

**A program evaluation of the State of Alabama Independent
Living Services Program**

by

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Abstract

The transition to independent living is a celebration of leaving a dependency life stage and transitioning into a life stage of autonomy. However, for individuals with significant disabilities who require assistance, they are often excluded from this writ of passage (Lachat, 2002). Historically, social and economic factors have relegated individuals with disabilities to the margins of society, preventing any consideration or opportunity to be independent, self-determining, to control one's life, or even exert choices (Lachat, 2002).

The independent living movement was considered “the last civil rights movement” (Dreidgner, 1989, p. 94). From this movement, an independent living philosophy emerged that began to change the social and individual perception of individuals with disabilities. This philosophy emphasized personal self-worth and value regardless of the disability, the ability to control one's life, and full participation in society. Fundamentally, the independent living philosophy is all about quality of life, with assistance that is directed by the individual (DeJong, 1983).

Adopting the independent living philosophy and applying the quality of life construct, the State of Alabama Independent Living (SAIL) Service Program, a division of the Alabama Department of Rehabilitation Services (ADRS), assists eligible individuals who have a physical or intellectual disability prepare for, and live independently in the community (SAIL, 2015). However, program evaluations about Independent Living (IL) services are largely absent from the literature.

This program evaluation sought to understand the way independent living services are provided by SAIL's Independent Living specialists and do these services enhance the IL consumer's quality of life (QOL). Results showed that 1,035 IL consumers were served during the evaluation time-period; of these, 684 IL consumers met their independent living goals. To determine QOL, the program evaluator developed and utilized proxy variables based on Schalock's (2004) Core Quality of Life Domains and Most Commonly Used Indicators table. The proxy variables were used to measure certain QOL components reported in the data for IL consumers served.

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List of Abbreviations

ABA	Architectural Barriers Act
ADA	American's with Disabilities Act
ADRS	Alabama Department of Rehabilitation Services
CIL	Centers for Independent Living
CMS	Centers for Medicare and Medicaid Services
CRAB	Committee for the Removal of Architectural Barriers
CRS	Children's Rehabilitation Services
DBAC	Disabled and Blind Action Committee
DIA	Disabled in Action
DSO	Delta Sigma Omicron
DSP	Disability/Disabled Students Program
EI	Early Intervention
HIM	Handicapped Integration Movement
IL	Independent Living
NAACP	National Association for the Advancement of Colored People
PUSH	People United in Support of the Handicapped
QOL	Quality of Life
SAIL	State of Alabama Independent Living
SMILE	Systems for Managing Information on the Leading Edge

SOFEDUP Student Organization for Every Disability United for Progress

SSDI Social Security Disability Income

SSI Supplemental Security Income

SQL Structured Query Language

SWD Students with Disabilities

VR Vocational Rehabilitation

WIOA Workforce Innovation and Opportunity Act

WIA Workforce Investment Act

Organization of the Study

This study is organized into five chapters. An overview of the study is presented in Chapter One. Chapter Two examines relevant literature regarding the historical treatment of individuals with disabilities to include the individual, societal, and legislative response to disability. Additionally, DeJong's (1979) development of the independent living paradigm and the quality of life construct as it pertains to individuals with disabilities is reviewed, as well as the emergence of the State of Alabama Independent Living (SAIL) Services Program within the Alabama Department of Rehabilitation Services.

Chapter Three discusses the methods for completing this study. First, this section explains the research design and why it was selected. It then describes the preparatory actions that occurred prior to the initiation of the study, such as data gathering and treatment. Next evaluation questions and the evaluation plan are identified, including interpretation procedures and data analysis.

Chapter Four presents the results of this study, using secondary de-identified data to answer the research questions. Where data are available, quality of life indicator results are presented, as well.

Chapter Five provides a discussion of these findings in relation to the existing body of literature. Quality of life indicators are addressed, as one of the objectives of the SAIL program is to ensure that quality of life is enhanced for those individuals receiving services. Additionally provided is information regarding study limitations, a discussion of the implications, and

suggestions for future research with individuals who receive services through the Independent Living program.

CHAPTER I. INTRODUCTION

According to the U.S. Census Bureau (2010) there are approximately 56.7 million Americans, 19 percent of the population, living with a disability. Of whom, more than half report a significant disability. Some individuals require assistance from another person with everyday tasks such as dressing, eating, toileting, housekeeping, balancing a checkbook, and other activities of daily living (Fricke, 1993). While this assistance is necessary for some, all individuals with disabilities should be afforded the right to the same choices, control, and freedom as any other person. Controlling and guiding one's life means making cultural and life style choices from socially or culturally acceptable options (Schalock & Verdugo, 2015). These acceptable options would be those options available for both people with and without disabilities. There should be no discriminatory practices by limiting people with disabilities to a particular or set number of options from which to choose (Schalock & Verdugo, 2015).

For most, these personal choices should decrease the dependence upon others when making decisions and performing everyday activities (Fricke, 1993). It includes taking risks and having the right to succeed or fail, and assuming responsibility for one's decisions and actions. Being able to control and direct one's life leads to self-determination, independence, and a quality of life of his or her own making (DeJong, 1978).

Independent Living

The term independent living is relative; however, for people with disabilities what is of most importance is the ability to choose the level of independence or dependence appropriate for

an individual's lifestyle and social patterns (DeJong, 1978). Additionally, it is important to note the difference between independent living and living independently. Living independently infers that proclaimed experts and professionals train an individual with a disability to perform and accomplish activities of daily living independently without continued assistance. Independent living is focused on the quality of life experience with assistance (DeJong, 1978). The person with a disability is not an invalid who requires care, but a person who needs assistance with certain activities, that he or she controls and manages (Scotch, 2009).

Crewe and Zola (1987) postulated that individuals with disabilities are unconcerned with individual task performance and are more focused on their quality of life with assistance. Their lived life is more than the ordinary physical tasks of daily living. It extends beyond the physical accomplishment to the personal, political and socio-economic choices they choose to make (Scotch, 2009).

The concept of independent living is certainly not a new one. The desire to gain control and responsibility for one's life is paramount to virtually all individuals. Independence is something we all hope to one day obtain, and for most it is an automatic and unconscious progression. However, for people with disabilities, particularly those with significant physical disabilities who require assistance, they are often excluded from this writ of passage (Lachat, 2002). Rarely are they afforded the opportunity to be independent, to be self-determining, to control their own life, or even exert choices (Lachat, 2002). Due to a combination of social and economic factors, many people with disabilities are relegated to the margins of a society, provided only with obligatory consideration with regard to primary social issues (Lachat, 2002). They are oftentimes hidden away in institutions, granted special education, engaged in supported employment, and provided with segregated housing. While the notion of independent living for

people with disabilities is not new, our society, even with all its remarkable advancements in the area of equality, takes a somewhat passive stance with regard to this issue (Lachat, 2002).

While we applaud some of the efforts and progress we make as a society with regard to disability equality, numerous attitudinal, architectural, and institutional barriers continue to exist; and the task of assisting people with a disability falls mainly on family members, local organizations and government agencies (Duggan & Linehan, 2013). In light of these barriers, the reality for many people with disabilities is that life is merely one of daily existence, with minimal level of support and acceptance that further contributes to their historically reinforced dependency status (Faughnan, 1979).

Our society is not completely dispassionate with regard to action. History has taught us that the will and determination of individuals like Fred Fay, Ed Roberts and Judith Heumann, can spark a cultural revolution resulting in significant change (Patterson, 2012). Over time, the independent actions of just a few individuals with disabilities fueled a larger social movement in what became known as the independent living movement (Patterson, 2012). Through this movement, individuals with disabilities acted as change agents. No longer would they remain on the educational, political, and societal periphery, they would fight for their rights to full participation and to demand equality with their fellow citizens. The independent living movement evolved from a social movement to a catalyst of change by redirecting the course of disability policy and practice (Patterson, 2012).

Independent Living Movement

The independent living movement can be referred to as "the last civil rights movement" (Dreidgner, 1989, p. 94) and comes after a long series of movements for rights for labor, women, and African Americans. This grassroots movement, started by people with disabilities and their

desire for independence, marks another significant and crucial chapter in our society. It represents a new beginning, a shift in the balance of power and a source of hope for people with disabilities who have historically been forced to remain on the social periphery.

Like any other social movement, independent living is a product of its culture and its time. Such movements become possible when, according to Turner (1969), society no longer views adversity with pity, but rather as an opportunity for social justice. The desire of individuals with disabilities to experience control over their lives is not an issue of charitable consideration, rather it is one of an individual's right to experience all that life has to offer (Turner, 1969).

Independent Living Philosophy

From this movement, an independent living philosophy emerged that emphasized personal self-worth and value regardless of the disability, the ability to control one's life, and full participation in society. When an individual with a disability exercises these rights, then he or she determines their life course and its quality. Fundamentally, the independent living philosophy is all about quality of life, with assistance that is directed by the individual (DeJong, 1983).

Quality of Life Concept

The concept of quality of life has been increasingly related to individuals with disabilities. Verdugo, Schalock, Keith and Stancliffe (2005), assert that this idea is being used in the following manner: as an awareness that offers a sense of reference to and guidance from a personal perspective; as a social construct for improving personal well-being and advocating for program, community and societal change; and as a framework for conceptualizing, measuring, and applying the quality of life construct.

State of Alabama Independent Living Services Program

Adopting the independent living philosophy and applying the quality of life construct, the State of Alabama Independent Living (SAIL) Service Program, a division of the Alabama Department of Rehabilitation Services (ADRS), assists eligible individuals who have a physical or intellectual disability prepare for and live independently in the community (SAIL, 2015). SAIL provides Alabamians with the most significant disabilities specialized in-home education and counseling, attendant care, training, and medical services. The overall objective of this program is to ensure independent living at home, work, school, and community; and enhance the quality of life for those individuals receiving services. Services are provided through the Independent Living Services, the SAIL Waiver, or the Homebound Waiver programs. However, program evaluations with regard to Independent Living services are largely absent from the literature. This study examined only the Independent Living Specialist service delivery efforts, including a quality of life component, for individuals with disabilities.

Purpose of the Study

The purpose of this study is to evaluate the services provided by the SAIL Independent Living (IL) Service Program to individuals with significant disabilities living in their respective community. In addition, the results of the study may provide an opportunity to develop recommendations for programmatic improvement.

Overarching Research Questions

This study evaluated the Independent Living Service Program, a division of SAIL, within the Alabama Department of Rehabilitation Services by answering the following questions:

1. What are the top five services provided by IL to help individuals with significant disabilities function independently in their home between January 1, 2014 through December 31, 2016?

2. How many cases were opened during this time-period?
3. What is the most common disability diagnosis and cause of those served during this time-period?
4. What is the average caseload size during this time-period?
5. What is the average expenditure per consumer?
6. What is the average length of time a consumer is served?
7. What is the most common living arrangement of the consumer upon closure?
8. Do IL services align with the IL mission statement, specifically providing a higher quality of life?

Overview of the Methodology

The evaluation examined existing data in the ADRS case management system from individuals with disabilities who have been served through the IL Service Program, a division within the Alabama Department of Rehabilitation Services. The methodology utilized included a quantitative analysis, as well as the development of a data dictionary to determine quality of life components within the existing data.

Significance of the Study

To understand the scope of the IL service methods provided to individuals with the most significant disabilities and evaluate service delivery outcomes, existing data were collected from the ADRS case management system, and analyzed. For purposes of this study, significant disability is defined as an intellectual, mental, or physical impairment that results in a substantial impediment requiring nursing facility level of care criteria. Examples of such impairments include, but are not limited to: quadriplegia, traumatic brain injury, amyotrophic lateral sclerosis, muscular dystrophy, spinal muscle atrophy, severe cerebral palsy, stroke and other substantial

neurological impairments, severely debilitating diseases, or rare genetic diseases. The disability is not related to the aging process. The information gained from this program evaluation can be used locally by each district SAIL administration and staff, statewide by the SAIL state office administrators, Alabama Department of Rehabilitation Services (ADRS) and the state of Alabama, and nationally by the Centers for Medicare and Medicaid Services (CMS), to identify effective service delivery methods, possible service delivery gaps, and areas for future improvement.

CHAPTER II. REVIEW OF THE LITERATURE

Historical Treatment of Individuals with Disabilities in America

Institutionalization and the Medical Model of Disability

The arrival of World War I veterans returning home with significant physical disabilities led to the rapid legislative push to provide these veterans with supports and services. However, the legislation for individuals born with an intellectual or physical disability still focused on the exclusion of these individuals via institutionalization. Institutional laws made the separation between the individual with a disability and their family easy to accomplish. Once excluded, separated, and isolated, the family member and society as a whole, are absolved of all responsibility (Smart, 2009). The responsibility is now in the hands of the medical professional,

Because of the way the medical profession is organized and the mandate it receives from society, decisions related to medical diagnoses and treatment are virtually controlled by the medical professions.... By defining a problem as medical, it is removed from the public realm where there can be discussion by ordinary people and put on a plane where medical people can discuss it (Conrad, 2004, p. 22).

This medical model of disability, also known as the disease model, segregated individuals into two categories: normal and pathological (Smart, 2009). Normal is defined simply as those without pathology. In order to determine a pathological diagnosis, medical professionals would utilize “objective, clear-cut, standardized measurements” (Smart, 2009, p. 60). For those individuals who physicians believed disability could be cured, treatments were implemented.

Those who fell short of meeting the standards for normality were determined incurable and labels like abnormal, dysfunctional, and deficit were ascribed. This deficit ascription placed individuals with disabilities in a devalued social group. Once devalued, these individuals had very little control of their physical environment. In order to treat, but not cure these individuals, they were often housed in institutions. Their medical treatment plans were then carried out by the physicians or attending staff without consultation or interference from the patient or family.

By 1914, mandated institutionalization laws were in effect in over 30 states (Stroman, 2003). Individuals with disabilities, regardless of the severity of the condition, were institutionally housed in large buildings resembling dormitories. Institutions were often underfunded, understaffed, and lacked structure and daily routines that provided opportunities for personal growth (Halpern, Sakkett, Binner, & Mohr, 1980; Stroman, 2003). Individuals who lived in these institutions were mistreated, abused, neglected and some were even subjected to unusual treatments including unwanted sterilization. This lack of reasonable care further perpetuated the devalued label of individuals with disabilities.

Institutionalization replaced eugenics as the common practice for treating individuals with disabilities. Both the medical and societal movements excluded and marginalized individuals with disabilities as they were considered deviant, possessing undesirable traits. However, for one such disability group, fair and equitable treatment was on the horizon.

Disability legislation for those with acquired disabilities

World War I soldiers

For soldiers returning home from World War I, who acquired their disability during service to the United States, advocacy efforts, disability awareness campaigns and legislative agendas were actively pursued. The Smith-Hughes Act of 1917 (P.L. 64-347) was the first piece

of legislation passed as a result of these efforts (Hillison, 1995). Through this Act veterans were granted rehabilitation services. The following year, the Smith-Sears Act (P.L. 65-178) was passed largely in part to waning service funds in the Smith-Hughes Act. The Smith-Sears Act was the first law that allotted federal funds to provide support services to injured war veterans. Two years later, the Smith-Fess Act (P.L. 66-236), a state-federal vocational rehabilitation program, was enacted to provide provisions to non-military employees who sustained a disabling condition while employed in an industrial work environment (Ledbetter & Field, 1978). These services included, but were not limited to, prosthetic limbs, counseling, and new job placement for those individuals who had acquired a disability at their previous industrial employment setting. While certain individuals with acquired disabilities were receiving services through federal programs, individuals with disabilities who did not meet the required qualifications were receiving no services. This discrimination would be remedied by the passage of the Social Security Act of 1935 (P.L. 104-193) which permanently established a vocational rehabilitation program.

President Roosevelt and legislative reforms

The need for social insurance became evident with the emergence of the American Industrial Revolution. Prior to this period most individuals were farmers, laborers, or craftsmen and could provide for their own sustenance. When in financial or familial need, individuals could rely on their extended family for assistance. This shift from preindustrial to industrial communities constituted a new need for economic security and social provisions (Ledbetter & Field, 1978). The Great Depression was an additional contributing factor for this need.

The Great Depression that began in 1929 affected all Americans, but especially hard hit were the elderly and individuals with disabilities. Older workers, who had worked their entire

life to support their family, were the first to lose their job and were now living in poverty. Individuals with disabilities, who were fortunate enough to be employed, lost their jobs as well and were not likely to be rehired.

Within the first 100 days of his Presidency in 1933, Franklin Roosevelt addressed Congress concerning the nations rising unemployment levels (Maher, 2015). In response, Congress established the Social Security Act. This new program provided federal funded benefits for the elderly and assistance for individuals who were blind or had other disabilities (Jaeger & Bowman, 2005). Additionally, the Act extended existing vocational rehabilitation programs and services to individuals who were born with disabilities.

As the economy began to recover and federal programs were established World War I veterans, who had acquired a disability while fighting for their country, demanded the government increase their services (Test, Aspel, & Everson, 2006). When World War II began and a new group of America soldiers were returning home with acquired disabilities, political and social need for disability services increased. Congress could no longer simply give a cursory nod to the issue of disability services, rather they were forced to address the welfare and long-term needs for these soldiers. New legislation would be required to enable rehabilitation veterans with disabilities.

The Barden-LaFollette Vocational Rehabilitation Act (P.L. 78-113) of 1943 and the Hill-Burton Act (P.L. 725-79) of 1946 were both passed to aid returning war veterans. The Barden-LaFollette Act declared that vocational rehabilitation programs receiving federal funds would extend their services to include physical rehabilitation as a goal for veterans who acquired disabilities. In addition, the Act authorized services to individuals with a significant disability or a mental health diagnosis. The Hill-Burton Act authorized a series of construction grants to build

hospitals, public health centers, and rehabilitation facilities to help individuals with disabilities (Browning, 1998). These legislative Acts were indicators that disability awareness and rights were being heard and addressed for civilians and service members who acquired a disability; however, for those born with a disability, institutionalization was the prevailing societal norm.

Institutional legislation and reform

The New York State Association for Retarded Children v. Carey

The New York State Association for Retarded Children v. Carey (1975) lawsuit was a turning point in the advancement of the legal rights of people with disabilities to live in dignity. The case brought public attention to the horrific conditions in which children and adults were living at Willowbrook State School in New York. More importantly, it set precedents for individuals with developmental disabilities living in institutions to be treated ethically and humanely (Lawton, 2015). No longer was the presumptive placement of an individual with a disability in an institution, rather placements were expanded into the community. Individuals would receive in home services, the availability and quality of day programs increased, and public education rights for children with disabilities were established.

In 1938, construction began in the Willowbrook section of Staten Island, New York to build a large facility for children and adults with intellectual disabilities. However, instead of opening for its original purpose, the facility was converted into a U.S. Army hospital and named Halloran General Hospital. When the war ended, proposals were presented to turn the facility over to the Veterans Administration. Instead the facility opened in October 1947 as originally planned by the New York Department of Mental Hygiene and named Willowbrook State School (Lawton, 2015).

Chronically underfunded, understaffed, and overcrowded the conditions at Willowbrook were horrific. The institution's overcrowding fostered abuse, dehumanization, and a public health crisis. During the first few years the facility was in operation hepatitis outbreaks were common. Hepatitis was so rampant that medical researchers took advantage of the situation and used it as an opportunity for treatment experimentation purposes. Between 1963 and 1966, healthy children were intentionally, and without their consent, infected to test the effectiveness of various vaccines. Researchers defended their practices by pointing out that the children would most likely contract hepatitis while at Willowbrook anyway, and contracting the disease in a carefully controlled environment would be better than contracting it in one of the institutional wards (Lawton, 2015).

Reports of the living conditions were brought to the attention of Senator Robert Kennedy. Senator Kennedy was personally familiar with the injustices individuals with disabilities often faced. At the age of 23, his sister, Rosemary, underwent a prefrontal lobotomy as a 'cure' for her intellectual disability. The operation was a failure and Rosemary was left completely incapacitated. To avoid public scandal, Rosemary was institutionalized at St. Coletta School for Exceptional Children in Wisconsin (Shorter, 2000). In 1965, the Senator paid an unannounced visit to Willowbrook.

During his visit, Kennedy found thousands of residents without proper clothing, living in filth and human excrement, and likened the institution to a "snake pit" (The Minnesota Governor's Council on Developmental Disabilities, The ADA Legacy Project, 2013). The public visit elevated the shocking conditions at Willowbrook into the national spotlight. The state of New York quickly responded by developing a five-year improvement plan. Minor modifications were immediately made at the facility; however, the inhumane conditions that brought

Willowbrook into public consciousness quickly returned. By 1969, Willowbrook was over capacity, housing 6,200 children and adults with developmental and physical disabilities in a facility meant to accommodate 4,000 (Lawton, 2105).

In January 1972, Geraldo Rivera, an investigative reporter for WABC television station in New York, was contacted by a physician who had been recently fired for speaking out about the deplorable conditions at Willowbrook. Rivera's exposé, *Willowbrook: The Last Disgrace* was watched by millions and exposed a host of appalling conditions, including serious overcrowding, unsanitary conditions, dehumanizing practices, and regular abuse of residents (Lawton, 2015). Not only was the general public outraged, but so were the family members of the residents who lived at Willowbrook. A class action lawsuit was filed by the parents of Willowbrook residents on March 17, 1972 claiming the conditions at Willowbrook violated the constitutional rights of their children (Lawton, 2015).

The plaintiffs alleged that the existing conditions violated the residents' constitutional right to treatment under the Due Process Clause of the Fourteenth Amendment and that their denial of a public education violated the Equal Protection Clause of the Fourteenth Amendment. They demanded immediate injunctive relief to improve conditions at Willowbrook including hiring more staff, providing basic necessities like clothing, adequate medical care, opportunities to leave their beds, interaction with the community, and therapy services (Lawton, 2015).

On April 30, 1975, the case was settled when U.S. District Court Judge Orrin Judd signed the Willowbrook Consent Judgment: *New York State Association for Retarded Children, Inc., et al., v. Hugh L. Carey*, 393 F. Supp. 715 (1975). The Willowbrook Consent Judgment provided guidelines and requirements for operating the institution and established new standards of care for all Willowbrook residents.

...regardless of the degree of handicapping conditions, are capable of physical, intellectual, emotional and social growth, and upon the further recognition that a certain level of affirmative intervention and programming is necessary if the capacity for growth and development is to be preserved, and regression prevented (New York State Association for Retarded Children, Inc., et al., v. Hugh L. Carey, 1975).

Additionally, the Willowbrook Consent Judgment outlined specific procedures and instructions for treatment of residents, including hiring additional staff, education, programming evaluation, proper medical and dental care, and resident living. Significantly, the Judgment also declared the primary goal of the institution and the New York Department of Mental Hygiene as to “ready each resident...for life in the community at large” (New York State Association for Retarded Children, Inc., et al., v. Hugh L. Carey, 1975) and called for Willowbrook residents to be placed in the least restrictive environment.

In 1974, during the litigation of the case, Willowbrook State School was renamed the Staten Island Developmental Center. Nine years later, the State of New York announced plans to close Willowbrook, but did not provide an actual closing date. By the end of March 1986, the number of residents housed there had dwindled to 250 (down from 5,000 at the height of the scandal exposed by Rivera), and on September 17, 1987 the last residents left (Lawton, 2015).

The Willowbrook Consent Judgment was ground breaking because of what it accomplished and for the heightened public awareness of the conditions at large state-run institutions for individuals with intellectual and developmental disabilities. Willowbrook left behind a shameful legacy; however, it sparked a generation of disability advocates and policy makers, and led to a deinstitutionalization movement that began in the late 1960s and continues

to this day. Two significant court cases that followed the Willowbrook Judgement are the Wyatt v Stickney (M.D. Ala. 1971) and Halderman v. Pennhurst State School & Hospital (1977).

Wyatt v. Stickney

Bryce State Hospital in Tuscaloosa, Alabama, housed approximately 5,200 patients, most of whom were involuntary committed for mental illness [sic]. A portion of the hospital's funding was provided through the state's cigarette tax. In 1970, the Alabama legislation decided to cut the cigarette tax specifically earmarked for mental health services (Johnson, 1975).

This tax cut set off a chain of reductions in the already overcrowded state mental health facilities. Bryce was forced to fire approximately 100 employees. After the layoffs only three medical doctors with psychiatric training, one psychologist, and 2 social workers with master's degrees in social work remained at the facility. These six professionals were left to serve the entire hospital (Johnson, 1975). The living conditions and lack of appropriate treatments at Bryce were intolerable and deplorable. Staffing ratios and living conditions in Alabama's other facilities, Partlow State School and Hospital in Tuscaloosa and Searcy Hospital in Mount Vernon, were not much better (Johnson, 1975).

On October 23, 1970, former Bryce staff members filed a lawsuit against Dr. Stonewall Stickney, Commissioner of the Alabama Department of Mental Health and the State of Alabama Mental Health Officer, in the U.S. District Court for the Middle District of Alabama seeking reinstatement of their positions at Bryce. They claimed that patients in the institution would receive inadequate treatment without the necessary staff. The suit was expanded to include patients in Searcy Hospital and Partlow State School and Hospital (Wyatt v. Stickney, M.D. Ala. 1972).

When the case was filed, Alabama ranked 50th out of 50 states for expenditures for the care of people with mental illness [sic] or mental retardation [sic] residing in public institutions. Alabama expenditures per patient per day was 50 cents to provide the physical institution, clothing, and food for these facilities. The conditions at these hospitals were so inhumane that the editor of the Montgomery Advertiser newspaper described the state's residential institutions as concentration camps, similar to those run by the Nazis in Germany during World War II (Carr, 2004). The public knew very little about the horrible living and treatment conditions at these facilities; residents were out of sight and out of mind.

In order to personalize and strengthen their case the staff decided to include patient, Ricky Wyatt as a plaintiff. Fifteen-year-old Ricky was the nephew of Mrs. W.C. Rawlins, one of the laid-off employees at Bryce. He was committed to Bryce by court order in 1969 for misbehaving in a group home in Selma, Alabama. The hope was that institutionalization would force Ricky to behave. Ricky had no mental health diagnosis and the physicians at Bryce simply considered him a juvenile delinquent (Johnson, 1975).

The purpose of the lawsuit was threefold: 1) establish a constitutional right to treatment on behalf of people with mental illness [sic], 2) establish a constitutional right to habilitation on behalf of people with mental retardation [sic], and 3) set minimum standards regarding safety, education, training, medication, nutrition, physical accommodations, staff/patient ratios, individualized treatment, and aftercare (Carr, 2004). As revealed through research and testimony, the living conditions at the state institutions were appalling. Patients were left unattended, could wander from ward to ward, and have access to unlocked medicine cabinets. Patients would accidentally overdose on prescription medications and die. A boy diagnosed with profound mental retardation [sic] had a garden hose inserted in his rectum by the attending staff and filled it with

water. His spleen ruptured, killing him. Other examples of horrifying incidents brought before the court included a resident who was scalded to death, as well as a resident who was restrained in a strait jacket for nine years to prevent hand and finger sucking (Carr, 2004).

Not only were atrocious acts of neglect and abuse revealed, but dangerous building and safety conditions as well. Bryce Hospital had no fire safety equipment or fire escape plans. Fire hydrants had been installed on the Bryce campus in 1923; however, the fire hose couplings used in the 1970s were not compatible to a 1923 hydrant. At Partlow, the switchboard shut down at 5:00 pm, cutting off phone communication if the fire department needed to be contacted after hours (Carr, 2004).

After hearing the testimony and arguments in the case, U.S. District Court Judge Frank M. Johnson, Jr. ruled on March 12, 1971 that thousands of individuals who had been involuntary committed to Bryce “have a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition” (Wyatt v. Stickney, M.D. Ala. 1972). He further added

...there can be no legal (or moral) justification for the State of Alabama’s failing to afford treatment—and adequate treatment from a medical standpoint—to the several thousand patients who have been civilly committed to Bryce for treatment purposes. To deprive any citizen of his or her liberty upon the altruistic theory that the confinement is for humane therapeutic reasons and then fail to provide adequate treatment violates the very fundamentals of due process (Wyatt v Stickney, M.D. Ala. 1971).

On August 22, 1971, the plaintiffs requested the patients who were involuntarily committed at Searcy and Partlow be added to the lawsuit claiming conditions at their institutions were no better than at Bryce (Carr, 2004).

Judge Johnson gave Bryce six months to establish standards and implement a fully compliant treatment program. During this time, the conditions, programs, and standards to provide a patient a realistic opportunity to improve their mental health were thoroughly investigated. The investigation revealed that while Bryce was deficient in providing a humane physical and psychological environment, sufficient qualified staff to administer treatment, and individualized treatment plans, it was obvious that good faith efforts were being made to meet the desired standards (Wyatt v. Stickney, M.D. Ala. 1971).

In December 1971, after the six-month probation period, Judge Johnson ruled that Bryce had failed to formulate proper treatment standards. Additional expert testimony revealed the treatment program at Bryce was entirely insufficient. Judge Johnson ordered all parties to develop and produce medical and constitutional standards for the operation of Bryce, Searcy and Partlow (Carr, 2004).

The following month the parties convened in Atlanta, Georgia, to follow the orders from Judge Johnson: develop standards of care for the state institutions. The parties developed two agreements. One specified the necessary standards at Bryce and Searcy Hospitals in order to define minimally adequate mental treatment at a state psychiatric institution. The second agreement covered the standards to be enforced at Partlow. Both agreements were filed with the district court and a hearing was held on the Bryce and Searcy agreement on February 3 and 4, 1972 (Wyatt v. Stickney, M.D. Ala. 1972).

The Partlow hearing was conducted February 28 through March 2, 1972 and upon conclusion of the hearing, an emergency court order required immediate actions be taken at Partlow. These actions included the hiring of 300 additional staff, the installation of an

emergency light system and procedures for emergency evacuation, and revision of kitchen sanitation procedures (Carr, 2004).

In his decisions, Judge Johnson applied what came to be known as the Wyatt Standards (Carr, 2004). These standards detailed the basic requirements to ensure that the three previously found deficiencies of: 1) providing a humane physical and psychological environment; 2) sufficient qualified staff to administer treatment, and 3) individualized treatment plans, were promptly corrected. Additionally emphasized was the downsizing of state institutions and the increase of community services (Wyatt v. Stickney, M.D. Ala. 1972).

Over the next three decades, Wyatt v. Stickney and the implementation of the Wyatt standards were often disputed in federal court, ultimately leading to numerous consent decrees. During this time, community based services were being developing in Alabama, allowing individuals living in institutions to transition into the community. The case finally ended in 2003 when U.S. District Court Judge Myron H. Thompson officially approved the settlement of the original class action, and dismissed the lawsuit (Wyatt ex rel Rawlins v Sawyer, M.D. Ala. 2004).

Halderman v. Pennhurst State School & Hospital

Originally known as the Eastern Pennsylvania Institution for the Feeble Minded and Epileptic, Pennhurst was once seen as a model institution during an era when the solution to dealing with disability was forced segregation and sterilization. The facility was situated on a large tract of land in Chester County near the borough of Spring Hill. Numerous buildings were constructed on the site including resident's hall that would accommodate up to five hundred, a school, gymnasium, drill hall, work shop, and hospital. On November 23, 1908, the first resident was placed in at Pennhurst. He was listed as "Patient number 1," a labeling system that would be

carried forward for all the thousands of Pennhurst's residents (Pennhurst memorial & preservation alliance, 2015).

By 1912, Pennhurst was overcrowded. Originally built for epileptics [sic] and individuals with intellectual and developmental disabilities, there was intense societal pressure, due to the eugenics movement, to admit any person regarded as different. This even included immigrants, orphans, and criminals (Pennhurst memorial & preservation alliance, 2015). This practice continued for several years and Pennhurst became a human dumping ground for the disabled [sic], unwanted, and unnatural. Eventually the mission of the institution was clarified and only individuals with intellectual disabilities were admitted.

In 1916, Pennhurst's Board of Trustees considered plans for further increasing the institutions capacity. However, this increase was not to address the overcrowding problem, but to take in female residents. Keeping in mind the presence of the eugenics movement, females who were considered feeble-minded were considered a greater menace to society. It was erroneously believed that the feeble-minded female was more likely to bear defective [sic] and disabled [sic] children. State institutions were not adequately equipped to care for all the feeble-minded, and therefore the feeble-minded females were institutionalized and sterilized. The building plan was to erect exclusively female cottages to house approximately 1,200 girls. The cottages would be a sufficient distance from the existing buildings as male and female residents were segregated. The female campus was not completed until 1930 (Pennhurst memorial & preservation alliance, 2015).

The Board of Trustees published the Pennhurst biennial report on May 31, 1930. It records that there were 1,247 residences and 192 employees. The report also states that two of the female cottages were nearly completed and with a capacity of at least 300, some of the

overcrowding should be temporarily relieved. However, this would be short-lived. The Board reports that as of publication date, there were currently 900 admission applications on file, with new applications coming in at a rate of 250 per year. During the two-year period covered by the report, 240 individuals were admitted (Pennhurst memorial & preservation alliance, 2015).

By 1955, the in-house population of Pennhurst peaked at 3,500 residents. Two buildings on campus were opened in former tuberculosis sanitariums. Hundreds of residents were transferred to these facilities which allowed for additional placements and the Pennhurst population grew to 4,100 residents. Two more annexes are 'spun off' from Pennhurst in 1961, becoming the Hamburg and White Haven State Schools (Pennhurst memorial & preservation alliance, 2015).

By the mid-1960s, Pennhurst had been open for sixty years. It housed 2,791 people, most of them children, which was about 900 more than the institution could adequately accommodate. In 1968, WCAU news reporter Bill Baldini, documented the overcrowded, abusive, and inhumane living conditions of the residents with developmental disabilities at Pennhurst. He released a five-part television exposé called “Suffer the Little Children” that shocked and angered the public. The administrators interviewed in the exposé recognized they were not providing adequate care or services to the residents. Only 200 residents participated in any kind of art, education, or recreation programs that would help facilitate educational, emotional, creative, and social improvements. Administrators admitted that many of the residents were high-functioning enough to improve with the right services and supports. In addition to the shortage of programs, the older buildings were in desperate need of repair, there was a budget shortfall of four million dollars, and only 9 medical doctors and 11 teachers, none with special

education training, remained at Pennhurst. Administrators felt their hands were tied by the lack of state funding (Pennhurst memorial & preservation alliance, 2015).

Certainly, the staff and administrators would have been an easy target for society to blame, but before that could happen, Baldini intervened. In his exposé, Baldini blamed society's indifference regarding the treatment of individuals with disabilities for allowing such conditions to persist. He appealed to viewers to contact their state legislator and demand change (Pennhurst memorial & preservation alliance, 2015).

A class action lawsuit was filed on May 30, 1974, in the U. S. District Court for the Eastern District of Pennsylvania on behalf of Terri Lee Halderman, as well as former and current residents of Pennhurst. Halderman, age 20, had been a Pennhurst resident for 10 years, suffering a series of unexplained injuries during her residency. The plaintiffs hired prominent civil rights attorney David Ferleger, as their legal counsel. The suit named as defendants the institution, its superintendents, and the state officials responsible for Pennhurst's operations. The plaintiffs claimed their institutionalization violated their constitutional rights under the First, Eighth, Ninth and Fourteenth Amendments, as well as under federal civil rights laws and the Pennsylvania Mental Health and Mental Retardation Act of 1966. They sought damages, institutional improvements, equitable relief, and provisions for education, skills training, and integration into community settings. However, their ultimate goal was the closing of Pennhurst (Halderman v. Pennhurst State School & Hospital, E.D. Pa. 1977).

The case went to trial in 1977, with U.S. District Court Judge Raymond J. Broderick presiding. After a thirty-two-day trial, Judge Broderick found that conditions at Pennhurst were not only dangerous, with the residents often physically abused or drugged by staff members, but also inadequate for the 'habilitation' of the retarded [sic]. Pennhurst was overcrowded,

understaffed and lacked the programs needed for adequate habilitation. He found that various unwarranted forms of restraints, including seclusion rooms, physical restraints and psychotropic drugs, were utilized as a means of resident control due to inadequate staffing. The physical environment was found to be so unsafe that it was prohibitive to acquiring new skills and skills already obtained were readily lost. Residents were found to have been subject to abuse by both other residents and staff (Halderman v. Pennhurst State School & Hospital, E.D. Pa. 1977).

Judge Broderick gave a sweeping ruling in the plaintiffs' favor. He found that the Pennhurst residents had three distinct sets of constitutional rights: 1) Right to Habilitation, citing the Due Process Amendment, the right to be free from cruel and unusual punishment, as well as the Wyatt v Stickney, and N.Y. State Association for Retarded Children v. Carey (Willowbrook) cases. Judge Broderick held that residents should be provided a skills learning opportunity in the least restrictive environment (Halderman v. Pennhurst State School & Hospital, E.D. Pa. 1977); 2) Right to be Free from Harm, citing the Eighth and Fourteenth Amendments, as well as the N.Y. State Association for Retarded Children v. Carey (Willowbrook) case; Judge Broderick held that the residents of Pennhurst had the constitutional right to be free from physical harm (Halderman v. Pennhurst State School & Hospital, E.D. Pa. 1977); and 3) Right to Non-Discriminatory Habilitation. Judge Broderick found that residents were confined, isolated and segregated; and subsequently were not treated equally (Halderman v. Pennhurst State School & Hospital, E.D. Pa. 1977). Judge Broderick also ruled that the segregation of the residents of Pennhurst "in an institution in which they have been and are being denied minimally adequate habilitation [violated] their Equal Protection Rights as guaranteed by the Fourteenth Amendment to the Constitution" (Halderman v. Pennhurst State School & Hospital, E.D. Pa. 1977).

As determined by the Court, the conditions at Pennhurst were so deplorable that the above-mentioned rights had been violated. Judge Broderick ordered Pennhurst to find “suitable community living arrangements” and “community services as are necessary to provide them with minimally adequate habilitation” for all current Pennhurst residents (Halderman v. Pennhurst State School & Hospital, E.D. Pa. 1977). To ensure success, and to oversee the appropriate placement of each resident and the eventual closure of Pennhurst, Judge Broderick established a Special Master.

Over the next few decades, various aspects of Judge Broderick’s initial ruling were appealed. The first appeal was taken before the Third Circuit Court of Appeals where the decision was upheld. The order went into effect in 1979 and for the first time secured community living arrangements for school-age Pennhurst residents. A year later, the Pennhurst case was heard before the Supreme Court. This would be the first of three attempts to reverse the lower court’s ruling. During the 1985 Supreme Court proceedings, Judge Broderick wrote,

No one . . . anticipated that this civil action commenced on May 30, 1974 would be actively litigated for more than ten years, requiring 2,192 docket entries, about 500 Court orders, twenty-eight published opinions, and three arguments before the U.S. Supreme Court” (Halderman v. Pennhurst State School and Hospital, E.D. Pa. 1985).

While the appeal of the original ruling was pending, a settlement agreement was reached between the parties to provide community based services and living arrangements for the remaining residents of Pennhurst. The settlement also included the closure of Pennhurst the following year (Halderman v. Pennhurst State School and Hospital, E.D. Pa. 1985).

Pennhurst closed in 1987, a year later than ordered. Despite the closure, litigation continued through the 1990s to enforce the settlement agreement, which was not being well

implemented by the state. Many former residents were not being provided the community based services and living arrangements required. Both the state of Pennsylvania and Chester County were found in contempt by the court for numerous agreement violations (Pennhurst memorial & preservation alliance, 2015).

Olmstead v. L.C.

In addition to the previously mentioned law suits and subsequent legislative changes, *Olmstead v. L.C.* (P.L. 98-536), is one of America's most significant civil rights decision for individuals with disabilities. The *Olmstead* case (P.L. 98-536) was brought by two women, Lois Curtis and Elaine Wilson, who had mental health and cognitive disabilities, and who had been voluntarily admitted to the psychiatric unit in the state-run Georgia Regional Hospital. Ms. Curtis' first institutional placement was at the age of 13. In 1992, as a now young adult, she was readmitted for inpatient psychiatric treatment. A year later her mental health treatment team determined she could live in the community with needed services. However, she was not discharged to a community based treatment program, and remained institutionalized until 1996. Ms. Wilson encountered a similar experience. She was admitted to an inpatient psychiatric unit in 1995. In response to her request for community treatment, the hospital proposed discharging her to a homeless shelter. Ms. Wilson successfully challenged this proposition. A year later, her treating physicians determined that Ms. Wilson could receive treatments in the community. Like Ms. Curtis, another year went by before Ms. Wilson was finally discharged in 1997 (Rosenbaum, Frankfort, Law, & Rosenblatt, 2012).

Curtis contacted community legal services seeking assistance to stop her repeated and unnecessary institutionalization; and help her get treatment in the community. Wilson's mother did so, as well. Sue Jamieson, an attorney with the Atlanta Legal Aid Society, filed a lawsuit on

their behalf. Invoking title II of the American's with Disabilities Act (ADA), which bars discrimination against qualified persons with disabilities under public programs, the women claimed that Georgia's Medicaid program failed to provide covered services in the most integrated settings appropriate for their health needs (Rosenbaum, 2000). The lawsuit, which is known as "Olmstead v L.C." or "the Olmstead decision" navigated the legal system to the highest court in the country, The United States Supreme Court. The case name comes from the defendant, Tommy Olmstead, who was Georgia's Commissioner for the Department of Human Resources.

In order to better understand Jamieson's claim, a review of title II of the ADA is necessary. This title states that individuals with disabilities may not be discriminated against, by denying participation in or benefits of governmental services, activities, and programs provided by state and local government entities.

In implementing the regulations of this title, local and state governments must "administer services, programs, and activities in the most integrated setting appropriate" (P.L. 98-536), in order to meet the needs of individuals with disabilities. Additionally, this setting must be one in which an individual with a disability could, to the fullest extent possible, have opportunities to interact with individuals without disabilities. The regulations also require that local and state governments make reasonable modifications to procedures, policies and practices to avoid disability discrimination, unless the modifications would fundamentally alter the nature of the activity, program or services provided. These three notions: most integrated setting, reasonable modification, and fundamental alteration, were the considering factors in the Olmstead claim (Rosenbaum, 2016).

On June 22, 1999, in her opinion for the United States Supreme Court, Justice Ruth Bader Ginsburg, held in *Olmstead v. L.C.*, that individuals with disabilities have a qualified right to receive state funded community level supports and services; and in denying Curtis and Wilson these rights they were unjustly segregated and discriminated against, both a violation of title II of the Americans with Disabilities Act. The Court held that individuals with disabilities have a qualified right to receive community-based supports when 1) such services are determined appropriate by the person's professional treatment team; 2) the individual does not oppose community-based living; and 3) the provision of community-based services would be a reasonable accommodation, considering resources available and the similarly situated needs of others receiving disability services (Rosenbaum, et. al., 2012). While the *Olmstead* decision involved plaintiffs with a mental health disability, subsequent guidance of community-based services proved that individuals with all types of disabilities can benefit from the above-mentioned principles.

The Supreme Court based its holding on two evident judgments of the ADA when it was enacted by Congress. First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life"(Rosenbaum, 2016, p. 587). Second, Congress found that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (Rosenbaum, 2016, p. 588). This act of Congress and the Supreme Court once again sought to eliminate disability-based discrimination and promote the integration of people with disabilities in the community.

The Willowbrook, Wyatt, and Pennhurst cases all helped push the deinstitutionalization movement further. The verdicts to all of these cases were critical to the passage of landmark federal civil rights legislation protecting individuals with disabilities – including the Protection and Advocacy System as outlined in the Developmental Disabilities Assistance and Bill of Rights Act of 1975, The Education for All Handicapped Children Act, also passed in 1975, and the Civil Rights of Institutionalized Persons Act of 1980. These laws were the first federal civil rights legislation protecting people with disabilities (Lawton, 2015).

The Olmstead ruling was one of the most important civil rights legislation for individuals with disabilities. After decades of institutionalization, isolation and segregation, community-based services were now federally mandated. Integration and inclusion would finally be a reality for individuals with disabilities who had lived on the societal periphery. While deinstitutionalization and community-based services were litigiously fought in America's court system another movement was emerging as well.

The Independent Living Movement

Leaders in the Independent Living Movement

Deinstitutionalization provided, for the first time in history, an opportunity for people with disabilities to live free and independent lives. From this, a community and a culture with history, values, and an objective were born. Key players and their grassroots advocacy lead to the emergence of this movement, the development of Centers for Independent Living (CIL) across America, and the passing of the Rehabilitation Act of 1973.

Fred Fay and the University of Illinois. Frederick Allan Fay was reared in Bethesda, Maryland. He was a member of the rifle team at Bethesda-Chevy Chase High School and excelled in athletics. He was an accomplished gymnast and one afternoon in 1961, as Fay was

practicing on the trapeze in his family's backyard, he lost his grip and fell. He landed on his forehead, breaking two vertebrae in his neck. After several months of hospitalizations and immobilization, Fay left Maryland to attend the Warm Springs Institute for Rehabilitation in Warm Springs, Georgia. The Institute was founded in 1927 by Franklin Delano Roosevelt for post-polio and spinal cord injury rehabilitation, and was determined that it never become a hospital. Like most institutions, it was criticized for abuse and racism; however, the facility boasted a barrier free environment that provided a place for people with disabilities, particularly adolescents, to come together and form lasting relationships. Fay stayed seven months at Warm Springs and returned home to complete his senior year of high school (Patterson, 2012).

In the fall of 1962, Fay enrolled at the University of Illinois, Urbana-Champaign campus. His decision to attend this university was influenced by his stay at Warm Springs. Administrators would often refer students with disabilities (SWDs) to the universities nationally prominent Rehabilitation Education Services Program developed by Timothy Nugent in 1948. Here he met other SWDs, even some who had spent time at Warm Springs, and this group formed a tight knit community that Fay referred to as The Wheelchair Ghetto. While the SWDs shared dormitories with those students who did not, SWDs attended segregated classes together, went to rehabilitation together, rode the adapted bus together, and advocated together (Patterson, 2012).

Delta Sigma Omicron (DSO), a male and female fraternity original formed in 1949, published annually two University of Illinois student newspapers, The Spokesman and Sigma Signs. Because of the university's Rehabilitation Education program, the national spotlight was often pointed in their direction. The DSO took advantage of this opportunity to promote higher education for people with disabilities throughout the nation, further their social and recreational welfare, raise awareness about disability discrimination, and advocate for disability rights. They

saw their organization as the bridge between people with disabilities and those without (Patterson, 2012).

In 1964, Fay and sixty other SWDs surveyed every classroom on campus for accessibility and noted necessary curb ramps. DSO established an architectural barriers committee to address the findings. They lobbied the administrators, local business owners, and Campus Businessmen's Association to make the campus more accessible (Fay, 2001). Frustrated by the lack of response from the administrators, Fay developed a picture for publication in the student newspaper of the administration dressed as Ku Klux Klan members holding signs that said Disabled Keep Out. The picture was intercepted by Nugent before it was published (Fay, 2001). Fay's point in designing the picture was to compare the oppression and segregation of the students with disabilities on campus with the treatment of African Americans. Nugent was equally unsatisfied with the university's slow response to the curb ramp appeal and chose a different approach. He and a small group of students took sledgehammers to main curbs to force the university to rebuild them (Patterson, 2012).

Tim Nugent took his advocacy efforts beyond the university class room and streets and into the gym. He founded The University of Illinois Wheelchair Basketball Program in 1948. He believed that wheelchair sports were the most effective student centered program in ending discrimination toward people with disabilities. SWDs participated in sports and used athleticism to revive public perceptions of people with disabilities. It also provided an opportunity for socialization and networking across the country. Each edition of Sigma Signs devoted a significant section to wheelchair sports, emphasizing ability, strength, and agility (Patterson, 2012).

The first basketball wheelchair team in the country was known as the Gizz Kids. They toured multiple cities in the US and abroad competing against able bodied teams using wheelchairs. The basketball games were an avenue to raise consciousness and educate the public about people with disabilities. These games would directly challenge the common stereo types that people with disabilities were helpless and dependent. DSO member Bob MacGregor commented in the Spokesman, “The public’s view of the sedentary, back room, fragile cripple is simple shattered” (Editorial, 1972). The Gizz Kids were financially independent of the University. They donated half their proceeds to disability organizations like the National Paraplegia Foundation and the National Polio Foundation.

In 1969, sophomore Gwen Phillips was a student who used a wheelchair for mobility and a Gizz Kids cheerleader. She complained to the wheelchair basketball team’s head coach about the exclusion of female cheerleaders participating in away games. Phillips appealed to the coach in writing, highlighting the public opportunity to bring awareness to the value of all athletes, including cheerleaders. She also emphasized the oppression experienced by many women with disabilities and the importance of disabled [sic] female role models. The coach denied her request for the female cheerleaders traveling with the team. Two years after her appeal, Phillips and other female students with disabilities formed their own wheelchair basketball team, Ms. Kids (Patterson, 2012).

Over the next decade, the students with disabilities spearheaded disability rights movements and formed disability rights organizations. Fred Fay was instrumental in sparking these movements and organizations. In 1966, Fay graduated with a bachelor’s degree in psychology and earned his doctorate in 1972 in educational psychology (Patterson, 2012). The

experiences he had and networks he developed proved to his fight for accessibility in Washington D.C.

Judith Heumann, Bobbi Linn, Frieda Tankus and the New York movement. At 18 months old Judith Heumann contracted polio which resulted in quadriplegia (Heumann, 1998-2000). When Judith was old enough to attend school, her mother successfully battled the Brooklyn School District to allow her daughter to attend mainstream schools. Even though she was allowed to attend, she was still subject to isolation and inaccessibility. During the summer, Judith would attend Camp Jened in Hunter, New York. It was one of the few camps for teenagers with disabilities, and much like Warm Springs, it was completely accessible. The camp offered standard activities, but also included baseball, cookouts, and crafts; and because of its location at the foot of the Catskill Mountains offered camping opportunities. It was here that Judith met her closest friends and future activists, Bobbi Linn and Frieda Tankus (Patterson, 2012).

In 1965, Heumann enrolled at Long Island University, Brooklyn Campus. She perused a degree in Education, hoping to become a teacher. She was one of the first students on campus to use a wheelchair and appealed to the administration to make the dormitories accessible so she could live on campus. In 1967, Heumann and Ted Childs, a Health Sciences professor and a National Association for the Advancement of Colored People (NAACP) activist established the Disability Students Program (DSP). Their goal was to advocate for a more accessible campus and provide student services for SWDs. Both saw the organization as a political engine to lobby for disabled [sic] student's rights in higher education. Heumann and other students with disabilities involved in DSP established Handicapped Integration Movement (HIM) to demand equal rights and accessibility in higher education. In 1969, the members of HIM organized a

conference at the university to raise awareness about disability discrimination in employment, education, housing, and transportation that individuals with disabilities faced (Patterson, 2012).

Throughout college Heumann remained friends with Bobbi Linn, who attended Hofstra University on Long Island, and Frieda Tankus who attended Brooklyn College. Linn and fellow SWDs formed People United in Support of the Handicapped (PUSH). Likewise, Tankus joined with other SWDs and established their own organization the Student Organization for Every Disability United for Progress (SOFEDUP) (Patterson, 2012).

PUSH sought to make their campus more accessible by making modifications to commons spaces, as well as making dorms wheelchair accessible. They held workshops and distributed pamphlets around campus to educate faculty and students without disabilities about SWDs. SOFEDUP and the Student Government Association at Brooklyn College joined forces to protest against students having to choose a university based on its accessibility and not academic merit. They specifically addressed the inaccessibility of their campus. They occupied the office of Brooklyn College President demanding the campus be made accessible. He committed to making new construction on campus accessible and created the Dean's Committee on the Disabled (Francis, 1971). This group included not only students, but administrators and faculty; addressing campus disability issues like accessibility, admissions, and services. SOFEDUP held luncheons and in service training programs to educate faculty, administrators and SWDs about the needs of individuals with disabilities. They raised funds to offer scholarships and/or services to students with disabilities; and sponsored intermural wheelchair sports including table tennis, football, karate, and basketball (Francis, 1971). SOFEDUP was not satisfied to simply reach the Brooklyn College population, but extended their reach, spreading their mission to the City University New York system (Patterson, 2012).

Heumann, Linn and Tankus developed strong advocacy skills while students in their respective New York schools. They utilized these skills after college when publicly protesting discriminatory practices and policy against people with disabilities. These three ladies highlight the significant role student organizations played in providing a platform to bring disability awareness and advocacy to the public's attention.

Ed Roberts and The University of California, Berkeley. Ed Roberts and his entire family contracted polio in 1952. He was 14. After his illness, Roberts was paralyzed from the neck down. Initially, he required at least 12 hours in an iron lung, a large metal cylinder one must lay in to regulate breathing for paralyzed respiratory muscles (Patterson, 2012).

When Roberts returned to school he did so with a portable respirator attached to his wheelchair. After high school graduation, and two years at a local community college, he applied to the University of California in Berkeley to study Political Science. His application was denied and Roberts recalled an administrator telling him, "We tried cripples, and they don't work" (The Disability Rights and Independent Living Movement, 2014). Roberts filed a lawsuit against the University and won. In 1962, he began attending classes at Berkeley. He still required the use of his iron lung and since it would not fit in his dorm room he was forced to reside at the university hospital, Cowell Memorial (Patterson, 2012).

By the end of the 60s a dozen students lived in the third-floor wing of Cowell Hospital. Hale Zukas was one of the first to join Roberts. In 1968, the first woman with a disability was admitted. The experience at Berkeley was different from Illinois, as there was not a Rehabilitation Education Services Program and students lacked institutional support. Both universities did provide SWDs the opportunity to form lasting relationships founded on the

shared experience of being a SWD. Roberts and other students at Berkeley were involved in the Civil Rights Movement and Roberts is quoted as saying,

When I was at U.C. Berkeley in the '60s, I and almost every other student on campus became involved in the Civil Rights Movement. We were fighting for the basic rights of black people. But during my involvement in that movement, I suddenly realized something that has been extremely important to me – that I am a part of a minority that is as segregated and devalued as any in America's history. I quickly found that other disabled students shared my feelings. We all felt a sense of anger, frustration and isolation. The more we talked the more it became apparent that we needed to organize if we were going to create our own civil rights movement (The Disability Rights and Independent Living Movement, 2014; Patterson, 2012, p. 479).

It was from this belief that the original residents of Cowell Hospital formed the Rolling Quads. Roberts attempted to unify with other minority groups and reached out to Native American and Black Power activists, but they did not understand the similarities in their respective activism and refused to unite (Patterson, 2012).

In 1969, the 12 members of the Rolling Quads lobbied the university to establish a Disabled Students Program (DSP). Roberts, Hale Zukas, and Herb Willsmore applied for a grant from the Department of Health, Education and Welfare under one of President Johnson's Great Society initiatives, the Higher Education Act of 1965. They needed the grant to fund the salaries of the DSP director and counselors, but also needed additional funds for wheelchair repairs, student financial support, accessible vans, and funds to travel to and from conferences. The DSP was awarded the grant, and employed a full-time staff. Their goal was to make significant changes to campus. A year later they established the Committee for the Removal of Architectural

Barriers (CRAB). CRAB catalogued architectural barriers and initiated the removal of them. DSP was successful in raising money for their organization. Their campaign, Quarters for Cripples, convinced the Association of Students of the University of California to increase student fees by 25 cents to supplement their grant and cover operating expenses. DSP explained that while for most students it was merely a quarter, for students with disabilities it could ensure their independence (Patterson, 2102).

The following year the Rolling Quads took a road trip to Sacramento to protect their educational funding through protest. Governor Reagan proposed to cut the Rehabilitation Services budget which would have significantly endangered the future of the organization and eliminated medical attendants for SWDs. The protests were a success and Governor Reagan rescinded the budget cuts before the beginning of the school year (Patterson, 2012).

Looking to connect with larger community organizations, the Rolling Quads joined forces with the California Association of the Physically Handicapped. Together they petitioned the Oakland City Council and Mayor demanding curb cuts in sidewalks and at major intersections, and accessible drinking fountains and telephone booths. As graduation neared, they built on the success at Berkeley to advocate on a national level (Patterson, 2012).

Advocacy Opportunities Beyond Campus

As each of the student advocates graduated they looked for advocacy opportunities beyond their respective university. After graduation, Heumann continued to pursue a career in education. Her vocational rehabilitation counselor warned her that teachers using wheelchairs were historically denied licensure. She passed oral and written exams, but failed the medical exam and was denied a license to teach. She filed a lawsuit against the New York City Board of Education (Heumann v Board of Education of the City of New York, 1970). The lawsuit was the

first civil rights case of its kind and brought Heumann and disability rights into public view. The publicity served as the impetus for founding Disabled in Action (DIA), with Heumann serving as the first president and Bobbi Linn and Frieda Tankas serving on the board of directors (Rousso, 2004).

In the summer of 1972, Disabled in Action guided their wheel chairs into the middle of Manhattan's Madison Avenue and for 45 minutes they blocked traffic protesting Richard Nixon's veto of the Rehabilitation Act of 1973. The New York police were powerless to remove the protesters as none of the police cars were equipped for passengers with disabilities. DIA carried their protest to Washington D.C. after a second veto by President Nixon. They coincided their two day protest with the annual meeting of the President's Committee on Employment of Handicapped. More than 200 gathered at the Lincoln Memorial for a candlelight vigil and the next morning marched 2 ½ miles to the capitol. DIA networked with other grassroots disability organizations and it quickly grew along the East Coast, establishing chapters in Boston, New Jersey and Baltimore (Patterson, 2012).

Fred Fay and his mother established the Metropolitan Washington Chapter of the National Paraplegia Foundation and the Opening Doors Campaign to bring awareness about physical barriers and negative social attitudes toward people with disabilities. Opening Doors also provided peer counseling for individuals with a newly acquired spinal cord injury. One of Opening Doors most famous clients was Alabama Governor George Wallace, who was paralyzed after an assassination attempt in 1972 (Patterson, 2012). The Opening Doors Campaign organized a wheelchair basketball game between the Gizz Kids and the Richmond Rebels. They invited government officials who would be influential in removing architectural barriers. Fay and the Gizz Kids once again challenged public understanding, underscoring the

irony that on a flat basketball court these athletes were not disabled, but that the same young men were unable to enter a building due to steps (Carvajal, 1967). Opening Doors also testified before Congress in support of legislation to eliminate architectural barriers in public transportation (Patterson, 2012).

Serving as the political arm for the Disabled Student Program, The Rolling Quads established the Disabled and Blind Action Committee of Northern California (DBAC). In 1972, after hearing of the protest conducted by DIA in New York, DBAC protested at the federal rehabilitation services office in San Francisco with signs attached to their chairs reading Cripple Power. That same year, Willsmore and Zukas founded the Centers for Independent Living. Ed Roberts would join them the following year and become known as the Father of the Independent Living movement. This was one of the first organizations of its kind. The directors lobbied the state and national officials for funds and civil rights for people with disabilities which also attracted other activists like Judith Heumann (Patterson, 2012).

Fay, Heumann, and Roberts focused their advocacy efforts on securing civil rights for persons with disabilities and the passage of the Rehabilitation Act of 1973. Representatives from Illinois, California, and New York made contributions to the development of Section 504 of the Rehabilitation Act. Four members of the Rolling Quads worked on the original language including the concepts in Sections 503 and 504. Timothy Nugent and Ted Childs were both consulted during the drafting of the legislation (Patterson, 2012).

The Rehabilitation Act of 1973

After many disability rights protests across the country, The Rehabilitation Act (P.L. 93-112) was passed in 1973. This piece of legislation signaled a profound shift in federal public policy and specifically addressed equal access for people with disabilities regarding architectural,

employment, and transportation barriers (Golden, Kilb, & Mayerson, 1993). This Act has several sections. Section 501 focuses on the hiring practices of the federal government and prohibits discrimination against qualified individuals with disabilities. Section 502 establishes the Architectural and Transportation Barriers Compliance Board to enforce standards set under the Architectural Barriers Act (ABA) of 1968. In addition to its enforcement role, the Board developed and maintains the guidelines that set accessibility standards under the ABA. Section 503 prohibits employment discrimination on the basis of physical or intellectual disability and requires affirmative action by businesses with federal contracts or their subcontractors. Section 504 prohibits federal agencies, or programs or activities that receive federal dollars to discriminate against individuals with disabilities. Requirements under this section include reasonable accommodations for employees with disabilities; program accessibility; effective communication with people who have hearing or vision disabilities; and accessible new construction and accessible modifications to existing buildings. Each federal agency has their own set of Section 504 regulations that apply to their programs. For example, the Department of Health and Human Services ensures that doctor's offices, clinics, and medical equipment are accessible to individuals with disabilities. Another federal agency, the U.S. Department of Education, ensures that students with disabilities receive educational services needed to be successful in school. This section also establishes the Client Assistance Demonstration Projects to provide assistance, inform, and advise people with disabilities regarding all available benefits under the Rehabilitation Act. Section 508 requires access to communication and computer technology be accessible to individuals with disabilities. An accessible system is one that can be operated in a variety of ways. For example, an individual who is blind or has low vision may need a computer screen reader or a monitor magnification system.

The Rehabilitation Act recognized that an individual with a disability would often suffer the inevitable consequences of a lack of appropriate education, unemployment, and poverty. The Act identified the root of many of these problems as the inaccessibility of the environment and societal prejudices encountered by individuals with disabilities. For the first time, people with disabilities were viewed as a collective group and not just diagnostic subgroups; and this group faced similar discrimination in employment, education, and access to society. As such, they constitute a legitimate minority group that deserves basic civil rights protection (Golden, Kilb, and Mayerson, 1993).

The Independent Living Movement in Relation to Other Social Movements

The passing of the Rehabilitation Act of 1973 helped shape the movement for independent living. As the independent living movement evolved several other complementary social movements developed as well. These movements include: civil rights, consumerism, self-help, de-medicalization and self-care, and deinstitutionalization, normalization, and mainstreaming. While these movements share similar values and assumptions, each emerged as a response to a different social problem; and to some degree each influenced the movement for independent living. To fully appreciate the origins and ideology of the independent living movement, it is important to consider the contributions of other social movements (DeJong, 1978).

Civil Rights Movement

The civil rights movement of the 1960s had far reaching influence beyond the African American community. Through the public protests, speeches, and marches demonstrated by the civil rights movement, other minority and disadvantaged groups were made aware of their rights and how their rights were being ignored and denied. Initially, the civil rights movement was

concerned with African Americans right to vote, the opportunity to run for and hold an elective office, and public desegregation in all areas. As the movement grew, benefit rights such as equitable pay for equitable work, medical assistance, educational opportunities, and other entitlements were added (DeJong, 1978).

Concerns for both civil and benefit rights spilled over to the movement for independent living. Individuals with disabilities utilized African American social protest practices like demonstrations and sit-ins, as well as legal and legislative channels. The 1973 Rehabilitation Act is a reflection of this movement's civil rights interests, particularly in the area of discriminatory employment practices. However, as discussed in the previous section, civil rights for individuals with disabilities did not simply concern employment. Individuals with physical disabilities claimed their civil rights were deprived when architectural and environmental barriers prevented them from participating in social and political events in their respective communities. These barriers also prevented access to proper medical care. For individuals with the most significant disabilities they claimed their rights to community living were violated because without income assistance or attendant care benefits, many would be involuntarily committed to institutions (DeJong, 1978).

The civil rights movement brought social awareness to discriminatory practices due to racism and in turn effected the movement for independent living. Individuals with disabilities recognized that they too were discriminated against and that prejudice against disability was rooted in cultural attitudes. The civil rights movement inspired the movement for independent living to investigate the source of attitudes and behaviors toward individuals with disabilities (DeJong, 1978).

Consumer Movement

The history of the consumer movement began in the early 1970s when the civil rights movement, the women's movement, and the independent living movement were in full force. This movement affects nearly all social classes and groups. According to Cravens & Hills (1970), the consumer movement is defined as, "...a social force within the environment designed to aid and protect the consumer by exerting legal, moral, and economic pressure on business" (p. 24). While the consumer movement is studied, researched, and reviewed more in business settings, its history is noteworthy as a movement that influenced the movement for independent living.

One of the basic assumptions of consumerism is a distrust of seller or service provider. The onus is on the consumer to be informed about product reliability or service adequacy. Once informed, consumer sovereignty, the power to choose the products or services received, can be exercised (Cravens & Hills, 1970). However, for individuals with disabilities, it is often the professional who has been sovereign (DeJong, 1978).

This professional dominance in disability policy, service delivery, and rehabilitation was challenged with the rise of consumer sovereignty. Prior to the passage of the Rehabilitation Act of 1973, vocational rehabilitation counselors could determine case planning for an individual with a disability with little input from the individual. Now, the client and counselor must draft together an individualized written rehabilitation plan outlining client goals and objectives. Beyond vocational rehabilitation, Independent Living Centers offered peer support, advice on legal rights and benefits, affordable housing options, and other services for individuals with disabilities (DeJong, 1978).

Consumer sovereignty is imbedded in the philosophy of the independent living movement (DeJong, 1978). Individuals with disabilities are the experts on their daily lived lives.

They are the ones to best judge their wants, desires, and needs; and can determine the most appropriate services to meet those needs. When determining how to organize their services, individuals with disabilities primarily rely on their own ingenuity to secure the rights and benefits for which they are entitled. If the individual is unaware or uncertain of where to search, self-help organizations are a viable option.

Self-help

A large variety of groups, from the Female Improvement Society to Alcoholics Anonymous, are represented in the self-help movement (Withorn, 1977). There are now self-help groups for almost every imagined human condition or problem – alcoholism, drug addiction, bullying, smoking cessation, mental health conditions, elder abuse, and of particular interest for this discussion, disability. Self-help organizations view themselves as peer counseling support groups that serve as valid options to established consumer service agencies (Durman, 1976). These groups usually address issues and needs not managed by other social institutions (DeJong, 1978).

For individuals with disabilities, centers for independent living have become the primary go to for self-help. The centers can serve as both as an addition to the social services system and as an alternative service provider. As an addition, centers can assist in additional funding for accessible public transportation such as free bus passes. As an alternative, centers may provide peer counseling and advocacy services not provided by social service organizations (DeJong, 1978).

Like consumerism, the self-help movement has a general distrust of professionally dominated services. The intention of self-help organizations is to give individuals the

opportunity to control their lives and the services used. These organizations teach, encourage and promote consumer advocacy and sovereignty (DeJong, 1978).

De-medicalization and self-care

De-medicalization can be considered an extension of the self-help movement with regard to health and medical care. The assumption is that individuals can and ought to take greater responsibility for their personal health needs. Some refer to the de-medicalization trend as the self-care movement. The movement goes beyond the physical fitness social rhetoric of daily exercise, eating healthy, not smoking, and drinking less alcohol. It encourages individuals to practice proactive healthcare, and in doing so could potentially avert chronic health conditions from arising (DeJong, 1978).

Historically, individuals with disabilities have had their health care managed by the medical system with little to no input by the individual being treated. The movement for independent living asserts that once management of the disability is obtained by the individual, continued medical supervision is determined by the individual, not the medical care system. The management of disability is primarily a personal matter and secondarily a medical matter. If this practice is not respected and observed by both parties, dependency behaviors can result. An example of this dependency behavior is: an individual with a disability engages in clingy or submissive behavior with a professional, this behavior then elicits care-giving behaviors from the professional. The perception of the relationship changes from one of independence and autonomy, to not being able to survive without the help of the professional. This dependency status is in direct conflict with rehabilitation and independent living goals (DeJong, 1978).

Deinstitutionalization, normalization, and mainstreaming

The deinstitutionalization movement is one that includes many disabling conditions (DeJong, 1978). As discussed in the previous section on institutionalization, the fight for freedom for individuals with physical and intellectual disabilities was long and litigious. In 1963, a similar deinstitutionalization movement occurred in the community mental health movement with President John F. Kennedy signing the Community Mental Health Act. This Act provided federal funding for community-based care and treatment facilities allowing individuals with a mental health diagnosis to leave institutional confinement and move into the community. The movement for independent living contends that all individuals with disabilities have the right to receive all supports and services necessary to live in their community.

Associated with the deinstitutionalization movement are the ideas of normalization and mainstreaming. These two concepts are mainly discussed in connection with children and young adults with developmental disabilities. Society, physicians, and even family members once believed these individuals were best served by confining them in institutions or segregating them into special education classes. At the time of deinstitutionalization and for decades to follow, the belief shifted to one in which a child or young adult with a developmental disability could be “mainstreamed” into school and society and become “normal” (DeJong, 1978, p. 442). However, normalization exceeds mere deinstitutionalization. According to Dybwad (1973), it assumes that: “Normal on our earth is trouble and strife, trial and tribulation and the handicapped [sic] person has the right to be exposed to it. Normalization...includes the dignity of risk...” (p. 57). Therefore, normalization takes deinstitutionalization one step further to incorporate the potential for failure, a certainty the deinstitutionalization movement did not generally acknowledge. The independent living movement asserts that individuals with disabilities have the right to choose, and in this choice is the dignity of risk (DeJong, 1978).

The Independent Living Paradigm

The independent living movement was more than a social movement for individuals with disabilities seeking rights and entitlements. This movement, and the other social movements discussed, reshaped the way in which disability was defined by both the individual and society. Individuals with disabilities no longer considered themselves sick, damaged, or deficient and in need of fixing. Most important was individual autonomy; decisions must be made by the individual, not by the medical or rehabilitation professional. The real issues facing individuals with disabilities were the social and attitudinal barriers; solutions could be found by directly addressing these barriers. This shift in thinking and in American disability policy created a new paradigm.

Developed by Gerben DeJong in the late 1970s (DeJong, 1978) the independent living (IL) paradigm proposed a shift from the medical model to the independent living model. In order to better understand DeJong's IL paradigm, it is important to review the origins of his theory.

DeJong's Borrowed Definition of Paradigm

DeJong borrowed his use of the word paradigm from Kuhn's often cited work, *The Structure of Scientific Revolutions* (Kuhn, 1970). Kuhn, a historian of the natural sciences, recognized that scientific facts did not simply evolve, but were products of new ways of thinking - new scientific paradigms. For scientists, reality is defined by paradigms. They provide a structure for problem identification and solution. This definition is applicable to not only the natural sciences, but social sciences, political policy, and the independent living movement as well (DeJong, 1978).

Within Kuhn's set of criteria for defining paradigm are two important concepts: anomaly and paradigm shift. Anomaly is defined as something that is unusual or unexpected (Merriam-

Webster, n.d.). These unusual events cannot be explained by the current paradigm in place. If too many anomalies occur simultaneously or concurrently, individuals, typically ones unaffected by the event, search for an alternative explanation or paradigm. The second concept is paradigm shift, replacing one paradigm with another. Anomalies do not necessarily cause a paradigm shift and a paradigm shift only occurs if there is a new paradigm option. Both concepts are important in the independent living movement (DeJong, 1978).

The Paradigm of Rehabilitation

Dominant in disability policy is the rehabilitation paradigm. Obstacles in this paradigm are generally: the inability to perform or poor performance of activities of daily living; or an inadequate skill set preventing gainful employment. If the individual is unable to adequately perform activities of daily living or acquire gainful employment, professional assumptions are that individual has a problem. In order to alleviate this problem, the individual with a disability should acquiesce to the guidance and instruction of their medical professional or vocational rehabilitation counselor. When this behavior occurs, individual autonomy disappears and the individual takes on the role of patient or client. Individuals with disabilities cannot be successful in the vocational rehabilitation process if lose their ability to choose a life direction (DeJong, 1978).

The Individuals with Significant Disabilities Anomaly

In, *Independent Living for Physically Disabled People*, Crewe and Zola (1987) point out anomalies that have occurred, but are difficult to explain by the independent living paradigm. They claim the “most important anomaly” (Crewe & Zola, 1987, p. 22) is the fact that individuals with significant disabilities were achieving independence without the assistance of professional rehabilitation. For individuals with significant disabilities, rehabilitation counselors

typically determine and dictate needed services for employability and activities of daily living. However, included in their number of those individuals achieving independence without assistance were those determined by their rehabilitation counselor, too significantly disabled to benefit from any rehabilitative services. Evident was the fact that professional rehabilitation services were not a prerequisite for independent living. As a result, individuals with significant disabilities have bypassed the professional rehabilitation programs and sought an alternative paradigm (DeJong, 1978).

The Independent Living Paradigm

DeJong (1978) asserts that the emergence of the independent living paradigm is, to some extent, a response to the anomaly represented by individuals with significant disabilities. According to the paradigm the locus of the problem seldom resides in the individual, but in the physical and social environments including the rehabilitation process. The rehabilitation paradigm is seen as part of the problem as it creates a dependency relationship between the professional and client. The individual with a disability must cast off the subjugated role of patient and take on the role of consumer. In order to depict the core values that influence the delivery of services for individuals with disabilities, DeJong (1978 & 1983) developed the analytic paradigm in Table 1.

Table 1

A Comparison of the Rehabilitation and Independent Living Paradigms

Item	Rehabilitation Paradigm	Independent Living Paradigm
Definition of problem	Physical impairment; lack of vocational skill; psychological maladjustment; lack of motivation and corporation barriers	Dependence on professionals, relatives, and others; inadequate support services; architectural and economic barriers

Locus of problem	In individual	In the environment; in the rehabilitation process
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, vocational counselor and others	Peer counseling; advocacy self-help; consumer control; removal of barriers and disincentives
Social role	Patient/client	Consumer
Who controls	Professional	Consumer
Desired Outcomes	Maximum activities of daily living; gainful employment; psychological adjustment; improved motivation; completed treatment	Self-direction; least restrictive environment; social and economic productivity.

These core values influenced the development of the independent living philosophy and the evolution of the independent living program at the national level.

The Philosophy of the Independent Living Movement

The philosophy of the independent living movement is based on four beliefs: 1) all human life has value; 2) any person, regardless of impairment, has the ability to choose; 3) individuals who are disabled by society's reaction to physical, intellectual, and sensory impairments, and to emotional distress have the right to assert control over their lives; 4) and all individuals with disabilities have the right to participate fully in society (Morris, 1994). Essentially, the independent living philosophy espouses living like everyone else – having opportunities to control and direct one's life with minimal reliance on others in decision making and in performing daily activities.

This philosophy is interwoven through the fabric of advocacy, outreach, and service delivery efforts. Disabled People's International (1981), a consumer-led organization, considers

independent living as a process that individuals with disabilities must control individually, and collectively. The philosophy emphasizes one's right to self-determination. Self-determination implies that one takes responsibility for his or her life, minimize dependency on others, and exercise their ability to be contributing members of society (Lachat, 2002).

The philosophy is not designed to avoid the possibility of risk or potential failure. DeJong (1983) points out that it is the dignity associated with personal decisions to take risks that defines the independent living movement. Without the possibility of failure an individual with a disability lacks true independence.

The independent living movement and its underlying philosophy gives rise to many unique accounts of personal achievement. While some accounts may expose noteworthy triumphs resulting in widespread social change, others may be more subdued resulting in a positive change affecting only the life of a single individual. Regardless of the perceived magnitude of the accomplishments, it is the change that is present in the day-to-day lives of individuals with disabilities that gives life to the movement. Without the realization of these individual victories, the movement serves no real purpose.

Whether an individual with a disability struggles mightily to achieve the goal of independent living or adapts life around the disability; the objective is the same, self-direction and the freedom to choose their life course. This is the undercurrent running through the independent living movement and philosophy. When people with disabilities embrace these philosophical principles, self-perception is changed. No longer do they consider themselves passive recipients of care marginalized by society, but self-directed and powerful. Disability began to be seen as a natural, not extraordinary and certainly not a tragic, life experience (DeJong, 1978).

As the independent living movement and philosophy swept through the country, and people with disabilities demanded equal rights, an unfortunate event occurred during the 1972 presidential run for office that would have significant impact on disability service delivery systems. This event was the attempted assassination of Alabama Governor George Wallace. His recovery, rehabilitation, and restoration was detailed in newspaper articles and television broadcastings, and brought disability awareness, advocacy, equality, and policy before the local and national spotlight once again.

Alabama Governor George Wallace

On May 15, 1972, Alabama Governor and Presidential hopeful, George Wallace, had a scheduled appearance in Laurel, Maryland. The Alabama Governor was running for President of the United States and the Maryland primary was quickly approaching. The Governor needed to make several appearances and speeches in Maryland before continuing on the campaign trail. After his speech in Laurel, and against the advice of his Secret Service detail, Wallace stepped into the crowd to greet the audience. Arthur Bremer, a discontented drifter whose only objective was national recognition, stepped toward Governor Wallace, shooting him five times with a .38-caliber revolver (Frederick, 2007).

Two of the gunshot wounds were quite serious, one perforated his stomach and another entered through the spinal canal. To control for the internal bleeding and potential infection cause by the leaking gastrointestinal system, immediate procedures were taken to stabilize the abdominal area. The spinal injury would be addressed once the Governor was stabilized (Frederick, 2007).

Upon evaluation of the spinal injury, doctors determined Governor Wallace would never walk again. Adjusting to his paralysis was difficult for Wallace. He would have moments of false

hopes that he would regain feeling and use of his legs when different forms of stimulation led to movement of his toes, reflexive foot action, or brief moments of sensation. Doctors cautioned Wallace and his family about the possibility of Wallace ever gaining mobility (Frederick, 2007).

After rigorous physical therapy and multiple surgeries, Wallace returned to the presidential campaign trail. Determined to remain an active and viable candidate, he spent eighteen months on the road campaigning, his last speech at the Democratic National Convention in Miami. Upon his return to Alabama, the Governor was exhausted and was immediately admitted to Spain Rehabilitation Hospital in Birmingham. While away, the governor's mansion was modified to be wheelchair accessible; a chairlift was installed, doorways were widened, and entry and exits steps were replaced with ramps (Frederick, 2007).

At Spain Hospital, Wallace underwent two more surgeries for abdominal abscesses and completed another round of physical therapy. While there, Wallace crossed paths with a young girl. She was riding on the back of her boyfriend's motorcycle when it crashed in a tractor trailer. The boyfriend walked away from the accident with scratches. Her injuries were quite severe and she was diagnosed with quadriplegia. Since his assassination attempt, Wallace was particularly attuned to individuals with paraplegia and quadriplegia, and he struck up a friendship with this young girl. After her accident, unable to deal with their daughter's disability, her parents deserted her. Her boyfriend ultimately did so as well. Wallace visited her everyday he was at Spain and called her frequently after he left (Frederick, 2007).

Through this friendship, Wallace realized the serious lack of community resources in the state of Alabama. During his unprecedented third term as governor, Wallace called a special legislative session in 1975. Among agenda items discussed was The Alabama Program for Spinal Cord Injuries. This program would provide home care, medical equipment and supplies,

transportation, and home modifications for individuals with paraplegia or quadriplegia. Particularly targeted for admission into the program were low income individuals (Frederick, 2007).

Without the personal experiences and influence of Governor Wallace it is likely the program would have been of little interest to the legislature and the states most vulnerable citizens ignored. In addition to the program, Wallace created the George C. Wallace Urology Rehabilitation and Research Center at the University of Alabama at Birmingham. This center studied bladder function problems unique to individuals with spinal cord injuries (Frederick, 2007).

Initiated by Governor Wallace's efforts and financed by the state legislature, Alabama is one of the few states to implement a Homebound Rehabilitation Program (Trieschmann, 1980). Today it remains the only single state funded Homebound program. In order to implement services through this program, the State of Alabama Independent Living Service (SAIL) was developed as a division within the Alabama Department of Rehabilitation Services.

The Alabama Department of Rehabilitation Services (ADRS)

The ADRS History

The concept of vocational rehabilitation began after World War I with the passing of the Smith-Sears Act of 1918 in response to the influx of veterans with devastating injuries returning home from the war. Alabama has a long history of serving people with disabilities. That history began with Alabama Congressman John H. Bankhead, Sr., who introduced the Smith-Fess Act of 1920 also known as the U. S. Civilian Rehabilitation Act, after recognizing the impact of similarly devastating injuries on civilians. This Act earmarked funds for the vocational guidance and training of individuals in need of rehabilitation after such an injury. Services included

assistance with occupational adjustment, the purchase of prosthetic devices, and placement in employment. The Alabama legislature passed the Alabama Enabling Act of 1921 in response to the federal legislation, appropriating state funds to match the federal funds. This Act established a rehabilitation program in the Division of Vocational Education under the Alabama State Department of Education. The purpose of the rehabilitation program was to provide training and employment placement for individuals with physical disabilities acquired through injuries. The focus of services changed from mere physical restoration for individuals to a more holistic rehabilitation that included work and social aspects of life (Alabama Department of Rehabilitation Services, 2016).

In 1926, the Alabama Department of Education superintendent met with individuals interested in identifying and treating children with disabilities. From this meeting a task force was formed. This task force met with the president of the International Society for Crippled [sic] Children and resulted in the formation of the Alabama Society for Crippled [sic] Children and Adults. The Society was comprised of volunteers with a shared vision of better accessibility to services for children with disabilities within the State. These volunteers identified a need for service expansion beyond orthopedics for children with disabilities and agreed that all funds raised or donated by the Society would be disbursed through the Department of Education. The Society held and sponsored the first field orthopedic clinic in 1926 in Dothan, Alabama. The development of new clinics throughout the state pioneered a community-based system of care and propelled Alabama forward in serving children with disabilities; and began to lay the groundwork for future collaboration with adult vocational rehabilitation (Alabama Department of Rehabilitation Services, 2016).

During the Great Depression, funding for all Alabama departments of state government was decreased by almost 50% (Downs, 2015). Despite these drastic financial cuts, state leaders recognized the need for adult disability services and two rehabilitation workers were retained: E. H. Gentry and O. F. Wise. These pioneers are synonymous with vocational rehabilitation in Alabama. The Social Security Act of 1935 placed federal vocational rehabilitation services within the U. S. Department of Education. Crippled [sic] Children's Service was placed in the Children's Bureau at the federal level, but states could designate its location. Through Alabama Act 35-398, the Alabama Legislature placed Crippled [sic] Children's Service within the Alabama Department of Education. This action paved the way for a unique partnership between services for children with disabilities and the adult vocational rehabilitation services. It also initiated the development of a state department that provided services across the life continuum for people with disabilities. Alabama is the only state in the U.S. to provide such a continuum of services for people with disabilities within one governing agency. This continuum of services concept was intended to provide a pathway from one system to another to promote opportunities for employment, provide stability and security, as well as a better quality of life for people with disabilities (Alabama Department of Rehabilitation Services, 2016).

Community-based services continued to expand in scope and number of locations in an effort to meet the needs of rural Alabamians with disabilities. Meanwhile, on the federal level, the Barden-LaFollette Act of 1943, also referred to as the Vocational Rehabilitation Amendments, expanded services to adults to include physical restoration. This amendment also required states to submit a written State Plan to the federal government describing the state's activities with regard to service delivery compliance (Alabama Department of Rehabilitation Services, 2016).

The Rehabilitation Act of 1973 created a mandate for the vocational rehabilitation (VR) program to serve individuals with severe disabilities. This Act had several sections previously discussed in greater detail. Additionally, the Act provided that an individualized written rehabilitation program be established to ensure that consumers of VR services be involved in the development of their rehabilitation process. The Rehabilitation Act Amendments of 1978 (P.L. 95-602) created comprehensive services for independent living to include the Independent Living Program and Independent Living Centers. This movement toward independence for people with disabilities brought forth the concepts of peer counseling, disability advocacy, and self-advocacy.

The 1992 Amendments to the Rehabilitation Act (P.L. 102-569) introduced the concept of consumer choice as it related to career options and focused the VR program on competitive employment for people with disabilities. The reauthorization of the Act assumes that people with disabilities can work and can be gainfully employed through their unique abilities and skills in an appropriate job of their choosing. The amendments also created the State Rehabilitation Advisory Council and developed the concept of presumptive eligibility of services for individuals who were receiving Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) benefits.

On January 3, 1995, the Alabama Department of Rehabilitation Services was created by the State legislature, separating it from the Alabama Department of Education. State legislators and officials recognized the increased demand of rehabilitative services and determined that an independent state agency could best serve Alabamians with disabilities. While separated from the Alabama Department of Education a strong partnership between the two agencies remains (Alabama Department of Rehabilitation Services, 2016).

The 1998 Workforce Investment Act (WIA) (P.L. 105-220) was intended to make services more efficient for individuals with disabilities seeking employment by developing one-stop career centers. This one-stop system was designed to empower job seekers by providing them with access to information, job training, and resources. The four principles behind WIA were 1) universality, 2) customer choice, 3) integration of services and 4) accountability for results (Wehman, 2013). In 2014, the Workforce Innovation and Opportunity Act (WIOA) was signed into law, reauthorizing WIA for six years. It set guidelines for funding of rehabilitation services to include pre-employment transition services for individuals with disabilities who may qualify for vocational rehabilitation services, especially increasing opportunities for individuals with disabilities who face barriers to employment. The intent of the WIOA is to strengthen the connection between education and career preparation (WIOA, 2014).

ADRS Overview of Programs

The Alabama Department of Rehabilitation Services is unlike other states' rehabilitation programs because the departmental umbrella provides services across the life-span. The continuum of services approach provides individuals with disabilities a single point of entry into services and helps them transition through the department's four primary programs if needed or as their needs change. These programs serve different age groups including: Early Intervention, Children's Rehabilitation Services, Vocational Rehabilitation Service, and Independent Living/Homebound Services (Alabama Department of Rehabilitation Services, 2016).

Alabama's Early Intervention System. The continuum of services for individuals with disabilities begins with Early Intervention (EI). This program provides assistance to infants and toddlers from birth to age three with disabilities or developmental delays. EI coordinates a statewide network of providers who assist these children and their families in accessing needed

resources and services. In addition, the program prepares young children for preschool or other community-based programs by offering assessments, non-medical health services, service coordination, training, and family support (Alabama Department of Rehabilitation Services, 2016).

Children's Rehabilitation Service. If needed services can continue with Children's Rehabilitation Services (CRS). CRS serves children with physical disabilities and chronic diseases from birth to age 21. Services include evaluations, medical services, adaptive and assistive technology, and case coordination; and can be provided in the consumer's home, school, or other community setting. CRS works closely with the Alabama school system to ensure that children with disabilities are receiving needed accommodations in order to be successful in the classroom. CRS conducts a Teen Transition Clinic to assist adolescents with disabilities transition to secondary education, employment, independent living, and adult medical care. Alabama's Hemophilia Program, also housed within CRS, serves children and adults with life-threatening blood disorders (Alabama Department of Rehabilitation Services, 2016).

While the transition process in CRS is mainly focused on the health and medical transition needs, multi-focal opportunities exist. CRS care coordinators have an opportunity to work with students from childhood through adolescence and into early adulthood and could facilitate the development of the student's independent living and self-advocacy skills. In addition, CRS care coordinators may act as liaisons between the student and vocational rehabilitation during the transition process (Alabama Department of Rehabilitation Services, 2016).

Vocational Rehabilitation Service. The largest program within the ADRS is the Vocational Rehabilitation (VR) Service. It provides educational and vocational assistance to

adolescents and adults with disabilities. VR works in partnership with local school systems, colleges, universities, community rehabilitation programs, and businesses to provide services related to postsecondary academic goals, obtaining and maintaining employment, or both. Vocational assessments, counseling, job training, assistive technology, orientation and mobility training, and job-placement assistance are also provided. For individuals with visual and hearing impairments, and traumatic brain injuries, specialty services are provided to help obtain employment and live independently. Additionally, VR produces a variety of specialized training and educational materials for persons with disabilities on topics such as advocacy, emergency preparedness, and job readiness. The program works closely with other state agencies, including the Alabama Medicaid Agency, and the Departments of Industrial Relations, Human Resources, and Education, to provide and accept referrals, ensure access to services, and improve the quality and efficiency of services (Alabama Department of Rehabilitation Services, 2016).

State of Alabama Independent Living (SAIL) Program Service. SAIL provides Alabamians with the most significant disabilities specialized in-home education and counseling, attendant care, training, and medical services. The overall objective of this program is to ensure independent living at home, work, school, and in the community. This program has three components: 1) the Medicaid SAIL waiver; 2) Homebound Services; and 3) Independent Living Services (Alabama Department of Rehabilitation Services, 2016).

The Medicaid SAIL waiver. Created in 1992, the SAIL waiver provides services to individuals with severe disabilities allowing them to remain in their home or community and avoid institutional placement. In order to be eligible for these services one must be 18 years of age or older, a resident of the state of Alabama, the onset of the disability must have occurred prior to age 60 and not associated with aging, restricted in activities of daily living, and

medically and financially eligible as determined by Medicaid. State funds are initially expended for the provision of services with a 70% reimbursement from the Alabama Medicaid Agency. Services provided can include case management, personal and assistant care services, medical supplies, assistive technology and home modifications for accessibility. The mission of this program is that through the provision of in home services individuals with significant disabilities are able to achieve their maximum potential in the home environment and enhance their quality of life (Alabama Department of Rehabilitation Services, 2015).

Homebound waiver. In 1978, Governor George Wallace was instrumental in passing legislation that created the Homebound program. It was designed to enable individuals with severe traumatic brain injury and/or cervical spinal cord injury as a result of an external trauma to remain in their home. In order to be eligible for these services one must be 16 years of age or older, a resident of the state of Alabama, must have a significant medical disability that would require institutionalization, reside in their own home, and be dependent on others for activities of daily life like, feeding, bathing, and dressing. It is the only program that is entirely state funded. Services provided can include guidance and counseling, medical equipment and supplies, medications, limited attendant care, and home modifications for accessibility. In addition to the services mentioned, one of the key features of this program is the home health team. This team primarily consists of a counselor, independent living specialist, case manager, and registered nurse. Other medical professionals like physical, occupational, and speech therapists can be consulted if needed. The goal of the team is to help the individual live as independently as possible and enhance their quality of life with the services provided (Alabama Department of Rehabilitation Services, 2015).

Independent living (IL) support services. Individuals with disabilities who are served in this program are encouraged to achieve their maximum potential. In order to receive services, one must have a significant disability(ies) that limits his or her ability to function independently at home, community, or to engage or continue in employment. The program is 100% federally funded. Services include advocacy, information and referral, peer support, and independent living skills training. As part of this training, the IL specialist and consumer work together to develop a suitable goal(s) which is realistically obtainable. Achievement of this goal(s) will enable an individual with a disability to live independently in their home, community, or potential employment aligned with their capacities and abilities. Additionally, the program advocates and encourages a higher quality of life for all individuals with a disability (Alabama Department of Rehabilitation Services, 2015).

Core services offered through independent living. Regardless of the disability, or independent living program through which one might be receiving services, there are few programs that offer the wide range of services provided through IL. Service delivery methods and programs can differ in response to the unique needs of individuals with mobility, sensory, emotional, or cognitive disabilities. Cutting across these differences are a set of core services that include advocacy, information and referral, independent living skills training, and peer support and mentoring. Other independent living services include, transportation, personal attendant care, durable medical equipment, housing assistance, communication options, educational and vocational resources, general counseling, and social/recreational opportunities. Described below are the four core services provided through all independent living programs (Lachat, 2002).

Advocacy. Advocacy is paramount to the independent living mission. Consumer control and self-reliance are central themes in advocacy assistance. Reflecting such fundamental

principles as the right to control one's life and make choices, this core service includes a process that enables consumers to act on their own accord and oppose accepted norms of dependency (Lachat, 2002).

Consumer advocacy utilizes a variety of approaches in order to position people with disabilities to take charge of their life and overcome potential barriers that inhibit independence. Advocacy support has a twofold approach. In the favored approach, an IL staff member encourages self-advocacy through a critical thinking and problem-solving process that identifies multiple strategies; and when and how to utilize them to overcome barriers. In another approach, an IL staff member might act on behalf of the consumer when deemed appropriate. In either approach, the intent is to motivate the consumer to action in coping with challenges and in seeking noteworthy levels of autonomy. Advocacy training may be provided on an individual basis as well as in group settings where peer connection enriches the process (Lachat, 2002).

By increasing self-advocacy skills, individuals learn how to effectively interact with agencies, service providers, employers, and others in order to acquire needed benefits, services, or accommodations. Additionally, individuals are encouraged to participate in the legislative process, including voter registration for individuals with disabilities. Systems Advocacy is accomplished when disability advocates bring public awareness to the barriers inhibiting people with disabilities from full inclusion in the community. Through participation in the legislative process, public awareness activities, and other disability issue related campaigns, advocates can work to encourage and influence positive changes on the local, state, and federal level (Lachat, 2002).

Information and referral. It is essential for individuals with disabilities to have access to information and referral services. In order to achieve an independent lifestyle, individuals

need information on available resources, options and social and/or political issues that may influence service delivery. Obtaining this information can help an individual evaluate their situation and identify the needed services and resources. Referral assistance is also essential since achieving independence frequently requires a collection of agencies and community organizations. These agencies and community organizations often provide information and referral services to other service providers and the community at large. This collaboration effort is instrumental in increasing public awareness of disability issues and providing available service and resource options to people with disabilities from varying agencies and the community (Lachat, 2002).

Referral assistance involves developing a network of contacts, maintaining updated directories, and a collection of information resources. This requires independent living programs to develop an information base including a wide range of IL topics and the various types of agency services available, as well as how consumers can access such services. A complete data base should include local, state, and federal laws that affect the lives of people with disabilities (Lachat, 2002).

In addition, information and referral assistance can be a valuable source for research data on consumer and community needs. By keeping accurate information and referral requests records and statistics, agencies can determine trends, unmet needs, and gaps in service delivery. This data can be used to develop funding recommendations, planning for new programs, and advocacy endeavors (Lachat, 2002).

Independent living skills. Skills development spans all content areas related to independent living; including self-care and personal growth, daily living skills, effective communication, and financial management. The individual identifies an area(s) or topic(s) in

which there is a need for more independence and is provided with skill development training individually or in a group setting. Skill training options could include homemaking, shopping, self-advocacy, personal assistant management, recreation and leisure, and transportation. The objective is to increase the independent living skills, keeping in mind the end goal to help the individual acquire control of their life (Lachat, 2002).

Peer counseling and mentoring. Since the inception of the independent living movement, disability advocates emphasized the need for and involvement of individuals with disabilities to serve as role models. Role models who could encourage, mentor, and counsel others with disabilities. A cornerstone of IL services has been peer counseling. A basic premise of peer counseling is that people with disabilities share a related experience and are uniquely qualified to assist one another. Through this core service area, a peer counselor, peer advocate or peer mentor, who has accomplished their desired level of independence, shares their knowledge, experiences, and lessons learned with an individual or a group. This counseling process provides the consumer with IL options, methods in how to approach certain situations, and attempts to boost confidence. Consumers may receive other benefits from the peer counseling process, like coping skills, problem solving skills, trustworthiness, increased assertiveness, and self-reliance. The consumer is not the only one who experiences benefits from the peer counseling experience. Counselors can benefit through improved interpersonal and communication skills and the feeling of accomplishment from helping others (Lachat, 2002).

In each of the SAIL programs and core services delivered, one mission is clear: provide supports and services that help individuals with disabilities improve their quality of life. This can only occur if the services delivered are of quality to the consumer. It is imperative for service agencies to listen to their consumers and assist in determining the most appropriate supports and

services. Engaging in this dialog empowers the consumer through the freedom of choice, and provides an opportunity for consumers to control and determine their quality of life.

The Journey to Quality of Life

Emerging Disability Paradigm

The study of disability is changing. Today, societal perception about the causation of disability and the improvements in disability policy and practice has shifted how we think about disability. We also approach individuals with disabilities very differently than in the past. Schalock (2004) theorized a new disability paradigm was emerging with significant implications for policy, practice, and the concept and measurement of quality of life.

Reframing the concept of disability has additionally helped to better recognize the disabling process and the lives of individuals with disabilities. It was obvious the disability concept was changing during the mid and latter part of the 20th century, as evidenced by the deinstitutionalization movement, independent living movement, and legislative enactment and implementation. These changes have contributed to the emergence of a new way of considering disability that focuses on functional limitations, personal well-being, individualized supports, and personal competence and adaptation (Schalock, 2004).

Functional Limitations. Nagi's (1979) definition of disability as "a form of inability or limitation in performing roles and tasks expected of an individual within a social environment" (p. 3) and its related emphasis on personal functioning and functional measures gave rise to the functional limitations component of the disability paradigm. The advantages of functional measures, as discussed by Hahn and Hegamin (2001), include a distinct emphasis on terms such as inability or limitation, roles and tasks, and expectations of individuals with disabilities. Each term has contextual merit and suggests medical or programmatic intervention to solve the

disability problem. Functional measures additionally allow individual assessment of disability and disability distribution in the general population (Larson, Lakin, Kewak, & Anderson, 2001).

The Developmental Disabilities Act of 1984 and the American's with Disabilities Act of 1990 definition of disability is also a basis for the functional limitations component (Hahn, 2000). Both Acts define disability as an impairment that restricts major life activities. Currently, the most often utilized disability-related measures include assessments to evaluate activities of daily living, instrumental activities of daily living, and physical tasks or limitations. Functional limitations are influenced by social and environmental barriers and are basic to the definition of disability. The World Health Organization in 2001 defines functioning as "all body functions, activities and participation" (p. xviii) and disability as "impairments, activity limitations and participation restrictions" (p. xviii); and that environmental factors determine barriers or pathways to functioning. These obstacles, and their improvement, are influenced significantly through contextual factors regarding the individual and the environment (Schalock, 2004).

Personal Well-Being. Within the second component of the disability paradigm are three trends: 1) the civil rights movement, in which social and political efforts focused on empowerment and inclusion of individuals; 2) social programs that emphasized equity and opportunity leading to a fuller, more meaningful, quality of life; and 3) the personal well-being evolution which promoted personal power, contentment, and the idea of personal well-being as multidimensional. Two key principles are reflected in these trends: positive psychology and quality of life (Schalock, 2004).

Positive Psychology. According to Seligman and Csikszentmihalyi (2000), the purpose of positive psychology is help individuals change negative ways of thinking about life to one in which positive qualities are emphasized. Three themes are central to positive psychology: 1)

positive experiences to include contentment with the past, happiness in the present, and an optimistic outlook for the future; 2) positive personality or individual traits, such as self-determination and direction, courage, compassion, maturity, and wisdom; 3) and positive social institutions to include positive human experiences, social relationships, and activities that foster a better community (Schalock, 2004).

Quality of Life. The concept of quality of life has been increasingly related to individuals with disabilities. Verdugo, Schalock, Keith, and Stancliffe (2005), assert that this idea is being used in the following manner: as an awareness that offers a sense of reference to and guidance from a personal perspective; as a social construct for improving personal well-being and advocating for program, community and societal change; and as a framework for conceptualizing, measuring, and applying the quality of life construct. The quality of life construct has two aspects that are pertinent to the personal well-being component of the paradigm. They are core domains and core indicators of personal well-being. Eight core domains have been identified and are accompanied by core indicators that provide an indication of the individual's well-being (Schalock, 2004).

The disability paradigm has additional merit due to the positive psychology and the quality of life concepts. The emphasis on positive experiences and personal potential provides the structure to develop quality services, determine quality outcomes, and understand personal well-being as multidimensional. These two aspects additionally provide reasoning for individualized supports (Schalock, 2004).

Individualized Supports. The third component of the disability paradigm is individualized supports, and has been defined as resources and techniques that expect to advance personal well-being in all areas of life as well as increase individual functioning. (Luckasson et

al., 2002). Advocates of supports have significantly influenced education and rehabilitation programs. In rehabilitation, individualized supports are being used as the basis for consumer directed planning and consumer choice, as well as systems reviews and modifications. In education, individualized supports are being used as the basis for student centered special education plans, including related services like speech, occupational, and physical therapy. Additionally included are opportunities for inclusion, peer mentoring, advocacy, and personal growth. (Thompson, et al., 2002).

Personal Competence and Adaptation. Personal competence and adaptation is the fourth component of the paradigm. It is primarily based on an understanding that competence, or intelligence, and adaptive behavior are multidimensional; and that these two constructs merge.

Intelligence embodies several dimensions. Conceptual intelligence is the ability to solve abstract problems, use and understand symbolic processes, and typical school-related competencies (Neisser, et al. 1996). Social intelligence involves understanding and managing successfully social and interpersonal items, including the ability to exhibit appropriate relational behavior and social skills, to be compassionate and self-reflective, and to achieve desired personal goals (Cantor & Kihlstrom, 1987). Sternberg (1984) defined practical intelligence as an individual's successful adaptation and mastery of their personal real-world environment. This includes activities of daily living, vocational interests, and recreation and leisure.

Adaptive behavior is also multidimensional. This behavior includes physical competence behaviors involving motor skills, walking, eating, and toileting; independent living behaviors such as cooking, cleaning, dressing, and bathing; cognitive, communication, and academic behaviors involving the ability to understand and use language, reading and writing skills, and

managing personal finances; and social competence behaviors involving the formation and maintenance of relationships, social activities, and social reasoning (Schalock, 2004).

Merging of intelligence and adaptive behavior can be described in the following manner. Practical intelligence corresponds with the adaptive behavior of independent living skills in that real-world daily environments include performing certain personal activities of daily living. Conceptual intelligence relates to cognitive, communication, and academic behavior because both incorporate learning objectives. Social intelligence correlates to social competence behavior since both take into account personal relationships and social skills. The physical competence adaptive behavior may be regarded as a part of practical intelligence because one could infer that successful adaptation and mastery over one's environment would include accommodating for functional limitations. The comprehensive concept is personal competence and adaptation (Schalock, 2004).

The disability paradigm and its four components promote a new way of thinking about disability. Instead of focusing on the individual and the problem that lies within, consideration is given to the organizational, social, and environmental aspects of disablement. When consideration becomes advocacy, action, and policy, individuals with disabilities are provided with the freedom of choice, the possibility of risk, and control over one's quality of life.

Quality of Life - Historical Context

Historically, the interest in quality of life (QOL) evolved from four sources (Schalock et al., 2002). First was a shift away from the notion that scientific, medical, and technological advances were the only methods through which an individual with a disability could improve his or her life. With deinstitutionalization, an understanding emerged that inclusion in family, community, and society could positively impact quality of life. In addition, changes in perception

of individuals with disabilities as well as the removal of environmental barriers helped foster social inclusion, involvement, and participation in the community in which one lived. Second, for those individuals with disabilities who were receiving community-based services, measuring the outcomes of those services and how they impacted the individual's QOL became an area of interest for service providers. The third shift was the consumer empowerment and patients' rights movements that emphasized person centered planning, personal outcomes, and self-determination where individuals could direct their life path and its quality. The fourth and final shift was the unfolding of social behavior changes that introduced the multidimensional aspects of QOL (Schalock, 2004).

Over the past three decades, the QOL concepts applied to individuals with disabilities have generated a great deal of interest (Schalock, 2004). These concepts have been challenged in terms of theory and practical purpose regarding social policy, service program design and delivery, and service evaluation. Of significant interest is the notion that QOL concepts, evaluations, and outcomes are relevant and measurable; and effect education, health and social service programs (Schalock, 2004).

Quality of Life Domains and Indicators

Domains within the QOL construct refer to the set of factors composing personal well-being (Schalock, 2004). The set represents the range over which the QOL construct extends and recognizes the multidimensionality of a life of quality. The most frequently referenced eight core QOL domains are: interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and rights (Verdugo, Schalock, Keith, & Stancliffe, 2005). Essential to any proposed QOL model is that the domains represent the complete QOL construct. The eight QOL domains were initially developed based

on the international QOL literature and validated in a series of cross-cultural studies (Schallock, 2004).

QOL core indicators are life related domain specific perceptions, behaviors and conditions that provide an indication of one’s well-being. These indicators are used to operationally define its corresponding QOL domains and for assessing quality outcomes. The indicator items refer to an individual’s perceived well-being or as the valued personal life experiences and circumstances. These experiences and circumstances are a result of some activity, intervention, or service; and are measured based on the quality indicators (Verdugo et al., 2005). Typically, two or three items are used to measure each QOL indicator. Table 2 represents the core QOL domains and most commonly used indicators.

Table 2

Core Quality of Life Domains and Most Commonly Used Indicators

Core QOL domain	Indicators and descriptors
Emotional well-being	Contentment (satisfaction, moods, enjoyment) Self-concept (identity, self-worth, self-esteem) Lack of stress (predictability and control)
Interpersonal relations	Interactions (social networks, social contacts) Relationships (family, friends, peers) Supports (emotional, physical, financial, feedback)
Material well-being	Financial status (income, benefits) Employment (work status, work environment) Housing (type of residence, ownership)
Personal development	Education (achievements, education status) Personal competence (cognitive, social, practical) Performance (success, achievement, productivity)
Physical well-being	Health (functioning, symptoms, fitness, nutrition) Activities of daily living (self-care, mobility) Leisure (recreation, hobbies)

Self-determination	Autonomy/personal control (independence) Goals and personal values (desires, expectations) Choices (opportunities, options, preferences)
Social inclusion	Community integration and participation Community roles (contributor, volunteer) Social supports (support network, services)
Rights	Human (respect, dignity, equality) Legal (citizenship, access, due process)

Principles for Measuring Quality of Life

The eight QOL core domains and their corresponding indicators described above reflect the framework for the QOL concept. They also provide a sense of reference and guidance from the individual's perspective and environment. In addition to the domains and indicators, QOL principles have emerged in international QOL literature that provide the basis for its measurement. These principles need to be considered to provide a unified standard from which to measure quality of life (Verdugo et al., 2005).

In 2002, Schalock and others investigating QOL and related measures, formed an international panel to develop common principles regarding the measurement of QOL (Schalock et al., 2002). An additional assembly of 40 professionals working internationally on QOL measurement and application concepts evaluated the original principles to determine social validity for three variables: desirability, feasibility, and effectiveness (Brown, Keith, & Schalock, 2004). The results of the social validity evaluation were discussed and edited and five core principles for measuring quality of life emerged. They are: 1) measurement in QOL involves the degree to which people have meaningful life experiences of personal value; 2) measurement in QOL reflects the degree to which life's domains contribute to a full and interconnected life; 3) measurement in QOL considers the context of environments that are important to individuals:

where they work, live and play; 4) measurement in QOL includes both common human experiences and those unique, individual life experiences; and 5) measurement in QOL enables individuals to move toward a meaningful life they enjoy and value (Verdugo et al., 2005).

The strategies used to measure QOL within the guiding principles are drawn from interrogatories based on the research of Verdugo, Schalock, Keith, and Stancliffe (2005). The first question to consider is what to measure. This should be the QOL domains and indicators, and valued personal experiences and circumstances that are a result of some activity, intervention, or service. The second is how to subjectively and objectively measure these experiences and circumstances. Next, who should be involved in the measurement. This would include the individual with the disability and family and friends who know the individual well. Where and when to assess should be considered as well. Assessments should be conducted in a familiar and natural environment to the individual and when to assess would depend on the questions being asked. The last question to consider is what type of research methods will best capture individual quality outcomes (Verdugo et al., 2005).

The QOL concept is multidimensional and complex to assess. However, at its core the QOL concept provides a sense of reference to and guidance from an individual point of view, an overarching principle to increase individual well-being, and as a common language and framework to guide coordinated efforts for current and future endeavors. As the understanding of the QOL concept and its assessment significance increase, this concept can be used as a positive change agent in public policy, service delivery programs, and disability reform (Verdugo et al., 2005).

Principles and concepts for measuring QOL have the potential to allow a new perspective on disability, issues relating to disability, as well as contribute to the development and evaluation

of supports, services, and policies for individuals with disabilities. This new perspective can have significant implications for individuals with disabilities with regard to societal and personal treatment and consideration (Brown, 1997). Since SAIL's inception, the mission of the program has claimed that in-home services provided through all programs would enhance a consumer's quality of life. However, this claim has never been researched. In order to determine if the IL program is accomplishing this mission statement, an evaluation is required.

CHAPTER III. METHODS

A program evaluation is generally used to answer how well a program has met pre-determined goals and expectations (Creswell, 2013; Vogt, 2007), Researchers use both quantitative and qualitative methods to examine the research problem(s) from different perspectives in order to gain a broader understanding of the data (Teddlie & Tashakkori, 2009). In using established information systems as data sources for evaluation purposes, sources of data can be divided into three groups; 1) systematically gathered data; 2) treatment documentation; and 3) clinical/administrative judgment (see Table 3) (Kapp & Anderson, 2010).

Systematically gathered data includes a wide range of information currently and regularly collected by the agency to meet existing program needs, and state and federal requirements. Systematically gathered information is often stored in automated information systems (Kapp & Anderson, 2010). This is true for the ADRS as their data are stored in their agency developed data base called Systems for Managing Information on the Leading Edge (SMILE). Data stored in this type of electronic format allow for the data to be cleaned, manipulated, and analyzed for the program evaluation. While many automated information systems focus on administrative procedures, often agencies maintain additional systems to inform clinical and/or medical practices, or to respond to specific federal and/or state mandates for quality assurance purposes (Kapp & Anderson, 2010). The data stored in these entries are vital to conducting program evaluations.

Treatment documentation includes data that are usually stored and updated routinely in case files and/or case notes. These documents, often regarded as routine paperwork, can contain a wealth of valuable data as they include vital information like initial assessments, service plan and plan goals documentation, disability diagnosis, service outcomes, etc. In addition, treatment documentation can include critical information about the operation of the program (Kapp & Anderson, 2010).

A third data source is clinical/administrative judgment (Kapp & Anderson, 2010). This data is often not considered in the evaluation process because of the personal nature that exists within the case notes. Most data systems include a case notes option for administration, clinicians and/or case managers to record personal encounters with the consumer, and consumer's compliance with the service plan. Information gathered within these case notes can contain judgement evaluations and observations from the perspective of the employee entering the case notes (Dybicz, 2004; Klein & Bloom, 1995). Typically, program evaluations focus on key components of the program process, and clinical/administrative judgement are not routinely collected for data analysis; however, case notes can contain a valuable source of insight into case manager, consumer, familial, and care giver relationships, as well as consumer service plan compliance (Kapp & Anderson, 2010). For purposes of this descriptive study, clinical/administrative judgements are not collected for data analysis because they are the evaluations, observations, and opinions of the employee, and are not specifically captured in the data. Employees also have a choice as to whether this information is entered, so these data lack reliability and to some extent validity, for comparison purposes. The program processes of IL services, including quality of life, are the focus of this study; and clinical/administrative

judgements are not included, but may be worthy of future consideration, if greater consistency is required of the employees.

Table 3
Available Data Sources

<i>Available Data Sources</i>		
<i>Source</i>	<i>Description</i>	<i>IL Variables</i>
Systematically gathered data	Information that is routinely collected on an ongoing basis.	Basic demographics, application and closure date, disability diagnosis, disability cause, service plan, and living arrangement at application and closure.
Treatment documentation	Information stored in case files.	Service plans and goals, educational achievement, employment status at application, financial supports and status
Clinical/administrative judgment	Information acquired by observing the service delivery process on a regular basis.	Practitioner and/or specialist insights on compliance or non-compliance of service plan and evaluation of met and unmet needs. Family and/or care givers supportiveness of the service plan.

Although data systems often generate standardized reports, many important evaluation questions cannot be answered by these reports alone. Key service delivery questions can often be addressed by creating data sets from the information systems and organizing them around specific questions (Kapp & Anderson, 2010).

Purpose

The purpose of this study is to evaluate the State of Alabama Independent Living Program Services, including a quality of life component. The results provide further information on service gaps and areas that have yet to be addressed by the SAIL program; and legitimize the need for additional research.

Research Design

A descriptive study research design is used to examine secondary, de-identified data to answer the following questions:

1. What are the top five services provided by IL to help individuals with significant disabilities function independently in their home between January 1, 2014 through December 31, 2016?
2. How many cases were opened during this period?
3. What is the most common disability diagnosis and cause of those served?
4. What is the average caseload size during this period?
5. What is the average expenditure per consumer?
6. What is the average length of time a consumer is served?
7. What is the most common living arrangement of the consumer upon closure?
8. Do IL services align with the IL mission statement, specifically providing a higher quality of life?

According to Jackson (2009) a descriptive study design not only answers the what questions, but the type, how many, and how much questions as well, because it provides an accurate description of the incidence of a phenomenon or can be utilized to predict certain outcomes in program or organization evaluations. A descriptive study is non-experimental as information is collected without manipulating the environment. These studies do not determine cause and effect, rather they describe situations.

Participants

Alabama has a unique population of consumers who receive services through the Alabama Department of Rehabilitation's SAIL Service program. In order to be eligible for IL

services, the individual must have or need the following: 1) a significant disability; 2) require nursing facility level of care criteria, meaning the individual is dependent on others for activities of daily living like, feeding, bathing, and dressing; and 3) inability to maintain independence. Independent Living services prevent nursing home placement by providing specialized in-home education, counseling, attendant care, training, and medical services. Participants must request IL services and are required to have a goal of independent living at the time of application. This goal must be maintained by the participant throughout the duration of service provision. For purposes of this study, participants are individuals with the most significant disabilities who requested and received services through the IL Services program between January 1, 2014 through December 31, 2016.

Different agencies and organizations time requirements for effective program evaluations vary and the program evaluator must take into consideration the scope of the evaluation when establishing time parameters (McDavid, Huse & Hawthorn, 2012). For purposes of this research, this particular three-year period for the evaluation was requested by the SAIL Services program leadership due to changes in administration during this time. The rationale of the leadership was to evaluate if the IL program was robust enough to maintain efficient and effective service delivery methods during leadership transition. Additionally, this three-year period allows for more accurate service delivery measurements as some IL services may take longer to initiate, deliver, and record outcomes than others.

Demographics of Participants

Of the 1,035 IL consumers served between January 1, 2014 and December 31, 2016, the following demographics were captured in SMILE. Forty-nine percent ($n = 510$ consumers) of the population reported their gender as male; 51% ($n = 525$) female. At the time data was retrieved

from SMILE, an “other” or “do not wish to disclose” gender option was not available. Ethnic group description identified Black or African American as 46% ($n = 475$ consumers) and White as 54% ($n = 554$) as the most frequently reported ethnic group. American Indian or Alaska Native represented 1% ($n = 1$); Asian represented 2% ($n = 2$); and Native Hawaiian or Other Pacific Islander represented 3% ($n = 3$) of the consumers served. In SMILE, there is not an “other” option for ethnic group nor is there the ability to select more than one ethnic group (see Table 4).

Table 4

Demographic Information of IL Consumers (N=1035)

Demographics	<i>f</i>	%
Gender	1035	100%
Male	510	49.3%
Female	525	50.7%
Ethnicity	1035	100%
Black or African American	475	45.9%
White	554	53.5%
American Indian or Alaska Native	1	0.1%
Asian	2	0.2%
Native Hawaiian or Other Pacific Islander	3	0.3%

When selecting the age range demographics, the program evaluator used Aghevli and Mehran (1981) optimal grouping rule. They propose that age grouping consist of selecting cutoff ages for groups such that the age differences are a minimum within each group and a maximum

between groups. The resulting age group representation then provides the best portrayal of the initial distribution. This type of grouping minimizes the possibility of information loss.

The ages of IL consumers at the time of application ranged from 1 to 100 years. The ages of consumers at the time of case closure ranged from 3 to 102. To examine frequency of age in a meaningful way, the variables age at application and age at closure were recoded into different variables to associate the age of the consumer with an age group.

The continuous variables of age at application and age at closure were recoded as different ordinal variables titled age group at application and age group at closure respectively. Numerical values, ranging from zero to six, representing six different age groups were assigned to consumer cases depending upon the consumer’s age at application and at closure. A value of zero was created to categorize any cases with missing data, as it should be noted that a value for age at closure is not captured until the case is closed in the data system. The following age categories were developed for statistical analysis: 0 – Age not captured; 1 – Birth to 19 years old; 2 – 20 to 34 years old; 3 – 35 to 44 years old; 4 – 45 to 64 years old; and 5 – 65 and Older.

Age demographics analyzed at application found birth to 19 years old as 10% ($n = 102$ consumers); 20 to 34 years old as 25% ($n = 260$); 35 to 44 years old as 11% ($n = 115$); 45 to 64 years old as 35% ($n = 359$); and 65 and older as 19% ($n = 199$) consumers served (see Table 5).

Table 5

Age Range of IL Consumers at Application (N=1035)

Age Range at Application	<i>f</i>	%
	1035	100%
Birth to 19 years old	102	9.9%
20 to 34 years old	260	25.1%

35 to 44 years old	115	11.1%
45 to 64 years old	359	34.7%
65 years and older	199	19.2%

Age demographics analyzed at case closure found dates not captured due to the case still being open as 26% ($n = 270$ consumers); birth to 19 years old as 3% ($n = 34$); 20 to 34 years old as 18% ($n = 181$); 35 to 44 years old as 7% ($n = 75$); 45 to 64 years old as 28% ($n = 286$); and 65 and older as 18% ($n = 189$) consumers served (see Table 6).

Table 6

Age Range of IL Consumers at Case Closure (N=1035)

Age Range at Case Closure	<i>f</i>	%
	1035	100%
Age not captured	270	18.3
Birth to 19 years old	34	3.3%
20 to 34 years old	181	17.5%
35 to 44 years old	75	7.2%
45 to 64 years old	554	53.5%
65 years and older	189	18.3%

To aid in the analysis of the disability impairment demographics, disability categories were recoded into smaller subgroupings. These smaller subgroupings reduce the complexity in the analysis of the data without adversely impacting the interpretation. The program evaluator determined the subgroupings by examining the nineteen different disability impairment categories captured in SMILE for similarities between impairments. The impairment similarities

were then grouped in to a broader impairment category. Disability impairment demographics were recoded as different nominal variables titled “physical,” “cognitive,” “respiratory,” “mental health,” “visual,” “hearing loss/deafness,” and “communicative”. After recoding Table 7 is a crosswalk representation of the disability impairment and the new disability type subgroup.

Table 7

*Disability Impairment and Disability Type
Crosswalk*

Disability Impairment	Disability Type					
	Physical (f= 879)	Cognitive (f= 54)	Respiratory (f = 24)	Mental Health (f = 45)	Hearing Loss/Deafness (f = 26)	Communicative (f = 7)
Both Mobility and Manipulation/Dexterity Orthopedic/Neurological Impairments	510	-	-	-	-	-
Mobility Orthopedic/Neurological Impairments	138	-	-	-	-	-
Manipulation /Dexterity Orthopedic/ Neurological Impairments	121	-	-	-	-	-
Cognitive Impairments (involving learning, thinking, processing information and concentration)	-	54	-	-	-	-
Other Physical Impairments (not listed above)	40	-	-	-	-	-
General Physical Debilitation (fatigue, weakness, pain, etc.)	47	-	-	-	-	-
Other Orthopedic Impairments (e.g., limited range of motion)	23	-	-	-	-	-
Respiratory Impairments	-	-	24	-	-	-
Other Mental Impairments	-	-	-	22	-	-
Psychosocial Impairments (interpersonal and behavioral impairments, difficulty coping)	-	-	-	9	-	-

Other Visual Impairments	-	-	-	-	12	-
Communicative Impairments (expressive/receptive)	-	-	-	14	-	-
Blindness, unable to read print in any form w/ aids or devices	-	-	-	-	6	-
Blindness, both eyes, with best correction not more than 20/200 or less than 20-degree arc	-	-	-	-	8	-
Hearing Loss, Primary Communication Auditory	-	-	-	-	-	3
Deafness, Primary Communication Visual	-	-	-	-	-	3
Other Hearing Impairments (Tinnitus, Meniere's Disease hyperacusis, etc.)	-	-	-	-	-	-
Deafness, Primary Communication Auditory	-	-	-	-	-	-
Hearing Loss, Primary Communication Visual	-	-	-	-	-	-

Disability type demographics found physical impairment as 85% ($n = 879$ consumers); cognitive impairment as 5% ($n = 54$); mental health impairment as 4% ($n = 45$); hearing loss/deafness as 3% ($n = 26$); respiratory as 2% ($n = 24$); and communicative as 0.7% ($n = 7$) consumers served (see Table 7). Visual impairment is not represented as there were no consumers who identified their disability impairment as visual.

Table 8

Disability Type by Subgroupings (N=1035)

Disability Type	<i>f</i>	%
	1035	100%
Physical	879	84.9%
Cognitive	54	5.2%
Mental health	45	4.3%
Hearing loss/deafness	26	2.5%
Respiratory	24	2.3%
Communicative	7	0.7%

After re-coding Table 9 is a crosswalk representation of disability cause and their disability type.

Table 9

Disability Cause and Type Crosswalk

Disability Cause	Disability Type					
	Physical (<i>f</i> = 879)	Cognitive (<i>f</i> = 54)	Respiratory (<i>f</i> = 24)	Mental Health (<i>f</i> = 45)	Hearing Loss/Deafness (<i>f</i> = 26)	Communicative (<i>f</i> = 7)
Accident/injury (other than TBI or SCI)	26	1	-	-	2	1
Alcohol Abuse or Dependence	-	-	-	-	-	-
Amputation	51	-	-	-	-	-
Anxiety Disorders	-	-	-	-	-	-
Arthritis and Rheumatism	42	-	-	-	-	-
Asthma and other Allergies	1	-	7	-	-	-
Attention-Deficit Hyperactivity Disorder (ADHD)	-	1	-	2	-	-
Autism	-	3	-	6	-	-
Blood Disorders	6	-	-	-	-	-
Cancer	12	-	-	1	-	-
Cardiac and other Conditions of the Circulatory System	14	-	5	-	-	-
Cause unknown	32	-	1	-	8	4
Cerebral Palsy	105	1	-	4	-	-
Congenital Condition of Birth Injury	32	-	-	-	1	1
Cystic Fibrosis	-	-	-	-	-	-
Depressive and other Mood Disorders	-	-	-	3	-	-
Diabetes Mellitus	35	-	-	-	7	-
Digestive	2	-	-	-	-	-
Drug Abuse or Dependence (other than alcohol)	-	-	-	-	-	-
Eating Disorders (e.g., anorexia, bulimia, or compulsive overeating)	-	-	-	-	-	-

End-Stage Renal Disease and other Genitourinary System Disorders	5	-	-	-	-	-
Epilepsy	9	2	-	-	-	-
HIV and AIDS	-	-	-	-	-	-
Immune Deficiencies excluding HIV/AIDS	4	-	-	-	-	-
Mental Illness (not listed elsewhere)	-	-	-	3	-	-
Mental Retardation	5	7	-	12	-	-
Multiple Sclerosis	39	-	-	-	1	-
Muscular Dystrophy	23	-	-	-	-	-
Parkinson's Disease and other Neurological Disorders	15	1	-	1	-	-
Personality Disorders	-	-	-	-	-	-
Physical Disorders/Conditions (not listed elsewhere)	93	2	2	1	5	1
Polio	5	-	2	-	-	-
Respiratory Disorders other than Cystic Fibrosis or Asthma	5	-	7	-	-	-
Schizophrenia and other Psychotic Disorders	-	-	-	4	-	-
Specific Learning Disabilities	-	6	-	1	-	-
Spinal Cord Injury (SCI)	154	-	-	-	-	-
Stroke	109	-	-	3	-	-
Traumatic Brain Injury (TBI)	55	30	-	4	2	-

Study Variables

The study variables for the research design questions were analyzed **as** follows:

- Demographic questions regarding gender, age, primary race/ethnicity, and disability category were analyzed using descriptive statistics and aggregate data measures.

Aggregate data refers to numerical or nominal data that is: 1) gathered from various sources as well as on different measures, factors, or individuals, and 2) organized into data or report summaries. These aggregate data measures are commonly used for public reporting purposes or statistical analysis - i.e., looking at patterns, making correlations, or uncovering data and experiences (Hidden curriculum, 2014). ADRS' SMILE case management system captures demographic data at the time of application. Only demographic data elements that indicate significant groupings were used in the analysis.

Data Analyses

The program evaluator used descriptive statistics and quantitative measurement procedures for data analysis. Consumer demographics were analyzed using descriptive and frequency analysis.

- The first research question, what are the top five services provided by IL to help individuals with disabilities function independently in their home between January 1, 2014 through December 31, 2016, was evaluated using descriptive statistics to determine frequencies and ranking.
- Research question two, how many cases were opened during this time-period, was evaluated using descriptive statistics to determine frequency and percent.

- Research question three, what is the most common disability diagnosis and cause of those served during this time-period, was determined using descriptive analysis. A cross tabulation table was used to determine both disability diagnosis and cause.
- Research question four, what is the average caseload size during this time-period, was determined using descriptive analysis, SPSS custom tables and means.
- Research question five, what is the average expenditure per consumer, was determined using compare means statistics to obtain the average expenditure for both open and closed cases.
- Research question six, what is the average length of time a consumer is served, was determined using means to evaluate length of time a consumer is served for both open and closed cases.
- Research question seven, what is the most common living arrangement of the consumer upon closure was determined using descriptive statistics to calculate frequency and percentage.
- Research question eight, do IL services align with the IL mission statement, specifically providing an increased quality of life, was determined by identifying data collected in the SMILE case management system that correlates with Schalock's (2004) Core Quality of Life Domains and the Most Commonly Used Indicators model (see Table 2). Schalock's model identifies eight core QOL domains as: interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and rights (Verdugo, Schalock, Keith, & Stancliffe, 2005). Corresponding to these core QOL domains are indicators and descriptors. These indicators are used to operationally define its corresponding QOL domains, and for

assessing quality outcomes. The indicator items refer to an individual's perceived well-being, or as the valued personal life experiences and circumstances. These experiences and circumstances are a result of some activity, intervention, or service; and are measured based on the quality indicators (Verdugo et al., 2005). Typically, two or three items are used to measure each QOL indicator. The SMILE case management system does not specifically capture core QOL domains. It does; however, capture core QOL indicators and descriptors related to the core QOL domains of interpersonal relations, material well-being, personal development, and self-determination. The program evaluator identified core QOL indicator and descriptor variables captured in the SMILE case management system related to the above-mentioned domains. Once the variables were chosen, data were analyzed to determine whether IL services align with the IL mission statement, specifically providing an increased quality of life.

Procedure

To access data contained in SMILE, the program evaluator sought, and was granted permission from the ADRS to receive a secondary, de-identified consumer data set for the purpose of an academic research initiative. The program evaluator requested the data set include IL cases served during the time-period January 1, 2014 through December 31, 2016. Approval to receive the data was expressed in the form of a Department issued Data Sharing Agreement for De-Identified Data (Appendix A) and signed by the Director of the SAIL program on December 20, 2016.

For purposes of this research, a descriptive study design was utilized to conduct an evaluation by analyzing secondary data maintained in the ADRS SMILE case management system. The evaluation determined consumer demographics, top services provided to consumers

by IL, cases opened, most common disability diagnosis and cause, average caseload size, average expenditure per consumer, and the average length of time a consumer was served. Additionally, quality of life indicators were examined, but only to the extent that applicable data were collected by the IL program for those specific consumers represented in the ADRS data set.

Method of Data Retrieval

Retrieval. All data for this research study was retrieved from the ADRS' electronic database that provides the storage, security, access, and retrieval of data supporting the SMILE case management system. SMILE is the sole source of record for consumer's case services and the official system of record for case management activities performed by the ADRS employees. SMILE is managed by a Microsoft software product titled Microsoft SQL Server. SQL is an acronym for structured query language, which is a common programming language used in database programming (International Organization for Standardization / International Electrotechnical Commission, 2011). Microsoft uses SQL in the naming of its product to indicate that the product is based on the structured query programming language. SMILE's database relies upon Microsoft's SQL Server product for its management and administration capabilities. This database is located on premise, in an ADRS owned facility.

As permitted via the data sharing agreement and on the authorized date established by the Auburn Institutional Review Board (see Appendix B), the program evaluator requested that the ADRS database administrator provide the de-identified consumer data set that represents consumers served January 1, 2014 through the December 31, 2016 period. The data elements requested from the ADRS were identified using the naming conventions as they appear in the SMILE case management system input screens and listed in the data dictionary (see Appendix C). The request included specific data filtering parameters, such as cases served in the specific

three-year period to ensure that only the requested data were provided. The request also specified the output format for these data be provided in a Microsoft Excel spreadsheet format.

Cleaning. The program evaluator used Microsoft Excel to clean and screen the data and remove any incomplete or erroneous data records. Sorting and filtering each data column identified missing data elements and identified where data need additional clarification by naming variables and values, as necessary. Data were also examined for input errors and varied format such as those commonly found in elements pertaining to date or time (Tabachnick & Fidel, 2007). Originally, 1038 data records were identified. Through the cleaning process three records were removed due to incomplete data. Additionally, through this cleaning process, data ranges were examined for alignment with values identified in the data dictionary. ADRS' case management system enforces data validation on all input methods ensuring that the data entered adheres to the required format, prohibiting erroneous data input.

Transformation. Data elements existing with one-to-many relationships, such as a consumer having more than one Planned Service, required the creation of additional variables prior to import into SPSS or restructuring of the data after import. The SMILE database stores data using a relational database design, resulting in data associated with a single consumer being stored in multiple subject-based tables. Subject-based tables allow for the organization of data into individual tables based on the data's subject matter. For example, demographic data for all the ADRS consumers are stored in a single table with a unique row of data existing for each consumer. Services provided to the ADRS consumers are stored in a separate table with a single row of data existing for each service provided. This type of database design results in a single consumer record stored in one table to be related to one or more service records in another table, thus establishing a one-to-many association among the data. A unique data identifier for each of

the ADRS consumers is stored with the consumer record, or row, in the consumer table. The same unique data identifier is also stored with each service record, or row, in the services table. Unique data identifiers contained in the data, such as the case number, are used to associate the data elements stored in the various tables and allows for the extraction of the associated case information for consumer.

Transformation of the data was performed by the program evaluator using Microsoft Excel and the Statistical Package for the Social Science (SPSS). Much of the data used in this evaluation currently exists in the SMILE database with a one-to-many relationship. Data elements with one-to-many relationships required the creation of additional variables to eliminate the possibility of duplicated data during statistical analysis. The creation of these additional variables occurred prior to import into the SPSS or were restructured after import. Using the SPSS, text variables from the source data were recoded into nominal, ordinal, or the ratio equivalent as necessary for statistical procedures. Variable names resembled the data element names listed in the data dictionary.

Importing: The data contained in the Excel spreadsheet was imported using the SPSS Database Wizard utility. A copy of the data, as initially provided in the Excel spreadsheet, was maintained in its original and unaltered form.

Summary

Chapter III provides a description of this evaluation and how to use established information systems as data sources for evaluation purposes. Participants and study variables for the evaluation are identified. This chapter presented the data analyses procedures used to answer each research question. Finally, this chapter also provides the procedure for retrieval of the data. Results from analyses are provided in Chapter IV, Results.

CHAPTER IV. RESULTS

This chapter provides the findings from the evaluation of the Independent Living (IL) Services Program. Additionally, this study examined certain quality of life domains and indicators developed by Schalock (2004) and found in the existing data. Results from the program evaluation and quality of life indicators are presented in this chapter. This chapter begins with a list of the research questions for this study. Next, the findings for each of the research questions are described. This chapter concludes with a summary of the evaluation findings.

This study investigated the following questions:

1. What are the top five services provided by IL to help individuals with disabilities function independently in their home between January 1, 2014 and December 31, 2016?
2. How many cases were opened during this time-period?
3. What is the most common disability diagnosis and cause of those served during this time-period?
4. What is the average caseload size during this time-period?
5. What is the average expenditure per consumer?
6. What is the average length of time a consumer is served?
7. What is the most common living arrangement for the consumer upon closure?
8. Do IL services align with the IL mission statement, specifically providing a higher quality of life?

Research Question One

What are the top five planned services provided by IL to help individuals with disabilities function independently in their home between January 1, 2014 and December 31, 2016? Planned services are those services arranged by the IL specialist in order to provide the consumer with the most options available within the scope of the program. Consumers may select from more than one available service. The program evaluator analyzed the planned services data collected using SPSS to provide descriptive statistics of frequency and percent (see Table 10).

Table 10

Top Five Planned Services Provided to IL Consumers During Date Range

Top five planned services provided	<i>f</i>	%
	3265	78.5%
Information and Referral	747	22.9%
Assistive Devices/Equipment	743	22.8%
Other	459	14.1%
Housing, Home Modifications and Shelter	368	11.3%
Preventative Services	211	6.5%

Examination of the top five services provided showed 3,265 delivered services across the entire 1,035 IL population. Approximately 80% of the population received these top five services. The remainder of the population received a service or services other than those identified as a top five planned services. Approximately 23% of IL consumers received information and referral as one of the top two services provided between January 1, 2014 to

December 31, 2016. Information and referral includes, but is not limited to, providing direction to additional available services and resources outside the IL Services program, assisting the consumer in connecting with other agencies and community organizations, and helping the consumer to develop a network of contacts and information resources. The second service was assistive devices/equipment as approximately 23% of IL consumers received these services. Assistive devices/equipment includes, but is not limited to: augmentative and alternative communication (AAC) devices, medical equipment and supplies, home modifications for accessibility, and other items that assist the consumer in activities of daily living. Other services represented 14% of the population. Other services are those not identified by a specific variable in SMILE, but are developed by the IL specialist and the consumer to assist the individual in meeting their independent living goals. Housing, home modifications, and shelter represented 11% of the population and are those services provided to consumers to assist in locating accessible housing or shelter, or to make modifications to an existing home so it is accessible by the consumer. These modifications can include, but are not limited to, wheelchair accessible ramps, widening doorways, and bathroom modifications. Preventative services represented almost 7% of the population and are those services which help the consumer restore to good health or maintain good health. These services can include, but are not limited to, referral to a waiver program that provides in home attendant care, medical supplies, or durable medical equipment.

Research Question Two

How many cases were opened during this time-period?

To answer this question, the program evaluator recoded the variable of “application date” captured in SMILE to a new variable titled “application year.” Four variables were created

representing the consumer’s calendar year of application for IL services. Three variables, “2016”, “2015”, and “2014”, were created to group consumers into the three years represented in the evaluation, January 1, 2014 through December 31, 2016. A fourth value, “2002 through 2013”, was created to group consumers who applied for services prior to the January 1, 2014 initiation date of this evaluation and were receiving services during the evaluation period. By analyzing the applicants in this manner, the program evaluator was able to distinguish those consumers who entered the IL program during the evaluation years from those consumers who entered for services prior to the evaluation period. The new variable grouped individuals in the following manner: consumers with an application date between January 1, 2014 through December 31, 2014 were recoded as 2014; consumers with an application date between January 1, 2015 through December 31, 2015 were recoded as 2015; consumers with an application date between January 1, 2016 through December 31, 2016 were recoded as 2016.

The entire IL population served during the January 1, 2014 through December 31, 2016 was 1,035 consumers. To represent the entire consumer population in the evaluation, consumers with an application date prior to January 1, 2014 were recoded as 2002 through 2013. Cases represented in this variable were in open service status during the time of the evaluation. The number of consumer cases opened during year 2014 was 20% ($n = 207$); 2015 was 14% ($n = 141$); 2016 was 34% ($n = 356$); and 2002 through 2013 32% ($n = 331$). The data for cases opened were analyzed using SPSS to provide descriptive statistics of frequency and percent (see Table 11).

Table 11

Consumer Cases Opened During January 1, 2014 through December 31, 2016

Consumer Cases Opened	<i>f</i>	%
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	1035	100%
2014	207	20.0%
2015	141	13.6%
2016	356	34.4%
2002 through 2013	331	32.0%

Results show that year 2016 had the most cases opened at 356 new or returning consumers. Next, the years of 2002 through 2013, showed 331 consumer cases opened prior to the initial evaluation date of January 1, 2013. Cases in this variable remained open and continued to receive services during the evaluation period. The third highest recording of cases opened was in 2014 at 207; and the fewest cases opened was in 2015 at only 141 cases.

Research Question Three

What is the most common disability diagnosis and cause of those served during this time-period?

In order to determine the most common disability and cause the program evaluator examined the results represented in Table 7, *Disability Impairment and Disability Type Crosswalk* and Table 9, *Disability Cause and Type Crosswalk*. Table 7 shows the most frequent disability impairment is: “both mobility and manipulation/dexterity orthopedic/ neurological impairment” ($n = 510$). An individual in this disability impairment category presents a minimum of two impairments within the both mobility and manipulation/dexterity orthopedic/ neurological impairment category. When examining Table 7, this disability impairment corresponds to the disability type of “physical,” meaning an individual with both mobility and manipulation/dexterity orthopedic/ neurological impairment identifies as having a physical disability, but with perhaps, more than one diagnosis. Table 9 presented spinal cord injury ($n =$

154) as the most frequent disability cause in the physical disability type. Descriptive statistics cross tabulation was used to analyze and determine the most common cause associated with a disability. Table 12 indicates the most common cause associated with both mobility and manipulation/dexterity orthopedic/neurological impairments is spinal cord injury ($n = 111$) (see Table 12).

Table 12

Most Common Disability Diagnosis and Cause

Disability Diagnosis and Cause		
Both Mobility and Manipulation/Dexterity Orthopedic/Neurological		
Cause	<i>f</i>	Impairment
Spinal Cord Injury	154	111
Stroke	112	109
Cerebral Palsy	110	105

Results show that of the 154 IL consumers who have a spinal cord injury, 111 consumers have both mobility and manipulation/dexterity orthopedic/neurological impairments. Of the remaining 43 consumers who have a spinal cord injury, their disability manifests in an impairment other than both mobility and manipulation/dexterity orthopedic/neurological impairment. The second most common cause is stroke ($n = 112$). Data is not captured as to what caused the stroke to occur, simply that the consumer experiences both mobility and manipulation/dexterity orthopedic/neurological impairments due to a stroke event. Of those consumers, 109 report both mobility and manipulation/dexterity orthopedic/neurological impairments. Cerebral palsy ($n = 110$) is the third most common cause, with 105 reporting both mobility and manipulation/dexterity orthopedic/neurological impairments.

Research Question Four

What is the average caseload size during this time-period?

To determine caseload size, the program evaluator identified each of the eight caseloads. These eight caseloads are divided among seven IL specialists. One specialist is assigned two caseloads due to the demographic area represented and the funding source.

Caseloads represent IL consumers receiving services within a specific demographic area and are given a nominal identifier, a caseload ID, in SMILE. Caseloads are assigned to the IL specialist serving their designated demographic area. It is possible for IL specialist to change caseloads and for consumer cases to open and close in a caseload; however, the caseload ID remains constant. While the caseload ID does not identify consumers in the caseload, it can identify the IL specialist assigned to a particular caseload. There are seven IL specialists in Alabama serving seven different regions throughout the state. One IL specialist works two caseloads, as there is an alternative funding source for one and expenditures spent need to remain separate. To de-identify the original eight caseload numbers, the program evaluator changed the original number to one of the following variables “1,” “2,” “3,” “4,” “5,” “6,” “7,” and “8.” These new variables are nominal and are not representative of any order or ranking.

The program evaluator used descriptive statistics custom tables and means to obtain the average caseload size. For caseload ID 1, the average number of consumers served in 2014 was 77; in 2015, the average number of consumers served was 52; and in 2016, an average of 88 consumers were served. The mean for caseload ID 1 over the three-year research time-period was an average of 72 consumers served. For caseload ID 2, the average number of consumers served in 2014 was 59; in 2015 the average number of consumers served was 57; and in 2016 the average number of consumers served was 76. The mean for caseload ID 2 over the three-year research time-period was an average of 64 consumers served. For caseload ID 3, the average

number of consumers served in 2014 was 83; in 2015 the average number of consumers served was 80; and in 2016 the average number of consumers served was 72. The mean for caseload ID 3 over the three-year research time-period was an average of 78 consumers served. For caseload ID 4, the average number of consumers served in 2014 was 54; in 2015 the average number of consumers served was 58; and in 2016 the average number of consumers served was 73. The mean for caseload ID 4 over the three-year research time-period was an average of 62 consumers served. For caseload ID 5, the average number of consumers served in 2014 was 107; in 2015, the average number of consumers served was 118; and in 2016 the average number of consumers served was 118. The mean for caseload ID 5 over the three-year research time-period was 114. For caseload ID 6, the average number of consumers served in 2014 was 63; in 2015 the average number of consumers served was 66; and in 2016 the average number of consumers served was 97. The mean for caseload ID 6 over the three-year research time-period was 75. For caseload ID 7, the average number of consumers served in 2014 was 55; in 2015 the average number of consumers served was 57, and in 2016 the average number of consumers served was 66. The mean for caseload ID 7 over the three-year research time-period was 59. For caseload ID 8, the average number of consumers served in 2014 was 42; in 2015 the average caseload number was 38; and in 2016 the average caseload number was 88. The mean for caseload ID 8 over the three-year research time-period was 72 (see Table 13).

Table 13

Average Caseload Size by Year

Caseload ID	Caseload Size by Year			Mean
	Year			
	2014 (n=540)	2015 (n=526)	2016 (n=627)	
1	77	52	88	72
2	59	57	76	64

3	83	80	72	78
4	54	58	73	62
5	107	118	118	114
6	63	66	97	75
7	55	57	66	59
8	42	38	37	39

Results show that caseload 5 has the highest averages; 2014 ($n = 107$), 2015 ($n = 118$), and 2016 ($n = 118$); as well as having the highest average caseload ($X = 114$) during the three-year evaluation period. Caseload 3 has the next highest averages; 2014 ($n = 83$), 2015 ($n = 80$), and 2016 ($n = 72$), and the mean ($X = 78$). Caseload 6 has the third highest cases: 2014 ($n = 63$), 2015 ($n = 66$), and 2016 ($n = 97$), and the mean ($X = 75$). Caseloads 7 and 8 have the lowest average cases of all the caseloads; however, both these caseloads are served by one IL specialist.

Research Question Five

What is the average expenditure per consumer?

In order to determine the average expenditure per consumer and accurately assess the financial investment expended per consumer, the program evaluator distinguished between open and closed cases. At the time this data set was obtained, 270 of the 1,035 consumers were currently receiving services through the IL program. Expenditures for closed cases represent the total financial investment made until such time that an outcome was obtained and the case closed. Once the case is closed additional financial investment for that consumer is not possible. Expenditures for open cases represent the total financial investment made as of the date this data set was obtained, at which time an outcome had yet to be determined. It is possible that an open case will require additional financial resources as services continue until such time that a case outcome is determined and the case closed.

To analyze the average expenditure per consumer for both open and closed cases, the

program evaluator created a new variable titled “closure status”. By converting or transforming “date of closure” into the new variable, the program evaluator recoded cases having a value in the date of closure field as “closed” and recoded cases having a null value in the date of closure as “open”. This allowed for the two groups of cases to be examined separately as well as combined.

The program evaluator compared means to obtain the average expenditure per consumer for both open and closed cases. For all IL consumers ($n = 1035$), the mean, or average, expenditure per consumer is \$535.25 over the life of the case. Examining cases grouped by closure status, the average expenditure for closed cases was \$658.28; and for open cases the average expenditure was \$412.22 (see Table 14).

Table 14

Average Expenditure Per Consumer

Closure Status	Life of Case Expenditures	
	<i>N</i>	<i>M</i>
	1035	\$535.25
Closed	765	\$658.28
Open	270	\$412.22

During the evaluation time-period of January 1, 2014 through December 31, 2016, \$535.25 total average was expended over the life of the case. Expenditures for provided services within the scope of the program included, but were not limited to, durable medical equipment, medical supplies, assistive technology, home modifications and other items needed to assist the consumer in performing activities of daily living. As of December 31, 2016, the evaluation end date, \$658.28 on average was spent on cases already closed ($n = 765$). Of the remaining open cases ($n = 270$), \$412.22 on average was spent in service provision.

Research Question Six

What is the average length of time a consumer is served?

To determine the average length of time a consumer is served, the program evaluator distinguished between open and closed cases. At the time this data set was obtained, 270 of the 1,035 consumers were currently receiving services through the IL program. The amount of time in service for a closed case represents the total amount of time required to obtain a closure outcome for that consumer. Consumers receiving services have yet to obtain a closure outcome and their service length of time is unknown, but the service length of time for open cases is available for analysis.

To analyze the average length of time a consumer is served, the program evaluator created a new variable titled “days served”. Days served was selected as the optimal variable over “month” or “year” variables as consumers can choose to terminate their services at any time. An additional consideration for selecting days served as the variable is the health of the population being served. Independent Living services are provided to those individuals with the most significant disabilities and a case can close within days of service provision due to disability related medical complications resulting in the death of the consumer.

The number of days between the consumer’s application and closure date was determined using the SPSS compute variable function. The program evaluator substituted the date of 12/31/16 as the closure date for consumers currently in service status. This allowed the program evaluator to examine the two groups separately as well as combined. The program evaluator determined the average length of time a consumer is served for both open and closed cases (see Table 15).

Table 15

Average Length of Time a Consumer is Served

Closure Status	Average Time of Service Provision per Consumer	
	<i>N</i>	<i>M</i>
	1035	514.84
Closed	765	597.33
Open	270	432.35

For all IL consumers ($n = 1035$), the mean, or average, length of time a consumer is served was 514.84 days, or approximately one year and five months. IL consumers with an open ($n = 270$) case the average length of time served was 432.35 days, or approximately one year and three months. IL consumers who received services during the evaluation period, but whose case was closed ($n = 765$) during this time; the average length of service provision was 597.33 days, or approximately one year and eight months.

Research Question Seven

What is the most common living arrangement of the consumer upon closure?

SMILE offers the following options for describing a consumer's living arrangement: (a) assisted living, (b) dependent with family and friends, (c) independent, (d) institution – hospital, (e) institution – hospital rehabilitation, (f) institution – jail, (g) institution - nursing home, (h) institution – transition living, and (i) other. Although these variables represent the available options an IL specialist can choose when describing a consumer's living arrangement, two of the potential options did not occur in this data set; institution – hospital rehabilitation and institution, and institution – jail. Descriptive statistics was used to determine frequency and percentage for only those living arrangement options that were present within the data set. Consumers reported living arrangements as: dependent with friends and family ($n = 625$), independent ($n = 81$), other ($n = 32$), institution – nursing home ($n = 22$), assisted living ($n = 2$), institution – hospital ($n =$

2), and institution – transition living ($n = 1$). Additionally included in the analysis are cases not closed ($n = 270$) (see Table 16).

Table 16

Most Common Living Arrangement at Closure

Living arrangement at closure of IL consumers	<i>N</i>	%
	1035	100%
Dependent with friends and family	625	60.4%
Independent	81	7.8%
Other	32	3.1%
Institution – Nursing Home	22	2.1%
Assisted Living	2	0.2%
Institution – Hospital	2	0.2%
Institution – Transition Living	1	0.1%
Cases not closed	270	26.1%

The most common living arrangement upon case closure is dependent with friends and family ($n = 625$), followed by independent ($n = 81$). These two living arrangement categories represent more than half of the IL consumer closed case population. Approximately 26% of the entire population had cases that were not closed; therefore, living arrangement upon closure has yet to be determined.

Research Question Eight

Do IL services align with the IL mission statement, specifically providing a higher quality of life?

To answer research question eight, the program evaluator utilized Schalock’s (2004) Core Quality of Life (QOL) Domains and Most Commonly Used Indicators table as a guide to identify QOL domains and indicators captured in the SMILE case management system. This table was introduced in Chapter 2 as Table 2, but is provided again as Table 17 for clarification.

Table 17

Core Quality of Life Domains and Most Commonly Used Indicators

Core QOL domain	Indicators and descriptors
Emotional well-being	Contentment (satisfaction, moods, enjoyment) Self-concept (identity, self-worth, self-esteem) Lack of stress (predictability and control)
Interpersonal relations	Interactions (social networks, social contacts) Relationships (family, friends, peers) Supports (emotional, physical, financial, feedback)
Material well-being	Financial status (income, benefits) Employment (work status, work environment) Housing (type of residence, ownership)
Personal development	Education (achievements, education status) Personal competence (cognitive, social, practical) Performance (success, achievement, productivity)
Physical well-being	Health (functioning, symptoms, fitness, nutrition) Activities of daily living (self-care, mobility) Leisure (recreation, hobbies)
Self-determination	Autonomy/personal control (independence) Goals and personal values (desires, expectations) Choices (opportunities, options, preferences)
Social inclusion	Community integration and participation Community roles (contributor, volunteer) Social supports (support network, services)
Rights	Human (respect, dignity, equality) Legal (citizenship, access, due process)

The program evaluator examined the existing data in the SMILE case management system to identify core QOL domains and indicators. The specific domain and indicator variables used in Schalock’s table do not directly correlate with the data captured in SMILE. Therefore, proxy variables were developed to serve in place of Schalock’s domain and indicator variables. These proxy variables have a close correlation with the QOL domain and indicator variables of interest (Boslaugh & Watters, 2008). Additionally, only those QOL domains and indicators found in Schalock’s table where a close correlation could be established with the data variables captured in SMILE were analyzed.

Schalock’s first core QOL domain that provides an opportunity for analysis is the core domain *Interpersonal relations*. The QOL indicators and descriptors that operationally define interpersonal relations are: *Interactions* (social networks, social contacts), *Relationships* (family, friends, peers), and *Supports* (emotional, physical, financial, feedback). Of the three, relationship and supports data are captured in SMILE. Relationships (family, friends and peers) data are entered into SMILE in the “Application Independent Living (IL) Basic Marital” status field. Descriptive statistics was used to determine frequency and percentage for the marital status data captured in SMILE. Marital status variables were analyzed and identified the consumer’s as one of the following: divorced 19% ($n = 197$); married 20% ($n = 208$); never married 44% ($n = 459$); separated 4% ($n = 40$); and widowed 12% ($n = 131$) (see Table 18).

Table 18

QOL indicator and descriptor – Relationships (family, friends, peers)
Application IL Basic Marital status

Marital status of IL consumers	<i>N</i>	%
	1035	100%

Divorced	197	19%
Married	208	20.1%
Never Married	459	44.3%
Separated	40	3.9%
Widowed	131	12.7%

Results of IL consumer’s marital status at application show that approximately 44% of the population has never been married. Married is the next highest reported relationship status, accounting for approximately 20% of the population; followed by divorced with 19%.

Supports (emotional, physical, financial, feedback) data is entered into SMILE in the “Application Independent Living (IL) Personal Assistance” field. Supports data in SMILE are captured as one of the following variables: (a) Alabama Head Injury foundation, (b) Children’s Rehabilitation Services (CRS), (c) family and friends, (d) Homebound (waiver), (e) none available, (f) other, (g) VR (vocational rehabilitation), (h) Waiver E (elderly) and D (disabled), (i) Waiver MRDD (mental retardation and developmental disabilities), and (j) Waiver SAIL. These data were analyzed to determine frequency and percentage for the supports data captured in SMILE. All supports variables were analyzed and personal assistance received by IL consumers was reported in descending order as follows: family and friends ($n = 792$), other ($n = 78$), Waiver E and D ($n = 47$), Waiver SAIL ($n = 45$), none available ($n = 44$), Homebound ($n = 15$), CRS ($n = 5$), VR ($n = 4$), Waiver MRDD ($n = 3$) and Alabama Head Injury Foundation ($n = 2$) (see Table 19).

Table 19

*QOL indicator and descriptor – Supports (emotional, physical, financial, feedback)
Application IL Personal Assistance*

Personal Assistance received by IL consumers	<i>N</i>	%
	1035	100%
Family and Friends	792	76.5%
Other	78	7.5%
Waiver E and D	47	4.5%
Waiver SAIL	45	4.3%
None Available	44	4.3%
Homebound	15	1.4%
CRS	5	0.5%
VR	4	0.4%
Waiver MRDD	3	0.3%
Alabama Head Injury Foundation	2	0.2%

Results show that approximately 76% of IL consumers at application have their personal assistance needs met by friends and family. Other is the second highest category at almost 8%. Other personal assistance can represent, but is not limited to, private pay personal assistance; a home health agency providing personal assistance for a specific short-term period of time, usually after a hospitalization; assistance provided by the Department of Public Health, or other agency; and assistance provided by a non-profit, or religious organization.

Schallock's second core QOL domain analyzed is *Material well-being*. The QOL indicators and descriptors that operationally define material well-being are: *Financial status*

(income, benefits), *Employment* (work status, work environment), and *Housing* (type of residence, ownership). All three indicators and descriptors are found in SMILE data.

Financial (income, benefits) status data is captured in SMILE in “Application IL Financial Primary Source of Support” (income). SMILE offers the following options for describing the Financial Primary Source of Support (income) of IL consumers: (a) all other public sources, (b) all other sources of support, (c) annuity or other non-disability insurance benefits, (d) current earnings, interest, dividends, rent, (e) family and friends, (f) private relief agency, (g) public assistance without federal funds (GA only), (h) public assistance, at least partly with fed funds, (i) public institution – tax supported, (j) Social Security Disability Insurance (SSDI), and (k) worker’s compensation. Although these variables represent the available options an IL specialist can choose when describing a consumer’s financial primary source of support (income) three of the potential options were not reported: private relief agency, public institution – tax supported, and worker’s compensation. These data were analyzed to determine frequency and percentage for only those Financial Primary Source of Support (income) options that were reported. The results in descending order are: family and friends ($n = 500$), public assistance, at least partly with fed funds ($n = 257$), Social Security Disability Insurance (SSDI) ($n = 102$), current earnings, interest, dividends, rent ($n = 54$), all other public sources ($n = 52$), all other sources of support ($n = 42$), annuity or other non-disability insurance benefits ($n = 5$), and public assistance without federal funds (GA only) ($n = 5$) (see Table 20).

Table 20

QOL indicators and descriptors – Financial status (income, benefits)
Application IL Financial Primary Source of Support (income)

Primary Source of Support received by IL consumers	<i>N</i>	%
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	1035	100%
Family and Friends	500	48.3%
Public Assistance, at least partly with Federal support	257	26.6%
Social Security Disability Insurance (SSDI)	102	9.9%
Current earnings, interests, dividends, rent	54	5.2%
All other public sources	52	5.0%
All other sources of support	42	4.1%
Annuity or other non-disability insurance benefit	5	0.5%
Public assistance without Federal funds (GA only)	5	0.5%

Results show that at application family and friends are the primary source of financial support for approximately half, 48%, of IL consumers served. Public assistance, at least partial with federal dollars following at almost 27%. Public assistance can include state only funded programs, federally funded only programs, or a combination of both state and federal funds. Social Security Disability Insurance is the third highest reported percentage of financial support represented at almost 10%.

Financial status data are captured in SMILE in “Application IL Financial Source of Medical Insurance” (benefits). Medical insurance in SMILE is captured as one of the following variables: (a) Medicaid, (b) Medicare, (c) Medicaid and Medicare, (d) no insurance, (e) Blue Cross/Blue Shield, (f) Blue Cross/Blue Shield and Medicare, and (g) other. Descriptive statistics were used in order to determine frequency and percentage. Results in descending order are: Medicaid ($n = 355$), Medicare ($n = 197$), Medicaid and Medicare ($n = 147$), no insurance ($n =$

107), Blue Cross/Blue Shield ($n = 83$), Blue Cross/Blue Shield and Medicare ($n = 80$), and other ($n = 66$) (see Table 21).

Table 21

QOL indicators and descriptors – Financial status (income, benefits)
Application IL Financial Source of Medical Insurance (benefits)

Source of Medical Insurance at Application	<i>N</i>	%
	1035	100%
Medicaid	355	34.3%
Medicare	197	19%
Medicaid and Medicare	147	14.2%
No Insurance	107	10.3%
Blue Cross/Blue Shield	83	8%
Blue Cross/Blue Shield and Medicare	80	7.7%
Other	66	6.4%

Results show Medicaid being the primary source of medical insurance at approximately 34%, followed by Medicare at 19%. A combination of both Medicaid and Medicare was the third highest at slightly over 14%.

Employment data is captured in SMILE in “Application IL Work History: Work Status at Application.” SMILE offers the following options for describing a consumer’s Work Status at Application: (a) employment with supports in integrated setting, (b) employment without supports in integrated setting, (c) extended employment, (d) homemaker, (e) not employed: all other students, (f) not employed: other, (g) not employed: student in secondary education, (h) not employed: trainee, intern or volunteer, (i) self-employment (except Business Enterprises

Program) (BEP), and (j) unpaid family worker. These variables represent the available options an IL specialist can choose when describing a consumer’s Work Status at Application, only one unpaid family worker, did not occur in this data set. Descriptive statistics were used to determine frequency and percentage for only those Work Status at Application options that were reported. The results in descending order are: not employed: other ($n = 1012$), employment with supports in integrated setting ($n = 9$), employment without supports in an integrated setting ($n = 5$), extended employment ($n = 4$), homemaker ($n = 1$), not employed: all other students ($n = 1$), not employed: students in secondary education ($n = 1$), not employed: trainee, intern or volunteer ($n = 1$), and self-employed (except BEP) ($n = 1$) (see Table 22).

Table 22

QOL indicators and descriptors – Employment (work status, work environment)
Application IL Work History: Work Status at Application

Work Status at application of IL consumers	<i>N</i>	%
	1035	100%
Not employed: Other	1012	97.8%
Employment with supports in integrated setting	9	0.9%
Employment without supports in an integrated setting	5	0.5%
Extended employment	4	0.4%
Homemaker	1	0.1%
Not employed: All other students	1	0.1%
Not employed: Students in secondary education	1	0.1%
Not employed: Trainee, intern or volunteer	1	0.1%

Self-employed (except BEP)

1

0.1%

Approximately 98%, almost the entire data set, identified as not employed: other at application. This percentage is not an indication of their previous work experience or future work potential. This simply represents employment status at application. The second most frequent work status is employment with supports in integrated setting at 9% ($n = 0.9$).

Housing data is captured in SMILE in “Application IL Financial Living Arrangement.” This data provides information on how the living arrangements for the individual receiving IL services are funded. Financial living arrangements in SMILE are captured as one of the following variables: (a) assisted living, (b) dependent with family and friends, (c) independent, (d) institution – hospital, (e) institution – hospital rehab, (f) institution – jail, (g) institution - nursing home, (h) institution – transition living, and (i) other. Although these variables represent the available options an IL specialist can use when describing the consumer’s Financial Living Arrangement at application; only one institution – jail, was not reported. Descriptive statistics were used to determine frequency and percentage for only those Financial Living Arrangement options that were reported. The results in descending order are: dependent with friends and family ($n = 880$), independent ($n = 133$), institution – nursing home ($n = 5$), other ($n = 5$), institution – hospital ($n = 4$), institution – hospital rehab ($n = 4$), assisted living ($n = 2$), and institution – transition living ($n = 2$) (see Table 23)

Table 23

*QOL indicators and descriptors – Housing (type of residence, ownership)
Application IL Financial Living Arrangement*

Financial living arrangement at application of IL consumers	<i>N</i>	%
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	1035	100%
Dependent with friends and family	880	85.0%
Independent	133	12.9%
Institution – Nursing Home	5	0.5%
Other	5	0.5%
Institution – Hospital	4	0.4%
Institution – Hospital Rehab	4	0.4%
Assisted Living	2	0.2%
Institution – Transition Living	2	0.2%

Results show that 85% of IL consumers at application are dependent on their family and friends for financial assistance with regard to housing. Financial housing assistance from friends and family can also be monetary in order to help the individual maintain and keep their current residence by paying necessary bills and rent or mortgage payments. Approximately 13% of consumers served live independently and use their own funds to pay necessary living expenses.

Housing data is also captured in SMILE in “Application IL Basic Type of Institution.” This data provides information on the type of institution or residence in which the individual receiving IL services is living. Housing data in SMILE are captured as one of the following variables: (a) alcoholic treatment center, (b) community mental health center – inpatient, (c) correctional institution – adult, (d) correctional institution – juvenile, (e) drug treatment center, (f) general hospital, (g) halfway house, (h) health/other special living arrangements, (i) hospital or specialized facility for chronic illness, (j) institution for the aged, (k) not in institution at referral, (l) private institution for the mentally retarded [sic], (m) private mental hospital, (n)

psychiatric inpatient unit of general hospital, (o) public institution for the mentally retarded [sic], (p) public mental hospital, (q) school or other institution for the blind, and (r) school or other institution for the deaf. Although these variables represent the available options an IL specialist can use when describing the consumer’s Basic Type of Institution application; 12 of the potential options did not occur in the data set: alcoholic treatment center, community mental health center – inpatient, correctional institution – adult, correctional institution – juvenile, drug treatment center, halfway house, private institution for the mentally retarded [sic], private mental hospital, psychiatric inpatient unit of general hospital, public mental hospital, school or other institution for the blind, and school or other institution for the deaf. Descriptive statistics were used to determine frequency and percentage for only those Basic Type of Institution at application options that were reported. The results in descending order are: not in institution at referral ($n = 1008$), general hospital ($n = 10$), institution for the aged ($n = 6$), hospital or specialized facility for chronic illness ($n = 5$), health/other special living arrangement ($n = 4$), and public institution for the mentally retarded [sic] ($n = 2$) (see Table 24).

Table 24

*QOL indicators and descriptors – Housing (type of residence, ownership)
Application IL Basic Type of Institution (type of residence)*

Type of Institution at Application of IL consumers	<i>N</i>	%
	1035	100%
Not in institution at referral	1008	97.4%
General hospital	10	1.0%
Institution for the aged	6	0.6%
Hospital or specialized facility for chronic illness	5	0.5%

Health/other special living arrangement	4	0.4%
Public institution for the mentally retarded	2	0.2%

Result show that at application a majority of IL consumers, 97%, are not living in an institution at referral. The remaining variables totaled constitute approximately 3% of the population served.

Additional housing data is captured in SMILE in “Application IL Financial Home Ownership.” This data provides information on home ownership status. Home ownership in SMILE is captured as one of the following variables: (a) owns home, (b) rents home, and (c) other. Descriptive statistics were used to determine frequency and percentage for all the variables as all are captured in SMILE. The results in descending order are: owns home ($n = 493$), rents home ($n = 250$), and other ($n = 292$), (see Table 25).

Table 25

*QOL indicators and descriptors – Housing (type of residence, ownership)
Application IL Financial Home Ownership*

Home Ownership at Application of IL consumers	<i>N</i>	%
	1035	100%
Owns home	493	47.6%
Other	292	28.2%
Rents home	250	24.2%

Approximately 48% of IL consumers at application own their own home. Other represents 28% of the IL population. Other home ownership status can mean, but is not strictly defined as: living in a family owned home in which no rent or mortgage is paid; living in a home

in which rent or mortgage is paid by family, friends, service program, or agency; or living with friends and/or family. IL consumers who rent their home represent approximately 24% of the population served.

Schalock's third core QOL domain analyzed is *Personal Development*. The QOL indicators and descriptors that operationally define Personal Development are: *Education* (achievements, education status), *Personal competence* (cognitive, social, practical), and *Performance* (success, achievement, productivity). Only education is found in SMILE data.

Education data are captured in SMILE in "Application IL Education: Grade Level at Application." This data provides information on the highest grade level achieved or the number of years of formal schooling received for individuals receiving IL services. Grade level at application in SMILE is captured as one of the following variables: (a) no education, (b) completion of 1st grade or 1 year of formal education, (c) completion of 2nd grade or 2 years of formal education, (d) completion of 3rd grade or 3 years of formal education, (e) completion of 4th grade or 4 years of formal education, (f) completion of 5th grade or 5 years of formal education, (g) completion of 6th grade or 6 years of formal education, (h) completion of 7th grade or 7 years of formal education, (i) completion of 8th grade or 8 years of formal education, (j) completion of 9th grade or 9 years of formal education, (k) completion of 10th grade or 10 years of formal education, (l) completion of 11th grade or 11 years of formal education, (m) completion of 12th grade or 12 years of formal education, (n) 13 total years of education or 1 year of post-secondary education, (o) 14 total years of education or 2 years of post-secondary education, (p) 15 total years of education or 3 years of post-secondary education, (q) 16 total years of education or 4 years of post-secondary education, (r) 17 total years of education or 5

years of post-secondary education, (s) 18 total years of education or 6 years of post-secondary education, and (t) 19 total years of education or 7 years of post-secondary education.

Descriptive statistics were used to determine frequency and percentage for all the variables as all were reported. Results of highest grade level achieved for IL consumers in descending order are: completion of 12th grade or 12 years of formal education ($n = 574$), 14 total years of education or 2 years of post-secondary education ($n = 68$), 16 total years of education or 4 years of post-secondary education ($n = 65$), completion of 11th grade or 11 years of formal education ($n = 55$), completion of 10th grade or 10 years of formal education ($n = 49$), completion of 9th grade or 9 years of formal education ($n = 47$), completion of 8th grade or 8 years of formal education ($n = 37$), 13 total years of education or 1 year of post-secondary education ($n = 27$), completion of 7th grade or 7 years of formal education ($n = 20$), 18 total years of education or 6 years of post-secondary education ($n = 19$), completion of 6th grade or 6 years of formal education ($n = 16$), no education ($n = 15$), completion of 5th grade or 5 years of formal education ($n = 8$), completion of 3rd grade or 3 years of formal education ($n = 6$), completion of 4th grade or 4 years of formal education ($n = 6$), completion of 1st grade or 1 year of formal education ($n = 5$), completion of 2nd grade or 2 years of formal education ($n = 5$), 15 total years of education or 3 years of post-secondary education ($n = 5$), 19 total years of education or 7 years of post-secondary education ($n = 5$), 17 total years of education or 5 years of post-secondary education ($n = 3$) (see Table 26).

Table 26

QOL indicators and descriptors – Education (achievements, status)
Application IL Education

Highest Grade Level Achieved at Application	<i>N</i>	%
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	1035	100%
Completion of 12 th grade or 12 years of formal education	574	55.5%
14 total years of education or 2 years of post-secondary education	68	6.6%
16 total years of education or 4 years of post-secondary education	65	6.3%
Completion of 11 th grade or 11 years of formal education	55	5.3%
Completion of 10 th grade or 10 years of formal education	49	4.7%
Completion of 9 th grade or 9 years of formal education	47	4.5%
Completion of 8 th grade or 8 years of formal education	37	3.6%
13 total years of education or 1 year of post-secondary education	27	2.6%
Completion of 7 th grade or 7 years of formal education	20	1.9%
18 total years of education or 6 years of post-secondary education	19	1.8%
Completion of 6 th grade or 6 years of formal education	16	1.5%
No education	15	1.4%
Completion of 5 th grade or 5 years of formal education	8	0.8%
Completion of 3 rd grade or 3 years of formal education	6	0.6%
Completion of 4 th grade or 4 years of formal education	6	0.6%
Completion of 1 st grade or 1 year of formal education	5	0.5%
Completion of 2 nd grade or 2 years of formal education	5	0.5%
15 total years of education or 3 years of post-secondary education	5	0.5%
19 total years of education or 7 years of post-secondary education	5	0.5%
17 total years of education or 5 years of post-secondary education	3	0.3%

More than half, 55.5% of IL consumers at application have completed the 12th grade or have had a minimum of 12 years of formal education. The next highest variable is 14 total years of education or 2 years of post-secondary education at 6.6%. Not only is there is a large discrepancy between these two variables, but this is true for the remaining variables, as well. Most IL consumers have less than a 12th grade education. Additionally, there are very few who have a completed post-secondary education.

Education data in SMILE is further identified by the type of education a consumer has completed at the time of application. Education type is better defined as an educational outcome variable in SMILE. These outcomes are accomplishments related to education. Education type is captured as one of the following variables: (a) Associate, (b) Bachelor, (c) Certificate of Attendance, (d) Certificate of Completion, (e) Diploma, (f) Diploma – Occupational, (g) Diploma – Vocational Technical., (h) GED, (i) less than high school, (j) Master, and (k) Ph.D. All education type variables are captured in SMILE. Results of analysis in descending order are: Diploma ($n = 477$), less than high school ($n = 281$), Bachelor ($n = 65$), Associate ($n = 64$), Certificate of attendance ($n = 48$), GED ($n = 44$), Master ($n = 22$), Certificate of completion ($n = 16$), Diploma – Vocational Technical. ($n = 8$), Diploma – Occupational ($n = 7$), and Ph.D. ($n = 3$) (see Table 27).

Table 27

*Application IL Education
Education Type*

<i>Education type at application of IL consumers</i>	<i>N</i>	<i>%</i>
	1035	100%
High School Diploma	477	46.1%

Less than high school	281	27.1%
Bachelor	65	6.3%
Associate	64	6.2%
High School Certificate of attendance	48	4.6%
GED	44	4.3%
Master	22	2.1%
High School Certificate of completion	16	1.5%
High School Diploma – Vocational Tech.	8	0.8%
High School Diploma – Occupational	7	0.7%
Ph.D.	3	0.3%

Almost half of IL consumers at application received a high school diploma at 46%. Individuals who had less than a high school education represent approximately 27% of the population served. The third highest variable is Bachelor’s degree, as approximately 6% of IL consumers have achieved this educational outcome.

Schalock’s fourth core QOL domain analyzed is *Self-determination*. The QOL indicators and descriptors that operationally define Self-determination are: *Autonomy/personal control* (independence), *Goals and personal values* (desires, expectations), and *Choices* (opportunities, options, preferences). Of the three, goals and personal values, and choices data are captured in SMILE. This information is gathered by the IL specialist at the time of application.

Goals and personal values data are captured in SMILE in “Plan IL Goal.” This goal is determined by the individual receiving services and IL specialist at application. Consumers have the option to develop more than one IL goal, selecting a primary goal and secondary goals. In

order to achieve both the primary and secondary goals, IL services may be delivered concurrently. For purposes of this evaluation, only the primary goal is analyzed. Plan IL Goals are captured as one of the following variables: (a) be able to continue working, (b) be able to get things I need in the community, and (c) be able to stay as independent as I can in my home. Results of analysis in descending order are: be able to stay as independent as I can in my home ($n = 877$), be able to get things I need in the community ($n = 150$), and be able to continue working ($n = 8$) (see Table 28).

Table 28

*QOL indicators and descriptors - Goals and personal values (desires, expectations)
Plan IL Goal*

IL Goal	<i>N</i>	%
	1035	100%
Be able to stay as independent as I can in my home	877	84.7%
Be able to get things I need in the community	150	14.5%
Be able to continue working	8	0.8%

Result show that approximately 85% of IL consumers have an IL goal of being able to stay as independent as they can in their own home. Approximately 15% have an IL goal to be able to get the things they need in the community. Very few IL consumers, only 8%, have an IL goal to be able to continue working.

Choices data are captured in SMILE in “Plan IL Planned Service Description.” These planned services are included in the SAIL consumers Independent Living Plan. Consumers can choose multiple service options to accomplish their IL goal, meaning more than one service may be needed before all IL goals are met. These service options are described as one of the

following variables: (a) communication, (b) community based living, (c) community services, (d) community/social preparation, (e) educational, (f) information access/technology, (g) mobility, (h) other, (i) personal resource management, (j) relocation from nursing home or institution, (k) residential, (l) self-advocacy/self-employment, (m) self-care, and (n) vocational. Results of analysis in descending order are: self-care ($n = 949$), other ($n = 510$), mobility ($n = 488$), personal resource management ($n = 279$), community services ($n = 273$), residential ($n = 248$), information access/technology ($n = 164$), educational ($n = 134$), community based living ($n = 83$), communication ($n = 55$), vocational ($n = 44$), self-advocacy/self-employment ($n = 26$), community/social preparation ($n = 6$), and relocation from nursing home or institution ($n = 6$) (see Table 29)

Table 29

*QOL indicators and descriptors – Choices (opportunities, options, preferences)
Plan IL Planned Service Description*

IL Planned Services	<i>N</i>	%
	3265	100%
Self-care	949	29.1%
Other	510	15.6%
Mobility	488	14.9%
Personal Resource Management	279	8.5%
Community Services	273	8.4%
Residential	248	7.6%
Information Access/Technology	164	5.0%
Educational	134	4.1%

Community Based Living	83	2.5%
Communication	55	1.7%
Vocational	44	1.3%
Self-Advocacy/Self-Employment	26	0.8%
Community/Social Preparation	6	0.2%
Relocation from Nursing Home or Institution	6	0.2%

Results show that of the 1,035 IL consumer population, multiple service options ($n = 3265$) were chosen to meet IL goals. Self-care was the top service requested by IL consumers at 29%, followed by other at approximately 16%. Other planned services are services not identified by a specific variable in SMILE, but are developed by the IL specialist and the consumer to assist the individual in meeting their independent living goals. An example of other planned services could include driving instruction for an individual with paraplegia learning to drive a car with hand controls. Mobility was the third highest requested planned service at almost 15%. Mobility planned services can include, but is not limited to, durable medical equipment like wheelchairs, power chairs or walkers; or home modifications like accessible ramps or widened doorways to provide mobility in and out of the home.

Additional choices data is captured in SMILE in “Plan IL Planned Service, General Service Description.” These services are an extension of the previous IL Planned Service Description and provide further clarification of planned services. Both IL Planned Service Description and IL Planned Service, General Service Description are provided in conjunction to assist the consumer in accomplishing their IL goal. SMILE offers the following options for Planned Service, General Service Description: (a) advocacy, (b) assistive devices/equipment, (c)

children’s, (d) communication, (e) counseling and related, (f) family, (g) housing accessible, (h) housing home modifications and shelter, (i) IL skills training and life skills training, (j) information and referral, (k) legal, (l) mental restoration, (m) mobility training, (n) other, (o) peer counseling (includes cross-disability), (p) personal assistance services, (q) physical rehabilitation, (r) preventive services, (s) prosthesis and other, (t) recreational, (u) rehabilitation technology, (v) therapeutic treatment, (w) transportation, (x) vocational, and (y) youth. Only one, youth, was not reported in in the Planned General Service Description. Youth can be defined as those services provided for individuals in the age group between childhood and adulthood.

Descriptive statistics were used to determine frequency and percentage for only those IL Planned Service, General Service Description that were present in the data. The results of analysis in descending order are: information and referral ($n = 747$), assistive devices/equipment ($n = 746$), other ($n = 459$), housing, home modifications, and shelter ($n = 367$), preventative services ($n = 211$), IL skills training and life skills training ($n = 152$), personal assistance services ($n = 102$), counseling and related ($n = 93$), transportation ($n = 65$), advocacy ($n = 60$), therapeutic treatment ($n = 57$), rehabilitation technology ($n = 41$), prostheses and other ($n = 40$), communication ($n = 26$), vocational ($n = 26$), mobility training ($n = 19$), physical restoration ($n = 18$), children’s ($n = 4$), mental restoration ($n = 4$), legal ($n = 3$), peer counseling (includes cross disability) ($n = 3$), and housing accessible ($n = 1$) (see Table 30).

Table 30

*QOL indicators and descriptors – Choices (opportunities, options, preferences)
Plan IL Planned Service, General Service Description*

IL Planned Services, General Service Description	<i>N</i>	%
	3265	100%

Information and referral	949	22.9%
Assistive Devices/Equipment	743	22.8%
Other	459	14.1%
Housing, Home Modifications, and Shelter	367	11.2%
Preventative Services	211	6.5%
IL Skills Training and Life Skills Training	152	4.7%
Personal Assistance Services	102	3.1%
Counseling and Related Services	93	2.8%
Transportation	65	2.0%
Advocacy	60	1.8%
Therapeutic Treatment	57	1.7%
Rehabilitation Technology	41	1.3%
Prostheses and Other Related Services	10	1.2%
Communication	26	0.8%
Vocational	26	0.8%
Mobility Training	19	0.6%
Physical Restoration	18	0.6%
Family Support	12	0.4%
Recreational	12	0.4%
Children's	4	0.1%
Mental Restoration	4	0.1%
Legal	3	0.1%
Peer Counseling (includes cross disability)	3	0.1%

Results show that of the 1,035 IL consumer population, multiple service options ($n = 3265$) were chosen in order to meet IL goals. Information and referral was the most requested service at almost 23%. Assistive devices/equipment was next at again almost 23%, followed by other at 14%. Other services are those not identified by a specific variable in SMILE, but are developed by the IL specialist and the consumer to assist the individual in meeting their independent living goals.

“IL Planned Service Completion Outcome” is the final choices data captured in SMILE. This data provides the IL goal outcome of the planned services provided. Since a consumer has the option to have a primary and secondary goal(s), completion outcome does not indicate case closure. The primary goal may have been achieved, but the secondary goal(s) has yet to be accomplished. For purposes of this evaluation only the service completion outcome for the primary goal is analyzed. Variables for the IL Planned Service Completion Outcome are: (a) agree to discontinue, (b) agree to modify, (c) met, (d) met partially, (e) met substantially, (f) not met, and (g) in progress. In progress means that the IL consumer is still receiving services outlined as their primary IL goal. Although these variables represent the available options an IL specialist can choose when describing the IL Planned Service Completion Outcome, only (e) met substantially did not occur in the data set. Descriptive statistics were used to determine frequency and percentage for only those IL Planned Service Completion Outcome options that were present within the data set. The results of analysis for service completion of the primary goal in descending order are: met ($n = 2245$), in progress ($n = 500$), agree to discontinue ($n = 190$), met partially ($n = 164$), not met ($n = 147$), and agree to modify ($n = 19$) (see Table 31).

Table 31

*QOL indicators and descriptors – Choices (opportunities, options, preferences)
IL Planned Service Completion Outcome*

IL Planned Service Completion Outcome	<i>N</i>	%
	3265	100%
Met	2245	68.8%
In Progress	500	15.3%
Agree to Discontinue	190	5.8%
Met Partially	164	5.0%
Not Met	147	4.5%
Agree to Modify	19	0.6%

Results show that of the 1,035 IL consumer population, multiple service options (n = 3265) were chosen to meet IL goals. These service options would result in a planned service completion of the IL goal(s). It is also possible for services to still be in progress if the goal has yet to be achieved. The highest percentage of IL Planned Service Completion Outcome was goal Met at almost 69%. Approximately 15% of consumers were still in the process of receiving services to achieve their IL goal., followed by 6% who agreed to discontinue their service and not achieve their planned IL goal.

Quality of life data captured at case closure is found in two of Schalock’s QOL domains. They are *self-determination* and *material well-being*. In the self-determination domain, QOL indicators are identified as *goals and personal values*. Realistic and achievable goals are determined by the IL specialist and the consumer. Once a primary goal is determined, consumers have the option to select a secondary goal(s). Once all goals are achieved the case is closed.

Variables captured in SMILE at case closure are: (a) goals met, and (b) goals not met. In order to represent the entire population in the data set, a third variable for analysis was created; “cases not closed”. Results from analysis are: goals met ($n = 684$), goals not met ($n = 81$), and cases not closed ($n = 270$) (see Table 32).

Table 32

*QOL indicators and descriptors - Goals and personal values (desires, expectations)
IL Plan Goal Outcome at Closure*

IL Plan Goal Outcome at Closure of IL Consumers	<i>N</i>	%
	1035	100%
Goals met	684	66.1%
Goals not met	81	7.8%
Cases not closed	270	26.1%

Of all IL consumers served during the evaluation time-period, more than half, 66%, successfully accomplished all their independent living goals, thus resulting in case closure. Approximately 26% of IL consumers were still receiving services during the evaluation time-period, their case not closed, and; therefore, a goal outcome has yet to be determined. Goals not met represented approximately 8% of consumers served. These cases were closed without all independent living goals being completed. Reason for case closure was also evaluated.

Additional data is captured at case closure to determine the reason the case was closed and services terminated. Variables captured in SMILE are: (a) death, (b) doesn't want further services, (c) employment maintained, (d) failure to cooperate, (e) goal(s) met (both primary and secondary), (f) health and safety of participant, (g) health and safety of specialist, (h) institutionalized, (j) moved, (k) no severe impairment, (l) non-compliant, (m) other, (n) too

severe, (o) unable to locate, and (p) unable to participate. In order to represent the entire population in the data set, an additional variable for analysis was created; cases not closed.

Results from analysis are: goals met ($n = 606$), death ($n = 62$), unable to locate ($n = 29$), doesn't want further services ($n = 16$), non-compliant ($n = 15$), failure to cooperate ($n = 9$), institutionalized ($n = 7$), other ($n = 7$), moved ($n = 5$), unable to participate ($n = 3$), health and safety of participant ($n = 2$), health and safety of specialist ($n = 2$), no severe impairment ($n = 2$), and cases not closed ($n = 270$). There were no data reported for the variables employment maintained and too severe as these were not selected as reasons for case closure (see Table 33).

Table 33

<i>IL Reason for Closure</i>		
Reason for Closure of IL Consumers Case	<i>N</i>	%
	1035	100%
Goal met	606	58.6%
Death	62	6.1
Unable to locate	29	2.8%
Doesn't want further services	16	1.5%
Non-compliant	15	1.4%
Failure to cooperate	9	0.9%
Institutionalized	7	0.7%
Other	7	0.7%
Moved	5	0.5%
Unable to participate	3	0.3%
Health and safety of participant	2	0.2%

Health and safety of specialist	2	0.2%
No severe impairment	2	0.2%
Cases not closed	270	26.1%

Results show that approximately 59% of IL consumer’s reason for case closure was due to their goal(s) being met. Death was the second highest reason for case closure at 6%. Unable to locate was third highest at almost 3%. When a consumer has a change of residence or contact information, it is the consumer’s responsibility to inform the IL specialist. If this does not occur, the IL specialist should use all provided resources to contact the consumer. If contact is not established within three months of the first attempt, the IL specialist will close the case due to an inability to locate the consumer. Reason for case closure was not selected for 26% of the IL consumers as their cases are currently in service status.

The only QOL data captured at case closure in Schalock’s QOL domain *material well-being* is *financial status* (income, benefits). In SMILE, financial status at closure is identified as “Closure IL Financial Primary Source of Support “(income). Variables within financial status at closure are: (a) all other public sources, (b) all other sources of support, (c) annuity or other non-disability insurance benefits, (d) current earnings, interest, dividends, rent, (e) family and friends, (f) private relief agency, (g) public assistance without federal funds (GA only), (h) public assistance, at least partly with fed funds, (i) public institution – tax supported, (j) Social Security Disability Insurance (SSDI), and (k) worker’s compensation. In order to represent the entire population in the data set, an additional variable for analysis was created; cases not closed.

Results from analysis in descending order are: family and friends ($n = 358$), public assistance, at least partly with Fed funds ($n = 157$), all other sources of support ($n = 81$), all other

public sources ($n = 75$), current earnings, interest dividends, rent ($n = 49$), Social Security Disability Insurance (SSDI) ($n = 43$), annuity or other disability insurance benefits ($n = 1$), private relief agency ($n = 1$), and cases not closed ($n = 270$). There were no data captured for the variables public assistance without federal funds GA only, public institution – tax supported, and worker’s compensation, as these were not reported as a primary source of support at closure (see Table 34).

Table 34

QOL indicators and descriptors – Financial status (income, benefits)
Closure IL Financial Primary Source of Support (income)

Primary Source of Support at Closure of IL consumers	<i>N</i>	%
	1035	100%
Family and friends	358	34.6%
Public assistance, at least partly with Federal funding	157	15.2%
All other sources of support	81	7.8%
All other public sources	75	7.2%
Current earnings, interest, dividends, rent	49	4.7%
Social Security Disability Insurance (SSDI)	43	4.2%
Annuity or other disability insurance benefits	1	0.1%
Private relief agency	1	0.1%
Cases not closed	270	26.1%

The primary source of support at case closure is family and friends representing approximately 35% of the population. Public assistance, at least partly with federal funding is next at 15%. Third, is all other sources of support at approximately 8%. IL consumers in service

status represented 26% of the population as their cases are not closed and a primary source of support at closure has yet to be determined.

Summary

This research study evaluated the Independent Living services provided by the State of Alabama Independent Living Services Program. Furthermore, this study examined Schallock's (2004) core Quality of Life Domains and Most Commonly Used Indicators and Descriptors in relation to service provision for IL consumers. Demographics of the IL consumers served during the research time-period were gathered. This data provided the gender, ethnicity, age range, disability impairment, disability type, and disability cause of the IL population being evaluated. Based on the data evaluated, most of the IL consumers reported having both mobility and manipulation/dexterity orthopedic/neurological impairment and were receiving more than one service in order to reach their independent living goal(s). IL consumers were also dependent on friends and family to assist with living arrangement. On average, an IL consumer would receive service provisions for approximately one year and three months, with IL services expending \$535.25 over the life of the case.

Quality of life domains and indicators were evaluated using proxy variables where a close correlation could be established between Schallock's core QOL domains and most commonly used indicators, and the data captured in SMILE. For the QOL domain interpersonal relations and its corresponding indicators and descriptors of relationships and supports, almost half of IL consumers reported their relationship status as never married and their primary support, both emotionally and financially, was friends and family. For the QOL domain material well-being and its corresponding indicators and descriptors of financial status, employment, and housing results show approximately half, 48% of IL consumers are dependent on family and

friends as their primary source of financial support and their primary source of medical insurance was Medicaid. Approximately 98% of IL consumers reported their employment status as unemployed. For housing, IL consumers again reported being dependent on their friends and family. Educational achievement and type reported approximately half of the IL consumers having received a high school diploma. For the QOL domain self-determination and its corresponding indicators and descriptors of goals and personal values, and choices; approximately 85% of the IL consumers reported the IL goal to be able to stay as independent as possible in their home. In order to maintain independence, service choices are provided to the consumer and the consumer has the option to select more than one service. Self-care was the most frequently chosen planned service and information and referral was the most frequently selected general service. With service provision, the intended outcome is that the consumers IL goal is achieved. More than half of IL consumer's reported planned outcome at case closure and reason for case closer was due to goal(s) being met.

CHAPTER V. DISCUSSION

The purpose of this study was to evaluate the services provided by State of Alabama Independent Living (SAIL) Program Services, specifically the Independent Living program and Independent Living specialists service delivery efforts. Additionally included was a quality of life component based on Schalock's (2004) Core Quality of Life Domains and Most Commonly Used Indicators table. IL specialist assists eligible Alabamian's with the most significant disabilities by providing specialized in-home education and counseling, attendant care, training, and medical services. The overall objective of this program is to ensure independent living at home, work, school, and community; and enhance the quality of life for those individuals receiving services (SAIL, 2015). However, program evaluations regarding independent living services are largely absent from the literature. This study provided an opportunity to add to that limited body of literature. To do so, the program evaluator examined the existing available sources of IL data from the ADRS case management information system called SMILE. This examination identified the participant's demographics and provided the findings for the research questions posited.

The demographics of the 1,035 IL consumers served reported a fairly equal distribution between gender and ethnicity. Male consumers constituted 49% of the population and female was 51%. Almost all participants identified their ethnicity as either: black or African American at 46%, or white 54%. The age range of consumers served was reported to be the highest for 45 to 64-year-old in both IL application and case closure status. The most common impairment

reported was both mobility and manipulation/dexterity orthopedic/neurological which corresponds to the disability type of “physical.” The leading cause of this physical impairment was spinal cord injury, followed by stroke, and then cerebral palsy. The demographic summary of the IL population evaluated in this study is: consumers reported as either male or female; black or African American, or white; ranging in age between 45 and 64 years old; having both mobility and manipulation/dexterity orthopedic/neurological impairment cause by either a spinal cord injury, stroke or cerebral palsy which resulted in physical limitations.

Interpretation of Findings

Research Question 1 - *What are the top five services provided by IL to help individuals with significant disabilities function independently in their home between January 1, 2014 through December 31, 2016?*

IL consumers may select to receive one or more services when developing their independent living plan. As the consumer’s needs change over the life of the case, new or additional services may be required to best serve that individual. During this evaluation time-period, consumers requested and received 3,265 services. The reported top five services are: (a) information and referral, (b) assistive devices/equipment, (c) other services, (d) housing, home modifications, and shelter; and (e) preventative services. Approximately 80% of the IL consumer population received these top five services.

Information and referral is one of the core services offered through IL (Lachat, 2002). It is important for individuals with physical disabilities to have information on available resources, services, and service providers to achieve and maintain an independent lifestyle. This information allows the consumer to make an informed choice about services available to meet their specific need. Services can include the procurement of assistive devices or equipment in

order to help the consumer perform activities of daily living. For individuals with a physical disability accessible housing is critical as it provides the ability to remain independent in the home and community and avoid institutional placement. When the existing or available housing is not accessible for the consumer, IL services can authorize funds to make home modifications for accessibility.

In those instances where the home is accessible and some services are being provided; other and preventative services may be needed and requested by the consumer. Again, information and referral is important. The IL specialist must have a network of local and state contacts, directories for service providers, and a collection of agencies and community organizations that serve this particular population. Having this wealth of information allows the IL specialist pass along to the consumer options for other and preventative services not provided by IL.

The most important concept within the top five services provided by IL is individual autonomy. Individuals with disabilities cannot fully realize true independence if they lose their ability to choose (DeJong, 1978). IL specialist should assist the consumer when selecting an appropriate service provision, but the ultimate decisions must be made by the consumer.

Research Question 2 - *How many cases were opened during this period?*

In reviewing the cases opened during the evaluation time-period of January 1, 2014 through December 31, 2016, the program evaluator examined the positions of leadership for each year as this may have influenced cases opened. In 2014, SAIL had three employees in leadership positions; a director, a SAIL waiver program director, and an IL program director. In 2015, the SAIL director and the SAIL waiver program director retired from state service. The vacant positions were not backfilled, meaning there was no one in training to assume the responsibility

of director or SAIL waiver director. These positions remained open for a short period of time until a new director was hired. Shortly thereafter, a new program director for the SAIL waiver was hired. With the new director and SAIL waiver director in place, the IL program director vacated that position to take a job in academia. Once again, the position was not backfilled leaving another vacancy. In early 2016, a new IL program director was hired as well as a new Homebound director. The Homebound director position was an addition to management not previously established in SAIL. By the spring of 2016, SAIL was under new leadership. With this new leadership came new requirements for all IL staff. One of these requirements was a mandated increase in caseload size for IL specialist, SAIL waiver, and Homebound caseload managers.

In 2014, the number of cases opened was 207. During the 2015 leadership transition year, only 141 cases were opened. It is possible that fewer cases were opened during this time-period due to sporadic periods where leadership was not present. 2016 showed the most cases opened at 356. Inferences could be made that this increase is a direct result of the mandated increase in caseload size.

Research Question 3 - *What is the most common disability diagnosis and cause of those served during this time-period?*

The most common cause associated with both mobility and manipulation/dexterity orthopedic/neurological impairments was spinal cord injury, followed by stroke, and then cerebral palsy. Table 12, *Most Common Disability Diagnosis and Cause*, shows that 111 consumers with a spinal cord injury report both mobility and manipulation/dexterity orthopedic/neurological impairments. The second most common cause was stroke, as 109 IL consumers reported both mobility and manipulation/dexterity orthopedic/neurological

impairments due to a stroke event. Cerebral palsy was the third most common cause, with 105 consumers reporting both mobility and manipulation/dexterity orthopedic/neurological impairments.

For those consumers who reported spinal cord injury, stroke, or cerebral palsy as their disability cause not all reported both mobility and manipulation/dexterity orthopedic/neurological impairments. Of the 154 consumers who reported a spinal cord injury, only 111 reported both mobility and manipulation/dexterity orthopedic/neurological impairments. There were 112 consumers who reported stroke as their disability cause, of those, 109 reported both mobility and manipulation/dexterity orthopedic/neurological impairments. The 110 consumers who reported cerebral palsy as his or her disability cause, 105 reported both mobility and manipulation/dexterity orthopedic/neurological impairments. Spinal cord injury, stroke, or cerebral palsy can cause other limitations than the ones reported and identified in this study.

Examining both the most common disability causes and diagnoses, it is evident that most of the IL consumers reported both mobility and manipulation/dexterity orthopedic/neurological impairments due to either a spinal cord injury, stroke or cerebral palsy. All consumers who report both this disability cause and diagnosis have been categorized in the recoded disability type “physical.” Therefore, many of the IL services focus on addressing the needs of consumers with physical impairments.

Of the top five services identified in Research Question 1, two services, assistive devices/equipment and housing, home modifications and shelter are specific to IL consumers with physical impairments. Consumers can develop more than one IL plan over the life of the case to accomplish their goals and each plan may have more than one service requested.

Therefore, among the entire 1,035 IL consumer population, a total of 3,265 services were developed. Of those total planned services, the second most common service requested was assistive devices/equipment; 743 plans were developed to receive this service. The fourth most common was housing, home modifications, and shelter; 368 plans were developed to receive this service. Both the service plan of assistive devices/equipment and housing, home modifications and shelter align with the unmet needs reported among the IL consumers whose disability type is physical. Individuals with a physical disability may need assistive devices like transfer boards, reachers, weighted pens, large grip eating utensils, and other items, to independently accomplish activities of daily living. They may also need equipment related to their physical disability like a wheelchair, shower chair, Hoyer lift, and other items, to overcome barriers to independent living. IL specialist work with the consumer to identify needs, develop a plan(s) and goal(s) and provide services related to mobility and manipulation/dexterity orthopedic/neurological impairments that cause physical limitations.

Research Question 4 - *What is the average caseload size during this time-period?*

The results from Table 13 *Average Caseload Size by Year*, showed an increase across six of the eight caseload ID's by the end of the evaluation period. Caseloads represent IL consumers receiving services within a specific demographic area and are given a nominal identifier, a caseload ID, in SMILE. Caseload are assigned to the IL specialists serving their designated demographic area. It is possible for IL specialists to change caseloads and for consumer cases to open and close in a caseload; however, the caseload ID remains constant.

In 2014 the total caseload size for all caseload ID's was 540, meaning during this year there were 540 Alabamians served through IL services. In 2015 the total caseload size was for all caseload ID's was 526, a slight drop from the previous year. During 2016, the last year of the

evaluation period, the total caseload size for all caseload ID's was 627; an increase of over 100 new consumers from the previous year.

The likely reason for total caseload ID fluctuation during evaluation time-period may be the change in leadership positions. During 2014 SAIL leadership and management positions consisted of a SAIL director, a SAIL waiver program director and an IL program director. It is difficult to determine if caseload standards for IL's were established for this year as there is no historical documentation for review.

In 2015, SAIL key leadership positions were vacated; the SAIL director and SAIL waiver program director retired. Both positions were vacant for a short period of time until a new SAIL director and SAIL waiver program director were hired. During this time-period, it is possible these two significant vacancies may have disrupted the IL specialist ability, and perhaps, desire to add consumers to their caseload. There may have been uncertainty and speculation among the IL specialist about the new leadership and possible questions about job security. While it cannot be determined exactly what caused the slight decrease between the 2014 and 2015 years, the change in the SAIL director and SAIL waiver program director may be a noteworthy cause.

Additionally interesting is the decreased difference in caseload size between 2014 and 2015. In 2014, 540 consumers had open cases in IL. In 2015, 526 consumers had open cases in IL. The difference of new consumers served between these two years is only 14. This difference is not particularly significant when reviewing annual caseload size. It is possible to speculate that the decrease in cases may be due to the change in the SAIL director; however, what is evident is the viability of the IL program in general. During the transition between the previous SAIL administration and the new administration, the program continued the overall objective of serving individuals with disabilities. Despite the administration changes consumers continued to

seek and were provided services during the transition period. Services provided to consumers continued without interruption during the transition period.

By the spring of 2016, SAIL had all new leadership. In addition to the new SAIL director and SAIL waiver program director; a new IL program director was hired and an additional position of Homebound waiver director was created and filled. Under new leadership, all SAIL waiver caseload managers, Homebound caseload managers, and IL specials were required to carry a certain number of consumers on their caseload. This new requirement caused the IL caseload size increase between years 2015 and 2016.

Research Question 5 - *What is the average expenditure per consumer?*

In 1970, a lawsuit was filed against Dr. Stonewall Stickney, Commissioner of the Alabama Department of Mental Health and the State of Alabama Mental Health Officer in the U.S. District Court for the Middle District of Alabama by employees of Bryce Hospital. The employees were seeking reinstatement of their positions claiming that the patients in the institution would not receive adequate care and treatment without the necessary staff. This case became known as Wyatt v Stickney (Wyatt v. Stickney, M.D. Ala. 1972) and exposed the deplorable living condition of Alabamians with disabilities housed in institutions. At this time, Alabama was ranked 50th out of 50 states for expenditures for the care of people with mental illness [sic] or mental retardation [sic] residing in public institutions. Alabama expenditures per patient per day was 50 cents to provide the physical institution, clothing and food for these facilities (Carr, 2004).

The Wyatt v. Stickney lawsuit decision led to institutional reform and the development of community based services, allowing Alabamians with disabilities to transition out of institutional living and into the community. In 1995, the Alabama State legislature created the Alabama

Department of Rehabilitation Services. State legislators and officials recognized the demand and need for rehabilitative and independent living services for individuals with disabilities (Alabama Department of Rehabilitation Services, 2016). The SAIL Services program, a department within the ADRS, mission is to provide services that allow an individual with a disability to maintain their independence in the home, community, and work environment, as well as enhance quality of life. The expenditure of SAIL funds is necessary to facilitate these services and accomplish the mission of the program.

No longer are Alabamians with disabilities housed in institutions with substandard living conditions and inadequate funding. State programs like SAIL are providing financial assistance for services that promote independent living. During the evaluation time-period of January 1, 2014 through December 31, 2016, all IL 1,035 consumer served, were living in their respective communities and had received an average of \$535.25 spent over the life of each case. At the evaluation end date, December 31, 2016, an average of \$658.28 was spent on cases closed, and of the remaining open cases, \$412.22 on average was spent in service provision.

These IL dollar amounts spent during the evaluation time-period to promote independent living are a certainly a far cry from the nominal dollar amounts spent in the 1960s and 70s for institutional care. Assumptions can be made that the expenditure of funds to assist consumers to live independently did enhance quality of life. The first assumption is that IL funds spent provide in home services that promote and maintain independent living and without these services individuals with disabilities may be placed in institutions. Second, IL funds spent on medical supplies and equipment presumably allow for better self-care and overall better health, that prevent disability related illness, infections, and hospitalizations.

Research Question 6 - *What is the average length of time a consumer is served?*

The average length of time for all 1,035 IL consumers served during the evaluation time-period was 514 days, or approximately one year and five months. There were 270 consumers with an open case, meaning they were in active status and receiving services. The average length of time for service provision for consumers with an open case was 435 days, or approximately one year and three months. The number of consumers served during the evaluation time-period, but whose cases were closed was 765. Their average length of time for services was 597 days, or approximately one year and eight months.

Evidence based or best practices for length of time for independent living service provision and expected outcomes is largely absent from the literature. Therefore, estimating ideal service provision length of time to achieve an optimal outcome is difficult. It is possible that research on the length of time of service provision for independent living would be of interest and significance depending on the nature and scope of the services provided.

For IL consumers, their service plan(s) and IL goal(s) are unique and developed for an individual's specific needs. These plan(s) and IL goal(s) are fluid; meaning as individual needs change, service provision changes. Not only are the service plan(s) and IL goal(s) unique, but so is each IL consumer served. The same IL goal(s) for different consumers may be easier to accomplish for one individual than it is for another. Regardless of service plan(s), IL goal(s) or length of time needed to provide services; the IL specialist should, to the best of his or her ability, assist the consumer in successfully achieving their IL goal(s).

Research Question 7 - *What is the most common living arrangement of the consumer upon closure?*

According to Morris (1994), the independent living philosophy is based on the fundamental belief that any person, regardless of impairment, should have opportunities to

choose, control, and direct one's life with minimal dependence on others in decision making and in performing daily activities. The SAIL Services program and the IL service program have adopted the independent living philosophy, and as part of their mission statement, assist eligible individuals by providing services "to ensure independent living at home, work, school, and the community" (Alabama Department of Rehabilitation Services, 2015). However, the term independent living is subjective and can be defined from an individual and personal perspective. What may be considered independent to one may not be truly independent to another.

The most common living arrangement for IL consumers upon case closure was dependent with friends and family at 60%, more than half of the IL population served. Only 7% of IL consumers at case closure were actually living completely independent. These statistics could imply that the IL program is failing to meet its own mission statement, to ensure independent living. Even though results showed more than half of the IL population was dependent on friends and family for their living arrangement at case closure, dependent status is not specifically defined by the IL program. Just as the term independent is subjective and can be defined differently by individual consumers; the term dependent is subjective as well and can vary in interpretation.

Examples of this difference can be: one IL consumer may be dependent on friends and family to take him or her to medical appointments, but may live alone in a family owned home and independently perform all activities of daily living. For another IL consumer, the nature of their disability may necessitate living in the same home with friends and/or family to accomplish activities of daily living; however, they are completely independent when directing their medical treatment and care. For that individual, independent living may be as simple as exerting control over their health and well-being. Different independent versus dependent scenarios have limitless

variations. Individuals with disabilities are the ones who determine his or her personal definition of independence.

While some consumers may not have a choice regarding their living arrangements due to financial constraints or the nature of their disability necessitates living with friends and/or family, they are; however, given a choice and an opportunity for independence when developing an IL plan(s) and goal(s). IL specialist should encourage self-determination when assisting consumers with their IL plan(s) and goal(s). This emphasis on self-determination provides an opportunity for the consumer to take control and responsibility when exploring service provision options and selection. The consumer is then responsible for working his or her IL plan(s), with or without assistance, to achieve their IL goal(s). In working the IL plan(s) the consumer is not only responsible for and accountable to goal successes, but also for failures. DeJong (1983) asserts that without the possibility of failure an individual with a disability lacks true independence. To that end, it is possible to claim the IL Services program is accomplishing its mission of assisting IL consumer's in reaching their independent living goal; even if that IL goal is simply the dignity of choice; regardless of whether they are dependent on friends and family for their living arrangements.

Research Question 8 - Do IL services align with the IL mission statement, specifically providing a higher quality of life?

The mission of Independent Living (IL) Services is to encourage individuals with significant disabilities to achieve their maximum potential. IL consumers work with an IL specialist to develop a suitable realistically obtainable goal(s) to enable the consumer to live independently in their home and community. IL support services, additionally advocates and

encourages a higher quality of life for all individuals with disabilities (Alabama Department of Rehabilitation Services, 2015).

To answer research question eight, the program evaluator examined the existing data set captured in the SMILE case management system to determine if quality of life variables were recorded. During the initial review, the program evaluator searched the data for the specific terms “quality of life” and “enhance” as those are the terms used in the mission statement of SAIL (Alabama Department of Rehabilitation Services, 2015). When it was determined that specific terms to indicate quality of life were not recorded, the program evaluator researched quality of life peer reviewed articles, tables, and models specific to individuals with disabilities.

Schalock’s (2004) Core Quality of Life (QOL) Domains and Most Commonly Used Indicators table was found to be the most comprehensive as it recognized the multidimensionality of quality of life. During the examination of Schalock’s table, it was discovered that specific domains did not directly correlate with the data reported in SMILE. However, the domains corresponding indicators and descriptors had a close association to some of the data reported in SMILE. This discovery provided the program evaluator an opportunity to examine quality of life using proxy variables. Proxy variables are those variables that are not a direct measure, but are strongly related to another variable and are then measurable through the proxy (Boslaugh & Watters, 2008). The program evaluator identified indicators and descriptors in Schalock’s table and, using proxy variables, identified associated variables found in SMILE to evaluate certain quality of life components. Only those variables where an association was made between Schalock’s indicators and descriptors and proxy variables identified in the SMILE data were reported and are discussed.

The most frequently referenced eight core QOL domains are: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (Verdugo, Schalock, Keith, & Stancliffe, 2005). These eight core domains are found in Schalock's (2004) Core QOL Domains and Most Commonly Used Indicators table. Corresponding with each QOL core domain are at least two QOL indicators and descriptors. These indicators and descriptors are used to operationally define its corresponding QOL domain and refer to an individual's perceived well-being or as the valued personal life experiences and circumstances. The experiences and circumstances are a result of some activity, intervention, or service; and are measured based on the quality indicators (Verdugo et al., 2005). Schalock's (2004) Core QOL Domains and Most Commonly Used Indicators table was introduced as Table 2 in the Literature Review. It was provided again in Results as Table 17 to provide clarification of data analysis.

Utilizing Schalock's (2004) Core QOL Domains and Most Commonly Used Indicators table as a guide, the program evaluator examined the existing data in the SMILE case management system to identify core QOL domains and indicators. Of Schalock's eight core QOL domains and indicators, only four were identified in SMILE data. These four are: interpersonal relations, material well-being, personal development, and self-determination. Discussed first are Schalock's QOL domains interpersonal relations and personal development. These domains had indicators and descriptors that correlated with data reported at application only. Material well-being and self-determination are then discussed as these domains had indicators and descriptors that correlated with data reported at both application and case closure.

Schalock's QOL core domain *interpersonal relations* has three indicators and descriptors that operationally define the core domain. They are: interactions (social networks, social

contacts), relationships (family, friends, peers), and supports (emotional, physical, financial, feedback). Only two, relationships and support data are captured in SMILE.

Relationships data is recorded in SMILE as marital status. For the IL consumers examined in this data set, results indicate that approximately 84% report his or her relationship status as never been married at 44%, married at 20%, or divorced at 19%. The data captured in the SMILE data system simply identifies the consumer's relationship status and no attempt by the IL program is made to correlate relationship status with QOL.

Assumptions can be made about the QOL of the IL consumer who has never been married and these assumptions can be interpreted as both positive and negative. One positive QOL assumption is that IL consumers who remain unmarried have the freedom to define self in relation to their own accomplishments, not in terms of dependency. They can control and direct their life without any dependence on a partner. Life success, personal achievement, and overcoming barriers that limit maximum potential can promote both self-efficiency and self-esteem (Morris, 1994).

Negative QOL assumptions about the IL consumer who has never been married may be rooted in societal stereotypes about individuals with disabilities. One negative stereotype regarding individual with disabilities is that they are helpless and dependent (Smart, 2009). This falsely perceived helpless and dependent status may make intimate relationships difficult to establish for individuals with disabilities. Regardless of whether the stereotype is perceived by the individual with a disability, by a prospective relationship partner, or by both parties, it may present an additional barrier to establishing relationships.

While it is possible to ascertain assumptions related to relationship status regarding individuals with disabilities, the reality for some is that his or her disability is so significant that a

relationship, such as marriage, is not a consideration for persistent pursuit. According to Table 8, *Disability Type by Subgroupings*, IL consumers examined in this data set indicate that approximately 85% have physical disabilities that would be considered significant. Although one may make assumptions related to the correlation of QOL and relationship status for these IL consumers based on the significance of his or her disability, the data does not reflect the IL consumer's perspective of his or her relationship status or their potential to establish a relationship. There is no data captured in SMILE that establishes a correlation between an IL consumer's marital status and their perceived QOL.

The QOL indicator, *Supports*, and its descriptor, physical, provides another avenue for making assumptions about IL consumers based on the data reported. Data at application showed that approximately 76% of consumers had physical supports for personal assistance needs met by family and friends. As with relationship status, the SMILE data does not establish or measure any correlation between the type of support a consumer received and perceived QOL. While the data does not provide a direct association between the type of support and perceived QOL, one may reasonably assume that that receiving some personal assistance support is preferred over the alternative of receiving no support.

The second of Schalock's QOL domain and indicators only reported at application is the core domain *Personal Development*. The three indicators and descriptions that operationally define Personal Development are: education (achievements, education status), personal competence (cognitive, social, practical), and performance (success, achievement, productivity). Only education data are captured in SMILE.

IL consumers are asked at application to provide their highest grade level achieved or the number of years of formal schooling received. They can choose from no formal education

through 19 years of education or 7 years of post-secondary education. Results showed that approximately 56% of IL consumers reported completion of the 12th grade or 12 years of formal education. Consumers are also asked at application to provide the education type, meaning their highest educational level obtained. They can choose from less than high school, through a variety of other educational options, with the highest being a PhD. Results showed approximately 46% of IL consumers received their high school diploma. Therefore, most IL consumers reported graduating from high school. The 10% difference between highest grade level achieved and educational type obtained are those consumers who reported 12 years of education, but the outcome was reported as an option other than high school diploma.

Educational achievement or obtainment is not a qualifying factor for individuals seeking SAIL services. This educational status would be a factor for those IL consumers wanting to work or return to work. Assumptions could be made that having a high school diploma could lead to a better quality of life because more employment opportunities exist for individuals with a high school diploma. However, in examining Table 28 *Plan IL Goal*, only eight consumers selected to “be able to continue working” as their IL goal. There is no significant correlation between educational achievement or obtainment, IL services received, and quality of life.

Schalock’s core domain, *material well-being*, has data reported at application and closure. The three indicators and descriptions that operationally define material well-being are financial status (income, benefits), employment (work status, work environment), and housing (type of residence, ownership). All three are reported in SMILE.

Results show that at application family and friends were the primary source of financial support for approximately half, 48%, of IL consumers served. At case closure, this percentage dropped to 35% of consumers being financially dependent on family and friends. The reason for

this decrease is not likely due to consumers beginning to receive Social Security Disability Insurance benefits (SSDI) or Supplemental Security Income during the evaluation period. Results show approximately 27% of IL consumers reported at application that only a portion of their financial support was federally funded, and at closure, this percentage dropped to 15%. Consumers who reported being dependent on SSDI as their primary source of financial support reported a decrease as well; from almost 10% at application to slightly over 4% at closure. There is no data reported to explain this decrease. A possible explanation could be that 26% of the IL consumers were still in service status at the end of the evaluation time-period and their primary source of support at closure had yet to be determined. Once these open cases close, percentages for primary sources of financial support at closure should increase, but it is uncertain to what degree.

As with supports status, SMILE data does not establish or measure any correlation between the primary source of financial support a consumer received and his or her perceived QOL. While the data does not provide a direct association, one may reasonably assume that receiving some financial support is preferred over the alternative of receiving no support. In both relationships and financial support, the primary source is friends and family.

Schalock's second indicator discussed in the core domain *material well-being* is employment. Approximately 98% of IL consumers at application identified as not employed. This high unemployment rate may be attributed to the fact that most of the individuals receiving IL services have a disability so significant that nursing home level of care is required. IL services are provided in home and prevent institutionalization. During the evaluation time-period there were only eight consumers out of the entire 1,035 population who choose to "be able to continue working" as their IL goal. It is likely these eight were referred to their local SAIL hybrid

counselor. This counselor serves a dual role: a SAIL waiver case manager and a vocational rehabilitation counselor. As the SAIL waiver case manager, services and equipment are provided through a Medicaid waiver. These services and equipment assist the consumer to remain independent in their home. As the vocational counselor, the consumer and counselor work together to make a realistic vocational goal(s). Once a goal(s) is established, employment plans are implemented. Both the SAIL waiver services and vocational services are provided in conjunction to provide the optimal outcome for the IL consumer in both independent living and employment.

The last of Schalock's indicators discussed in the core domain, *material well-being*, is housing. At application approximately 48% of IL consumers reported owning their home, 24% reported renting their home. Home ownership status, other than owning or renting a home, was reported as "other" and represented 28% of the IL population at application. Regardless of which housing status consumers chose, results showed that 85% of IL consumers at application are dependent on friends and family for financial assistance with housing. This percentage does not indicate the degree in which a consumer is financially dependent on family and friends for housing, how long financial assistance has been received or will continue to be received by the consumer.

Schalock's core domain, *self-determination*, has data reported at application and closure. The three indicators and descriptions that operationally define self-determination are autonomy/personal control (independence), goals and personal values (desires, expectations), and choices (opportunities, options, preferences). Only two, goals and personal values; and choices are reported in SMILE.

Results showed that at application approximately 85% of consumers selected an IL goal of “be able to stay as independent as I can in my home.” Approximately 15% had an IL goal to “be able to get things I need in the community.” Only 8% had an IL goal to “be able to continue working.” Approximately 26% of SAIL consumers were still receiving services during the evaluation time-period, their case not closed, and; therefore, a goal outcome has yet to be determined. Goals not met represented approximately 8% of consumers served. These cases were closed without all independent living goals being completed.

At case closure, more than half, 66% of all 1,035 IL consumers served during the evaluation time-period, had successfully accomplished all his or her independent living goals. SMILE data does not establish or measure any correlation between the services provided to achieve IL goal(s) and successful closure. However, with more than half of consumers reporting successful closure, assumptions can be made that service provision does lead to successfully accomplishing IL goals for most consumers.

Schalock’s second indicator discussed in the core domain *self-determination* is choices. Since consumers can choose more than one IL plan and each plan can have more than one service selected, results showed that 3,265 services options were chosen to meet IL goal(s). Consumers also have a choice when identifying planned services and general service requests. Results found self-care was the top planned service requested by IL consumers at 29%, followed by “other” at approximately 16%. Information and referral was the most requested service within general service requests at almost 23%. Assistive devices/equipment was next at almost 23%, followed by other at 14%.

In both planned services and general service requests, other services are reported in close percentages; planned other at 16% and general other at 14%. While not a high percentage, it is

significant enough to indicate service needs in both categories beyond the options available in SMILE. The other services option provides an opportunity for consumers to exercise self-determination. Consumers can select service options specific to their unique needs. In doing so consumers direct his or her life path and its quality, minimize dependency on others, and engage in society as contributing members (Lachat, 2002).

With-in the core domain *self-determination*, the indicator autonomy/personal control is present, but not reported as data in SMILE and is; therefore, not measurable. Autonomy/personal control is found when consumers independently select other planned services and/or other general services to accomplished their independent living goal(s). It is this autonomy, this ability to choose, that provides individuals with significant disabilities an opportunity to fully realize true independence (DeJong, 1978).

The only service completion outcome reported in SMILE is the planned service option. Results show that at the end of the evaluation period, almost 69% of consumers achieved their IL goal. This better than average percentage indicates that the services provided are of value, needed, and are utilized by the consumer in maximizing their highest potential and accomplishing their IL goal. Approximately 15% of consumers had services still in process, followed by 6% who agreed to discontinue their service and not achieve their planned IL goal.

Limitations of the Study

There are some limitations to consider when evaluating the results of this study. There is limited scholarship regarding independent living programs and service provision; and quality of life measurements for individuals with significant disabilities. When conducting the literature review the program evaluator found few peer reviewed research articles on quality of life concepts in relation to consumers receiving services through an independent living program.

This lack of prior research required the program evaluator to utilize more of an exploratory approach in examining quality of life for consumers receiving services through the State of Alabama's IL Services program.

This exploratory approach led to the development of proxy variables to determine quality of life components within the SMILE data set. After a thorough literature review, the program evaluator identified Schallock's (2004) Core Quality of Life (QOL) Domains and Most Commonly Used Indicators table as the most comprehensive in distinguishing QOL components. Additionally, Schallock's table provided a unified standard from which to measure quality of life (Verdugo et al., 2005). During the review of Schallock's table and the SMILE data, the program evaluator discovered there was not a direct association between the core domains and indicators and descriptors in Schallock's table and data reported in SMILE. Proxy variables were developed to assist in establishing an association between the two. Proxy variables are those variables that are not directly related, but are strongly associated to another variable and are then measurable through the proxy (Boslaugh & Watters, 2008). A limitation of the study is the development and utilization of proxy variables was based on Schallock's table instead of other QOL model or table options. Other program evaluators may have chosen a different QOL model or table resulting in outcomes specific to the chosen model or table. An additional limitation of the study is, the program evaluator's interpretation and utilization of the proxy variables. The perspective of the program evaluator is unique to that individual. Other program evaluators may interpret and utilize the proxy variables from a different perspective other than the original evaluator leading to alternative outcomes.

Cultural and other types of bias exist when examining the recorded data. Data examined in this study were limited to consumers residing in the state of Alabama and receiving services

from the State of Alabama Independent Living Program. While federal and state services provided to individuals with disabilities could be considered equivalent throughout the country due to similar federal and state regulations and mandates; cultural differences could affect an individual's perception, definition, and measurement of QOL.

Longitudinal effects may have impacted this study. The length of time for the program evaluation was limited to a three-year time-period, January 1, 2014 through December 31, 2016. When the evaluation time-period ended there were cases reported in the data still receiving services and no closure or outcome data was available. However, due to the timing unpredictability of service provision, there will always be open cases over any evaluation time-period.

Not all data recorded in SMILE is recorded at both application and closure of a case, this presents a void of measurable data. Some consumer data, which could indicate a change in goals, values, perceptions, and QOL components were either captured at application only or not captured at all, providing no capability by which to measure change. There was some consumer data captured at both application and case closure and did provide the program evaluator a method to measure change due to service provision. However, of the four core QOL domains where proxy variables were developed to evaluate QOL, only two, material well-being and self-determination had indicators that reported data at application and closure.

Much of the data reported in SMILE is self-reported data provided by the consumer in response to an IL specialist direct question. Consumers may be bias in their responses or IL specialist may interpret answered questions differently from what was intended by the consumer. Not all the data reported required independent verification, meaning that verification through a secondary source is not conducted to determine the accuracy of financial, health insurance, or

living arrangement data prior to providing services. Without secondary verification, the possibility for attribution and exaggeration exist (Gilbert & Malone, 1995).

Implications for Future Research

The overall objective and mission of the SAIL program is to ensure independent living at home, work, school, community, and enhance the quality of life for those individuals receiving IL services (SAIL, 2015). Currently the only method to determine if the quality of life for IL consumers is enhanced by the receipt of IL services is through the development of proxy variables. To accurately determine if services provided are enhancing the quality of life for consumers, a quality of life questionnaire should be developed and implemented. The IL specialist could use the questionnaire to obtain consumer information at application and again at case closure. Implementing this questionnaire consistently throughout the IL program would provide a method by which quality of life could be defined by the IL program. Once defined QOL for IL consumers served could be accurately measured and evaluated. Future researchers could more accurately measure quality of life, evaluate service provision, and possibly aid in the substantiation of SAIL's quality of life claim.

Additionally, a SAIL service satisfaction survey should be developed and implemented. IL specialist could provide this survey to the consumer after case closure to prevent any possibility of coercion. The survey could provide useful consumer feedback on service delivery methods, IL specialists professionalism, and the overall effectiveness of the IL program. It is possible that service delivery gaps, unmet needs, and failed follow through could be identified with the survey. Survey findings can provide opportunities for program improvement and provide researchers an opportunity to evaluate consumer satisfaction of delivered services.

Conclusion

This study represents the initial analysis of the State of Alabama's Independent Living Services program, specifically the Independent Living support services, and adds to the limited body of literature regarding independent living services. The purpose of the study was to evaluate IL services and consumers served during the evaluation time-period of January 1, 2014 through December 31, 2016. To aid in the evaluation, a QOL component was developed from Schalock's core QOL domains and corresponding indicators and descriptors.

Results showed that 1,035 consumers received IL services during the evaluation time-period. Most consumers reported his or her disability as both mobility and manipulation/dexterity orthopedic/neurological impairment and were receiving more than one service to accomplish independent living goals. Most of these consumers were dependent on friends and family for assistance with living arrangements.

QOL results showed that approximately half of the IL consumers had achieved an educational status of at least the 12th grade, most of which received a high school diploma. Most consumers reported never having married and were primarily dependent on friends and family for emotional, financial and housing support. IL plan(s) and goal(s) were chosen by the consumer and approximately half the consumers plan(s) and goal(s) were successfully met.

The results of this evaluation provide the SAIL administration an opportunity to review the research findings and identify service gap areas, areas for improvement in service delivery, better methods to collect and interpret quality of life data, and perhaps, identify other areas for change or improvement not analyzed in this study. Once areas for improvement are identified, the SAIL administration can develop new or enhance existing policies and procedures to ensure that service provision is best meeting the needs of IL consumers. The implementation of

improved service delivery methods can have significant positive effects on IL consumers and provide SAIL administration with measurable data in which to evaluate program effectiveness.

One area for review and possible change implementation is to identify and group barriers to independent living that are unique to each disability type. For example, Table 7: *Disability Impairment and Disability Type Crosswalk* showed that approximately half, 510 IL consumers, reported both mobility and manipulation/dexterity orthopedic/neurological impairment resulting in a physical limitation. By identifying and grouping specific barriers by disability type, interventions can be tailored, the provision of resources altered, and changes in policy made that more effectively address the specific barriers impacting a particular population. Targeted interventions and solutions can allow for more accurate and timely service provision by IL specialist reducing the likelihood of additional, and possibly unnecessary, services. Targeted interventions that provide more accurate and faster service delivery may improve consumer satisfaction and positively impact the consumer's perception of his or her quality of life.

The introduction of targeted interventions may result in more predictable costs associated with service delivery, thereby improving the accuracy and effectiveness of the SAIL administration's financial planning efforts. Effective financial planning may enable the administration to utilize a more proactive approach in the allocation of funds, thus providing IL specialist with greater planning capability throughout the year to assist IL consumers in achieving his or her independent living goals and objectives. With greater planning capability, assumptions can be made that the IL specialist has a greater probability of serving more consumers during the budget year while maintaining or even improving services for existing consumers.

The examination of barriers, development of targeted interventions, and improved financial planning are all methods in which the SAIL administration can evaluate the efficacy of the IL program. However, while effective, these methods alone do not sufficiently provide the necessary feedback for accurately determining program effectiveness as they lack input from the consumer. During the research phase of this evaluation, the program evaluator did not identify any usable evidence of an IL consumer service satisfaction survey that provided consumers the opportunity to evaluate the IL program. The program evaluation should not be limited to only examining the existing consumer data in the data set, but should include, as equal partners, the consumers perception and satisfaction of IL service program. While consumers may not have experience in conducting an IL service program evaluation or be familiar with the precise metrics used in determining effectiveness; they are experts in the lived experience of disability, overcoming barriers, and the techniques and solutions that are most effective.

When interpreting evaluation results, it is important to note that the results are specific to Alabamian consumers receiving services through state sponsored IL support services. The results are not necessarily generalizable to other IL programs within Alabama or to programs offered in other states. Continued research regarding independent living services is needed to provide Alabama IL and other IL programs opportunities for growth and improvement, thereby enhancing the quality of life for the consumers served.

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APPENDIX A

Data Sharing Agreement

**The Alabama Department of Rehabilitation Services
And
Sharon Weaver**

This Data Sharing Agreement is entered into by and between the Alabama Department of Rehabilitation Services (ADRS) and Sharon Weaver to establish the content, use, and protection of data needed to support the research specified in the intended use of data Section 2.0 (below).

1.0 Period of Agreement

The Agreement shall be in effect beginning December 20, 2016 and will remain in effect until terminated in writing by either party or until all data supplied by the ADRS is destroyed.

2.0 Intended Use of Data

De-identified case data pertaining to ADRS State Independent Living Services (SAIL) consumers is required in support of an academic dissertation and research initiative in the Auburn University Special Education, Rehabilitation, and Counseling Doctoral program. The intended use is limited to the contribution of the research findings to the academic field of study, but the findings will also be fully disclosed to the ADRS SAIL program as a resource for identifying any potential process or policy improvements.

3.0 Constraints on Use of Data

Data supplied by The ADRS shall not be shared with third parties without the written consent of the ADRS. ADRS data shall not be sold or used, internally or externally, for any purpose not directly related to the scope of use defined in this agreement without the written permission of the ADRS. Any published findings will only reference the ADRS SAIL provided data in aggregate or summary form. Data will not be combined with other information as to create a potential for individual consumer identification.

4.0 Data Security

All parties shall employ industry best practices, both technically and procedurally, to protect ADRS data from unauthorized physical and electronic access.

5.0 Data Categories

The following definitions shall be used to classify data for security purposes and for the purposes of this agreement.

De-Identified Data: The least restrictive class of data. Although it must be protected from unauthorized disclosure and/or modification, it is often public information or generally releasable under procedures for processing public records requests. Examples of this class of data are: demographic statistics and other data that cannot be directly associated with an ADRS consumer/client/patient.

Confidential Data: This class includes data for which specific protections are required by law or for which agencies are obligated to prevent identity theft or similar crimes or abuses. Examples of this class of data are: Social Security Numbers (SSN), medical data, peoples' names, driver's license numbers, birth date, address, e-mail addresses, telephone numbers or other Personal Identifying (PI) data, Protected Health Information (PHI) data addressed by the Privacy Act of 1974, the Health Insurance and Portability Act of 1996 and the HiTech Act of 2009. Also included are: agency source code or object code, agency security data, or other security related information.

6.0 Access to Data

Access to data must be limited to those staff members with a well-defined business need.

7.0 Compliance with Applicable Laws and Regulations

All parties shall comply with all applicable federal laws and regulations protecting the privacy of data including the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA) and the Privacy Act of 1974.

Requested By

Requestor Name: Sharon Weaver

Requestor Signature: Sharon Weaver

Organization: Student – Auburn University

Date: 12/20/2016

Authorized By

ADRS Name: Lisa Alford

ADRS Signature: Lisa R Alford

Organization: ADRS

Date: 12/20/16

APPENDIX B
IRB Approval Form

**AUBURN UNIVERSITY INSTITUTIONAL REVIEW BOARD for RESEARCH INVOLVING HUMAN SUBJECTS
RESEARCH PROTOCOL REVIEW FORM
FULL BOARD or EXPEDITED**

For information or help contact THE OFFICE OF RESEARCH COMPLIANCE (ORC), 115 Ramsay Hall, Auburn University
Phone: 334-844-5966 e-mail: IRBAdmin@auburn.edu Web Address: <http://www.auburn.edu/research/vpr/ohs/index.htm>

Revised 2.1.2014 Submit completed form to IRBsubmit@auburn.edu or 115 Ramsay Hall, Auburn University 36849.
Form must be populated using Adobe Acrobat / Pro 9 or greater standalone program (do not fill out in browser). Hand written forms will not be accepted.

1. PROPOSED START DATE of STUDY: May 22, 2017

PROPOSED REVIEW CATEGORY (Check one): FULL BOARD EXPEDITED

SUBMISSION STATUS (Check one): NEW REVISIONS (to address IRB Review Comments)

2. PROJECT TITLE: A Program Evaluation of the State of Alabama Independent Living (SAIL) Services Program

3. <u>Sharon M. Weaver</u>	<u>Doctoral Student</u>	<u>SERC</u>	<u>szw0023@auburn.edu</u>
PRINCIPAL INVESTIGATOR	TITLE	DEPT	AU E-MAIL
<u>6812 Glen Rose Way Montgomery, AL 36117</u>		<u>334-318-7267</u>	<u>sharonnanco1969@gmail.com</u>
MAILING ADDRESS		PHONE	ALTERNATE E-MAIL

4. FUNDING SUPPORT: N/A Internal External Agency: _____ Pending Received

For federal funding, list agency and grant number (if available). N/A

5a. List any contractors, sub-contractors, other entities associated with this project:
N/A

5b. List any other IRBs associated with this project (including Reviewed, Deferred, Determination, etc.):
N/A

PROTOCOL PACKET CHECKLIST

All protocols must include the following items:

- Research Protocol Review Form (All signatures included and all sections completed)
(Examples of appended documents are found on the CHSR website: <http://www.auburn.edu/research/vpr/ohs/sample.htm>)
- CITI Training Certificates for all Key Personnel.
- Consent Form or Information Letter and any Releases (audio, video or photo) that the participant will sign.
- Appendix A, "Reference List"
- Appendix B if e-mails, flyers, advertisements, generalized announcements or scripts, etc., are used to recruit participants.
- Appendix C if data collection sheets, surveys, tests, other recording instruments, interview scripts, etc. will be used for data collection. Be sure to attach them in the order in which they are listed in # 13c.
- Appendix D if you will be using a debriefing form or include emergency plans/procedures and medical referral lists (A referral list may be attached to the consent document).
- Appendix E if research is being conducted at sites other than Auburn University or in cooperation with other entities. A permission letter from the site / program director must be included indicating their cooperation or involvement in the project. NOTE: if the proposed research is a multi-site project, involving investigators or participants at other academic institutions, hospitals or private research organizations, a letter of IRB approval from each entity is required prior to initiating the project.
- Appendix F - Written evidence of acceptance by the host country if research is conducted outside the United States.

FOR ORC OFFICE USE ONLY			
DATE RECEIVED IN ORC:	_____ by _____	PROTOCOL	The Auburn University Institutional Review Board has approved this Document for use from <u>06/06/2017</u> to <u>06/05/2020</u> Protocol # <u>17-209 EX 1706</u>
DATE OF IRB REVIEW:	_____ by _____	APPROVAL	
DATE OF IRB APPROVAL:	_____ by _____	INTERVAL	
COMMENTS:			

6. GENERAL RESEARCH PROJECT CHARACTERISTICS

6A. Research Methodology

Please check all descriptors that best apply to the research methodology.

Data Source(s): New Data Existing Data

Will recorded data directly or indirectly identify participants?

Yes No

Data collection will involve the use of:

Educational Tests (cognitive diagnostic, aptitude, etc.)
 Interview
 Observation
 Location or Tracking Measures
 Physical / Physiological Measures or Specimens (see Section 6E.)
 Surveys / Questionnaires

Internet / Electronic
 Audio
 Video
 Photos
 Digital Images
 Private records or files

Other: De-identified secondary data

6B. Participant Information

Please check all descriptors that apply to the target population.

Males Females AU students

Vulnerable Populations

Pregnant Women/Fetuses Prisoners Institutionalized
 Children and/or Adolescents (under age 19 in AU)

Persons with:

Economic Disadvantages Physical Disabilities
 Educational Disadvantages Intellectual Disabilities

Do you plan to compensate your participants? Yes No

6C. Risks to Participants

Please identify all risks that participants might encounter in this research.

Breach of Confidentiality* Coercion
 Deception Physical
 Psychological Social
 None
 Other

*Note that if the investigator is using or accessing confidential or identifiable data, breach of confidentiality is always a risk.

6D. Corresponding Approval/Oversight

• Do you need IBC Approval for this study?

Yes No

If yes, IUA # _____ Expiration date _____

• Do you need IACUC Approval for this study?

Yes No

If yes, PRN # _____ Expiration date _____

• Does this study involve the Auburn University MRI Center?

Yes No

Which MRI(s) will be used for this project? (Check all that apply)

3T 7T

Does any portion of this project require review by the MRI Safety Advisory Council?

Yes No

Signature of MRI Center Representative: _____

Required for all projects involving the AU MRI Center

Appropriate MRI Center Representatives:

Dr. Thomas S. Denney, Director AU MRI Center
 Dr. Ron Beyers, MR Safety Officer

7. PROJECT ASSURANCES A Program Evaluation of the State of Alabama Independent Living (SAIL) Services Program

A. PRINCIPAL INVESTIGATOR'S ASSURANCES

1. I certify that all information provided in this application is complete and correct.
2. I understand that, as Principal Investigator, I have ultimate responsibility for the conduct of this study, the ethical performance this project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the Auburn University IRB.
3. I certify that all individuals involved with the conduct of this project are qualified to carry out their specified roles and responsibilities and are in compliance with Auburn University policies regarding the collection and analysis of the research data.
4. I agree to comply with all Auburn policies and procedures, as well as with all applicable federal, state, and local laws regarding the protection of human subjects, including, but not limited to the following:
 - a. Conducting the project by qualified personnel according to the approved protocol
 - b. Implementing no changes in the approved protocol or consent form without prior approval from the Office of Research Compliance
 - c. Obtaining the legally effective informed consent from each participant or their legally responsible representative prior to their participation in this project using only the currently approved, stamped consent form
 - d. Promptly reporting significant adverse events and/or effects to the Office of Research Compliance in writing within 5 working days of the occurrence.
5. If I will be unavailable to direct this research personally, I will arrange for a co-investigator to assume direct responsibility in my absence. This person has been named as co-investigator in this application, or I will advise ORC, by letter, in advance of such arrangements.
6. I agree to conduct this study only during the period approved by the Auburn University IRB.
7. I will prepare and submit a renewal request and supply all supporting documents to the Office of Research Compliance before the approval period has expired if it is necessary to continue the research project beyond the time period approved by the Auburn University IRB.
8. I will prepare and submit a final report upon completion of this research project.

My signature indicates that I have read, understood and agree to conduct this research project in accordance with the assurances listed above.

Sharon M. Weaver

Printed name of Principal Investigator

Sharon M. Weaver
Principal Investigator's Signature

5/3/17
Date

B. FACULTY ADVISOR/SPONSOR'S ASSURANCES

1. I have read the protocol submitted for this project for content, clarity, and methodology.
2. By my signature as faculty advisor/sponsor on this research application, I certify that the student or guest investigator is knowledgeable about the regulations and policies governing research with human subjects and has sufficient training and experience to conduct this particular study in accord with the approved protocol.
3. I agree to meet with the investigator on a regular basis to monitor study progress. Should problems arise during the course of the study, I agree to be available, personally, to supervise the investigator in solving them.
4. I assure that the investigator will promptly report significant incidents and/or adverse events and/or effects to the ORC in writing within 5 working days of the occurrence.
5. If I will be unavailable, I will arrange for an alternate faculty sponsor to assume responsibility during my absence, and I will advise the ORC by letter of such arrangements. If the investigator is unable to fulfill requirements for submission of renewals, modifications or the final report, I will assume that responsibility.

Jill Meyer

Printed name of Faculty Advisor / Sponsor

Jill Meyer
Faculty Advisor's Signature

5-3-17
Date

C. DEPARTMENT HEAD'S ASSURANCE

By my signature as department head, I certify that I will cooperate with the administration in the application and enforcement of all Auburn University policies and procedures, as well as all applicable federal, state, and local laws regarding the protection and ethical treatment of human participants by researchers in my department.

Jamie Carney

Printed name of Department Head

J. Carney
Department Head's Signature

5/3/17
Date

8. **PROJECT OVERVIEW:** Prepare an abstract that includes:
(350 word maximum, in language understandable to someone who is not familiar with your area of study):

- a) A summary of relevant research findings leading to this research proposal:
(Cite sources; include a "Reference list" or Appendix A.)
- b) A brief description of the methodology, including design, population, and variables of interest

The SAIL Service Program, a division of the Alabama Department of Rehabilitation Services, provides Alabamians with the most significant disabilities specialized in-home education and counseling, attendant care, training, and medical services. The overall objective of this program is to ensure independent living at home, work, school, and community; and enhance the quality of life for those individuals receiving services. Services are provided through the Independent Living Services, the SAIL Waiver or the Homebound Waiver programs. However, program evaluations in order to determine the effectiveness of delivered services are largely absent from the literature. The program evaluation will examine existing data in the Alabama Department of Rehabilitation Services case management system from individuals with disabilities who have been served through the SAIL Service Program, specifically the Independent Living Services program. The methodology utilized will include a quantitative analyses. A non-experimental descriptive study research design will be used to examine secondary, de-identified data to answer the overarching research questions. Additional variables of interest will be demographic questions regarding gender, age, primary race/ethnicity and disability category.

9. **PURPOSE.**

- a. Clearly state the purpose of this project and all research questions, or aims.

This study will evaluate the efficiency and effectiveness of the State of Alabama Independent Living (SAIL) Service Program, including a quality of life component by answering the following questions:

1. What are the top five services provided by SAIL to help individuals with disabilities function independently in their home between January 1, 2014 through December 31, 2016?
2. How many new cases were opened during this time-period?
3. What is the most common disability diagnosis of those served during this time-period?
4. What is the caseload number range and caseload average per Independent Living Specialist during this time-period?
5. What is the average expenditure per consumer?
6. What is the average length of time a consumer is served?
7. What is the most common living arrangement of the consumer upon closure?
8. Do SAIL services align with the SAIL mission statement, specifically providing increased quality of life?

- b. How will the results of this project be used? (e.g., Presentation? Publication? Thesis? Dissertation?)

Results from this study will be used to partially fulfill requirements for a dissertation. Additionally, results may be used in a professional conference, for publication and to re-evaluate the service delivery system of the SAIL service program.

10. **KEY PERSONNEL.** Describe responsibilities. Include information on research training or certifications related to this project. CITI is required. Be as specific as possible. (Include additional personnel in an attachment.) All key personnel must attach CITI certificates of completion.

Principle Investigator Sharon M. Weaver Title: Doctoral Student E-mail address szw0023@auburn.edu
Dept / Affiliation: SERC

Roles / Responsibilities:
Principal Investigator

Individual: Jill Meyer Title: Asso. Professor E-mail address jmm0079@auburn.edu
Dept / Affiliation: SERC

Roles / Responsibilities:
University faculty member and Sharon Weaver's chair; co-investigator

Individual: _____ Title: _____ E-mail address _____
Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ Title: _____ E-mail address _____
Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ Title: _____ E-mail address _____
Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ Title: _____ E-mail address _____
Dept / Affiliation: _____

Roles / Responsibilities:

11. **LOCATION OF RESEARCH.** List all locations where data collection will take place. (School systems, organizations, businesses, buildings and room numbers, servers for web surveys, etc.) Be as specific as possible. Attach permission letters in Appendix E. (See sample letters at <http://www.auburn.edu/research/pcob/2008/08/08/>)

Data will be collected from the Alabama Department of Rehabilitation Services (ADRS) agency developed data base called Systems for Managing Information on the Leading Edge (SMILE). This data set will be secondary, de-identified consumer data for the time-period of January 1, 2014 through December 31, 2016.

12. PARTICIPANTS.

a. Describe the participant population you have chosen for this project including inclusion or exclusion criteria for participant selection.

Check here if using existing data, describe the population from whom data was collected, & include the # of data files.

Participants are individuals with the most significant disabilities who requested and received services through the SAIL services program between January 1, 2014 through December 31, 2018. In order to be eligible for services, the individual must have or need the following: 1) a significant disability; 2) require nursing facility level of care criteria, and 3) inability to maintain independence. SAIL services prevent nursing home placement by providing specialized in-home education, counseling, attendant care, training, and medical services. Participants must request SAIL services and are required to have a goal of independent living at the time of application. This goal must be maintained by the participant throughout the duration of service provision.

Approximately 1000 consumer records are available to support this research effort.

b. Describe, step-by-step, in layman's terms, all procedures you will use to recruit participants. Include in Appendix B a copy of all e-mails, flyers, advertisements, recruiting scripts, invitations, etc., that will be used to invite people to participate. (See sample documents at <http://www.auburn.edu/research/ncpr/ncpr/sample.htm>.)

No recruitment procedures are required because the data to be examined is existing.

c. What is the minimum number of participants you need to validate the study? _____

How many participants do you expect to recruit? _____

Is there a limit on the number of participants you will include in the study? No Yes – the # is _____

d. Describe the type, amount and method of compensation and/or incentives for participants.

(If no compensation will be given, check here:)

Select the type of compensation: Monetary Incentives

- Raffle or Drawing incentive (include the chances of winning.)
- Extra Credit (State the value)
- Other

Description:

N/A

13. PROJECT DESIGN & METHODS.

- a. Describe step-by-step, all procedures and methods that will be used to consent participants. If a waiver is being requested, check each waiver you are requesting, describe how the project meets the criteria for the waiver.

- Waiver of Consent (including using existing data)
- Waiver of Documentation of Consent (use of Information Letter)
- Waiver of Parental Permission (for college students)

No Personally Identifying Information (PII) or Personal Health Information (PHI) will be requested from the Alabama Department of Rehabilitation Services (ADRS); no Waiver or Consent is required. The use of Non-Identifiable Information for the purpose of research is authorized by law which is disclosed to the consumer per the (ADRS) Privacy Statement as a disclaimer.

Source: <http://www.rehab.alabama.gov/Disclaimers>

Disclaimers: Use, Sharing and Protection of Health Information

"Other uses, sharing of health information or disclosures of health information required or allowed by law

(Federal/State): Research Purposes – ADRS may disclose specific health information to entities authorized to conduct a research project. When information is disclosed for research purposes, information that identifies you will not be disclosed."

- b. Describe the research design and methods you will use to address your purpose. Include a clear description of when, where and how you will collect all data for this project. Include specific information about the participants' time and effort commitment. (NOTE: Use language that would be understandable to someone who is not familiar with your area of study. Without a complete description of all procedures, the Auburn University IRB will not be able to review this protocol. If additional space is needed for this section, save the information as a .PDF file and insert after page 7 of this form.)

A descriptive study research design will be utilized to conduct a program evaluation by analyzing secondary, de-identified data maintained in the ADRS SMILE case management system. There is no time and effort commitment for the participant as the data is currently available for immediate retrieval from the case management system. Consumer's case data, specifically those consumers served by ADRS during the date range of January 1, 2014 through December 31, 2016, will be retrieved by ADRS once IRB approval has been granted. The ADRS data system administrator will retrieve the requested data from the production database of the SMILE case management system, limiting the data records retrieved based on the specific date parameters provided by the principle investigator. The production database is housed in a secure facility located at the ADRS central office in Montgomery Alabama. Once the data is retrieved and verified as accurate by the ADRS system administrator, the data will be provided to the principle investigator via encrypted email with the email containing attached password protected Microsoft Excel Spreadsheet. A separate email will be sent that will contain the password for the file.

13. PROJECT DESIGN & METHODS. *Continued*

- c. List all data collection instruments used in this project, in the order they appear in Appendix C. (e.g., surveys and questionnaires in the format that will be presented to participants, educational tests, data collection sheets, interview questions, audio/video taping methods etc.)

All data for this research study will be retrieved from the ADRS' electronic database that provides the storage, security, access, and retrieval of data supporting the SMILE case management system. SMILE is the sole source of record for consumer's case services and the official system of record for case management activities performed by ADRS employees. The principle investigator will request that ADRS retrieve data from the SMILE case management system based on specific date range criteria provided. Data will be provided to the principle investigator via encrypted email with an attached password protected Microsoft Excel Spreadsheet.

- d. Data analysis: Explain how the data will be analyzed.

The data will be analyzed using descriptive statistics. Depending on the data set retrieved it may be possible to analyze the data using inferential statistics, specifically correlation, analysis of variance and regression. SPSS will be used to analyze the quantitative data obtained from SMILE.

14. RISKS & DISCOMFORTS: List and describe all of the risks that participants might encounter in this research. If you are using deception in this study, please justify the use of deception and be sure to attach a copy of the debriefing form you plan to use in Appendix D. (Examples of possible risks are in section #6D on page 2)

N/A

15. **PRECAUTIONS.** Identify and describe all precautions you have taken to eliminate or reduce risks as listed in #14. If the participants can be classified as a "vulnerable" population, please describe additional safeguards that you will use to assure the ethical treatment of these individuals. Provide a copy of any emergency plans/procedures and medical referral lists in Appendix D. (Samples can be found online at <http://www.auburn.edu/research/protocols/sample.html#precautions>)

N/A

If using the Internet or other electronic means to collect data, what confidentiality or security precautions are in place to protect (or not collect) identifiable data? Include protections used during both the collection and transfer of data.

Data provided for this research resides in an ADRS managed database system as it was previously collected by ADRS staff. The collection, storage, handling, disposition, and transmission of data, is governed by State of Alabama security practices and policies. Identifiable consumer data will not be requested or provided in conjunction with this research effort. ADRS system administrator will, upon request, retrieve data from the SMILE case management system and provide it to the principle investigator via encrypted email with an attached password protected Microsoft Excel Spreadsheet as is required by ADRS and State of Alabama security policy.

16. **BENEFITS.**

- a. List all realistic direct benefits participants can expect by participating in this specific study.
(Do not include "compensation" listed in #12d.) Check here if there are no direct benefits to participants.

N/A

- b. List all realistic benefits for the general population that may be generated from this study.

N/A

17. PROTECTION OF DATA.

a. Data are collected:

- Anonymously with no direct or indirect coding, link, or awareness of who participated in the study (Skip to e)
- Confidentially, but without a link of participant's data to any identifying information (collected as "confidential" but recorded and analyzed as "anonymous") (Skip to e)
- Confidentially with collection and protection of linkages to identifiable information

b. If data are collected with identifiers or as coded or linked to identifying information, describe the identifiers collected and how they are linked to the participant's data.

N/A - Anonymous data only

c. Justify your need to code participants' data or link the data with identifying information.

N/A - Anonymous data only

d. Describe how and where identifying data and/or code lists will be stored. (Building, room number?) Describe how the location where data is stored will be secured in your absence. For electronic data, describe security. If applicable, state specifically where any IRB-approved and participant-signed consent documents will be kept on campus for 3 years after the study ends.

N/A - Anonymous data only

e. Describe how and where the data will be stored (e.g., hard copy, audio cassetts, electronic data, etc.), and how the location where data is stored is separated from identifying data and will be secured in your absence. For electronic data, describe security

ADRS will provide data in a password protected Microsoft Excel spreadsheet transmitted via encrypted email. The spreadsheet will be stored in a password protected cloud storage solution; Microsoft's One Drive. A single backup copy of the spreadsheet, with a new password, will be stored in a separate One Drive folder. All data sets created for SPSS will be stored in One Drive requiring authentication to access. The data stored in Microsoft One Drive is not located near identifiable data nor is One Drive accessible from any ADRS facility.

f. Who will have access to participants' data?

(The faculty advisor should have full access and be able to produce the data in the case of a federal or institutional audit.)

Faculty advisor and principle investigator will have full access to the participants de-identified data.

g. When is the latest date that identifying information or links will be retained and how will that information or links be destroyed? (Check here if only anonymous data will be retained)

APPENDIX C

Data Dictionary

Demographics

Gender

- 1- Male
- 2- Female

Age

- 0- Age not captured
- 1- birth to 19 years' old
- 2- 20 to 34 years' old
- 3- 35 to 44 years' old
- 4- 45 to 64 years' old
- 5- 65 and older

Primary Race/Ethnicity

- 1- American Indian or Alaska Native
- 2- Asian
- 3- Black or African American
- 4- Native Hawaiian or Other Pacific Islander
- 5- White

Disability Impairment Category

- 1- Both Mobility and Manipulation/Dexterity Orthopedic/Neurological Impairments
- 2- Mobility Orthopedic/Neurological Impairments
- 3- Manipulation /Dexterity Orthopedic/ Neurological Impairments
- 4- Cognitive Impairments (involving learning, thinking, processing information and concentration)
- 5- Other Physical Impairments (not listed above)
- 6- General Physical Debilitation (fatigue, weakness, pain, etc.)
- 7- Other Orthopedic Impairments (e.g., limited range of motion)
- 8- Respiratory Impairments
- 9- Other Mental Impairments
- 10- Psychosocial Impairments (interpersonal and behavioral impairments, difficulty coping)
- 11- Other Visual Impairments
- 12- Communicative Impairments (expressive/receptive)
- 13- Blindness, unable to read print in any form w/ aids or devices
- 14- Blindness, both eyes, with best correction not more than 20/200 or less than 20-degree arc
- 15- Hearing Loss, Primary Communication Auditory
- 16- Deafness, Primary Communication Visual
- 17- Other Hearing Impairments (Tinnitus, Meniere's Disease hyperacusis, etc.)
- 18- Deafness, Primary Communication Auditory
- 19- Hearing Loss, Primary Communication Visual

Disability Impairment Category subgroupings

- 1- Physical
- 2- Cognitive

- 3- Respiratory
- 4- Mental health
- 5- Visual
- 6- Hearing loss/deafness
- 7- Communicative

Disability Due To:

- 1- Cause unknown
- 2- Accident/injury (other than TBI or SCI)
- 3- Alcohol Abuse or Dependence
- 4- Amputation
- 5- Anxiety Disorders
- 6- Arthritis and Rheumatism
- 7- Asthma and other Allergies
- 8- Attention-Deficit Hyperactivity Disorder (ADHD)
- 9- Autism
- 10- Blood Disorders
- 11- Cancer
- 12- Cardiac and other Conditions of the Circulatory System
- 13- Cerebral Palsy
- 14- Congenital Condition of Birth Injury
- 15- Cystic Fibrosis
- 16- Depressive and other Mood Disorders
- 17- Diabetes Mellitus
- 18- Digestive
- 19- Drug Abuse or Dependence (other than alcohol)
- 20- Eating Disorders (e.g., anorexia, bulimia, or compulsive overeating)
- 21- End-Stage Renal Disease and other Genitourinary System Disorders
- 22- Epilepsy
- 23- HIV and AIDS
- 24- Immune Deficiencies excluding HIV/AIDS
- 25- Mental Illness (not listed elsewhere)
- 26- Mental Retardation
- 27- Multiple Sclerosis
- 28- Muscular Dystrophy
- 29- Parkinson's Disease and other Neurological Disorders
- 30- Personality Disorders
- 31- Physical Disorders/Conditions (not listed elsewhere)
- 32- Polio
- 33- Respiratory Disorders other than Cystic Fibrosis or Asthma
- 34- Schizophrenia and other Psychotic Disorders
- 35- Specific Learning Disabilities
- 36- Spinal Cord Injury (SCI)
- 37- Stroke
- 38- Traumatic Brain Injury (TBI)

Demographic questions were evaluated using descriptive statistics and aggregate measures. Aggregate data measures are commonly used for public reporting purposes or statistical analysis.

Research Questions

What are the top five services provided by IL to help individuals with disabilities function independently in their home between January 1, 2014 through December 31, 2016?

This research question was evaluated using descriptive statistics to determine frequency and ranking.

How many cases were opened during this time-period?

This research question was evaluated using descriptive statistics to determine frequency and percent.

What is the most common disability diagnosis and cause of those served during this time-period?

This research question was evaluated using descriptive statistics to determine frequency and percent. A cross tabulation table was used to determine both disability diagnosis and cause.

What is the average caseload size during this time-period?

This research question was evaluated using descriptive statistics, SPSS custom tables and means to calculate average caseload size.

What is the average expenditure per consumer?

This research question used means to obtain the average expenditure for both open and closed cases.

What is the average length of time a consumer is served?

This research question used means to evaluate length of time a consumer is served for both open and closed cases.

What is the most common living arrangement of the consumer upon closure?

Closure IL Living Arrangements

- 1- Assisted Living
- 2- Dependent with Family and Friends
- 3- Independent
- 4- Institution – Hospital
- 5- Institution – Hospital Rehab
- 6- Institution – Jail
- 7- Institution - Nursing Home
- 8- Institution – Transition Living
- 9- Other

This research question was evaluated using descriptive statistics to determine frequency and percent.

Do SAIL services align with the SAIL mission statement, specifically providing increased quality of life?

The program evaluator identified core QOL indicator and descriptor variables captured in the SMILE case management system related to the eight core QOL domains identified in Schallock's (2004) model. Once the variables were chosen, data were analyzed to determine whether SAIL services align with the SAIL mission statement, specifically providing an increased quality of life. The specific domain and indicator variables used in Schallock's table do not directly correlate with the data captured in SMILE. Therefore, proxy variables were developed to serve in place of Schallock's domain and indicator variables. These proxy variables have a close correlation with the QOL domain and indicator variables of interest (Boslaugh & Watters, 2008).

Quality of Life

Core QOL domain Interpersonal relations

QOL indicator and descriptor – Relationships (family, friends, peers)

Application IL Basic Marital status

- 1- Divorced
- 2- Married
- 3- Never Married
- 4- Separated
- 5- Widowed

Descriptive statistics was used to determine frequency and percentage for marital status data.

QOL indicator and descriptor – Supports (emotional, physical, financial, feedback)

Application IL Personal Assistance

- 1- Alabama Head Injury foundation
- 2- CRS
- 3- Family and Friends
- 4- Homebound
- 5- None Available
- 6- Other
- 7- VR
- 8- Waiver E and D
- 9- Waiver MRDD
- 10- Waiver SAIL

Descriptive statistics was used to determine frequency and percentage for personal assistance support data.

Core QOL domain Material well-being

QOL indicators and descriptors – Financial status (income, benefits)

Application IL Financial Primary Source of Support (income)

- 1- All Other Public Sources

- 2- All Other Sources of Support
- 3- Annuity or Other Non-disability Insurance Benefits
- 4- Current Earnings, Interest, Dividends, Rent
- 5- Family and Friends
- 6- Private Relief Agency
- 7- Public Assistance without Federal Funds (GA Only)
- 8- Public Assistance, at least Partly with Fed Funds
- 9- Public Institution – Tax Supported
- 10- Social Security Disability Insurance (SSDI)
- 11- Worker’s Compensation

Descriptive statistics was used to determine frequency and percentage for financial primary source of support data.

Application IL Financial Source of Medical Insurance (benefits)

- 1- Medicaid
- 2- Medicare
- 3- Medicaid and Medicare
- 4- No insurance
- 5- Blue Cross/Blue Shield
- 6- Blue Cross/Blue Shield and Medicare
- 7- Other

Descriptive statistics was used to determine frequency and percentage for financial source of medical insurance data.

QOL indicators and descriptors – Employment (work status, work environment)

Application IL Work History: Work Status at Application

- 1- Employment with Supports in Integrated Setting
- 2- Employment without Supports in Integrated Setting
- 3- Extended Employment
- 4- Homemaker
- 5- Not employed: All other Students
- 6- Not employed: Other
- 7- Not employed: Student in Secondary Education
- 8- Not employed: Trainee, Intern or Volunteer
- 9- Self Employment (except BEP)
- 10- Unpaid Family Worker

Descriptive statistics was used to determine frequency and percentage for employment, work status at application data.

QOL indicators and descriptors – Housing (type of residence, ownership)

Application IL Basic Type of Institution

- 1- Alcoholic Treatment Center
- 2- Community Mental Health Center – Inpatient

- 3- Correctional Institution – Adult
- 4- Correctional Institution – Juvenile
- 5- Drug Treatment Center
- 6- General Hospital
- 7- Halfway house
- 8- Health/Other Special Living Arrangements
- 9- Hospital or Specialized Facility for Chronic Illness
- 10- Institution for the Aged
- 11- Not in Institution at Referral
- 12- Private Institution for the Mentally Retarded
- 13- Private Mental Hospital
- 14- Psychiatric Inpatient Unit of General Hospital
- 15- Public Institution for the Mentally Retarded
- 16- Public Mental Hospital
- 17- School or Other Institution for the Blind
- 18- School or other institution for the Deaf

Descriptive statistics was used to determine frequency and percentage for housing, type of institution data.

Application IL Financial Living Arrangement

- 1- Assisted Living
- 2- Dependent with Family and Friends
- 3- Independent
- 4- Institution – Hospital
- 5- Institution – Hospital Rehab
- 6- Institution – Jail
- 7- Institution - Nursing Home
- 8- Institution – Transition Living
- 9- Other

Descriptive statistics was used to determine frequency and percentage for housing, financial living arrangement data.

Application IL Financial Home Ownership

- 1- Other
- 2- Owns Home
- 3- Rents Home

Descriptive statistics was used to determine frequency and percentage for financial home ownership data.

Core QOL domain Personal Development

QOL indicators and descriptors – Education (achievements, status)

Application IL Education

Grade level at application

00- no education

- 1- completion of 1st grade or 1 year of formal education
- 2- completion of 2nd grade or 2 years of formal education
- 3- completion of 3rd grade or 3 years of formal education
- 4- completion of 4th grade or 4 years of formal education
- 5- completion of 5th grade or 5 years of formal education
- 6- completion of 6th grade or 6 years of formal education
- 7- completion of 7th grade or 7 years of formal education
- 8- completion of 8th grade or 8 years of formal education
- 9- completion of 9th grade or 9 years of formal education
- 10- completion of 10th grade or 10 years of formal education
- 11- completion of 11th grade or 11 years of formal education
- 12- completion of 12th grade or 12 years of formal education
- 13- 13 total years of education or 1 year of post-secondary education
- 14- 14 total years of education or 2 years of post-secondary education
- 15- 15 total years of education or 3 years of post-secondary education
- 16- 16 total years of education or 4 years of post-secondary education
- 17- 17 total years of education or 5 years of post-secondary education
- 18- 18 total years of education or 6 years of post-secondary education
- 19- 19 total years of education or 7 years of post-secondary education

Descriptive statistics was used to determine frequency and percentage for education, highest grade level achieved data.

Education type

- 1- Associate
- 2- Bachelor
- 3- Certificate of Attendance
- 4- Certificate of Completion
- 5- Diploma
- 6- Diploma – Occupational
- 7- Diploma – Vocational Tech.
- 8- GED
- 9- Less than high school
- 10- Master
- 11- Ph.D.

Descriptive statistics was used to determine frequency and percentage for education type data.

Core QOL domain Self-determination

QOL indicators and descriptors - Goals and personal values (desires, expectations)

Plan II Goal

- 1- Be able to continue working
- 2- Be able to get things I need in the community

3- Be able to stay as independent as I can in my home

Descriptive statistics was used to determine frequency and percentage for IL goal plan data.

QOL indicators and descriptors – Choices (opportunities, options, preferences)

Plan IL Planned Service Description

- 1- Communication
- 2- Community Based Living
- 3- Community Services
- 4- Community/Social Preparation
- 5- Educational
- 6- Information Access/Technology
- 7- Mobility
- 8- Other
- 9- Personal Resource Management
- 10- Relocation From Nursing Home or Institution
- 11- Residential
- 12- Self/Advocacy/Self Employment
- 13- Self Care
- 14- Vocational

Descriptive statistics was used to determine frequency and percentage for choices, IL planned service description data.

QOL indicators and descriptors – Choices (opportunities, options, preferences)

Plan IL Planned Service, General Service Description

- 1- Advocacy
- 2- Assistive Devices/Equipment
- 3- Children's
- 4- Communication
- 5- Counseling and Related
- 6- Family
- 7- Housing Accessible
- 8- Housing, Home Modifications and Shelter
- 9- II Skills Training and Life Skills Training
- 10- Information and Referral
- 11- Legal
- 12- Mental Restoration
- 13- Mobility Training
- 14- Other
- 15- Peer Counseling (includes Cross-Disability)
- 16- Personal Assistance Services
- 17- Physical Rehabilitation
- 18- Preventive Services
- 19- Prosthesis and Other
- 20- Recreational

- 21- Rehabilitation Technology
- 22- Therapeutic Treatment
- 23- Transportation
- 24- Vocational
- 25- Youth

Descriptive statistics was used to determine frequency and percentage for choices, planned general service description data.

IL Planned Service Completion Outcome

- 1- Agree to Discontinue
- 2- Agree to Modify
- 3- Met
- 4- Met Partially
- 5- Met Substantially
- 6- Not Met
- 7- In Progress

Descriptive statistics was used to determine frequency and percentage for planned service completion outcome data.

Data captured at closure pertaining to core QOL domains

Core QOL domain Self-determination

Closure IL Outcome

- 1- Goals Met
- 2- Goals Not Met

Descriptive statistics was used to determine frequency and percentage for closure outcome data.

Reason

- 1- Death
- 2- Doesn't want further services
- 3- Employment maintained
- 4- Failure to cooperate
- 5- Goal(s) met
- 6- Health and safety of participant
- 7- Health and safety of specialist
- 8- Institutionalized
- 9- Moved
- 10- No severe impairment
- 11- Non-compliant
- 12- Other
- 13- Too severe
- 14- Unable to locate

15- Unable to participate

Descriptive statistics was used to determine frequency and percentage for reason of case closure data.

Core QOL domain Material well-being

Closure II Financial Primary Source of Support (income)

- 1- All Other Public Sources
- 2- All Other Sources of Support
- 3- Annuity or Other Non-Disability Insurance Benefits
- 4- Current Earnings, Interest, Dividends, Rent
- 5- Family and Friends
- 6- Private Relief Agency
- 7- Public Assistance without Federal Funds (GA Only)
- 8- Public Assistance, at least Partly with Fed Funds
- 9- Public Institution – Tax Supported
- 10- Social Security Disability Insurance (SSDI)
- 11- Worker's Compensation

Descriptive statistics was used to determine frequency and percentage for financial primary source of support at closure data.