning self-management skills; Employment Activities-Accessing and receiving job/task accommodations and completing work assignments; Health & Safety Activities-Taking medications, learning how to access emergency services, and maintaining physical and emotional well-being; and Social Activities-Socializing both in and

outside of the household and making and keeping friends" (Thompson et al, 2008).

The scores are expressed as raw scores and totaled. The total scores are then converted to standard scores and percentile ranks which are then connected to an overall SIS Support Needs Index (Thompson et al, 2004).

The second section of the *SIS* is entitled "Supplemental Protection and Advocacy Scale*"* (Thompson et al, 2004). Eight items including "advocating for self and obtaining legal services*"* are also posed, and the participant responds to the same three rating scales as in the Supports Needs Scale. The raw scores are tabulated and ranked from highest to lowest (Thompson et al, 2004).

The final section is entitled "Exceptional Medical and Behavioral Support Needs*"*(Thompson et al., 2004). The rating scale for each of the 29 items ranges from *0=no support needed to 2= extensive support needed* (Thompson et al, 2004). The raw scores are totaled and compared to the acceptable baseline score of 5. If the total is larger than five, then the question is asked whether or not there is a similar total for the other subscale in this section. For example, if a participant scores a nine on the *Behavioral Support Needs* section, a comparison question is answered with regard to that score of more than five being present in the *Medical* section as well. This study will produce a mean score for both of these sections for future comparison and analysis in Chapter 4.

The SIS data collection process

Once a participant had been identified and deemed eligible for the study, the primary investigator provided an overview of the assessment tool with both members of the team, the consumer, and the legal guardian/alternate caretaker. Completion of the necessary informed consent forms and the confidentiality forms were the first tasks completed prior to beginning the interview (see Appendices A & B). The setting in which the interview had taken place was a private setting in the participant's home or facility. The residential status was also coded as part of the intake interview. The interview took place in a quiet area free from distractions. The primary investigator recorded all of the responses to the questions with the questionnaire and pencil. Some pilot participants had stated that some consumers may regard the presence of a laptop or other technological data collection device as distracting (Thompson et al, 2004, p. 3). However, it was permissible and recommended that the participant utilize whatever mode of communication that is preferred. That is, a participant may need an interpreter (the proxy) or a voice output device to assist with the interview. Thompson and his colleagues (2005) created a set of guidelines for interviewing people with disabilities. They include key points such as using *person-first* language, speaking clearly and slowly to allow for processing time, and talking directly to the person being interviewed (Thompson et al, 2004, p. 3). The interview process was administered according to the *SIS* standardized instructions for administration. The interviews took approximately 1.5 to 2 hours in length. Questions were asked and answered back and forth as the process includes dialogue. There were prompted questions that were posed by the interviewer to ensure the participants comprehension of the material. The participant was told that he/she may be excused at any time if they state that they need a break. If the break appeared to be permanent, the completed portion will be scored but recorded as *incomplete*. If a target participant exhibited any of his or her targeted maladaptive behaviors, they will be given one break to return to calm. If the maladaptive behavior continued, the completed portion will be scored by recorded as incomplete. The primary investigator informed the liaison of any potential issues that arose during or immediately after the interview that required support services. This only took place at the request and the discretion of the participants. The participant was not deceived in any way. Upon the completion of the interview process, the target participant was given a small nominal token of appreciation (i.e., $10 gift card). This token was communicated in the preferred manner of communication of target participant. This token was given to the participants even if all of the interview questions had not been completed. Furthermore, the alternate caretaker also received the token gift card as well for his/her voluntary participation and assistance. Written informed consent was obtained from the legal guardian prior to the all of assessments. No information was shared with any involved party without this consent. All federal and state laws and regulations were followed with regard to the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and the protection of confidential consumer information.

Additional safeguards were put in place that ensured that this vulnerable population was not subjected to any unnecessary risks or discomforts as part of the assessment process. As discussed in Dalton & McVilly (2004), rigorous ethical safeguards are essential to create and monitor adherence to when researching within the Intellectual and Developmental Disability community. In addition to obtaining the necessary approvals for research from the academic institution, this researcher solicited additional approval from both the state-wide Advocacy Committee and pertinent established internal committees that regulated and monitored the ethical standards governing services for people with ID/DD in the state of Florida. The participant received a full debriefing which included an explanation of how their responses were coded and inputted into a system in which their individual identities were protected. The information gathered was maintained within a lock box during transportation and in a locked cabinet for storage. Furthermore, the participants were also informed that they were free to abstain from participation without any fear of retribution or recourse for doing so. No information shared during the assessment process was in violation of the *Zero Tolerance* (for Abuse, Neglect, and/or Exploitation) policy in the state of Florida. Therefore, no participants' confidentiality was breached even though he/she was informed that a breach of confidentiality would occur to further safeguard the consumer's rights. The benefits from participation were explained so that the participants will be adding information to the growing body of literature to enhance service delivery to people with ID/DD in the state of Florida.

Reliability & Validity

There have been many research articles that support both the reliability and validity of the *SIS* (Claes et al, 2009; Clay-Adkins, 2004; Wehmeyer et al, 2009; Kuppens et al., 2010; Thompson et al, 2008). In the original study that was outlined in the *SIS* manual, both areas of reliability and validity were statistically significant (Thompson et al, 2004, pp.112). In addition, a recent doctoral dissertation study conducted by Clay-Adkins (2004) seemed to support the significant findings in both areas of reliability and validity. A brief review of each concept is necessary.

Reliability can be defined as the consistency of scores over time (Thompson et al, 2004). In the *SIS*, there were two primary forms of reliability- test-retest and inter-rater reliability. Test-retest reliability is accomplished when the same test is re-administered after a brief period of time. Inter-rater reliability is accomplished when two or more researchers achieve consensus on the answers to the questions posed as part of the investigation. All reviewed published literature specific to the *SIS* supports the test-retest and inter-rater reliability scores as *excellent* (Thompson et al, 2004; Clay-Adkins, 2004) with correlation scores equaling r= 0.81 (test-retest) and r=0.54 (inter-rater). Both of these scores met the criteria for fair clinical significance (Clay-Adkins, 2004). It appears that inter-rater reliability is increased when the administrator of the tool has been trained prior to its implementation (Kuppens et al, 2010, p. 328).

Validity is defined as the presence of results that measure the underlying construct that they intend to measure (Thompson et al, 2004, p. 104). The four main types of validity include content, criterion-related, construct, and factor analysis (Clay-Adkins, 2004; Thompson et al, 2004; Kuppens et al, 2010). Content validity is achieved when the test in question accurately assesses for the target behaviors in question (Thompson et al., 2004, p. 105). This was substantiated through literature reviews, Q-sort technology, and field tests in the development of the test (p. 106). Criterion-related validity is achieved when the participant’s score correlates with a criterion measure (that is, an IQ score of 105 correlates with normal intelligence) (Thompson et al, 2004, p. 107).

The initial coefficient correlation scores were significant in that they exceeded 0.35 (the minimum figure). The subsequent test conducted by Clay-Adkins (2004) also supported this figure (p. 118). Construct validity refers to test scores that measure a characteristic or theoretical concept (Thompson et al, 2004, p. 109). The correlations in both validity tests support that the *SIS* with moderate to strong total scores (Clay-Adkins, 2004, p. 123). Factor validity was also assessed in a recent study by Kuppens and colleagues (2010) to be found statistically significant. Furthermore, they did verify that the *SIS* possesses adequate six-factor structure analyses across the levels of severity of disability (Kuppens et al, 2010, p. 336). It appears that the *SIS* meets or exceeds the statistical criteria established in order to be implemented as an assessment tool.

Plan of Analysis

Data analysis progressed to address each of the research questions as listed below.

The research questions and hypotheses were derived from existing literature reviewed on quality of life, level of support, deinstitutionalization, and intellectual and developmental disability.

In sum, the primary research question and hypotheses are as follows:

Research Question 1: Is there a relationship between the residential setting (Institution or Community) and level of support/quality of life of people with severe to profound intellectual/developmental disabilities

Null Hypothesis 1: Level of support/quality of life is independent of residential setting given a consistent level of severity (severe to profound) of intellectual/developmental disability.

Alternative Hypothesis 1: Level of support/quality of life is not independent of residential setting given a consistent level of severity (severe to profound) of intellectual/developmental disability.

The results from the *SIS* were entered into *SPSS 21.0.* Mean scores were determined on each of the sub-tests in the *SIS*. Once the tool had been scored as per the scoring guidelines, the one way ANOVA was conducted to assess for differences in means on each of the SIS scale scores and the Support Needs Index standard score among the two groups (institution and community) with pair-wise comparisons (t-tests) conducted to assess for differences between pairs of groups (i.e., medical and behavioral) when the overall ANOVA is statistically significant. The results were tabulated and presented in chapter 4.

Ethical considerations

Although much has been researched within the quality of life arena, there existed several ethical challenges with research in the field of Intellectual and Developmental Disabilities. The most prevalent concerns include the use of proxy respondents, obtaining legal expressed and informed consent, reducing acquiescence and nay-saying, and assessing the investigator's experience with the sample population.

The use of a *proxy* defined as *lay-people, community representatives, and those in position to serve as advocates for the interests of people with Intellectual disabilities in their care* (Lai et al, 2006, p. 116). Several researches support the use of proxy respondents in studies such as quality of life (Brown et al., 2009; Carnaby, 2007; Holburn et al., 2007; Lai et al, 2006; Lyden, 2006; Perkins, 2007). However, there are a number of recommendations that are strongly suggested by these authors. First, it is imperative that the process include the acquisition of corroborating information to support the findings (Carnaby, 2007). This was confirmed by Brown et al. (2009) in that both objective and subjective ratings are necessary and important to the overall research project. In addition, Lyden (2006) not only calls into question the capacity of the participant to consent but also the legal capacity of the proxy to consent as well. Finally, a baseline amount of time for the proxy to have known the participant is also suggested by Perkins (2007)—however, the author does not suggest a specific quantity of time. In this study, it is mandatory that the proxy have at least one calendar's knowledge of the participant.

The process of obtaining legal expressed and informed consent is paramount prior to any research project. Although there are legal guidelines upon which this consent is based (see Appendix for consent form), one study in particular (Lai et al., 2006) offered a four-part screening process. The authors believe that once these four conditions are met, a person is able to legally consent to research. The participant must possess *the ability to retain and comprehend information related to consent* (Lai et al, 2006, p. 115). It is important that the information was presented to the person is a way that they understand it. For example, a Braille consent form should be presented to a person with a visual impairment while a Spanish translator must present the information in such a way that the person who communicates only in Spanish can comprehend. Second, the person must have *the ability to appreciate that the information is of personal relevance* (p. 115). This was measured by the target participant acknowledging the change as a result of the issue being discussed. For example, a target participant's scheduled community outings to bowling would be curtailed once the participant informed the caretakers of his or her overall dissatisfaction with bowling. Third, the person must have *the ability to weigh the information to make a decision* (p. 115). Answers to the questions would be evidence and acquiescence and/or nay-saying would be addressed. Finally, the target participant had the *ability to communicate the decision* (p. 115). Communication may take place in many forms. The process of communication specific to each target participant was acknowledged and respected. In addition, Lei et al. (2006) asserts

> That those who are not competent should not be automatically excluded from research which is potentially beneficial to them as individuals or to the group they represent. (p. 115).

The presence of *acquiescence* (repeated yes) and *nay-saying* (repeated no) have been addressed in the literature. Although there was a discussion of these concepts earlier in this study, Finlay and Lyons (2002) have offered several suggestions in order to reduce the presence of these two confounding variables. First, a researcher can judge what type of answers the participant may give by offering the participant a *nonsense* question (to which the answer would be a certain no) and assess the response. Second, pairing questions that are opposite in meaning to prompt different responses is another technique. Third, presenting the same question in a different format later in the questioning process may also provide insight into how a participant might answer. This point is also often used in standardized tests as a means of checking for internal validity

(Finlay & Lyons, 2002, pp. 15-16). Finally, the investigator has the obligation to continuously monitor the participant's involvement in the assessment process. Performing these checks will inform the investigator as to how involved the participant has remained in the interview process. (Finlay & Lyons, 2002, pp. 15-16). These points have been taken into consideration and were incorporated into this investigator's study.

The final ethical challenge is ensuring that the researcher has prior expertise in the area of assessment with people with severe to profound intellectual and developmental disabilities. Carnaby (2007) asserts that good practice should always be the ultimate goal in clinical assessment. This includes providing a minimum training requirement that is met by the investigator. Although Carnaby (2007) does not specify, the authors of the *SIS* strongly suggest that the administrator of the tool possess at least one year experience in the field and a college degree (Thompson et al, 2004). In addition, the primary researcher in this study has participated in the administrator training of the tool. It should also be noted that the primary researcher possesses another suggested skill by Carnaby (2007) and Whitaker (2008) in that corroborative intake information will also be gathered to support the findings of the *SIS.*

Discussion

The previous three chapters have outlined and provided the support for this study. It is the hope of the primary investigator that this study supports the research hypothesis as outlined in this chapter. Identifying the differences in the level of support for each sample will assist in future service delivery. This is monumentally critical in the present as Federal and State governments dictate how funds are to be spent after a proposed 2.5% cut in Medicaid dollars. One obstacle in pursuing research into this population is the question of capacity of people with severe to profound ID/DD. Also, the use of proxy-respondents is not without criticism, however it does provide one avenue from which to obtain information into this population. Another major obstacle in conducting research is low participation. Although the primary researcher was limited as to the number of participants, the generalization of findings were analyzed and discussed in Chapters 4 and 5.

Chapter 4: Results

Introduction

This study assessed the levels of support needed to provide level of support/quality of life for people with severe to profound Intellectual Disabilities in two selected residential categories—Institutional and Community-based. In addition, exceptional medical and exceptional behavioral factors were analyzed to determine what if any statistical associations exist among the means. This chapter includes four sections: an overview of data collection process, data analysis and statistical results, main findings, and conclusions.

Overview of the Data Collection Process

As outlined in Chapter 3, the data collection process began after the Institutional Review Board (IRB) reviewed and approved the steps. The time frame for the data collection was September, 2013 through January, 2015. Each of the approved facility sites deputized a research liaison. This research liaison was trained by the primary researcher on the necessary tasks including identification of potential participants, communication of the relevant information including potential eligibility, and the contact information of the legal guardian for each participant. The liaison provided the primary researcher a mailing list of potential participants. Flyer invitations were mailed out to the potential participants. From the initial recruitment round, there were a total of 120 participants who were deemed eligible for participation and inclusion. The participant not only included the target participant (i.e,. the stakeholder or service recipient) but also the legal representative (i.e, legal guardian) and/or an alternative caretaker (with legal guardian's consent). Out of the total of 120 participants who were eligible and in agreement to participate, a total of 117 participants responded and were included. These included 58 participants who resided in the Community-based support system and 59 participants who resided in the Institutional support system. Three participant's data sets were excluded based upon the exclusion criteria set forth in Chapter 3. There were no adverse events that required further reporting to any agency or IRB during the research study. The results were summarized and are highlighted in Appendix.

In sum, the primary research question and hypotheses are as follows:

Research Question 1: Is there a relationship between the residential setting (Institution or Community) and level of support/quality of life of people with severe to profound intellectual/developmental disabilities

Null Hypothesis 1: Level of support/quality of life is independent of residential setting given a consistent level of severity (severe to profound) of intellectual/developmental disability.

Alternative Hypothesis 1: Level of support/quality of life is not independent of residential setting given a consistent level of severity (severe to profound) of intellectual/developmental disability.

Completed Data Analysis

The independent variables included specific demographic data. These discrete variables were as follows: gender, chronological age, ethnicity, level of Intellectual Disability, residential status, proxy respondent (legal guardian or alternative caretaker), Medical needs, Behavioral needs (challenges), alternative placement history, and supported employment services. Binary coding was completed on the discrete variables. After coding, the Statistical Package for the Social Sciences (SPSS) Version 21 was used to analyze the data.

Descriptive Statistics of Identified Discrete Variables

In the final data analysis of these variables, the majority of the participants with ID/DD were more male (N=66) than female (N=51). Therefore, 56% of the study population was males while 44% were females. The mean chronological age of the participants (which must have met and/or exceeded 18 years for inclusion in this study) was 43 years. This included a mean chronological age for Institution of 45.0 years with a standard deviation of 12.91 and the mean for Community 42.0 years with a standard deviation of 14.25. The youngest resident in the Institutional participant group was 18 and the oldest resident was 75. The youngest resident in the Community participant group was 18 and the oldest was 69. In analyzing ethnicity (race), there were 64 Caucasian participants (54.7%), 50 African-American participants (42.7%), and 3 “other/decline to answer” (2%). The most prominent level of Intellectual Disability was profound (70%); the severe level was at 30%. Residential status was statistically equally represented with Institution slightly higher (N=59) than Community-based (N=58). All of the subjects’ legal representatives (guardians) provided expressed and informed consent (N=117) 100%. Out of the respondents during the data collection process, the legal representatives (guardians) were the most represented (N=83) 71% with alternative caretakers (N=34) at 29%. Of the 117 participants, 51 (44%) had medical needs that scored a “5 or above” on the Exceptional Medical Supports index while 45 (38%) had behavioral needs that scored a “5 or above” on the Exceptional Behavioral Supports index. Of the 58 Community subjects, 50% (N=29) had Institutional residential placement in his or her history. This is slightly higher than the 59 Institutional subjects who had Community placement in his or her history at 41% (N=24). There were no subjects who received Supported Employment services at the time of this data collection for either residential placement subject group (N=0). These variables were configured and are summarized in Table 2.

Table 2

Frequency Table of Discrete Variables

Demographic Variables	Frequency (n=117)	Percent
Gender		
Male = 0	66	56
Female=1	51	44
Ethnicity		
Caucasian=0	64	54.7
African-American=1	50	42.7
Other/declined=2	3	2
Level of Intellectual Disability		
Severe = 0	35	30
Profound = 1	82	70
Residential status		
Institution=0	59	50.4
Community=1	58	49.5
Primary respondent		

Legal guardian = 0	83	71
Alternative caretaker = 1	34	29
Medical needs (>5)		
Yes = 0	51	44.0
No = 1	66	56
Behavioral needs (>5)		
Yes = 0	45	38.0
No = 1	72	62
History of alternative placement		
Institution = 0	24	41.0
Community = 1	29	50.0
Supported Employment services		
Yes = 0	0	0
No = 1	117	100

Descriptive Statistical Analyses

In evaluating the research question with subsequent hypotheses, descriptive statistical analysis was completed. These include identifying the means and standard deviations of each of the *Supports Intensity Scale*® subtests. These include the Supports Needs Index, Exceptional Medical Supports Index, and Exceptional Behavioral Supports Index. These analyses are tabulated and presented in Table 3.

Research Question 1: Is there a relationship between the residential setting (Institution or Community) and level of support/quality of life of people with severe to profound intellectual/developmental disabilities

From the analysis of the data, there was a hypothesized relationship between the level of severity of disability as measured by an ***increased*** level of support. Previous studies (as part of the statistical and standardization protocol) that were conducted as part of the initial statistical analyses of the *Supports Intensity Scale* included published analyses that would indicate an overall lower mean raw score and subsequent overall lower Supports Needs Index for people with Mild to Moderate Intellectual/Developmental Disabilities (X= 249.8 raw score; X=95 Supports Needs Index) than in comparison to the mean raw and overall Supports Needs Index for people with Severe to Profound Intellectual/Developmental Disabilities (X=428.7, X=109 Supports Needs Index). (Schalock, Thompson, & Tasse, 2008). This relationship is supported by the analyses conducted in this study. One-way analyses of variance were used to test for differences in means among the groups. In addition, pairwise comparisons (t-tests) were also conducted when the ANOVA was statistically significant. Further analysis with ANOVA with a significance at $p<0.05$ conducted for both Institutional and Community residential groups yielded a statistically significant difference in means between the Supports Needs Index (Standard Scores) (Comm X=102.87; Inst X=101.28). In evaluating the subscales, Home Living Activities (X=11.27 (Institution) X=10.58 (Community)), Lifelong Learning Activities (X=9.62 (Institution) X=9.87 (Community), and Employment Activities (X=8.72 (Institution) X=10.01 (Community) were statistically significant. The previous data seems to suggest that there is a higher level of support needed to provide employment training and opportunities for residents of an Institution as compared to those stakeholders residing in the community. Lifelong Learning Activities seem to be similar, however the sample from the Community appeared to have a higher level of support needed. This analysis is summarized in Tables 3 and 4.

The ANOVA analyses conducted between the means of “Exceptional Medical” and “Exceptional Behavioral” subgroups are more dramatic between the two residential samples. Using a $p<0.95$ for the ANOVA with the “Medical” group, there was a difference with the “Institution” subgroup marking a higher mean (X=7.8) in comparison to the “Community” subgroup (X=4.4). This finding suggests that the participants who reside in an Institution appear to require a higher level of support to meet their medical needs than those who currently reside in Community-based settings. These findings are summarized in Table 3 and Table 5.

The ANOVA analyses conducted between the means of “Exceptional Behavioral” across residential settings are also statistically significant. Using a $p<0.701$, there was a difference in means with the “Institution” subgroup again charting a larger average (X=5.38) in comparison to the Community mean (X=3.08). This data demonstrates that the participants who reside in an Institution appear to require a higher level of support to meet each stakeholder’s behavioral needs than the needs of those consumers who currently reside in Community-based settings.

These findings are summarized in Tables 3 and 6.

Null Hypothesis 1: Level of support/quality of life is independent of residential setting within the population of stakeholders living with severe to profound intellectual/developmental disability.

This null hypothesis can be rejected due to the differences analyzed via the ANOVA analyses.

Alternative Hypothesis 1: Level of support/quality of life is not independent of residential setting within the population of stakeholders living with severe to profound intellectual/developmental disability. The alternative hypothesis is also rejected because there are additional identifiable needs for levels of support in a person's medical and/or behavioral needs.

Table 3

Summary of Supports Intensity Scale® Subtest Variables

	Mean (n = 117)	Std Deviation (n = 117)
Supports Needs Index		
Community	102.87	2.334
Institution	101.28	2.40
Exceptional Medical		
Community	4.4	3.64
Institution	7.8	6.00
Exceptional Behavioral		
Community	3.08	4.03
Institution	5.38	5.10

Table 4

Summary of Supports Intensity Scale® - Mean SIS Standard Scale Scores by Residential Samples

	Institution		Community	
	N=59		N=58	
SIS Scale Scores	Mean	SD	Mean	SD
Home Living Activities	11.27	1.90	10.58	1.44
Community Living Activities	10.10	1.18	10.77	0.49
Lifelong Learning Activities	9.63	1.01	9.88	1.19
Employment Activities	8.72	0.96	10.01	0.13
Health and Safety Activities	10.87	0.54	10.57	0.62
Social Activities	10.59	0.72	10.76	0.75
Supports Needs Index	101.28	2.40	102.87	2.33

Table 5

Summary of Supports Intensity Scale® ANOVA and –t-test Analysis of Supports Needs Index

One-Sample Statistics

	N	Mean	Std. Deviation	Std. Error Mean
Institution Supports Need Index	59	101.2881	2.42864	.31618
Community Supports Need Index	58	102.8793	2.35512	.30924

One-Sample Test

	Test Value = 0					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
Insti-Supports Need Index	320.347	58	.000	101.28814	100.6552	101.9210
Comm-Supports Need Index	332.682	57	.000	102.87931	102.2601	103.4986

Table 6

Summary of Supports Intensity Scale® ANOVA and –t-test Analysis of Exceptional Medical Means

One-Sample Statistics

	N	Mean	Std. Deviation	Std. Error Mean
Insti-Exceptional Medical	60	7.8000	6.13078	.79148
Comm-Exceptional Medical	60	4.4000	3.70616	.47846

One-Sample Test

	Test Value = 0					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
Institution-Exceptional Medical	9.855	59	.000	7.80000	6.2163	9.3837
Community-Exceptional Medical	9.196	59	.000	4.40000	3.4426	5.3574

Table 7

Summary of Supports Intensity Scale® ANOVA and –t-test Analysis of Exceptional Behavioral Means

One-Sample Statistics

	N	Mean	Std. Deviation	Std. Error Mean
Institution-Exceptional Behavioral	60	5.3833	5.14894	.66473
Community-Exceptional Behavioral	60	3.0833	4.06845	.52523

One-Sample Test

	Test Value = 0					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence In the Difference	
					Lower	
Institution-Exceptional Behavioral	8.099	59	.000	5.38333	4.0532	
Community-Exceptional Behavior	5.870	59	.000	3.08333	2.0323	

In evaluating the research question and null hypotheses, the statistical analyses show a minimal significance of difference in the Supports Needs Index across the two main participant groups (Institution and Community). However, there does appear to be a greater significance of difference between the means of Exceptional Medical (F=0.517 R2= 0.901) and Exceptional Behavioral (F=0.734 R2= 0.701). The higher means of the Institution sample population would suggest that there is a difference (that is more support is needed) in providing supports for Exceptional Medical and Exceptional Behavioral needs (see Table 3).

Statistical Findings

Based upon the statistical analyses, there appears to be sufficient support for the hypothesis suggesting that there is a relationship between level of support and residential settings within the population of people with severe to profound Intellectual/Developmental Disabilities. Upon completion of the data analysis, it appears that the two main needs that influence the differences of levels of support appeared to be medical and behavioral needs. We can reject the null hypothesis that there exists no difference between these two samples (Institution and Community). However, these two domains of Exceptional Medical and Exceptional Behavioral may be statistically significant in the actual differences between the two residential groups. This appears to suggest that a person with a diagnosis of Severe to Profound Intellectual/Developmental Disability may receive the needed levels of support across both residential settings, however the difference in his/her medical and/or behavioral needs is paramount. That is, there may be a higher level of need of support for Medical and/or Behavioral needs in the Institution residential setting then in the Community setting.

Data Conclusions

In this study, the results of the Mean Analyses of Variances (ANOVA) revealed a difference in level of support between the two different residential groups (Institution/Community) within severe/profound Intellectual Disability. Although the level of support across residential settings did not differ significantly for all domains, there was a significant difference in level of supports with Medical and Behavioral domains. In sum, the participants who reside in an Institutional Setting require a higher level of support due to the Exceptional Medical and/or Exceptional Behavioral needs. In Chapter 5, the interpretations of the findings, limitations of this study, and recommendations for future research and implications for social changes will be discussed.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Although there is much research on quality of life and levels of support with people with mild to moderate Intellectual and Developmental Disabilities, there is a gap in the research measuring these constructs with people with severe to profound Intellectual and Developmental Disabilities. The purpose of this study was to address this gap by assessing the level of support of people living with severe to profound levels of Intellectual/Developmental disabilities (as defined as having a diagnosis of a tested IQ below 34) across residential settings. The expectation of the analyses was that there would be a more profound difference between the two residential groups' level of support in all areas—not just medical and/or behavioral needs. That is, the expectation for a higher level support needed in the Community was thought to be a possible outcome. This analysis is important because anecdotally there are stakeholders who have "failed" in the community due to the lack of adequate service provision of his/her medical and/or behavioral needs. However, there were no published accounts to substantiate the previous assertion. The inception of this study was ignited by this researcher's personal and professional observations over the past 30 years of service to stakeholders and families. Anecdotal data, albeit somewhat passionate, was insufficient to support the tested research question and subsequent hypotheses within this study. However, the findings support what anecdotal accounts had questioned. In addition, policy makers are in need of the accurate data upon which to base resource allocation (i.e., to what residential setting should budget allocations be attributed).

Interpretations of the Study

The current study postulated this main research question with subsequent null and alternative hypothesis testing.

Research Question 1: Is there a relationship between the level of support and residential setting within the level of severity of severe to profound Intellectual/Developmental Disability?

Null Hypothesis 1: Level of support is independent across residential settings.

Alternative Hypothesis 1: Level of support/quality of life is not independent across differing residential settings.

Although the level of support for basic needs including Lifelong Learning, Home Living, and Community Living was similar across both residential settings keeping all descriptive variables constant, the level of support was statistically different with factors including Medical and Behavioral needs. These measures were assessed at the $p<.05$ significance level and the variance in mean were calculated. Although the level of severity of *disability* might not be a factor, the level of severity of *Medical and/or Behavioral needs* was indeed a factor that accounted for a difference in the level of support. It also was apparent that there were differences between the two residential groups. This finding appeared to support previous studies (Schalock, Thompson, and Tasse, 2008) as well as the movement for social change within the state of Florida service delivery system. In 2010, the state of Washington reviewed the results of the SIS for approximately 1500 of its stakeholders (Lucenko, He, and Mancuso, 2010). One of the key findings of their research was “DD clients served in institutions have more severe behavioral support needs compared to individuals receiving other community-based services.” (Lucenko et al, 2010). This finding is supported within the scope of this study in that the level of support that is required to provide necessary services to sustain people with medical and behavioral needs is higher in an institution than in community. This has continued to be at issue within the state of Florida in the challenge of deinstitutionalization while ensuring that each stakeholder’s service plan is all-inclusive and “met” by his/her service providers.

Limitations of the Study

This study did confine itself to interviewing people with severe to profound developmental and intellectual disabilities and his/her proxy as defined by AAIDD (2008) (that are those individuals who have an identified IQ that is between these two ranges (below 20-34) who reside in an institution (ICF/DD) and those who reside in the community. The study occurred in various regions in Florida. The purposive sampling procedure decreased the generalization of the findings. Limiting information gathered from residents might have also decreased the generalization of the findings to occurrences in all states. It should also be noted that the duration of the data collection was longer than anticipated due to administrative changes in two of the three research sites.

It was assumed that the intellectual and medical impairment degree was a fixed variable. Although some medical conditions such as chronic aspiration secondary to swallowing difficulties may exacerbate and resolve during the research process, a person with these disabilities continue to be predisposed for these conditions. The intellectual level at the time of the initial screening for eligibility is what dictated whether or not this participant is included in this study. How one's behavior functions in the environment may change due to contingency adduction (or “rapid learning”) (Cooper, Heron, & Heward, 2007, p. 622). It was also ensured that the participants in this study will have an accompanying significant other (proxy) through which information is requested. One factor that was not expected but counter to what previous accounts as outlined by Blatt & Kaplan (1966) revealed was how many of the stakeholders’ families were both eager and compliant in their permission and participation in this study. Perhaps future research in evaluating family/proxy respondent participation particularly with people with a diagnosis of severe to profound Intellectual/Developmental Disabilities is warranted to refute such beliefs of abandonmnent.

Some additional limitations of this study were that the potential for noncooperation given that participant might not have cooperated, engaged in maladaptive behaviors, or did not fully comprehend the interview process. There were a total of three subjects (one subject from the Institutional group and two from the Community group) who were excluded based upon one or more the above-listed factors. The steps listed in the eligibility criteria as well as in the exclusionary criteria to address these limitations were consistently followed (i.e., giving frequent breaks, excluding the participant should the maladaptive behavior continue after given one warning, and prompting the proxy-respondent to communicate the information is a manner that is typical for the participant).

How each participant was treated by his or her own caretakers (i.e., differences in the two residential environment) was not a focus of this study but perhaps could be evaluated in a subsequent data analysis and review. The standardized method of administration of the single questionnaire implemented in this study minimized this potential variable.

Implications for Social Change

This finding that people with Exceptional Medical and/or Exceptional Behavioral needs are provided more levels of support in the Institutional setting is of paramount importance regarding the various movements occurring not only in Florida but also across the nation. Planning for success in meeting identified needs as the stakeholders transition from one residential service delivery environment (that is from Institutional to Community) to another is critical for future success. Prevention of Reinstitutionalization is key. Providing key policy makers with the necessary data in order to support the continuing cost plan allocations for institutional closures is both critical and preventative. One such suggestion offered by this researcher is to include a new classification of service provision. The category of service would be called "Transitional Medical care" and/or "Transitional Behavioral care." Each of these service delivery systems' mission statement would include a short-term length of stay in order to provide the level of support necessary to preserve the person's community placement. In theory, it would be more cost efficient than inpatient hospitalization for either medical and/or behavioral. Also, it would preserve the consumers' placement once the crisis subsides. One also needs to focus on the provision of support allocations for those stakeholders who have not demonstrated success while in Community residence as measured by stability of his/her medical and/or behavioral status. In Florida, the Agency for Persons with Disabilities (APD) has initiated a Task Force in order to address this issue—the placement in the community while preventing reinstitutionalization. It was encouraging to note that the majority of the sample participants included his/her legal guardian (71%) as well as their willingness to make a difference in the lives of future stakeholders. It is also encouraging because one of the most rapidly growing populations is people with Intellectual and/or Developmental Disabilities who were often placed in Institutions as children.

However, it was surprising to note that no sample participants in either residential sample indicated that they have received Supported Employment services (0%). This finding is unexpected given Florida’s movement to increase employment for our service delivery recipients. In 2014, Governor Scott increased the Agency for Persons with Disabilities’ (APD) budget by $36 million with a specific earmark for Supported Employment to receive $500,000. (Agency for Persons with Disabilities, 2012). Further evaluation of how successful supported employment placements (specifically for people with severe to profound Intellectual/Developmental Disabilities) is a recommendation for future research.

An additional unexpected outcome was that 41% of the Institutional sample stated that they previously resided in the community but had to return to

Institutional placement.   This recidivism or reinstitutionalization after community inclusion requires closer examination. The two most frequently cited rationales for changes or “failures” in placement mirror the two domains in this study—Exceptional Medical or Exceptional Behavioral needs. Testing these factors after perhaps a respite crisis intervention placement might be warranted for future research. Dr. Barbara Palmer, Agency for Persons with Disabilities (APD), spearheaded a task force to address these key issues facing Florida. An analysis of outcome data also is recommended both pre- and post-implementation of that action plan. (Agency for Persons with Disabilities, 2014).

Conclusion

The main goal of this study was to add to the growing body of research literature in the field of Intellectual/Developmental Disabilities with specific attention to the severe to profound range of disability as each stakeholder’s level of supports are met to enhance his/her quality of life. Research continues to support the deinstitutionalization movement for all stakeholders but a careful assessment and thorough action plan are both warranted and recommended. It is this researcher’s intention that our policy makers recognize the differences in levels of support that are substantiated herein. In recognition of these differences, so should there be differences in accommodating meeting those needs. The social implications for the findings suggest that there is no “one-size-fits-all” support or cost plan based solely upon one’s residential status or level of severity of disability but rather using the basis of each stakeholder’s individualized needs for successful support provision. Bridging the gap in *need identification* and *need* *satisfaction* is critical. The growing population suggests that the needs are increasing especially among the young adult and child population in Intellectual and Developmental Disabilities. Future directions of research might include a closer examination at the differences in levels of support for children who have varying degrees of Intellectual/Developmental Disability with an emphasis on medical and/or behavioral needs. An additional suggestion for research would be to correlate the findings of this study with the National Core Indicators tool implemented across the state of Florida to support reliability across both standardized tools of measurement.

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Appendix A: Consent Form A

CONSENT FORM- Legal guardian form-A (This consent form will reviewed after the overview form is reviewed with both the participant and the legal guardian).

You and _________ (name of son/daughter/ward) are invited to take part in a research study that evaluates "practical and support requirements of a person with an intellectual disability." Your ward/adult son or daughter was chosen for the study because he or she is at least 18 years of age, he/she has certain mental limitations (IQ is identified as at 34 or below), and he/she lives either in an institution (ICF/DD) or in the community (under the Home and Community-based Medicaid Waiver program). He/she also has established this residency for no less than one calendar year from the date of this consent. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part or not.

This study is being conducted by a researcher named Kristin Korinko, who is a doctoral student at Walden University. The acceptance of you and _______ (name of ward/son/daughter) into this study depends upon his or her meeting all of eligibility criteria (listed above). It is also important to determine that you and/or ______ (name ofyour son/daughter/ward) has no conflict of interest with the researcher (this means that your son/daughter/ward or you have not received and/or is not currently receiving any direct Behavior Analysis or Mental Health services from the researcher).

Background Information:
The purpose of this study is to assess the necessary levels of support for people with severe to profound levels of developmental disabilities (including health and behavioral needs) who reside and receive services in an institution (i.e., Intermediate Care Facility for the Developmentally Disabled/ ICF/DD) and those who receive services within the community (under the Home and Community Based Medicaid Waiver program (HCBS)). In other words, this study is looking into what exactly people with these disabilities need to live each day.

Procedures for the Participant:
If you agree to be in this study, you will be asked about how you live each day, what you need in certain areas, and how much help you require. You will have your legal guardian helping you with answering these questions.

You and your guardian will be asked a series of questions from a questionnaire titled "Supports Intensity Scale." This questionnaire takes about 60-90 minutes (1 hour) to complete. The questions may include information about your hobbies, your work, your interests, your health, and your progress.

I will be asking the questions, and both of you may answer them. The question will be presented to you first so that you have the chance to answer honestly and to the best of your ability. Your guardian may add to your answer or provide answer for you. You may stop at any time. You may ask any questions before, during, and/or after the interview has been completed. The actual questionnaire has both breaks built directly into the interview process. It will also remind me to ask you and your legal guardian to pause to see if you have any questions or problems up to that point.

Procedures for the Legal Guardian:

- Provide information on your ward/son/daughter to make sure that he/she meets the eligibility criteria discussed in the first section of this form. This means that the researcher has your permission to look at his/her current plan of support, habilitation plan, IQ (intelligence test results).
- Answer questions from a questionnaire called the "Supports Intensity Scale" that takes about 60-90 minutes (1 hour to an hour an a half) in length to complete.

Voluntary Nature of the Study:

Participant-

Your decision to participate in this study is up to you. But keep in mind that your legal guardian must consent for you to participate after you have decided to do it. Once we start, you may try it to see if you are comfortable. You can stop at any time. You can change your mind about answering the questions at any time. You can take breaks as needed at any time during this interview process.

No one will know other than you, me, and your legal guardian whether you answered these questions or not.

Guardian-

Your son/daughter/ward's participation in this study is voluntary contingent upon your approval as his/her guardian. This means that everyone will respect your decision of whether or not you want to be in the study. If you decide to join or decline in the study now, you can still change your mind during the study. If you feel stressed or uncomfortable during the study, you may stop at any time. You may skip any questions that you feel are too personal. You may also take breaks if needed.

****Please let the researcher know if you as the legal guardian would like for your son/daughter/ward to participate in this study, but you are not able to be here to answer these questions. There is an additional consent form for naming a proxy respondent (for example, a caretaker, staff, social worker, etc.) that you must complete.

Risks and Benefits of Being in the Study:

The only risk is if the participant shares information that falls into the category of suspected abuse, neglect, or exploitation. The State of Florida's Zero Tolerance policy requires the researcher to report this information to the proper authorities. No information will be shared with any involved party without this consent. All federal and state laws and regulations will be followed with regard to the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and the protection of confidential consumer information. The benefit of participating in this study is that you are helping us learn how to meet your needs better each day.

Compensation:
The participant will be given a small nominal token of appreciation (i.e., $10 gift card to Walmart or Target) at the time of the interview.

Confidentiality:
Any information you provide will be kept confidential. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact the researcher via cell phone or email. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Walden University's approval number for this study is **# 09-13-13-0011350, will expire on 7/6/15.**
The researcher will give you a copy of this form to keep.
Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I am agreeing to the terms described above. Signatures should be given for 1) consent that participant may participate and 2) consent that guardian may assist with providing answers to interview.

Printed Name of Participant ______________________________

Participant's written signature indicating review of consent ______________________________

Date of consent ______________________________

Legal Guardian's Written Signature ______________________________

Researcher's Written Signature ______________________________

Appendix B: Consent Form B

CONSENT FORM- Legal guardian form- B (This consent form will reviewed after the overview form is reviewed with both the participant and the legal guardian). This form is for the Legal Guardian to name is Caretaker/Proxy respondent.

You and _____ (name of your ward/son/daughter) are invited to take part in a research study that evaluates "practical and support requirements of a person with an intellectual disability." _____ (name) Your ward/adult son or daughter was chosen for the study because he or she is at least 18 years of age, he/she has certain mental limitations (IQ is identified as at 34 or below), and he/she lives either in an institution (ICF/DD) or in the community (under the Home and Community-based Medicaid Waiver program). He/she also has established this residency for no less than one calendar year from the date of this consent. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part or not.

This study is being conducted by a researcher named Kristin Korinko, who is a doctoral student at Walden University. The acceptance of your ward/son/daughter into this study depends upon his or her meeting all of eligibility criteria (listed above). It is also important to determine that your you and/or _____ (name of son/daughter/ward) has no conflict of interest with the researcher (this means that neither you nor ______ (name of your son/daughter/ward) or you have not received and/or is not currently receiving any direct Behavior Analysis or Mental Health services from the researcher).

Background Information:
The purpose of this study is to assess the necessary levels of support for people with severe to profound levels of developmental disabilities (including health and behavioral needs) who reside and receive services in an institution (i.e., Intermediate Care Facility for the Developmentally Disabled/ ICF/DD) and those who receive services within the community (under the Home and Community Based Medicaid Waiver program (HCBS)). In other words, this study is looking into what exactly people with these disabilities need to live each day.

Procedures for the Participant:
If you agree to be in this study, you will be asked about how you live each day, what you need in certain areas, and how much help you require. You will have your alternate caretaker helping you with answering these questions.

You and your caretaker will be asked a series of questions from a questionnaire titled "Supports Intensity Scale." This questionnaire takes about 60-90 minutes (1 hour) to complete. The questions may include information about your hobbies, your work, your interests, your health, and your progress.
I will be asking the questions, and both of you may answer them. The question will be presented to you first so that you have the chance to answer honestly and to the best of your ability. Your caretaker may add to your answer or provide answer for you.

You may stop at any time. You may ask any questions before, during, and/or after the interview has been completed.

The actual questionnaire has both breaks built directly into the interview process. It will also remind me to ask you and your caretaker to pause to see if you have any questions or problems up to that point.

Procedures for the Legal Guardian:

- Provide consent to the information on your ward/son/daughter to make sure that he/she meets the eligibility criteria discussed in the first section of this form. This means that the researcher has your permission to look at his/her current plan of support, habilitation plan, IQ (intelligence test results).
  - Identify an alternative caretaker who will serve as a proxy respondent.
  - Consent to the use of the alternative caretaker in the interview process.

  Procedures for the Alternative Caretaker (Proxy respondent):
  - Answer questions from a questionnaire called the "Supports Intensity Scale" that takes about 60-90 minutes (1 hour to an hour an a half) in length to complete.
  - Sign a confidentiality agreement which states that you agree to keep all responses to the questions confidential unless the information bears breaching per the "Zero Tolerance" policy in the State of Florida.

Voluntary Nature of the Study:

Participant-

Your decision to participate in this study is up to you. But keep in mind that your legal guardian must consent for you to participate after you have decided to do it. Once we start, you may try it to see if you are comfortable. You can stop at any time. You can change your mind about answering the questions at any time. You can take breaks as needed at any time during this interview process.

No one will know other than you, me, and your caretaker whether you answered these questions or not.

Caretaker/Proxy-

Your client's participation in this study is voluntary contingent upon the approval from his/her guardian. This means that everyone will respect his/her decision of whether or not he/she wants to be in the study. If he/she decides to join or decline in the study now, he/she can still change his/her mind during the study. If she/she begins to express any observable problems during the study, you may ask to stop at any time. You may skip any questions that you feel are too personal for your client. You may also request and take breaks if needed.

Risks and Benefits of Being in the Study:

The only risk is if the participant shares information that falls into the category of suspected abuse, neglect, or exploitation. The State of Florida's Zero Tolerance policy requires the researcher to report this information to the proper authorities. No information will be shared with any involved party without this consent. All federal and state laws and regulations will be followed with regard to the Health Insurance Portability and Accountability Act (HIPAA) of

1996 and the protection of confidential consumer information. The benefit of participating in this study is that you are helping us learn how to meet your needs better each day.

Compensation:
The participant will be given a small nominal token of appreciation (i.e., $10 gift card to Walmart or Target) at the time of the interview. The proxy respondent/caretaker will also receive a $10 gift card for their participation.

Confidentiality:
Any information you or your caretaker provide will be kept confidential. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact the researcher via cell phone or email. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Walden University's approval number for this study is **# 09-13-13-0011350, will expire on 7/6/15.**
The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I am agreeing to the terms described above. Signatures should be given for 1) consent that participant may participate and 2) guardian consent for the alternate caretaker/proxy respondent may assist with providing answers to interview.

Printed Name of Participant	____________________
Participant's written signature indicating review of consent	____________________
Date of consent	____________________
Legal Guardian's Written Signature	____________________
Researcher's Written Signature	____________________
**Alternate Caretaker's Written Signature	____________________

** A confidentiality agreement must also be signed by the alternate caretaker.

Appendix C: Confidentiality Form-Alternative Caretaker

I___________ **(alternate caretaker/ respondent):**

During the course of my activity in collecting data for this research:

Quality of Life of People with Profound Developmental Disabilities Across Residential Settings

I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Appendix D: Confidentiality Form-Research Liaison

________, Research Liaison:

During the course of my activity in collecting data for this research:

Quality of Life of People with Profound Developmental Disabilities Across Residential Settings

I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Appendix E: Confidentiality Form-Statistician

_______________, Statistician:

During the course of my activity in collecting data for this research:
“Quality of Life of People with Profound Developmental Disabilities Across Residential Settings”
I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.
By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant’s name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I’m officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Appendix F: Liaison Training Documentation Form

TRAINING DOCUMENTATION SIGNATURE SHEET

My signature below indicates that I have been fully informed of my role as a liaison in the research conducted by Kristin Korinko, a Doctoral candidate in Psychology from Walden University.

I understand that my duties include the following:
1) To identify appropriate participants for the study using the following eligibility criteria (severe/profound range of Intellectual/Developmental Disability; at least 18 years old; has resided in the current residence for at least one calendar year);
2) To distribute the flyer announcing the study to the person's legal guardian via U. S. mail, email, fax, or in person;
3) To clarify that the research is being conducted by an independent doctoral student who is in no way connected or associated with anyone providing direct services;
4) To reinforce that all further questions regarding the study should be directed to the researcher.
5) To assist the researcher in obtaining the necessary documentation to verify eligibility once the legal guardian has consented to participating in the study. These records include the demographic information (habilitation plan for ICF/DD programs; support plan for the Community Medwaiver programs) and the most recent Psychological evaluation (with the IQ (Intelligence Quotient) noted).
6) To serve as the single point of contact between the researcher and the site as appropriate. He/she will communicate to the researcher pertinent information that may include the daily activity schedules (so as not to interfere with each stakeholder's meaningful daily activities), areas of total privacy (for the interview to be held), and areas in which supporting documentation can be privately reviewed (i.e., current support/habilitation plans/psychological reports). The researcher will also communicate with the liaison if the person becomes emotionally distraught during and/or immediately after the interview process and requires support services.

I agree to serve as a liaison in this study.

____
Signature/date

Appendix G: Information Flyer to Legal Guardians

INFORMATION FLYER DISTRIBUTED TO THE POTENTIAL PARTICIPANTS (LEGAL GUARDIANS)
<Mailing address/fax/email>
Dear ________ (name),

My name is Kristin Korinko, and I am a Doctoral Candidate in Psychology at Walden University. You are receiving this flyer because _______ (name of your son/daughter/ward) has been identified as a potential participant in my study.

In order to be eligible for this study, _____ (name of your son/daughter/ward) must meet the following criteria:
(1) He/she must have an IQ (intelligence quotient) within the severe to profound level of Intellectual Disability (formerly referred to as "Mental Retardation") between the ranges of "Profound= below 20" to "Severe=20-34." This will need to be verified (i.e., the score is typically included in the Support Plan/ Habilitation Plan);
(2) He/she must be living either in an Intermediate Care Facility for people with Developmental and Intellectual Disabilities (ICF/DD) or in the community at large and served under the Home and Community-based Medicaid Waiver program;
(3) He/she must be within their current living arrangement for no less than one continuous calendar year from the date of the interview
(4) He/she must be at least 18 years of chronological age.

After working in the field of Intellectual Disabilities for over twenty years, I began to examine how effective certain systems have become in providing the necessary support for this population. I have completed an exhaustive research process that has lead me to this point. I am interested in interviewing people with Intellectual Disabilities and their legal guardians regarding this support. I am using a questionnaire called the "Supports Intensity Scale" that takes approximately 60-90 minutes to complete. I would be the primary interviewer. We would speak privately face-to-face. Your information would be kept confidential. Every participant would receive a small "Thank you" gift of a $10 gift card from either Walmart or Target.

I would like to have the opportunity to speak with you regarding my study. I would greatly appreciate any assistance that you can provide. Please remember that you are in no way obligated to participate. Also, I am conducting the research. The study is not associated with anyone providing services to the consumer.

If you would like to participate or have questions regarding the study, please contact me directly. You may email me or you may contact me via cell phone. Once this communication has been completed, an appointment date and time will be scheduled. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Walden University's approval number for this study is **# 09-13-13-0011350, will expire on 7/6/15**

Thank you. I am looking forward to hearing from you.

Sincerely,
Kristin Korinko, M. S.
Doctoral Candidate, Clinical Psychology
Walden University

Appendix H: Overview of the study

Overview of the study requirements (THIS OVERVIEW/SCRIPT WAS READ TO THE LEGAL GUARDIAN BY THE PRIMARY RESEARCHER IN PERSON AT A FACE TO FACE MEETING.)

Thank you for your interest in participating in my doctoral research. The study involves the following steps:

1) You and _____ (name of your son/daughter/ward) will be asked a series of questions from a questionnaire titled "Supports Intensity Scale." This questionnaire takes about 60-90 minutes to complete. The questions may include information about his/her hobbies, his/her work, his/her interests, his/her health, and his/her progress. I will be asking the questions, and all you have to do is answer them honestly and to the best of your ability. Although (______- name of son/daughter/ward) may not be able to respond verbally to some questions, other ways of responding including eye blinks (yes/no), eye contact (whose consensus may be indicative of a yes/no response), smiling/frowning, looking away, may be included as plausible responses. This will be clarified during the interview as to how she/he usually responds to questions. I will be trying to include your son/daughter/ward in as much of the interview process as possible. I may make notes including "person appeared willing to participate" which would also be reached by consensus—in other words, I would ask you if he/she is giving us the typical response for cooperation (for example). There may be some questions that he/she might not be able to answer at all. When this occurs, your response will be noted. The questions are very specific regarding level of support including "frequency"-how often; "daily support time"-how long; and "type of support"-level of prompting from none to full physical assistance. You may stop at any time and ask any questions to clarify before, during, and/or after the interview has been completed. The person may be excused during the interview at anytime as deemed necessary. He/she will be thanked for his/her participation. At that point, the interviewer will note the departure. The questionnaire process may continue or stop at the request of the primary participant (legal guardian or caretaker). In any case, this will be noted. IN THE EVENT THAT THE PERSON IS IN OBSERVABLE DISTRESS (OR BECOMES EMOTIONALLY DISTRAUGHT DURING AND/OR IMMEDIATELY AFTER THE INTERVIEW), THE NEED FOR SUPPORT SERVICES WILL BE REFERRED BY THE RESEARCHER TO THE LIASION. (It is not up to the researcher to determine what appropriate support service is required at that time, however the liaison will initiate the appropriate course of action).

2) The eligibility requirements were listed in the information flyer that was sent to you by the research liaison. The research liaison, (name the person here specific to the facility) has already screened for eligibility as he/she has access to the information. I

need to double check with you to make sure that ________ (name of your son/daughter/ward) is eligible.

First, is _____ (name) diagnosed with an IQ between profound and severe range of intellectual disability?

Second, is he/she at least 18 years of age?

Finally, has he/she lived in his/her present place for at least one continuous year?

If the answers to the above questions are all yes, then we can continue. If not, then thank you very much for your time and interest in my study.

I will be looking for a habilitation plan (ICF/DD) or a support plan (community) with the level of severity of intellectual disability indicated within this document. I may also be looking for the most current Psychological evaluation report which indicates the level of Intelligence Quotient (IQ) that is a minimum requirement for any person deemed eligible to receive services from the Agency for Persons with Disabilities (APD) and Medicaid. Any information will only be obtained after you have given your written consent. Once the written consent has been obtained, the reports will be OBTAINED IN WRITING before the interview actually takes place to confirm eligibility.

3) Your participation is completely voluntary, and you can stop at any time. The interview process will include you the guardian, your son/daughter, and me. If you can't be present for any reason, you may name a caregiver who knows ___ (name) well and has worked with him/her for at least one year. I will need to get your consent in allowing this caretaker to answer the questions prior to the interview.

4) I will be writing down all of your responses. I may ask additional questions of you in order to ensure that I have your intended response. We may also take breaks as needed (it is recommended in the questionnaire manual that breaks are not scheduled but granted upon request). Any person (guardian, son/daughter/ward, proxy, and/or interviewer) may request and grant a break. The notation of the break will be made the interviewer on the questionnaire tool. The actual questionnaire has both breaks and clarification questions built directly into the interview process.

5) Privacy is of the utmost importance. We can conduct this interview in an area in which you feel comfortable to speak honestly and without any fear of interruption or intrusion. It is recommended that the interview take place in a private room like a bedroom. Again, the interview will take between 60-90 minutes to complete.

6) After we have completed the interview, your son/daughter/ward will be given a small "Thank you" gift of a Walmart or Target gift card in the amount of $10.00. This token of appreciation is given regardless of how much is completed during the interview process. Your participation is vital and greatly appreciated!

7) Once we have completed the interview, your responses will be “coded” so that they will not be known to anyone. This information will also be transported safely in a lock box to preserve confidentiality.

8) Once all the results have been tabulated, I will be giving you a report summarizing what the study demonstrated.

At the conclusion of this overview, I will ask the guardian if he/she wants to proceed with scheduling an appointment for the interview.

Appendix I: Supports Intensity Scale

SUPPORTS INTENSITY SCALE

Note: Supports Intensity Scale by J. R. Thompson et al., 2004, Washington, DC: AAIDD. Copyright 2004 by AAIDD. Reprinted with permission.

Support Intensity Scale

Interview and Profile Form

Adult Version (ages 16 and up)

____
ID/Tracking Number

Name ______________________ Date SIS Completed _______/_______/_______
YR MO DAY

Address ______________________

City, Sate, Zip______________________ Date of Birth _______/_______/_______
YR MO DAY

Phone _______/_______/_______ Language Spoken at Home ______________________ Age ______________

Individuals or Organizations Providing Essential Supports: Gender Male Female

Name ______________________ Relationship ______________________ Phone _______/_______/_______

Name ______________________ Relationship ______________________ Phone _______/_______/_______

Name ______________________ Relationship ______________________ Phone _______/_______/_______

Other Pertinent Information ______________________

____

Respondent Name	Relationship to Individual	Language Spoken
1. ______________	______________	______________
2. ______________	______________	______________
3. ______________	______________	______________

Interviewer ______________________ Position ______________________

Agency/Affiliation ______________________ Phone _______/_______/_______

Address ______________________ Email ______________________

American Association on Intellectual and Developmental Disabilities	James R. Thompson, PhD Brian R. Bryant, PhD Edward M. Campbell, PhD Ellis M. Craig, PhD Carolyn M. Hughes, PhD	David A Rotholz, Phd Robert L. Schalock, PhD Wayne P. Silverman, PhD Marc J. Tasse, PhD

		Michael L. Wehmeyer

Section 1. Support Needs Scale

INSTRUCTIONS: Identify the Frequency, Daily Support, and Type of Support that is reported necessary for the person to be successful in the six activity domains (Parts A-F). Circle the appropriate number (0-4) for each measurement (i.e. Frequency, Daily Support Time, Type of Support) (See rating key below). Add across each line to obtain the Raw Scores. Sum the Raw Scored down to obtain the Total Raw Score for each Part

1. This scale should be completed without regard to the services or supports currently provided or available.
2. Scores should reflect the supports that would be necessary for this person to be successful in each activity.
3. If an individual uses assistive technology, the person should be rated with said technology in place.
4. Complete ALL items, even if the person is not currently performing a listed activity.

Part A: Home Living Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Using the toilet	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Taking care of clothes (includes laundering)	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Preparing food	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Eating food	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Housekeeping and cleaning	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Dressing	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Bathing and taking care of personal hygiene and grooming needs	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Operating home appliances	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Home Living Activities Enter the Raw Score (max= 92) on the SIS Profile, on page 8, Section 1A, Part A, Home Living Activities																

RATING KEY

Frequency How frequently is support needed for this activity?	Daily Support Time On a typical day when support in this area is needed, how much time should be devoted?	Type of Support What kind of support should be provided?
0 = none or less than monthly	0 = none	0 = none
1 = at least once a month, but not once a week	1 = less than 30 minutes	1 = monitoring
2 = at least once a week, but not once a day	2 = 30 minutes to less than 2 hours	2 = verbal/gestural prompting
3 = at least once a day but not once an hour	3 = hours to less than 4 hours	3 = partial physical assistance
4 = hourly or more frequently	4 = 4 hours or more	4 = full physical assistance

Section 1. Support Needs Scale, continued

Circle the appropriate number (0-4) for each measurement. (See rating key.) Complete all items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part B: Community Living Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Getting from place to place throughout the community (transportation)	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participating in the recreation/leisure activities in the community settings	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Using public services in the community	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
4. Going to visit friends and family	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Participating in preferred 6. community activities (church, volunteer, etc.)	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
7. Shopping and purchasing goods and services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Interacting with community members	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
9. Accessing public buildings and settings	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Community Living Activities Enter the Raw Score (max= 91) on the SIS Profile, on page 8, Section 1A, Part B, Community Living Activities																

Part C: Lifelong Learning Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Interacting with other in learning activities	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participating in training/educational decisions	0	1	2	3	X	0	1	2	3	X	0	1	2	3	4	
3. Learning and using problem solving strategies	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Using technology for learning	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Accessing training/educational settings	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Learning functional academics (reading signs, counting change, etc.)	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Learning health and physical education skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Learning self-determination skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
9. Learning self-management strategies	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Lifelong Learning Activities Enter the Raw Score (max= 104) on the SIS Profile, on page 8, Section 1A, Part C, Lifelong Learning Activities																

Section 1. Support Needs Scale, continued

Circle the appropriate number (0-4) for each measurement. (See rating key.) Complete all items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part D: Employment Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Accessing/receiving job/task accommodations	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Learning and using specific job skills	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Interacting with co-workers	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
4. Interacting with supervisors/coaches	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Completing work-related tasks with acceptable speed	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
6. Completing work-related tasks with acceptable quality	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
7. Change job assignments	0	1	2	X	X	0	1	2	3	4	0	1	2	3	4	
8. Seek information and assistance from an employer	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Employment Activities Enter the Raw Score (max= 87) on the SIS Profile, on page 8, Section 1A, Part D, Employment Activities																

Part E: Health and Safety Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Taking Medications	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Avoiding health and safety hazards	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Obtaining health care services	0	1	2	3	4	0	1	2	X	X	0	1	2	3	4	
4. Ambulating and moving about	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Learning how to access emergency services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Maintaining a nutritious diet	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Maintaining physical health and fitness	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Maintaining emotional well-being	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Health and Safety Activities Enter the Raw Score (max= 94) on the SIS Profile, on page 8, Section 1A, Part E, Health and Safety Activities																

RATING KEY

Frequency How frequently is support needed for this activity?	**Daily Support Time** On a typical day when support in this area is needed, how much time should be devoted?	**Type of Support** What kind of support should be provided?
0 = none or less than monthly	0 = none	0 = none
1 = at least once a month, but not once a week	1 = less than 30 minutes	1 = monitoring
2 = at least once a week, but not once a day	2 = 30 minutes to less than 2 hours	2 = verbal/gestural prompting
3 = at least once a day but not once an hour	3 = hours to less than 4 hours	3 = partial physical assistance
4 = hourly or more frequently	4 = 4 hours or more	4 = full physical assistance

Section 1. Support Needs Scale, continued

Circle the appropriate number (0-4) for each measurement. (See rating key.) Complete all items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part F: Social Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Socializing within the household	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participating in recreation/leisure activities with others	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Socializing outside of the household	0	1	2	3	4	0	1	2	4	4	0	1	2	3	4	
4. Making and keeping friends	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Communicating with others about personal needs	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Using appropriate social skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Engaging in loving and intimate relationships	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Engaging in volunteer work	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Social Activities Enter the Raw Score (max= 93) on the SIS Profile, on page 8, Section 1A, Part F, Social Activities																

Section 2. Supplemental Protection and Advocacy Scale

Circle the appropriate number (0-4) for each measurement. (see rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Rank the Raw Scores from highest to lowest (1=highest). Enter the four highest ranked activities (1-4) and their scores on the SIS profile

Protection and Advocacy Activities	Frequency					Daily Support Time					Type of Support					Raw Scores	Rank Raw Scores from highest to lowest
1. Advocating for self	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4		
2. Managing money and personal finances	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
3. Protecting self from exploitation	0	1	2	3	4	0	1	2	4	4	0	1	2	3	4		
4. Exercising legal responsibilities	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
5. Belonging to and participating in self-advocacy /supporting organizations	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
6. Obtain legal services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
7. Making choices and decisions	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
8. Advocating for others	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4		
List the four Protection and Advocacy Activities with the highest Raw Score (from highest to lowest) on the SIS profile, on page 8, Section 2																	

Section 3. Exceptional Medical and Behavioral Support Needs

Circle the appropriate numbers to indicate how much support is needed for each of the items below. Subtotal the circled 1's and 2's. Total the subtotals. (see rating key.) Complete ALL items.

Section 3A: Medical Supports Needed	No Support Needed	Some Support Needed	Extensive Support Needed
Respiratory Care			
1. Inhalation or oxygen therapy	0	1	2
2. Postural drainage	0	1	2
3. Chest PT	0	1	2
4. Suctioning	0	1	2
Feeding Assistance			
5. Oral Stimulation or jaw positioning	0	1	2
6. Tube feeding (e.g. nasogastric)	0	1	2
7. Parenteral feeding (e.g. IV)	0	1	2
Skin Care			
8. Turning or positioning	0	1	2
9. Dressing of open wound(s)	0	1	2
Other exceptional medical care			
10. Protection from infectious diseases due to immune system impairment	0	1	2
11. Seizure management	0	1	2
12. Dialysis	0	1	2
13. Ostomy care	0	1	2
14. Lifting and/or transferring	0	1	2
15. Therapy Services	0	1	2
16. Other(s) – Specify:	0	1	2
	Subtotal of 1's and 2's		
		Total (Add Subtotal of 1's and 2's)	

Enter Total on the SIS Profile, on page 8, Section 3A: Support Considerations Based on Exceptional Medical and Behavioral Support Needs, Medical

Section 3. Exceptional Medical and Behavioral Support Needs, continued

Circle the appropriate numbers to indicate how much support is needed for each of the items below. (see rating key.) Complete ALL items.

Section 3B: Medical Supports Needed	No Support Needed	Some Support Needed	Extensive Support Needed
Externally directed destructiveness			
1. Prevention of assaults or injuries to others	0	1	2
2. Prevention of property destruction (e.g. fire setting, breaking furniture)	0	1	2
3. Prevention of stealing	0	1	2
Self-directed destructiveness			
4. Prevention of self-injury	0	1	2
5. Prevention of pica (ingestion of inedible substances)	0	1	2
6. Prevention of suicide attempts	0	1	2
Sexual			
7. Prevention of sexual aggression	0	1	2
8. Prevention of nonaggressive but inappropriate behavior (e.g. exposes self in public, exhibitionism, inappropriate touching or gesturing)	0	1	2
Other			
9. Prevention of tantrums or emotional outbursts	0	1	2
10. Prevention of wandering	0	1	2
11. Prevention of substance abuse	0	1	2
12. Maintenance of mental health treatments	0	1	2
13. Prevention of other serious behavioral problem(s) Specify:	0	1	2
	0	1	2
	Subtotal of 1's and 2's		
		Total (Add Subtotal of 1's and 2's)	

Enter Total on the SIS Profile, on page 8, Section 3B:
Support Considerations Based on Exceptional
Medical and Behavioral Support Needs, Behavioral

Rating Key

0 = no support needed
1 = some support needed (i.e. providing monitoring and/or occasional assistance
2 = extensive support needed (i.e. providing regular assistance to manage the medical condition or behavior)

Supports Intensity Scale (SIS) Scoring Form & Profile

ID/Tracking Number

Name

____

Date SIS Completed

_______/_______/_______
YR MO DAY

Name of Interviewer

____

Section 1A: Support Needs Rating

1. Enter the Raw Scores for parts A-F from pages 2-5
2. Enter the Standard Scores and Percentiles using Appendix 6.2
3. Enter the SIS Support Needs index using Appendix 6.3

Activities Subscales	**Total Raw Scores (from pages2-5)**	**Standard Scores (See Appendix 6.2)**	**Subscale Percentile (See Appendix 6.3)**
A. Home Living			
B. Community Living			
C. Lifelong Learning			
D. Employment			
E. Health & Safety			
F. Social			
Standard Scores TOTAL (sum)			
SIS SUPPORT NEEDS INDEX (Composite Standard Score) (See Appendix 6.3)			
Percentile of Support Needs Index (See Appendix 6.3)			

Section 1 B: Support Needs Profile

Circle the Standard Score for each Activities and the SIS Support Needs index. Then connect the subscale circles to form graph.

Percentile	Home Living	Community Living	Lifelong Learning	Employment	Health & Safety	Social	SIS Support Needs Index	Percentile
99	17-20	17-20	17-20	17-20	17-20	17-20	>131	99
	15-16	15-16	15-16	15-16	15-16	15-16	124-131	
90	14	14	14	14	14	14	120-123	90
	13	13	13	13	13	13	116-119	
80							113-115	80
	12	12	12	12	12	12	110-112	
70							108-109	70
							106-107	
60	11	11	11	11	11	11	105	60
							102-104	
50	10	10	10	10	10	10	100-101	50
							98-99	
40	9	9	9	9	9	9	97	40
							94-96	
30							92-93	30
	8	8	8	8	8	8	90-91	
20							88-89	20
	7	7	7	7	7	7	85-87	
10	6	6	6	6	6	6	82-84	10
	5	5	5	5	5	5	75-81	
1	1-4	1-4	1-4	1-4	1-4	1-4	<74	1

		Section 3: Support Considerations Based on Exceptional Medical and Behavioral Support Needs

Section 2: Support Considerations Based on Protection and Advocacy Scores			**A. Medical**		
List the 4 highest ranked Protection and Advocacy Activities from page 5			1. Enter the number of Total points from page 6		
			2. Is this Total larger than 5?	**YES**	**NO**
Activity	Raw Score		3. Is at least one “2” circles for Medical Support Needed on page 6?	**YES**	**NO**
			B. Behavioral		
			1. Enter the number of Total points from page 7		
			2. Is this total larger than 5?	**YES**	**NO**
			3. Is at least one “2” circles for Behavioral Supports Needed on page 7?	**YES**	**NO**
			If “yes” has been circled on any of the questions above, it is highly likely that this individual has greater support needs than other with similar SIS Supports Needs Index		

Appendix J: Permission to use the Supports Intensity Scale

PERMISSION TO USE THE SUPPORTS INTENSITY SCALE

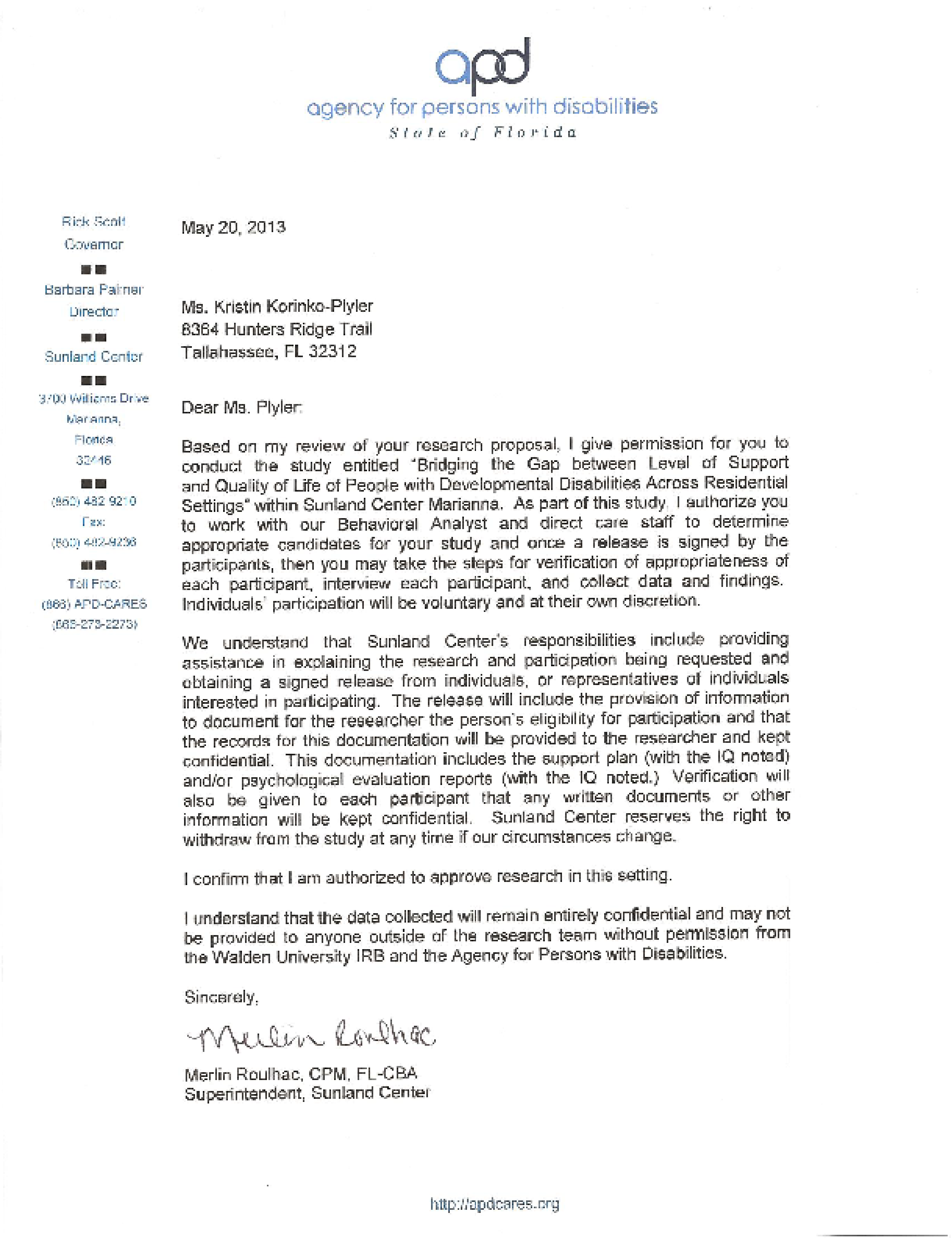
(Below is a copied text of an email from the AAIDD SIS Coordinator who granted permission for use of the tool).
Good Morning Kristin,

Thank you for your interest in using the Supports Intensity Scale® as part of your doctoral dissertation. In our past conversation, only use of the SIS® data for research purposes requires authorization from AAIDD, and entails completion of necessary forms. As this is not the case with your request, we appreciate you informing us of your intent to use the SIS. AAIDD can offer you a complimentary packet of SIS forms (25 forms), however the remainder will require you to purchase at AAIDD's bookstore (www.bookstore.aaidd.org)
As a reminder, the Supports Intensity Scale, and SIS are registered trademarks with the U.S. Patent Office. The registered symbol needs to be used for SIS and Supports Intensity Scale, only at the first placement in your text of your dissertation. That is to say, if the words are in your title of your dissertation, please use the registered symbol. Feel free to contact me if clarification is required. I would also need an address to send you the complimentary packet of SIS forms.

While this stage of anyone's doctoral program can feel harrowing, the fruits of your labor will be most gratifying. It's a major undertaking, but the final accomplishment is certainly worth it. I wish you all the best in your future.

Ravita Maharaj, PhD
Director, Supports Intensity Scale (*SIS) Program*
American Association on Intellectual and Developmental Disabilities (AAIDD)
501 Third Street, NW
Suite 200
Washington, DC 20001-2760
(202) 387-1968, ext 215
(202) 387-2193 (fax)
www.siswebsite.org
www.aaidd.org

Appendix K1: Permission to sample populations



apd
agency for persons with disabilities
State of Florida

Rick Scott
Governor

Barbara Palmer
Director

Sunland Center

3700 Williams Drive
Marianna,
Florida
32446

(850) 482 9210
Fax:
(850) 482-9236

Toll Free:
(866) APD-CARES
(866-273-2273)

May 20, 2013

Ms. Kristin Korinko-Plyler
6364 Hunters Ridge Trail
Tallahassee, FL 32312

Dear Ms. Plyler:

Based on my review of your research proposal, I give permission for you to conduct the study entitled "Bridging the Gap between Level of Support and Quality of Life of People with Developmental Disabilities Across Residential Settings" within Sunland Center Marianna. As part of this study, I authorize you to work with our Behavioral Analyst and direct care staff to determine appropriate candidates for your study and once a release is signed by the participants, then you may take the steps for verification of appropriateness of each participant, interview each participant, and collect data and findings. Individuals' participation will be voluntary and at their own discretion.

We understand that Sunland Center's responsibilities include providing assistance in explaining the research and participation being requested and obtaining a signed release from individuals, or representatives of individuals interested in participating. The release will include the provision of information to document for the researcher the person's eligibility for participation and that the records for this documentation will be provided to the researcher and kept confidential. This documentation includes the support plan (with the IQ noted) and/or psychological evaluation reports (with the IQ noted.) Verification will also be given to each participant that any written documents or other information will be kept confidential. Sunland Center reserves the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB and the Agency for Persons with Disabilities.

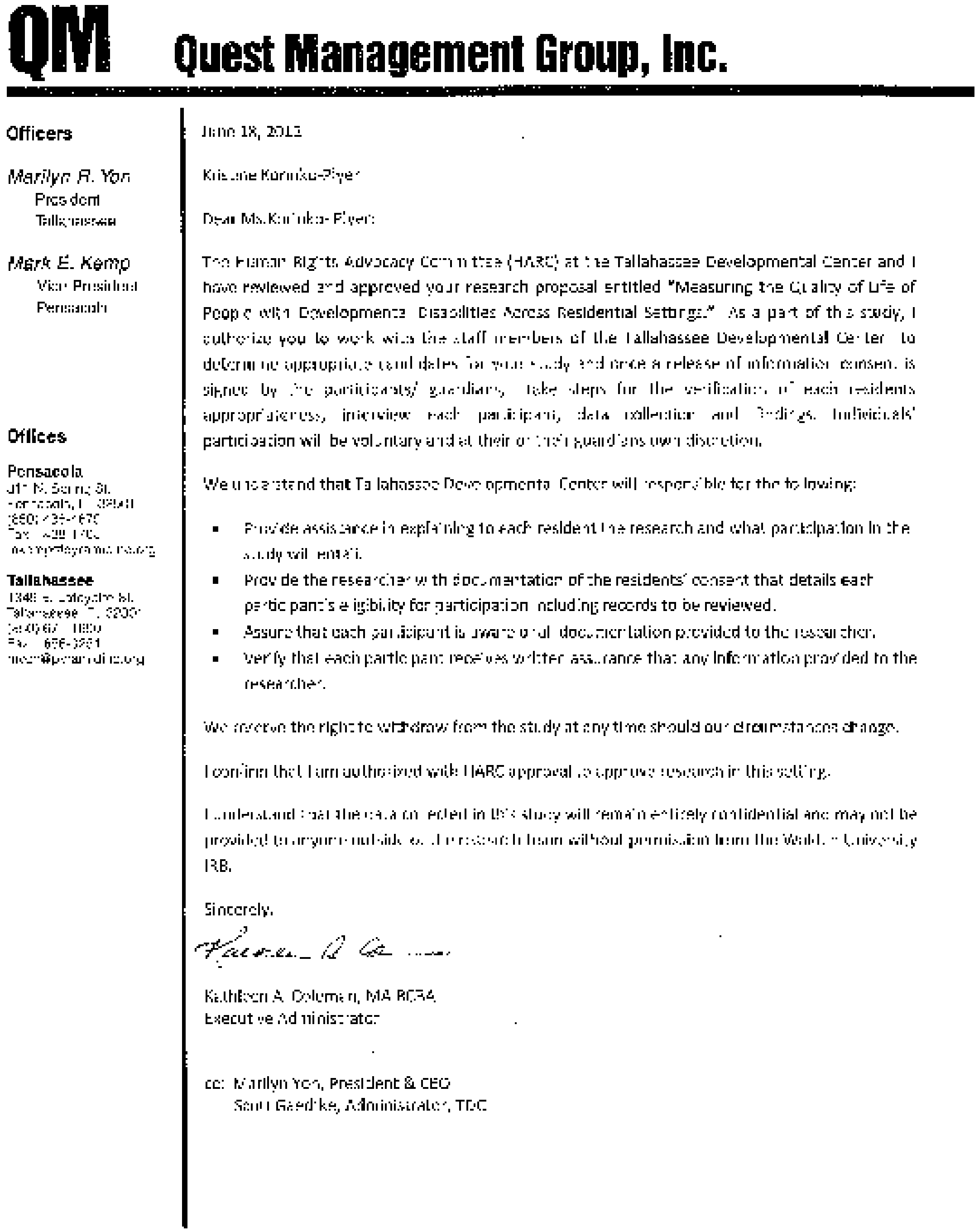
Sincerely,

Merlin Roulhac

Merlin Roulhac, CPM, FL-CBA
Superintendent, Sunland Center

http://apdcares.org

Appendix K2: Permission to sample populations



QM **Quest Management Group, Inc.**

Officers

Marilyn R. Yon
President
Tallahassee

Mark E. Kemp
Vice President
Pensacola

Offices

Pensacola
[illegible]
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[illegible]

Tallahassee
[illegible]
[illegible]
[illegible]
Fax [illegible] 656-3281
[illegible]

June 18, 2013

Kristine Kornicka-Piyer

Dear Ms. Kornicka-Piyer:

The Human Rights Advocacy Committee (HARC) at the Tallahassee Developmental Center and I have reviewed and approved your research proposal entitled "Measuring the Quality of Life of People with Developmental Disabilities Across Residential Settings." As a part of this study, I authorize you to work with the staff members of the Tallahassee Developmental Center to determine appropriate candidates for your study and once a release of information consent is signed by the participants/ guardians, take steps for the verification of each residents appropriateness, interview each participant, data collection and findings. Individuals' participation will be voluntary and at their or their guardians own discretion.

We understand that Tallahassee Developmental Center will responsible for the following:

- Provide assistance in explaining to each resident the research and what participation in the study will entail.
- Provide the researcher with documentation of the residents' consent that details each participant's eligibility for participation including records to be reviewed.
- Assure that each participant is aware of all documentation provided to the researcher.
- Verify that each participant receives written assurance that any information provided to the researcher.

We reserve the right to withdraw from the study at any time should our circumstances change.

I confirm that I am authorized with HARC approval to approve research in this setting.

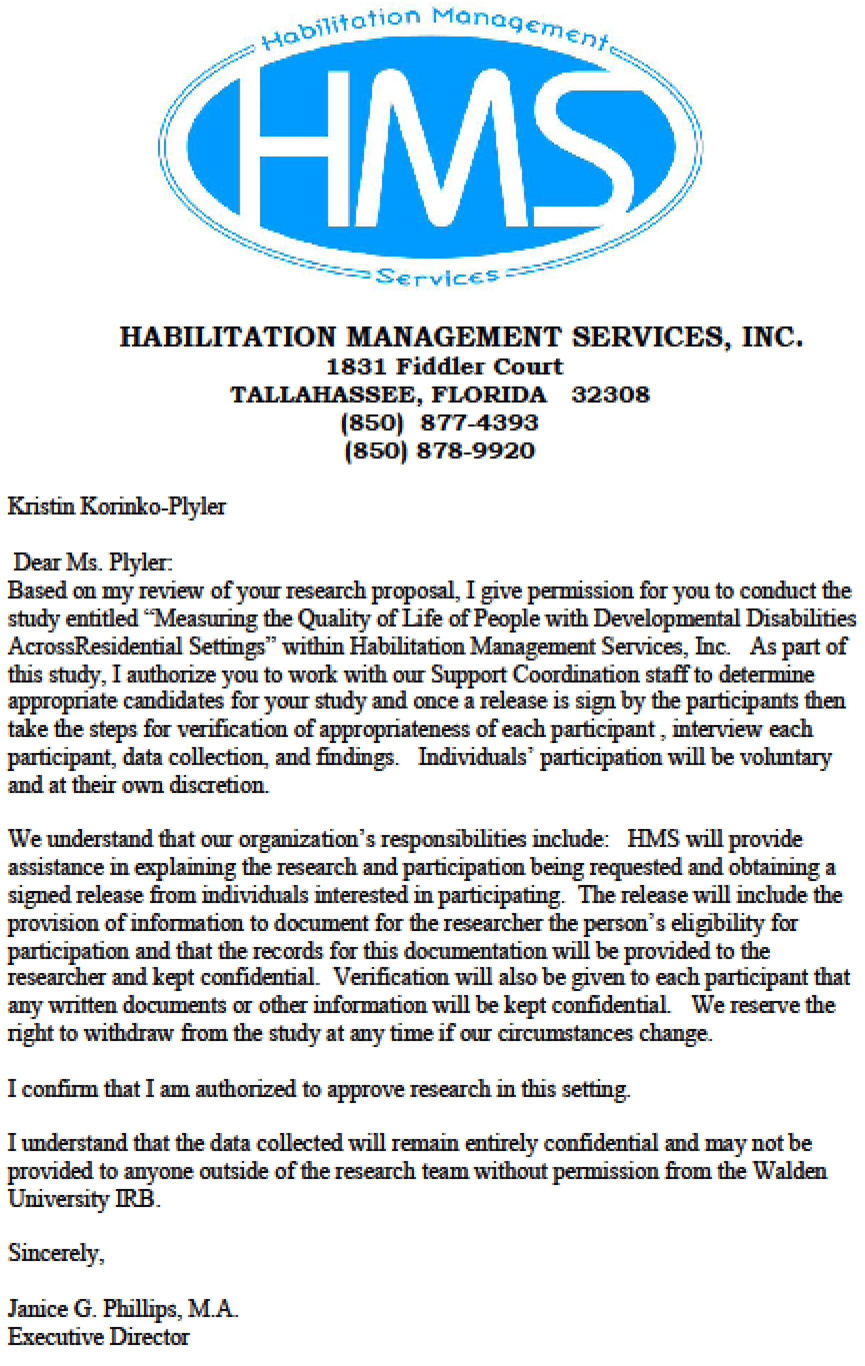
I understand that the data collected in this study will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

Kathleen A. Coleman, MA BCBA
Executive Administrator

cc: Marilyn Yon, President & CEO
Scott Gaedke, Administrator, TDC

Appendix K3: Permission to sample populations



HABILITATION MANAGEMENT SERVICES, INC.
1831 Fiddler Court
TALLAHASSEE, FLORIDA 32308
(850) 877-4393
(850) 878-9920

Kristin Korinko-Plyler

Dear Ms. Plyler:
Based on my review of your research proposal, I give permission for you to conduct the study entitled "Measuring the Quality of Life of People with Developmental Disabilities AcrossResidential Settings" within Habilitation Management Services, Inc. As part of this study, I authorize you to work with our Support Coordination staff to determine appropriate candidates for your study and once a release is sign by the participants then take the steps for verification of appropriateness of each participant , interview each participant, data collection, and findings. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: HMS will provide assistance in explaining the research and participation being requested and obtaining a signed release from individuals interested in participating. The release will include the provision of information to document for the researcher the person's eligibility for participation and that the records for this documentation will be provided to the researcher and kept confidential. Verification will also be given to each participant that any written documents or other information will be kept confidential. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

Janice G. Phillips, M.A.
Executive Director