The Relationship between Spending Per Person and Outcomes Achieved by Intellectually and Developmentally Disabled Americans

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ABSTRACT

The care and fair treatment of individuals diagnosed with intellectual and developmental disabilities (IDD) is a globally evolving concern. Within the United States, federal and state governments along with private sector organizations are tackling issues relating to housing, victimization, lack of financial resources, healthcare, loneliness, and quality of life of individuals diagnosed with IDD. Central to the issue of improved outcomes for the group are the associated costs. Most individuals in the U.S. diagnosed with IDD do not have income or assets sufficient to cover costs associated with their care. Therefore, federal and state governments have assumed the greatest share of associated costs. The purpose of this study is to determine whether relationships exist between state and federal funding allocations and outcomes achieved by individuals diagnosed with IDD. This study employs One-Way Analysis of Variance and Linear Regression methods to evaluate per person spending and quality of life outcomes achieved by individuals diagnosed with IDD residing in as many as 41 states and municipalities during years 2011, 2013 and 2015 using publicly available data. The study found that in all but one instance the amount of money allocated to provide care for individuals diagnosed with IDD was not significantly correlated to quality-of-life outcomes achieved by these individuals.

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Chapter I

INTRODUCTION

Background

Individuals diagnosed with intellectual disability, formerly known as mental retardation, and developmental disabilities, e.g., cerebral palsy, Asperger syndrome, and Downs syndrome represent a significant component of the global population. Maulik, Mascarenhas, Mathers, Dua & Saxena (2011) report slightly more than one percent of the global population meets diagnostic criteria for intellectual disability. The Centers for Disease Control (2015) found nearly 14 percent of children in the United States or approximately 1 in 6 met diagnostic criteria for a developmental disability in 2008, which represented a significant increase over previous years. Zablotsky, Black, & Blumberg (2017) conducted a three-year study spanning 2014 to 2016 referencing the same population. They found in 2016 that 6.99 percent of U.S. children between the ages of 3 and 17 years were diagnosed with a developmental disability which represented a significant increase from 5.76 percent in 2014. They attributed the increase to the diagnosis of developmental delays other than autism spectrum disorder and intellectual disability. They note their findings reflect a lower prevalence than previous studies because they used a strict definition of developmental disability which would have precluded the inclusion learning disabilities.

Although in some instances researchers have been able to identify the etiology of specific biological, environmental and mechanical anomalies that appear to correlate highly with and appear to predispose individuals to develop particular forms of intellectual and developmental disability; e.g., radiation, pharmacology, and injury, there are no clearly identified consistent predictors for most instances of these disorders. The etiologies for as many as 50 percent of individuals diagnosed with intellectual disability are unknown (Simpson, Mizen & Cooper, 2016). In all instances of developmental and intellectual disability, the injury, illness, or anomaly believed to cause the illness occurs prenatally or during childhood.

In recent years, the intellectually and developmentally disabled (IDD) population has received significant attention from federal and state governments. Several notable laws and court cases have led to important changes in how these individuals are treated and served within their respective communities. Two of the more notable laws are Civil Rights of Institutionalized Persons Act of 1980 (CRIPA) and Americans with Disabilities Act of 1990 (ADA). Of equal importance is the Olmstead v L.C. case of 1999 (Olmstead). Essentially, to ensure the civil rights of individuals hospitalized in state institutions, the federal government enacted CRIPA that authorizes the United States Attorney General to intervene on behalf of people whom are institutionalized when it has reason to believe civil rights violations are occurring (Puritz & Scali, 1998).

Enactment of the ADA, in a fashion similar to the Civil Rights Act of 1964, sought to protect disabled Americans from discrimination and ensure reasonable accommodations were made in the areas of work, public access, transportation and communication. The law afforded individuals choosing to exercise their rights protections against coercion and retaliation (Kanter, 2015). The ADA sought to integrate disabled Americans into the greater community. Olmstead v L.C. litigation resulted in the United States Supreme Court mandate to states that whenever most appropriate, residents of state institutions be relocated and served within their communities. The action was brought forth by the United States Attorney General Office on behalf of Lois Curtis and Elaine Wilson, individuals diagnosed with developmental disability and mental illness respectively, whom were at that time residing in a Georgia state run hospital. The Supreme Court ruled the state of Georgia had violated the rights of the individuals bringing the suit by not affording them community placements; instead, holding them in institutional settings that were medically unnecessary. The court ruled Georgia and other states must make "reasonable modifications to achieve integration in programs and services" (Teitelbaum, Burke & Rosenbaum, 2004).

Purpose of the Study

The process of systematically closing state run institutions and developing community capacity for individuals diagnosed with IDD is an expensive proposition and states are experiencing a variety of challenges as they seek to meet federal edicts. It is anticipated this study will provide evidence to support or refute the generally held belief amongst individuals within the industry that state funding allocations are correlated with outcomes for individuals diagnosed with IDD.

The purpose of the study is to determine whether a relationship exists between state and federal funding allocations and outcomes achieved by individuals diagnosed with IDD. There are few studies demonstrating relationships between state and federal funding and outcomes achieved by these individuals resulting in a paltry body of knowledge about the subject. The lack of research is, in part, due to the difficulties encountered by formal systems, e.g., state and local governments, responsible for managing human service delivery systems to frankly report reliable and measurable data about the results of their own efforts to provide services (Michaels, 2002). Although this study alone will not distinguish causal relationships, it will identify whether allocated funding correlates with outcomes experienced by individuals diagnosed with IDD. It is anticipated the results of this study will add to the general body of knowledge regarding the efficacy of state and federal efforts to fund IDD services that improve outcomes for individuals diagnosed with IDD. The current political and fiscal climate of state and federal government supports a study of this nature. As available financial resources tighten and needs for services increases, both state and federal partners are taking a closer look at how these limited resources are allocated. Further, it is hoped the results of this study will add credibility or disprove the commonly held belief of many parents, caregivers, and providers that the amount of money allocated for services is directly correlated to positive outcomes for individuals diagnosed with IDD.

Statement of the Problem

Individuals diagnosed with IDD need services that promote health, safety, and overall well-being. These services, typically provided by nonprofit organizations in a fee-for-service manner, are costly to states. Since the invention of Medicaid, state and federal governments have grappled with determining how to provide necessary supports and services to individuals diagnosed with IDD, while at the same time remaining fiscally responsible and ensuring other budgetary priorities are maintained. Since the 2008 recession, even greater attention has been given to the costs associated with providing IDD services. During the financial crisis, some states reduced reimbursement rates, capped service limits, and eliminated services resulting in an outcry from individuals diagnosed with IDD, families, caregivers and other advocates.

Advocates for IDD services and supports have historically and consistently called for expansion of programs and increased funding allocations in part due to the privatization of the service delivery mechanism. Since the 1970s, services have transitioned from being provided by state governments to other publicly and privately operated organizations relying wholly on Medicaid reimbursement (Walker & Osterhaus, 2010). Advocates claim expanded services and increased funding will produce better outcomes for the affected population. These claims are related to service provider's assertions Medicaid's reimbursement rates are much less than the actual cost of providing care and adversely impacts outcomes attainment by individuals diagnosed with IDD (Walker & Osterhaus, 2010). The variety of challenges associated with credibly identifying and quantifying outcomes for individuals diagnosed with IDD and the variables at play in determining how allocated state and federal funding are spent for service makes the argument for or against the assertion difficult. Further, the assertion is called into question by the Byrne et al. (2006). They report that studies have shown greater expenditures for healthcare services do not in all instances produce greater value or improve outcomes for consumers.

The service delivery system responsible for supporting individuals diagnosed with IDD is influenced by a quality-of-life paradigm which purports to promote fairness, liberty, inclusion and empowerment (Morisse et al., 2013). It is believed that implementing these practices will result in individuals developing interpersonal relationships along with emotional and physical well-being. The Quality-of-Life Paradigm is concerned with eight domains, personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, and material well-being (Morisse et al., 2013). This study, using six quality of life indicators, will examine the relationships between IDD spending per person and outcomes experienced by individuals diagnosed with IDD. The six quality of life indicators are: (1) the proportion of individuals diagnosed with IDD reporting he/she has someone to go to for help if they feel scared, (2) the proportion of individuals diagnosed with IDD reporting loneliness, (3) the proportion of individuals diagnosed with IDD reporting having friends who are not paid staff or family,(4) the proportion of individuals diagnosed with IDD reporting receiving annual health examinations, (5) the proportion of individuals diagnosed with IDD reported to overweight or obese, and (6) proportion of individuals diagnosed with IDD who exercise at least 30 minutes three times weekly. These quality-of-life indicators were chosen because they coincide with the eight quality-of-life domains.

Research Question

- Is IDD per person funding correlated to the reported outcomes experienced by individuals diagnosed with IDD?

Data relating to funding of services and outcomes experienced by individuals diagnosed with IDD will be obtained from readily available public sources. To control for outside influences that may confound the results, the researcher has identified economic, political and demographic variables that will also be included in the study.

Researcher Relationship to IDD Population.

The researcher has more than 20 years of experience serving individuals diagnosed with IDD. His experiences vary, but generally include direct care, management, administrative and quality assurance-improvement roles. The researcher's professional experience began as a volunteer on the second and third floors of the Allen Building located on Central State Hospital campus in Milledgeville, Georgia during the mid-1990s. The units housed individuals with various levels of IDD. Later, the researcher was hired by the hospital and worked as a Behavior Specialist/Behavior Analyst responsible for creating treatment plans and positive behavior support plans for residents diagnosed with IDD. Later, the researcher worked as a Qualified Mental Retardation Professional/ Behavior Specialist with ResCare, Inc. during the early 2000s. In the position, he was responsible for overseeing services provided to individuals diagnosed with IDD residing in group homes funded by Florida's Medicaid Home and Community Based

Waiver (HCBS). Eventually, he contracted with Florida's Agency for Healthcare Administration (AHCA) to become an independent support coordinator responsible for linking individuals diagnosed with IDD to community-based supports and services funded by the state's Medicaid waivers. Recently, the researcher was employed as a director with Columbus Community Services, the largest support coordination agency in the state of Georgia. In this role, he was personally responsible for overseeing case management services for nearly 1,400 individuals diagnosed with IDD in metropolitan Atlanta and North Georgia areas.

The researcher has also worked for Delmarva Foundation for Medical Care, Inc., the External Quality Review Organization required under Georgia's HCBS waiver to monitor the quality of supports and services provided to residents diagnosed with IDD. In his eight years with the organization, he worked as a Quality Improvement Consultant (QIC), QIC Lead, Quality Assurance Manager and Project Manager for the Virginia Commonwealth HCBS contract start-up. The researcher has travelled extensively in Georgia and Virginia in the execution of his duties which afforded him firsthand opportunities to speak with individuals diagnosed with IDD, their families, caregivers, and other stakeholders.

Bias

The researcher has invested many years of his professional life to supporting individuals with IDD. He acknowledges his bias in favor of the population. He is a long-time advocate for the IDD supports and services and has been socialized to work in a fee for service environment. Due to the researcher's close relationship to the IDD population, it is clear bias would need to be addressed and controlled. The researcher has never been employed or had vested interest in Human Services Research Institute (HSRI), Coleman Institute for Cognitive Disabilities, U.S. Bureau of Economic Analysis, U.S. Census Bureau, Kaiser Family Foundation, U.S. Bureau of

Economic of Analysis, or the Center for American progress, the organizations responsible for producing the data utilized in this study. In the interest of transparency, the researcher notifies the reader he has interacted with the National Core Indicators survey tool, the questionnaire used by Human Services Research Institute in the state of Georgia, as an assessor responsible for completing the document while working for Delmarva Foundation for Medical Care- a nonprofit contracted to provide labor to complete it.

Description of Chapters that Follow

The chapter that follows will describe the current state of the service delivery system responsible for providing care and support to individuals diagnosed with IDD. Further, it will detail historical and current challenges faced by the population and present the current economic challenges experienced by state and federal governments attempting to make fiscally sound decisions relating to caring for the population. The chapter relating to methodology will describe the factors and covariables under review as well as describe the analytical processes employed to respond to the research question. Finally, the last two chapters will convey the findings of the statistical analysis and draw conclusions while discussing future considerations.

Chapter II

REVIEW OF LITERATURE

Introduction

Individuals diagnosed with intellectual and developmental disability have unique experiences within American society. Many are unable to provide for their own care and well-being and require supports to live happy, healthy, and productive lives. The lines that follow will describe intellectual and developmental disability, the movement that lead to the elimination of the term "mental retardation" as a descriptor of people diagnosed with the disability, historical events that led to the current service delivery system, and legal and financial concerns faced by the population. The chapter concludes describing issues facing intellectually and developmentally disabled individuals in the areas of socialization and access to healthcare.

Intellectual Disability or Developmental Disability

Many believe the terms intellectual disability and developmental disability are interchangeable. However, these diagnoses are clinically distinct from one another. Specifically, intellectual disability is an actual diagnosis found in the *Diagnostic and Statistical Manual, 5th Edition* (DSM-V) while developmental disability is not. Using the *DSM-V* as a reference, a person may only receive a diagnosis of intellectual disability if he or she presents with below average intellectual functioning on a qualified cognitive assessment (Intellectual Quotient of 70 or less), possess deficits in at least two areas of adaptive functioning, and onset of the impairment occurs prior to 18 years of age (American Psychiatric Association, 2013).

Developmental disability is not a single diagnosis; instead, it consists of a diverse group of chronic conditions that have their etiology stemming from mental and physical disability. Examples of developmental disability include Downs Syndrome and Cerebral Palsy. The

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) describes a developmental disability as a condition that begins in childhood, results in significant handicap and is expected to continue for the lifetime of the affected individual. Further, the DD Act states the disabling condition results in significant impairment in the person's ability to perform vital life activities, e.g., independent living, economic self-self-sufficiency, learning, mobility, receptive and expressive communication, self-care, and autonomous direction. As a group, the causes of developmental disabilities are essentially unknown; however, some of the disorders have been linked to genetic and environmental factors. Developmental and intellectual disabilities are highly correlated and frequently occur simultaneously with individual exhibiting characteristics of both.

Prevalence

Much of the information that follows was produced more than ten years ago. Unfortunately, after a due diligent search the researcher was unable to identify more recent scholarly research in this area. Although dated, the researcher considers the available data viable due to the frequency with which other credible researchers continue to reference the sources cited and the absence of apparent socio-political-environmental factors occurring since the creation of this data that would negate or invalidate it. Intellectual disability is estimated to affect approximately one percent of the general population (Boat & Wu, 2015; Sullivan, Hussain, Threlfall & Bittles, 2004). It is estimated three to five percent of the U.S population meets diagnostic criteria for developmental disability (Petersilia, 2000; Poglar et al., 2000). Overall, the global incidence of intellectual and developmental disability diagnosis is on the rise (Petersilia, 2000; Poglar et al., 2000; Sullivan, Hussain, Threlfall & Bittles, 2004). Coexisting developmental disabilities are common. The American Psychiatric Association (2013) reports individuals diagnosed with IDD are also frequently diagnosed with neurodevelopmental, psychiatric, and medical disorders. It further reports cooccurring communication and learning disabilities, cerebral palsy, epilepsy and conditions related to genetic disorders are also common. Finally, more than one quarter of persons diagnosed with IDD also experience significant psychiatric problems, including increased ratees of schizophrenia, depression, and attention deficit hyperactivity disorder (Bouras & Holt, 2007; Fletcher et al., 2007)

Ethnic minority status, residing in deprived communities and belonging to households with lower socioeconomic status are correlated with higher rates of diagnosed intellectual and developmental disability (IDD)- particularly the less severe forms of the disorder (Emerson, 2012). A study conducted in the Metropolitan Atlanta area found that while the incidence of IDD varies significantly when controlled by age, race and sex, the prevalence of these disorders appeared to increase as the study cohort aged due to formal assessment and diagnosis not occurring until many children reach school age (Boyle et al., 2011). The study also found that within the same geographic area, socioeconomic factors and the use of standardized intelligence test normalized against the predominant culture were related to a perceived disparity between rates of IDD among Caucasian and African American children. This finding suggests the incidence of diagnosed IDD among African American children may be exaggerated due to the use of testing materials that are not normed for the group making it incapable of accurately capturing the intelligence of these children and assessors' failure to consider the social and economic factors that influence development that are not necessarily impediments to intellectual growth and functioning (Boyle et al., 2011). Although not explicitly stated, it might be conjectured similar challenges relating to testing and socioeconomic experience may result in findings of IDD for other ethnic minorities at greater numbers than amongst Caucasians.

Person First Language and Elimination of Mental Retardation

Individuals diagnosed with IDD, family members, medical professionals, and advocates for people with disabilities have for many years sought to promote the adoption of “Person First” language, also known as “Person Centered” language, which has been demonstrated to reduce the stigmatization experienced by the disabled (Degeneffe & Terciano, 2011). Person first language is communication that focuses on the individual who is being referenced and literally places the person before his or her disability. Examples of person first language include, “People with disabilities require services”, “She receives special education services”, and “He walks by using a walker.” Dunn and Andrews (2015) report Person First language fulfill several conditions believed generally acceptable when referring to any person; specifically, people are unique and should not be unduly characterized by their features. It is generally accepted that people who have been diagnosed with disabilities are not to be categorized based on their diagnoses because they differ in a variety of contexts, e.g., family make up, work or meaningful day activities, and relationship. Additionally, people should not be referred to using large and characterless terms because doing so degrades the person’s status and serves to segregate him or her from the general population (Dunn & Andrews, 2015). Collier (2012) reports opponents of person first language claim person first language is society’s latest effort to ascribe political correctness values upon a stigmatized group. He avers there is no empirical evidence to support assertions person first language reduces the level of insensitivity experienced by disabled persons. This assertion is corroborated by Gomes (2018), a University of Georgia student, who studied the effectiveness of person first language. Her study found person first language was most effective when it was explained in advance to study participants.

“Retarded” and “retard” are words that have been used for many years by physicians, psychologists, psychiatrists, and others within the medical profession to describe people with significant intellectual impairment. These words have over time become slang vernacular and used by the general public to infer something or someone is not intelligent, inferior, or slow. The words serve to demean and highlight a person’s lack of ability. These words have become hurtful and are intended to evoke shame in the person to whom they are directed. Cheshire (2014) reports the pejorative application of the words malign and insult children, adolescents, and adults with cognitive impairments. These words have so permeated American culture that regardless of the intended use of the words, such as to communicate a reduction or slowing of the growth, the words will likely offend. Individuals, family members and advocates for people with intellectual disabilities have lobbied congress and engaged in grassroots efforts to eliminate the use of “retard” and “retarded” as references for people diagnosed with IDD. Their efforts were successful and resulted in the October 5, 2010 passage of Rosa’s Law, Public Law 111-256 (S.S.C. 1400). Rosa’s Law requires the federal government to remove the term mental retardation from any laws and compels states to adopt similar terminology in state laws.

The diagnostic term, mental retardation, has been phased-out as a descriptor of people with intellectual disability. The latest edition of the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)* has replaced the diagnosis of mental retardation with intellectual disability. Support for promoting the use of the diagnostic term in the greater community continues to grow and is evidenced by the adoption of person-centered terminology by the Centers for Medicare and Medicaid and its subsequent requirement that states demonstrate their efforts to implement processes consistent with the practice. The U.S. Department of Justice has issued edicts to states that require them to offer individuals diagnosed with IDD opportunities to make informed choices about services and make efforts to respect the communicated preferences of these individuals. The passage of additional protections for individuals with disabilities further identifies the population as meaningful and contributing members of society. Further, it is becoming increasingly evident that many of the ills perpetrated against individuals diagnosed with IDD are being reversed improving their ability to live out the American Dream.

History recounts many incidents where research was performed on individuals diagnosed with IDD and other minority groups without their consent and which resulted in high harm with minimal benefit to the individual or group as a whole (McDonald & Raymaker, 2013). The harms allowed resulted in negative physical, psychological, social, legal and economic outcomes (McDonald, Conroy, & Olick, 2017). These past wrongs coupled with current perceived inequalities have lead individuals and advocates alike to seeks to correct misconceptions and influence policies that impact the group's quality of life. The disability rights movement mantra, "Nothing about us without us" is gaining momentum in all areas of the disability milieu, including the area of IDD research (Stack & McDonald, 2014). Implicit to it is the assertion that individuals diagnosed with IDD should be included as participants in research studies (Powers, 2017). It is widely believed among researchers, individuals diagnosed with IDD, and their caregivers that including the group in research will result in these persons feeling valued, included, and worthwhile. Further, these individuals will experience an increase in self-esteem, be provided opportunities to do something new while advocating for their own wants and needs and learn while contributing to the available body of research about their condition (McDonald, Conroy, & Olick, 2016).

Limited Research Conducted on IDD Population

Unfortunately, the researcher's efforts did not yield the expected wealth of literature regarding the topic and many of the events leading to the current level of interest in the population occurred decades ago. Therefore, the reader will note the collected resources used in this study span several decades. Generally, individuals diagnosed with IDD are not considered viable participants for research; however, there is a growing movement to include them. McDonald & Raymaker (2013) report in order that communities might address the disparities experienced by individuals diagnosed with IDD, it is imperative these individuals be included in public health research. The movement towards inclusion is global. The World Health Organization and World Bank (2011) reported research may make a substantial contribution to eliminating health inequalities and improving the welfare of the disabled. The movement toward inclusion involves more than merely allowing individuals diagnosed with IDD to participate. Disability rights advocates are espousing beliefs that researchers must share control of research design and implementation in order that the results might better benefit the IDD population and be of better overall quality (Bigby & Frawley, 2010). Fair and equal treatment are central to the movement. At its core is the belief research must be conducted in manner that is equal, reciprocal, cooperative, foster learning on both sides, empowering and promotes a balance between community action and the efforts of the researcher.

Individuals diagnosed with IDD pose unique challenges for investigators choosing to include them as research participants. Individuals diagnosed with IDD present with varying communication styles, which may impact the authenticity of the information gathered and make it difficult for researchers to obtain qualitative data (Biklen & Moseley, 1988). Receptive and expressive language skills related to cognitive and physical impairments may be problematic during the interview process (Wilkenfeld, 2015). These challenges have led many researchers to seek alternative means to obtain information. Existing research involving individuals diagnosed with IDD has primarily relied on proxy reports from caregivers and observers (Balandin & Goldbard, 2011). However, the practice of obtaining data from alternate sources is generally viewed as less than desirable. Advocates for individuals diagnosed with IDD claim the use of proxy respondents is an invalid and questionable practice (McDonald & Raymaker, 2013).

It is well documented many individuals diagnosed with IDD are able to provide valid responses when queried using few words and concrete examples are provided, understanding is explored, and when probed responses avoid generalities (Finlay & Lyons, 2001). Studies demonstrate proxy responses purporting to assess the subjective experience of individuals diagnosed with IDD, such as quality of life, perceived level of social supports, and stress differ significantly from the responses of these individuals themselves (Balboni, Coscarelli, Giunti, & Schalock, 2013; Schmidt et al., 2010). The assertion is borne out in the difference observed between responses of individuals diagnosed with IDD and their proxies relating to quality-of-life indicators and stress. Balboni, Coscarelli, Giunti, & Schalock (2013) reports individuals diagnosed with IDD tend to self-report their quality of life higher than ratings obtained by proxies. Similarly, Lunsky & Bramston (2006) found proxies tend to report individuals diagnosed with IDD experience greater levels of stress than is reported by individuals themselves. In the latter instance, the difference is due to proxies taking into consideration the perception of inadequacy that may not be internalized and reported by the person themselves.

Obtaining information about individuals diagnosed with IDD from the person with the diagnosis or by proxy is challenged by past professional encounters. Due to prior experiences, many individuals diagnosed with IDD are less trusting of nondisabled individuals offering help while probing deeply into the disabled person’s life and fear being labeled as their disability and treated disrespectfully (McDonald, Conroy, & Olick, 2017). Guardians and caregivers often believe individuals diagnosed with IDD are vulnerable and at risk of being coerced, victimized, and exploited by research (Wilkenfeld, 2015). It is believed the apprehension experienced by the population may be mitigated through the offer of choice. Taua, Neville, & Hepworth (2014) report it is imperative that individuals diagnosed with IDD, guardians and other caregivers choosing to participate in research are made aware of the benefits and risks associated with research. Further, participants should be cautioned the outcomes of research may not produce immediate results that affect the individual personally.

Methodological challenges in the areas of informed consent, privacy and confidentiality work against researchers seeking to conduct research involving individuals diagnosed with IDD (Wilkenfeld, 2015). Once a research project has been developed, issues involving accessibility and consent may change the characteristics of the participant pool (Welsby & Horsfall, 2011). Often, in an effort to protect individuals diagnosed with IDD from abuse, guardians refuse to consent to allow these individuals to participate in research which may adversely impact the findings. Efforts to include individuals are also hampered by institutional reluctance to authorize research. Lai, Elliott, & Ouellette-Kuntz (2006) reports there is evidence Institutional Review Boards assess research involving individuals diagnosed with IDD in a manner different than research conducted with individuals who do not have the diagnosis. It is speculated this is due to the scientific community generally believing the IDD population is “uniquely vulnerable” to psychological harm (McDonald et al., 2009). Through efforts to protect the group some researchers are, as a matter of general practice, unnecessarily restricting the autonomy of participants diagnosed with IDD contributing to the group’s exclusion from research (Northway, 2014).

History

Historically, shame and stigma surrounding the etiology of IDD and the lack of reasonable alternatives for community-based care led many parents to institutionalize their children. In many instances this occurred without revealing to siblings and other family members these children had been born (Pollack, 2011). Prominent families and famous individuals, including famed psychologist, Eric Erickson during the 1940s, and later renown playwright, Arthur Miller during the 1960s, institutionalized their children diagnosed with IDD without any announcement to family and took great efforts to shield information from the public (Pollack, 2011). Post President Franklin Delano Roosevelt's New Deal, the federal government still was not providing support to the families of individuals diagnosed with IDD. Services to the disabled were considered the responsibility of state and local governments. Federal expenditures for IDD services did not exceed $1 billion per year until 1950 (Braddock, 2010).

Post World War II (WWII) is viewed by many as the period marking the first time caregivers of individuals diagnosed with IDD organized and made demands on the federal government to amend public policy to provide a level of support to the population (Pollack, 2011). Prior to this time, families relied on over-crowded and underfunded state institutions many of which housed more than 3,000 individuals (Pollack, 2011). The end of WWII lead to greater public awareness of the conditions of individuals diagnosed with IDD in part due to the crimes perpetrated by Nazis against the group. Also, during WWII conscientious objectors had often been remanded to state institutions as caregivers for individuals diagnosed with IDD. After the war, many of these individuals wrote scathing accounts of the inhumane conditions they witnessed (Pollack, 2011).

The U.S., post WWII, was becoming progressive and conducive for parents, especially mothers, to organize and mobilize politically on behalf of their disabled children (Pollack, 2007).

It is around this time the National Association of Retarded Citizens (NARC) was established. Many mothers learned there were scores of other families experiencing similar challenges. These parents identified a collective need and began acting in a coordinated effort to obtain services and resources for their children. The parents mobilized around the understanding that they might help their own child by working with other parents with children in similar need (Pollack, 2011). By 1952, many states had NARC chapters offering direct services to individuals diagnosed with IDD (Pollack, 2011). In 1960, NARC had 681 local chapters and 62,000 members. The group exceeded 100,000 members by 1964 (Segel, 1974).

In the 1960s Eunice Shriver described deplorable conditions of institutions caring for disabled individuals in the *Saturday Evening Post* (Braddock, 2010). Ms. Shriver, the sister of President John F. Kennedy, was a staunch advocate for individuals diagnosed with intellectual disabilities due to her family's experiences caring for her sister, Rosemary Kennedy. During the early 1900s, professionals urged families to send intellectually disabled children to state run institutions. The Kennedy family initially resisted due to a belief Rosemary could be best cared for at home. Due to what Ms. Shriver describes as a mental decline, the Kennedy family eventually admitted Rosemary to a catholic institution serving individuals diagnosed with IDD. Ms. Shriver advocated for individuals diagnosed with intellectual disabilities to receive special education and vocational rehabilitation services, education of the general public about the intellectually disabled population to overcome prejudice and misunderstanding, research to increase the paltry body of available information, and encouraged grassroots efforts aimed at empowering communities to respond to the needs of the intellectually disabled (Shriver, 1962).

It is noteworthy Ms. Shriver does not share in her article her father, Joseph Kennedy, Sr., subjected Rosemary to a lobotomy in 1941 due to a belief she was vulnerable to exploitation and that issues stemming from her behaviors may have been dangerous to her brothers', John and Robert, developing political careers. Prior to the lobotomy, Rosemary was described as friendly, able to read, write, speak, dance and capable of completing all activities of daily living independently. After the procedure, she was almost completely disabled with a severely limited vocabulary and only partial use of her arms and legs (McNeil, 2015).

In 1967, Look Magazine published a series of graphic photos of institutions caring for individuals diagnosed with IDD titled "Christmas in Purgatory" (Trent, 1994). In 1972 Geraldo Rivera, using television cameras, exposed the deplorable conditions of Staten Island's Willowbrook Institution, a long running public institution caring for individuals diagnosed with IDD, resulting in policy responses at both the state and federal level (Rothman & Rothman, 1984). Since the turn of the millennium, wrongful death and reports of individuals diagnosed with IDD living in inhuman conditions continue to surface (Hakim, 2011).

Victimization

Research addressing the impact victimization has on individuals diagnosed with IDD is minimal. You will note most of the available information referenced on the topic is nearly 20 years old. Grattet & Jenness (2001) report disabled individuals, like other minorities, are unable to attract the full attention of the criminal justice system due to its inherent inaccessibility and disabled persons' marginal status resulting in crimes against these individuals frequently going unrecognized or ignored by law enforcement. Garret & Jenness (2001) go on to say the criminal justice system is not equipped to identify and respond to violence against these groups partially because the disabled population is viewed as a special entity instead of as a member of the general population and entitled to the same consideration and treatment afforded non-disabled individuals. Individuals diagnosed with IDD encounter the legal system more today than ever because they are overrepresented in cases involving physical, sexual, and emotional abuse (Ericson & Perlman, 2001). Individuals diagnosed with IDD who are victimized share characteristics with nondisabled victims including poverty, limited coping abilities, and family history of abuse (Petersilia, 2000). Individuals diagnosed with IDD commit violent acts at rates significantly less than non-disabled people (Walsh et al., 2001). It is estimated individuals diagnosed with IDD are 1-1.5 times more likely to be the victims of abuse and violence than non-disabled persons (Ericson & Perlman, 2001; Petersilia, 2000). Studies have found more than 70 percent of women diagnosed with developmental disabilities experience sexual assault within their lifetime (Petersilia, 2000).

The crisis of victimization within the IDD population has been acknowledged globally. The United States, Canada, Australia, and the United Kingdom are currently tracking violence among this population and are reporting high rates of substantiated abuse (McMahon, West, Lewis, Armstrong & Conway, 2004; Petersilia, 2000). Individuals diagnosed with IDD frequently lack the vocabulary to be able to report abuse (Petersilia, 2000). When accused of crimes, individuals diagnosed with IDD are less likely to understand their rights than non-disabled people.

Due to failure to understand coercive questions, individuals diagnosed with IDD have been wrongfully convicted of crimes (Erickson & Perlman, 2001). Robert Perske, an advocate who worked on behalf of people with developmental disabilities for more than 30 years, reported individuals diagnosed with IDD tend to be uniquely vulnerable and suggestible when interrogated (Perske, 2008). These individuals will agree with or say whatever is needed to end the interrogation resulting in confessions to crimes they have not committed. In 2008, Perske reported 53 men and women diagnosed with intellectual disabilities who had been falsely accused had been exonerated. In 2011, that list had grown to 75 (Perske, 2011). Unfortunately, Robert Perske passed away in 2016 and there does not appear anyone is documenting their efforts to continue his work of tracking and advocating for individuals diagnosed with IDD who have been potentially falsely incarcerated.

Individuals diagnosed with IDD are often overlooked as participants in legal proceedings due to a perception by the legal establishment the population is unable to serve as credible witnesses. When some individuals are faced with the stress of rigorous cross-examination, they experience confusion resulting in a change in their story (Petersilia, 2000). Individuals diagnosed with IDD are at increased risk of repeat victimization due to a high percentage of the perpetrators being caregivers and family members of the disabled victims (Petersilia, 2000). These individuals are also at increased risk of repeated abuse and violence because frequently perpetrators are able to prevent the disabled person from reporting, fleeing or physically resisting (Petersilia, 2000). It has been speculated individuals diagnosed with IDD are at increased risk of victimization due to perpetrators rationalizing their behavior by falsely adopting the belief these individuals are incapable of experiencing pain or that their actions do not cause them suffering (Petersilia, 2000). In many instances, due to lack of community support networks or programs capable of providing the necessary levels of care, individuals with intellectual disabilities are forced to return to abusive or otherwise unfortunate situations and may face reprisal for their report of abuse to authorities. McMahon, West, Lewis, Armstrong & Conway (2004) avers that if reporting does not result in convictions, then reporting abuse, neglect or exploitation is accompanied by an increased risk of retaliation.

Financial Support

States have been funding services for individuals diagnosed with IDD for more than 160 years (Hemp, Braddock & King, 2014). In 1950, the federal government approved financial support for individuals diagnosed with IDD by creation of Aid to the Permanently and Totally Disabled (APTD). In 1972, the establishment of Supplemental Security Income (SSI) program for the aged, blind and disabled replaced the APTD program and provided more robust financial benefit for the IDD population (Pollack, 2011). In 2010, nearly 1.5 million individuals diagnosed with IDD received SSI benefits (Social Security Administration, 2011). It is noteworthy that even when combined with Temporary Assistance for Needy Families (TANF) benefits and other types of support, SSI provides only a modest economic support resulting in low income continuing to be a major obstacle for the IDD population (Pollack, 2011). Currently, the maximum SSI benefit is $771 per individual and $1,157 per couple (Social Security Administration, 2019). Georgia’s TANF benefit is $280 and has been at this level since the 1990s (Burnside & Floyd, 2019).

In 1965, amendments to Social Security created the Disabled Adult Child program (DAC) authorizing payments to surviving children aged 18 or older of retired, disabled, or deceased workers. The DAC program was the first effort to ensure entitlement security for individuals diagnosed with IDD that might outlive their primary caregivers, whom were typically parents (Pollack, 2011). Under the DAC program the children of retired or disabled workers may receive up to 50 percent of the amount available to the parent and the child of a deceased worker may receive as much as 75 percent of the amount available to the worker (Pollack, 2011). In 1972, nearly 176,000 adults diagnosed with IDD received DAC benefits. By 2010 nearly 500,000 were receiving these benefits due to qualifying illness and disorders (Social Security Administration, 2010).

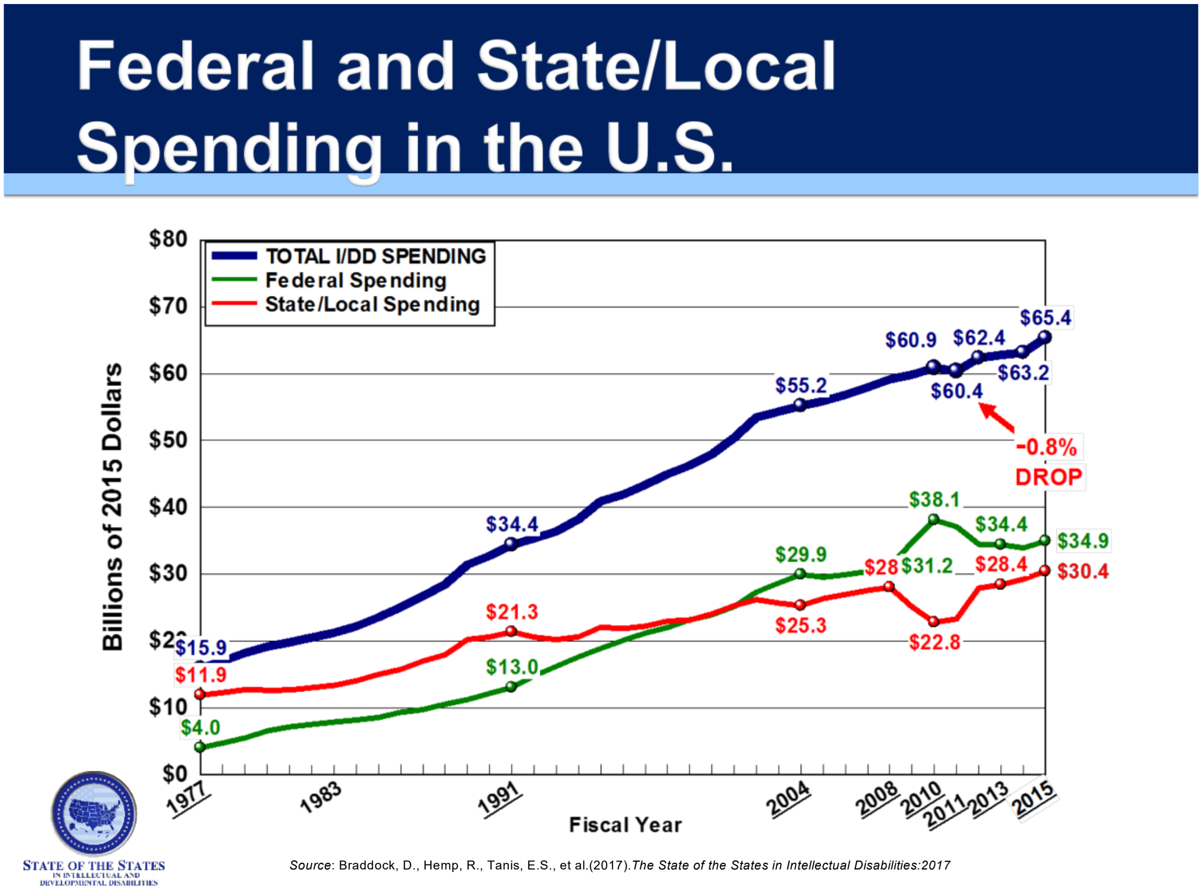
Medicaid

Medicaid, Medicare, and Title I education funding began in the 1960s and provided the largest federal funding for the IDD population to date. State Medicaid plans were created in 1965 by a cooperative effort between states and the federal government to provide health coverage to the indigent population. There is great variation between Medicaid programs in each state; no one model fits all programs. Economic factors may explain much of the variation due to wealthier states having a greater ability to pay for services through Medicaid programs than poorer states and states with greater numbers of poor individuals in need of healthcare resulting in a greater demand for the program resulting in limited supply of funding (Buchanan, Cappelleri, & Ohsfeldt, 1991). Political factors, such as the lobbying efforts by insurers and medical providers, may also impact states willingness to provide insurance to the poor. Studies have found that states with higher incomes typically spend more on Medicaid programs than states with lower incomes (Buchanan, Cappelleri, & Ohsfeldt, 1991). Medicaid is currently the primary payer for medical, long-term care, and school and community-based services for individuals diagnosed with IDD (Gettings, 2011). Medicaid's Intermediate Care Facility for Persons with Mental Retardation (ICF/MR), currently referred to as Intermediate Care Facility for Person's with Intellectual Disability (ICF/ID), settings and Medicaid's Home and Community Based Services provide the principle means by which the federal government funds services for the IDD population.

Public expenditures on IDD services have steadily increased over the past 40 years in large part due to political change (Pollock, 2011). Figure 1 demonstrates both state and federal funding for individuals diagnosed with IDD has steadily increased since 1977 and between 1991 and 2004 federal expenditures exceeded the combined total state funding for the first time. The figure also reflects the impact of the 2008 global recession. Generally, since 2004 federal and state expenditures have tracked upward at similar rates; however, by 2010 the federal share of expenditures was nearly $15 billion greater than the total state share. By 2015, the difference between state and federal expenditures had returned to pre-recession levels of $4.5 billion (Tanis, 2017).

Figure 1.

Federal and State/Local Spending in the U.S.



Federal and State/Local Spending in the U.S.

Source: Braddock, D., Hemp, R., Tanis, E.S., et al.(2017).*The State of the States in Intellectual Disabilities:2017*

Note. From “State of the States in Intellectual and Developmental Disabilities 2017,” by S. Tanis, (slide 12), 2017, Coleman Institute for Cognitive Disabilities.

IDD services are typically one of the largest line items in most state budgets and are somewhat resilient to retrenchment during fiscal stress (Pollack, 2011). However, it is noteworthy that declining tax revenue and sharp increases in demand for a variety of public assistance and social services have in recent years made IDD funding a target. Between 2008 and 2009, during the recession, 23 states reduced total IDD spending. If federal dollars are excluded, 47 states reduced spending between fiscal years 2008 and 2009 with the national average reduction being 12 percent (Pollack, 2011). Nationally, it is estimated about 475,000 individuals were on wait lists awaiting services in 2017 (Musumeci, Chidambaram, & O'Malley Watts, 2019). Many states have decreased or eliminated ancillary services resulting in individuals diagnosed with IDD losing services such as Occupational Therapy, Physical Therapy, and Speech-Language Pathology (Pollack, 2011). Financial reasons are contributing to long state wait lists. Approximately 72 percent of individuals diagnosed with IDD reside in the community with the support of family caregivers (Braddock et al., 2013). This trend is expected to continue due to the long waitlists many states maintain for out of home care (Heller & Schindler, 2009).

The Centers for Medicaid and Medicare program authorized Medicaid managed care more than 40 years ago as a cost containment effort (Burns, 2009). Managed care programs are considered the most efficient means of improving disabled individuals' access to services, which is considered problematic under fee-for-service models. States have commonly adopted managed care arrangements for behavioral health services; however, the practice has generally been viewed as not feasible for the IDD population. Ervin & Merrick (2014) report opponents of managed care point to historical evidence demonstrating managed care systems deny necessary care and the care provided is typically of low quality. Fee for services are commonly provided by nonprofit organizations (Walker & Osterhaus, 2010). Although managed care plans have gained popularity, research has not shown the practice to be effective in reducing health care expenditures when compared to fee for service models (Burns, 2009).

Noteworthy, fee for service was a major component of the movement away from institutionalization toward community-based care (Auger, 1999). Fee for service arrangements are akin to “governance by agreement” because it involves the government contracting with providers, negotiating rates and affords flexibility in meeting a variety of service needs (Goldsmith & Eggers, 2004). Essentially, the government is able to act as a broker of services. Federal, state and local governments share in the costs when human services are funded using a fee for service methodology (Walker & Osterhaus, 2010).

Residential and adult day services represent significant costs incurred by Medicaid (Walker, 2014). Federal and state governments rely on nonprofit organizations such as Easter Seals and Advocacy Resource Centers, former Association of Retarded Citizens, to deliver a variety of human services (Allard & Smith, 2014). Policy makers generally encourage the development and continued protection of nonprofits due to the public benefits they provide to society. Nonprofit benefits include direct payment, preferential regulatory treatment, tax exemptions and donor deductions (Brown, 2002).

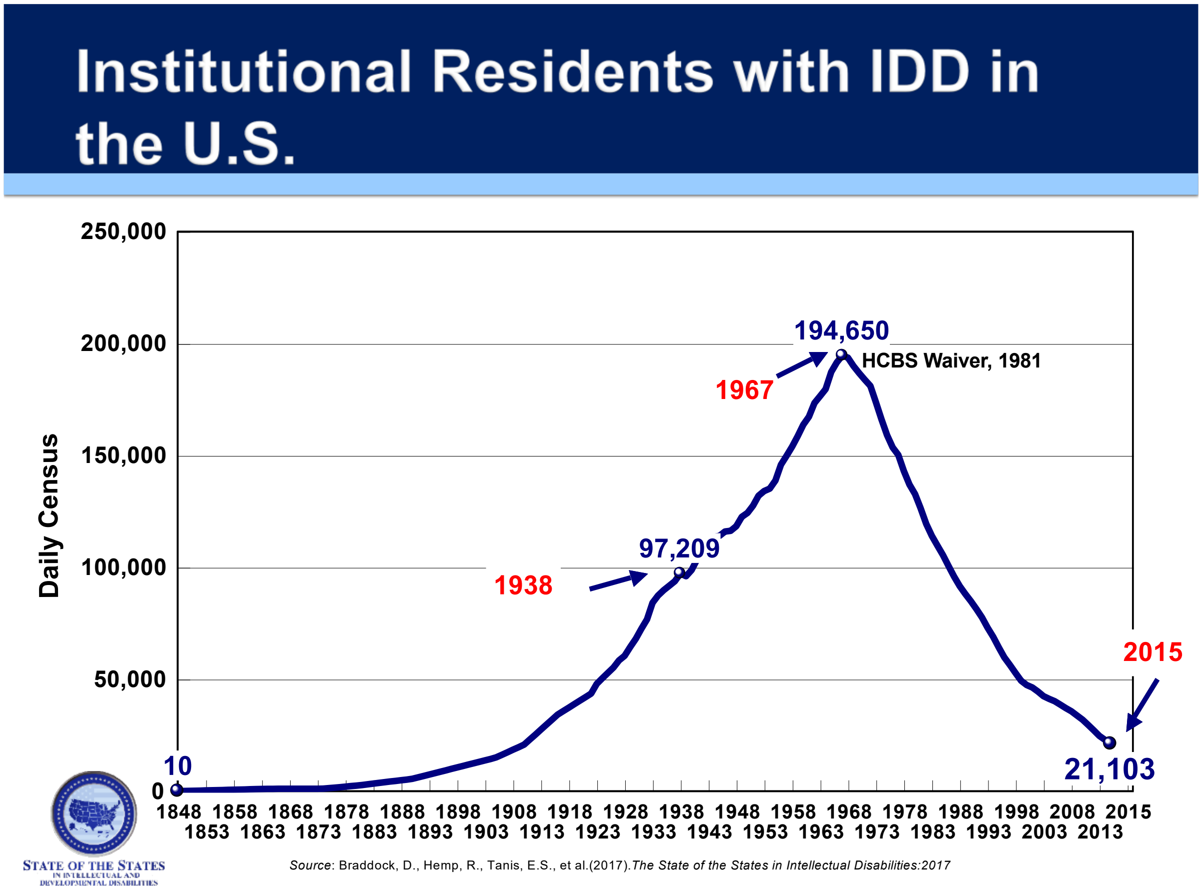
States are now considering implementing a managed care model for long-term services and supports rendered to individuals diagnosed with IDD. Essentially, states are seeking to reduce costs by moving away from fee-for-service plans. Gifford et al. (2011) reports the move is expected to increase access to care while improving the quality of care provided. In 2012, six states had converted long term services provided to individuals diagnosed with IDD by Medicaid funds to managed care. In 2013, over two-thirds of Medicaid spending could be attributed to services rendered to the elderly and disabled individuals (Rizzolo et al., 2013). By 2015 that number had grown to 14 states with three additional states planning to implement the practice the following year (National Association of States United for Aging and Disabilities, 2015).

Home and Community Based Services

In 2013, 66 percent of all Medicaid dollars was allocated to fund Medicaid Home and Community Based Services (HCBS) waivers (Braddock, Hemp, Rizzolo, Tanis, Haffer, & Wu., 2015). HCBS waivers were created in 1981 as an alternative to ICF/ID programs. Figure 2 demonstrates prior to the availability of HCBS waivers, most individuals diagnosed with IDD were housed in state-run intuitions. Between 1938 and 1967, nearly 100,000 of these individuals were added to the roles of state-run institutions resulting in nearly 195,000 residents nationally. The figure also demonstrates post HCBS waiver implementation, the number of individuals diagnosed with IDD remaining in institutional settings dropped significantly resulting in slightly more than 21,000 residents in 2015 (Tanis, 2017). Figure 3 demonstrates the popularity of the HCBS waivers. Since 1981, enrollment onto the HCBS waivers had reached 741,000 participants. Noteworthy the popularity of waivers was heightened after the 2008 global recession resulting in a growth of 30 percent between 2009 and 2015 (Tanis, 2017).

Figure 2.

Institutional Residents with IDD in the U.S.



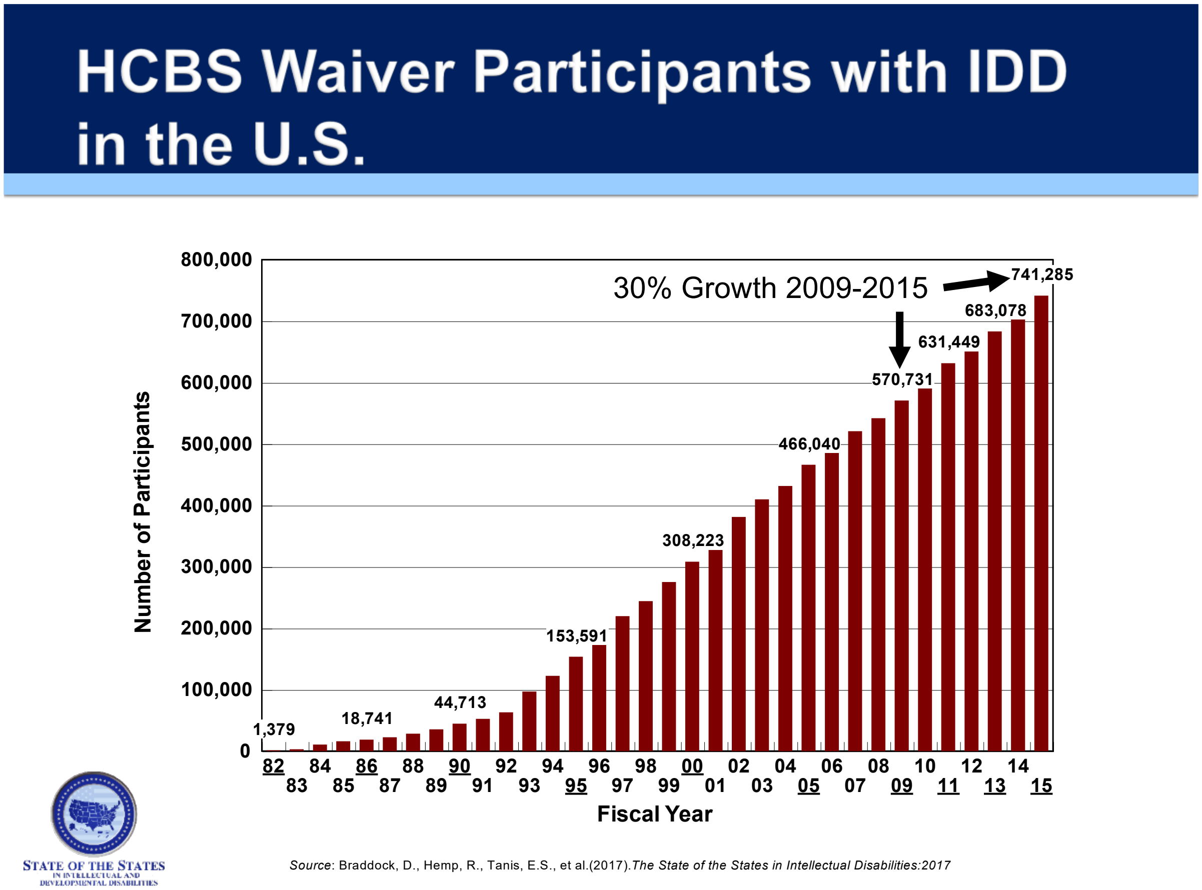
Institutional Residents with IDD in the U.S.

Source: Braddock, D., Hemp, R., Tanis, E.S., et al.(2017).*The State of the States in Intellectual Disabilities:2017*

Note. From "State of the States in Intellectual and Developmental Disabilities 2017," by S. Tanis, (slide 21), 2017, Coleman Institute for Cognitive Disabilities.

Figure 3.

HCBS Waiver Participants in the U.S.



HCBS Waiver Participants with IDD in the U.S.

Source: Braddock, D., Hemp, R., Tanis, E.S., et al.(2017).*The State of the States in Intellectual Disabilities:2017*

Note. From “State of the States in Intellectual and Developmental Disabilities 2017,” by S. Tanis, (slide 26), 2017, Coleman Institute for Cognitive Disabilities.

HCBS waivers allow states to develop and tailor community-based service programs for populations that have historically and due to support needs would require institutional care, including individuals diagnosed with IDD. HCBS waivers accomplish this by allowing states to identify target populations, services required to support these individuals within their community, qualifications of acceptable providers and manage costs (Friedman, 2017). Further, CMS allows states flexibility to determine eligibility requirements (Rizzolo et al., 2013).

Medicaid waivers allow states flexibility to waive some federal regulations, e.g., comparability, statewide application, and income requirements (Rizzolo et al., 2013). Allowing states to waive these requirements allows them to target specific populations and areas with great need. It also allows states to enroll individuals who due to income or other resources would be ineligible to receive services in nursing homes or ICF/ID or whom would have spouse or familial resources that would disqualify them from participation.

The Medicaid waiver also allowed states to cap enrollment and create waiting lists for HCBS services (Thompson & Burke, 2009). HCBS waivers must be cost neutral in that the average per capita costs are required to be less than or equal to the expenditures for the referenced population were it to receive institutional care. During the 1980s, in an attempt to control state Medicaid spending, the federal government created a rule requiring states to demonstrate that for every waiver slot created an institutional bed was eliminated. The requirement slowed states efforts to create waivers. During the 1990s, under the Clinton Administration, the rule was eliminated and states only had to show that the average cost to care for Medicaid waiver recipients was less than comparable care provided by a nursing home or ICF/ID (Thompson & Burke, 2009). During the Clinton Administration, the number of Medicaid waivers increased by 50 percent and the number of enrollees increased by 225 percent (Kitchener et al., 2005).

Every state and the District of Columbia maintains at least one Medicaid Waiver and HCBS is by far the most popular type. HCBS waivers services are typically provided through agency-direction or participant-direction models. The latter of which is designed to encourage waiver participants to exercise greater control of decisions relating to supports and services (Gross et al., 2012). Agency-directed programs typically afford individuals minimal opportunities to choose or exercise control over the service delivery process. Participant-direction is gaining popularity among states with many states formally adopting the practice. (Breihan, 2007).

HCBS waivers surpassed ICF/ID funding in 2000 as the largest funding source for long-term supports and services of people diagnosed with IDD (Braddock et al., 2015). There is considerable variation between states in terms of projected HCBS wavier spending, spending per participant and the average length of service participation (Rizzolo et al., 2013). Between 2008 and 2009, an unprecedented number of Americans relied on Medicaid due to rising unemployment resulting in an overall drop in the total Medicaid budget allotted for the IDD population.

The Centers for Medicaid and Medicare (CMS) by means of state Medicaid programs are now holding providers accountable for the costs and quality of the services they render. Instead of a strict fee for service model that rewards volume of services provided, CMS is encouraging state Medicaid programs to incentivize quality (National Association of Medicaid Directors (2017). In doing so, CMS is moving toward an outcome-based definition of services instead of one based solely on conventional attributes, e.g., settings or physical characteristics (Friedman, 2017). For example, conventional systems would provide the same rate of reimbursement based on the type of service provided, e.g., the daily rate for one provider of residential services would be the same for any other. In the new system, state Medicaid providers would be able to financially incentivize residential providers with better outcomes.

Affordable Care Act

Lack of healthcare insurance has been correlated to decreased rates of preventative care, lower rates of necessary care, and increased bankruptcy (Christopher et al., 2016). Studies have found that nationally, Medicaid is associated with improved access to medical care and control of chronic conditions (Christopher et al., 2016). The Affordable Care Act (ACA) of 2010 was implemented to expand Medicaid coverage for all U.S. residents with combined family incomes at or below 138% of the federal poverty level, including able-bodied adults without children who were previously not eligible for Medicaid (Han et al., 2015). States have historically had significant discretion in how they managed Medicaid resulting in considerable variation between them in the areas of eligibility and services offered. An intended result of ACA was to reduce this variation by mandating state Medicaid programs cover nearly all Americans with low incomes meeting the new guidelines. It was initially projected by 2014 nearly half of the qualified beneficiaries would receive coverage through Medicaid.

In 2012 the U.S. Supreme court ruled states are not required to adhere to ACA verbiage requiring they expand Medicaid eligibility (Han et al., 2015). Further, failure to expand would not result in a penalty to the state’s existing Medicaid program. Arguably, eliminating the expansion requirement resulted in more variation between state programs than prior to the ACA (Cantor, Thomson & Farnham, 2013). As of January 2019, 36 states and the District of Columbia had elected to expand in accordance with ACA (Denham & Veazie, 2019). Unfortunately, Medicaid expansion, access to care and related outcomes among low-income adults has received minimal study (McMorrow et al., 2016). McMorrow et al. (2016) found as the Medicaid entry threshold decreased the number of low-income uninsured individuals also decreased. They found decreasing the threshold increased the probability recipients received a general care visit to a doctor within a 12-months period. McMorrow et al. (2016) also found that as Medicaid eligibility increased, the likelihood a beneficiary would fall into the category of no psychological distress decreased. Psychological distress was described as feelings of depression, anxiety, agitation, despair, debasement, and a tendency toward emotional inertia.

It is noteworthy; the ACA expansion is different from previous Medicaid eligibility changes. First, ACA was highly publicized as an effort to improve access to health insurance to improve American population health. Secondly, outreach, individual mandate, new subsidies, and expanded coverage for childless adults were designed to increase use of the service well beyond previous levels (McMorrow et al., 2016). Both efforts have resulted in unprecedented public knowledge and interest in the expanded program.

Healthcare

Prior institutionalization of individuals diagnosed with IDD and the associated lack of care to the personal hygiene needs of residents has resulted in these individuals residing in community-based care settings having a greater incidence of infectious diseases than the general population (DeSchryver & Meheus, 2009). Individuals diagnosed with IDD are more likely to be diagnosed with tuberculosis, hepatitis B, and helicobacter pylori (Ouellette- Kuntz et al., 2005). Historically, individuals diagnosed with IDD have not lived as-long-as the general population resulting in the group having a lower incidence of several diseases that typically becomes common as people age (Sullivan, Hussain, Threlfall & Bittles, 2004). Generally, the life expectancy of individuals diagnosed with IDD is increasing at rates similar to those of the general population; however, the mortality rate remains much higher among this population (Cooper, Melville & Morrison, 2004; Hoghton, Martin & Chauhan, 2012; Ouellette- Kuntz et al., 2005).

Individuals diagnosed with IDD have medical needs that frequently remain unidentified and untreated due to communication challenges, diagnostic overshadowing, discrimination, or indifference on the part of healthcare practitioners or caregivers (Folch-Mas et al., 2017). Generally, these individuals suffer from a greater number of medical issues and often these conditions are related to the cause of their disability. These health disparities are often exacerbated by the lack of economic and social resources resulting in a mortality rate nearly three times that of the general population (McCallion & McCarron, 2014; Robertson et al., 2014). Studies have found individuals diagnosed with IDD have an increased risk and greater prevalence rates for a variety of ailments, including, epilepsy, diabetes, chronic constipation, dementia, gastrointestinal disease, thyroid disease, and genetic syndromes (Patterson, Doucette, & Lindgren, 2012).

In 1929, the median life expectancy for an individual diagnosed with Down Syndrome was 9 years (Strauss and Eyman, 1996). In the 1980s, the mean age of death was only 25 and by 1997 the median age of death was 49 years (Yang et al., 2002). Due to advances in the ability of physicians to correct heart conditions and in the medications used to correct thyroid problems, the median life expectancy is now 58 years (Skotko, 2017). Most individuals diagnosed with IDD will outlive their parents who are usually their primary caregivers. Pollock (2011) reports 731,000 individuals diagnosed with IDD are currently living with caregivers over the age of 60. Overall, due to the number of individuals diagnosed with IDD living longer, their representation among geriatric patients is growing (Kirkendall, Waldrop & Moone, 2012). The increasing life expectancy of individuals diagnosed with IDD has begun to strain the social services system due to its general lack of preparedness for addressing the health needs of the group resulting in inappropriate or lack of services (Kropf, 1996). By 2007, more than 430,000 individuals diagnosed with IDD had moved from public hospitals into community residential programs. As the population ages and requires increasingly complex health care, families and other caregivers are becoming increasingly concerned about how best to serve these individuals in the least restrictive environment. In order to provide continuity of care and honor the preferences of the person, many are being offered the opportunity to live out their final years in their current homes as an alternative to nursing home placement (Kirkendall, Waldrop & Moone, 2012).

Wealth and health are related. High rates of poverty are reported for individuals diagnosed with IDD resulting in a greater reliance on publicly funded services and insurance (Havercamp, Scandlin & Roth, 2004). Individuals diagnosed with intellectual disabilities are disproportionately poor and experience health disparities consistent with their lower socio-economic status (Bershadsky et al., 2012). Individuals diagnosed with IDD often rely on Medicaid and other public programs to fund their healthcare needs. Havercamp, Scandlin & Roth (2004) report many providers are unwilling to serve this population using these funding sources due to low reimbursement rates, high administrative overhead costs, and fear of being overwhelmed by patients diagnosed with IDD who require special care and attention.

Poor oral health can reduce function and lessen the quality of life of any individual suffering from it by adversely impacting physical, psychological, social, and economic well-being (Murthy, 2016). Individuals diagnosed with IDD are less likely than the general population to have had their teeth cleaned. Havercamp, Scandlin & Roth (2004) found individuals diagnosed with IDD are significantly more likely to report not receiving a dental cleaning within the past five years or having never received a cleaning. The lack of dental care is related to a general lack of knowledge among dental practitioners. Research has shown dental schools do not provide didactic training and as many as one quarter of them provide 5% or less clinical time working with patients diagnosed with IDD (Waldman & Perlman, 2002). The dental profession frequently underserves individuals diagnosed with IDD. Generally, dentists lack basic knowledge of the physical and psychological management concerns, have minimal experience with the population, expect disruption of their business due to behaviors and additional care, presuppose need for special equipment and facilities, and are concerned about low compensation associated with increased time (Waldman & Perlman, 2002).

Individuals diagnosed with IDD tend to live sedentary lifestyles (Ouellette- Kuntz et al., 2005). Lewis et al. (2002) found that individuals diagnosed with IDD are more than twice as likely as the general population to be obese. It has also been found individuals diagnosed with IDD residing with family and friends were twice as likely to be obese than those residing in other settings (Ouellette- Kuntz et al., 2005). The sedentary lifestyle common among the population has resulted in aging individuals diagnosed with IDD experiencing earlier onset of many chronic diseases including diabetes, heart disease, and hypertension (Bershadsky et al., 2012).

Generally accepted health care practices, medical and psychiatric services, are frequently overlooked or not followed when caring for individuals diagnosed with IDD (Lewis et al., 2002). Age, severity of IDD diagnosis, mobility challenges, overall health status and living arrangement influences whether a person receives routine preventative healthcare. Bershadsky et al. (2012) found that individuals residing with families or living independently within their communities are less like to receive routine preventative healthcare. Women diagnosed with IDD were significantly less likely to have received cervical and breast cancer screenings (Havercamp, Scandlin & Roth, 2004). Further, they found a significant number of these women over the age of 40 had never received a mammogram even though it is recommended women in this age group receive the assessment biennially. Lewis et al. (2002) found individuals diagnosed with IDD are less likely than non-disabled individuals to receive a psychiatric consultation.

Substantial efforts have been made by governments to improve the health care services provided to individuals diagnosed with IDD including legislative actions and financial incentives (Hoghton, Martin, and Chauhan, 2012). Generally, individuals diagnosed with IDD experience greater difficulty identifying health care providers, arranging transportation to health care appointments and funding health care than non-disabled individuals (Ouellette- Kuntz et al., 2005). Health care providers are beginning to use alternative methods to serve these individuals by providing greater access resulting in a rise in the use of techniques such as telemedicine (Perry, Byer & Holm, 2009).

The most common physical problems experienced by individuals diagnosed with IDD are epilepsy, mobility challenges, and sensory deficits (van Schrojenstein Lantman-de Valk & Noonan-Walsh, 2008). Individuals diagnosed with IDD have higher rates of vision and hearing loss and the incidence increases significantly as the population ages (Ouellette- Kuntz et al., 2005). Individuals diagnosed with IDD tend to have limited vocabulary and reading skills making it difficult for them to understand health related media and materials (Ouellette- Kuntz et al., 2005). Diagnostic overshadowing occurs when mental health professionals diagnose IDD and fail to utilize due diligence to ensure no other psychiatric conditions are present (Ahuja & Cornwell, 2004; Ali & Hassiotis, 2008). Although individuals diagnosed with IDD have a greater incidence of psychiatric illness, physicians are less likely to diagnose co-occurring disorders (Ali & Hassiotis, 2008). Mental illness occurs at greater frequency among individuals diagnosed with IDD than that of the general population and is estimated to be as much as 15 percent (Davidson et al., 1995). Often mental health providers are not well prepared to provide care to individuals diagnosed with IDD due to lack of training, minimal experience, or belief these individuals are unable to understand the process (Poglar et al., 2000).

Individuals diagnosed with IDD often have multiple treatment plans developed by medical professionals who are unaware of the assessments or medications each are providing resulting in unnecessary and potentially duplicative care (Kirkendall, Waldrop & Moone, 2012). A study in the Netherlands demonstrated individuals diagnosed with IDD are prescribed four times as many drugs as non-disabled persons (van Schrojenstein Lantman-de Valk & Noonan-Walsh, 2008). Communication between individuals diagnosed with IDD may be challenged because receptive language is usually much better developed than expressive language skills making it difficult for many to share how they feel (van Schrojenstein Lantman-de Valk & Noonan-Walsh, 2008). This lack of expressive communication skills often results in the appearance of other behaviors that may not be readily identifiable by physicians as communicating pain or other discomfort (van Schrojenstein Lantman-de Valk & Noonan-Walsh, 2008).

Loneliness

Loneliness is a manifestation of the discrepancy between a person's expectation of interpersonal relationships and the reality of those relationships (Heiman, 2001). Essentially, loneliness manifests when desired relations are non-existent. The IDD population is known to be lonelier than the general adult population (Stancliffe et al., 2010). Arguably, socially rewarding and stable relationships are one of the single most important factors known to influence a person's quality of life (McVilly et al., 2006). Relationships provide functional aid, emotional support, information, decision-making assistance, and opportunities to broaden natural support networks (Hughes, 1999). Relationships also guard against psychopathology and stress (McVilly et al., 2006).

Loneliness has been linked to depression and suicidality (Schinka et al., 2012). Other mental health challenges related to loneliness include anxiety and externalizing behavior (Hawkley & Capioppo, 2010). Externalizing behaviors include antisocial behavior, violation of society norms, disregard for the rights of others, and verbal or physical aggression. Smoking, alcohol abuse, obesity due to sedentary lifestyle and greater cognitive decline in later life are all associated with loneliness (Gilmore & Cuskelly, 2014). Prolonged loneliness may prompt a person's nervous system into flight or fight mode which inhibits dopamine production while increasing stress related hormones such as adrenaline and cortisol resulting in an increased susceptibility to chronic disease (Shaffer, 2019).

Kraus et al. (1992) found that among individuals diagnosed with IDD residing with family, 42 percent had no friends outside their immediate family. Petrovsky & Gleeson (1997) found that among disabled individuals maintaining competitive employment, 73 percent reported maintaining friendships at work while 97 percent reported having no friends outside the workplace. These findings are at odds with findings within the general population where individuals' report more than 70 percent of their time is spent socially with non-family members. Although efforts have been made to "integrate" individuals diagnosed with IDD into their communities, there has been very little gain in the area of socialization (McVilly et al., 2006). Integration refers to affording disabled individuals opportunities to participate in activities to an extent similar to non-disabled individuals, e.g., attending venues, fairs, shopping, etc.

In the general population, loneliness has been associated with a host of negative life outcomes (Gilmore & Cuskelly, 2014). Depression and associated suicidality, externalizing behavior and anxiety have all been linked to loneliness in the general population (Gilmore & Cuskelly, 2014). Although the etiology is not fully known, loneliness has been demonstrated as a trigger for inflammation within the body that increases physical health risks and cardiovascular disease (Hawkley et al., 2010). Loneliness has been linked to alcohol and substance use, reduced physical activity and associated obesity and greater cognitive decline in old age (Wilson et al., 2007). Currently, there is little research available addressing loneliness and its impact on the intellectually disabled population (Gilmore & Cuskelly, 2014).

Public Management/ Public Policy

Much of the available research demonstrates how individuals diagnosed with IDD live within their communities and is intended to inform public management and policy. Advocacy and grassroots organizations, such as Advocacy Resource Center (ARC), Service Providers Association for Developmental Disabilities (SPADD), American Association on Intellectual and Developmental Disabilities (AAIDD) and United Cerebral Palsy (UCP) are promoting programs and lobbying for public policy changes that favor the interests and needs of individuals diagnosed with IDD and their families. These organizations and other private agencies like them are the public management entities responsible for maximizing the return on public dollars allocated to serve individuals diagnosed with IDD and as of late are not forthcoming with their own internal practices that may be shared and discussed in this dissertation.

Chapter III

METHODOLOGY

Overview

Identifying methods of funding services to individuals diagnosed with IDD has been at the center of discussions at federal and state levels for several decades (Hemp, Braddock & King, 2014). Recent community-based service and person-centered planning mandates have added layers to these discussions that essentially revolve around identifying and overcoming logistical challenges and competing priorities to fund necessary services to millions diagnosed with these disorders. Limited funding, a growing and aging IDD population, and political volatility at state and federal levels complicate these discussions. This study examines the relationship between outcomes experienced by individuals diagnosed with IDD and economic factors identified in 41 states and the District of Columbia. The researcher conducts a cross sectional secondary data analysis identifying a variable related to IDD spending. This variable is dissected and contextually examined. The researcher also identifies six quality of life outcomes believed to be indicative of health and best possible outcomes for individuals diagnosed with IDD. No human subjects or identifiable information of human subjects were used. Instead, the dissertation utilizes de-identified data obtained from public sources. All data contained within this study is considered archival. On March 31, 2020, the Valdosta State University Institutional Review Board (IRB) exempted this dissertation from IRB oversight. The document is available for review in Appendix A.

Data Source

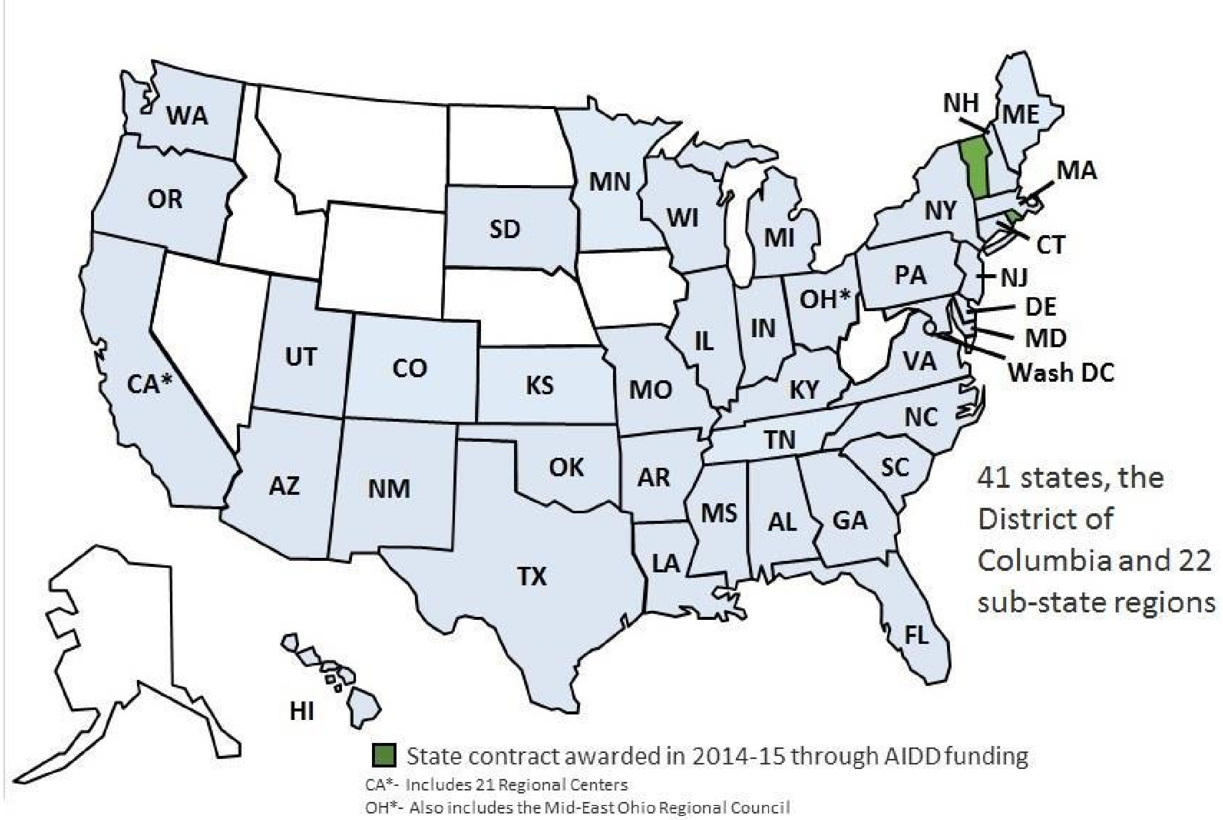
Data used in this study was obtained from a variety of public domain sources. Due to limited data demonstrating IDD spending, the study is restricted to most recent data available.

All data, including quality of life outcomes, was generated from sources reporting information specifically related to 2011, 2013 and 2015. Quality of life outcomes data was obtained from Human Service Research Institute (HSRI). The U.S. Bureau of Economic Analysis (USBEA), Kaiser Family Foundation, Center for American Progress, and the Coleman Institute for Cognitive Disabilities at the University of Colorado provided economic, demographic and political data.

HSRI is a leading nonprofit organization specializing in utilizing research in the field of intellectual and developmental disabilities to improve services, systems of care, and inform administrators responsible for shaping policy, priorities, and practice (Human Service Research Institute, 2017). HSRI has been involved in the field of intellectual disabilities since the mid 1970s. The organization collaborated with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and National Association of States United for Aging and Disabilities (NASUAD) to identify performance measures and indicators utilized to measure and benchmark the outcomes for people diagnosed with IDD (Human Service Research Institute, 2017). HSRI created the National Core Indicators (NCI). Participation in the NCI project is a volunteer effort by State Medicaid and disability agencies to measure their own performance utilizing surveys that address key concerns, including, employment, service planning, rights, community inclusion, choice, health and safety (National Core Indicators, 2017). The NCI Adult Consumer Survey is completed during face-to-face meetings and gathers data on approximately 60 outcomes. As of 2015, 41 states, the District of Columbia and 22 sub-state regions were participating in the NCI program. Figure 4 demonstrates state participation. Each state electing to participate was required to identify a minimum random sample of 400 individuals over the age of 18 diagnosed with IDD receiving a minimum of at least one publicly funded service other than case management. HSRI claims the sample allows for valid comparisons across 95% confidence level +/- 5% margin of error regardless of the size of service population (National Core Indicators, 2015). The data used in this study is available and readily accessible to the public at nationalcoreindicators.org.

Figure 4.

NCI State Participation 2014-15



41 states, the District of Columbia and 22 sub-state regions

🟩 State contract awarded in 2014-15 through AIDD funding

CA*- Includes 21 Regional Centers

OH*- Also includes the Mid-East Ohio Regional Council

Note. From “Adult Consumer Survey 2014-15 Final Report,” by National Core Indicators, (p. 222), 2015, Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services.

Appendix D contains demographic data obtained from NCI Adult Consumer Survey available for fiscal years, 2011, 2013 and 2015. State and municipality participation varies from year to year. As of 2015 Alaska, Idaho, Iowa, Montana, Nebraska, Nevada, North Dakota, and

Wyoming were not participants in the NCI Adult Consumer Survey project. Although participants in the NCI Adult Consumer Survey program during the 2015 session, Massachusetts, Maryland, Mississippi, New Mexico, Oregon, Rhode Island, Washington, and Wisconsin were not included in the reported data. The reason for their omission is not described on the NCI website.

Data demonstrating economic factors is the work product of USBEA and the Coleman Institute of Cognitive Disabilities. The researcher used briefs developed by USBEA aimed at describing the economic growth of states. USBEA anticipates the data can be used to analyze the economic status of each state and serve as a decision-making tool for federal and state government, academia and business associations (U.S. Bureau of Economic Analysis, 2016).

The Coleman Institute for Cognitive Disabilities at the University of Colorado is an organization committed to supporting research, development, sharing and education in cognitive disability. It was started in 2001 by the Regents of the University of Colorado by means of private endowment and is sustained by funding from its founding donors. The economic data reflected in this research demonstrating state spending is taken from the institute's State of the States in Developmental Disabilities Project, which is a venture funded by the U.S. Administration on Developmental Disabilities and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The project contains national longitudinal information about public spending for intellectual and developmental disabilities (Coleman Institute for Cognitive Disabilities, 2015).

Political factors data was obtained from Kaiser Family Foundation. Kaiser Family Foundation describes itself as a nonprofit public charity specializing in policy analysis, polling and journalism. The organization purports to focus on identifying how public policies, including the Affordable Care Act, Medicare and Medicaid, affects people using evidenced based analysis (Kaiser Family Foundation, 2020).

Independent Variable

One essential independent variable has been identified: IDD spending per person. For the purposes of this study per person spending is defined as the average dollars spent to provide care and support to each individual diagnosed with IDD by state or municipality and the data reported in datasets are a reflection of information produced by the Coleman Institute of Cognitive Disabilities.

Dependent Variables

Six dependent variables, also referred to as outcome variables have been identified: (1) the proportion of individuals diagnosed with IDD reporting he/she has someone to go to for help if they feel scared, (2) the proportion of individuals diagnosed with IDD reporting loneliness, (3) the proportion of individuals diagnosed with IDD reporting having friends who are not paid staff or family,(4) the proportion of individuals diagnosed with IDD reporting receiving annual health examinations, (5) the proportion of individuals diagnosed with IDD reported to overweight or obese, and (6) proportion of individuals diagnosed with IDD who exercise at least 30 minutes three times weekly.

Hypotheses

This dissertation proposes the six hypotheses that follow:

Hypothesis 1: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are more likely to report not having someone to go to for help if they feel scared, but those individuals that receive greater funding will more often report having someone to go to for help if they feel scared.

Hypothesis 2: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are at risk for experiencing loneliness, but those individuals that receive greater funding will report lower levels of loneliness.

Hypothesis 3: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services report limited opportunity to develop friendships with non-caregivers, but those individuals that receive greater funding will report having more friends who are not paid staff or family members.

Hypothesis 4: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are less likely to have access to annual health examinations, but those individuals that receive greater funding are will more often report having received an annual health examination.

Hypothesis 5: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are prone to be overweight or obese, but those individuals that receive greater funding will be less likely to report being overweight or obsess.

Hypothesis 6: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services report limited opportunities to exercise 30 minutes three times weekly, but those individuals that receive greater funding will be more likely to report exercising 30 minutes three times weekly.

This dissertation proposes the six null hypotheses that follow:

Null Hypothesis 1: No relationship exists between the amount of IDD spending per person and individuals reporting having someone to go to for help if they feel scared.

Null Hypothesis 2: No relationship exists between the amount of IDD spending per person and individuals reporting loneliness.

Null Hypothesis 3: No relationship exists between the amount of IDD spending per person and the individuals reporting having friends who are not paid staff or family.

Null Hypothesis 4: No relationship exists between the amount of IDD spending per person and individuals reporting receipt of annual health examinations.

Null Hypothesis 5: No relationship exists between the amount of IDD spending per person and individuals reported to be overweight or obese.

Null Hypothesis 6: No relationship exists between the amount of IDD spending per person and individuals reporting exercise 30 minutes three times weekly.

Control Variables

In order to minimize outside influences that may impact the effect of the identified dependent and independent variables, the researcher will employ the use of control variables. Six control variables, both qualitative and quantitative, believed to impact state spending have been identified: (1) state or municipality Medicaid expansion status, (2) state or municipality state poverty rates, (3) number of individuals diagnosed within a state or municipality receiving IDD services funded in whole or part by Medicaid, (4) total state or municipality IDD spending, (5) state or municipality gross domestic product (GDP), and (6) state or municipality per capita income.

Status of state and municipality decision to expand Medicaid was selected as a control variable due to expansion under the ACA generally resulting in additional funding which may be utilized by states to fund services to individuals diagnosed with IDD. Poverty rate was selected as a control variable due to initial paradoxical nature of ACA expansion. Olson (2015) reports states with the greatest need to expand Medicaid under the ACA due to poverty and extreme rates of uninsured citizens were the first to reject the measure while several states with the least need expanded. It would stand to reason that states with the greatest poverty rates would also have the greatest need of federal funding to support costs associated with caring for individuals diagnosed with IDD. The number of individuals diagnosed with IDD receiving services funded in whole or part by Medicaid and total IDD spending per state were selected to describe the costs states assume as they seek to fund services and provide care to the population. Finally, state GDP and per capita income were selected as control variables to be indicators of wealth. State legislators and individuals with access to greater financial resources may vote differently than less capable peers when responding to the challenge of funding services to individuals diagnosed with IDD.

Analytic Procedures

Descriptive Analysis

Descriptive analysis will be used to describe the basic features of data utilized in the study. It will summarize and provide frequency data about the population, quality of life outcomes and economic factors. Descriptive analysis will identify measures of frequency, central tendency, and dispersion of variation. All data reflected on the tables will be analyzed using descriptive statistics. Data was transferred in its entirety from credible sources previously described.

Regression Analysis

The One-Way Analysis of Variance (ANOVA) and Linear Regression is generated using Microsoft Office 365 statistical software. ANOVA is used to examine the relationship between independent and dependent variables. This software allows covariance to also be analyzed.

ANOVA was chosen for its ability to test the significance of group differences between two or more means as it analyzes variation between and within each group (Mertler & Vannatta, 2010). Linear Regression will be utilized to model and quantify the strength of the relationship between the independent and dependent variables by applying a linear equation to the reported data. The results will be considered statistically significant at .10 level. Correlation Coefficient Matrix is also generated and indicates the bivariate correlation, which reflects strength of relationships between all variables.

Study Limitations

The study uses numerical data in aggregate. Due to a variety of concerns associated with conducting a study of this nature, the researcher has decided to rely on aggregated data obtained from a secondary source. The researcher acknowledges aggregate data is generally less desirable due to a general loss of information when data is moved between micro to macro level evaluation (Clark & Avery, 1976). It is believed in this study the aggregate data is a viable source and it will produce useful results.

In the instance of this study, the use of secondary data allows the researcher to gain access to a sample much larger than would typically be attainable using conventional methods and other resources at the researcher's command. The larger sample will be more representative of the target population and in most instances allow greater validity and generalizability of the findings (Smith et al., 2008). The use of secondary data also means the study may be replicated, reanalyzed or reinterpreted allowing peer or future researchers opportunities to test their own ideas, models and theories (Johnston, 2014).

Chapter IV

RESULTS

Overview

The purpose of the study is to determine whether relationships exist between state and federal funding allocations and outcomes achieved by individuals diagnosed with intellectual and developmental disabilities (IDD). The study identifies six control variables that may also interact with funding to impact the specified outcomes achieved by individuals diagnosed with IDD. There are few studies in this area resulting in a paltry body of knowledge. The lack of research is in part due to the difficulties encountered by formal systems, e.g., state, and local governments responsible for managing human service delivery systems to frankly report reliable and measurable data about the results of their own efforts to provide services (Michaels, 2002). Although this study alone will not distinguish causal relationships, it will identify whether allocated funding correlates with outcomes experienced by individuals diagnosed with IDD and whether control variables also play a role.

Independent Variable

IDD spending per person has been identified as the only independent variable. Spending for IDD services and supports are typically one of the largest line items in most state budgets (Pollack, 2011). For the purposes of this study per person spending is defined as the averaged dollars spent to provide care and support to individuals diagnosed with IDD by state or municipality. This data is obtained from the Coleman Institute for Cognitive Disabilities which produced The State of the State in Intellectual and Developmental Disabilities which reported spending by state and municipality during fiscal years 2011, 2013 and 2015.

First Dependent Variable

The first dependent variable is the proportion of individuals diagnosed with IDD reporting he/she has someone to go to for help if they feel scared. Individuals diagnosed with IDD have varying capacity to provide for their own safety and well-being. It is estimated individuals diagnosed with IDD are 1-1.5 times more likely to be the victims of abuse and violence than non-disabled persons (Ericson & Perlman, 2001; Petersilia, 2000). Further, studies have found more than 70 percent of women diagnosed with developmental disabilities experience sexual assault within their lifetime (Petersilia, 2000).

Second Dependent Variable

Although efforts have been made to afford individuals diagnosed with IDD opportunities to participate in activities to an extent similar to non-disabled individuals there has been very little gain in the area of socialization (McVilly et al., 2006). The second dependent variable is the proportion of individuals diagnosed with IDD reporting loneliness. Loneliness is a manifestation of the discrepancy between a person's expectation of interpersonal relationships and the reality of those relationships (Heiman, 2001). Relationships provide functional aid, emotional support, information, decision-making assistance, and opportunities to broaden natural support networks (Hughes, 1999).

Third Dependent Variable

Individuals diagnosed with IDD have limited opportunities to participate in community activities or develop relationships with people who are not themselves disabled or caretakers. Kraus et al. (1992) found that among individuals diagnosed with IDD residing with family, 42 percent had no friends outside their immediate family. The third dependent variable is the proportion of individuals diagnosed with IDD reporting having friends who are not paid staff or family.

Fourth Dependent Variable

Individuals diagnosed with IDD have a mortality rate nearly three times that of the general population (McCallion & McCarron, 2014; Robertson et al., 2014). These individuals are associated with a greater incidence of infectious disease than the general population (DeSchryver & Meheus, 2009). Further, these individuals have medical needs that frequently remain unidentified or untreated (Folch-Mas et al., 2017). For these reasons, the fourth dependent variable is the proportion of individuals diagnosed with IDD reporting receiving annual health examinations.

Fifth Dependent Variable

Many individuals diagnosed with IDD live sedentary lifestyles and receive medications that contribute to reduced metabolism and increased appetite (Must et al., 2014). Obesity impacts both physical and psychological well-being (Lobstein et al., 2004). The fifth dependent variable is the proportion of individuals diagnosed with IDD reported to be overweight or obese. Researchers in countries around the world report the incidence of being overweight among the IDD population as between 28 and 71 percent while the incidence of being obese among the general population between 17 and 43 percent (Barnes, Howie, McDermott & Mann, 2013; Bhaumik et al., 2008).

Sixth Dependent Variable

Lewis et al. (2002) found that individuals diagnosed with IDD are more than twice as likely as the general population to be obese suggesting the population fails to exercise on a regular basis. When compared to the nondisabled population, individuals diagnosed with IDD engage in physical activity and exercise less than their nondisabled peers (Barnes et al., 2013;

Bhaumik et al., 2008). The sixth variable is proportion of individuals diagnosed with IDD who exercise at least 30 minutes three times weekly**.**

The study identifies six control variables, both qualitative and quantitative, believed to impact the independent variable. The first, is state Medicaid expansion status. Studies have found that nationally, Medicaid is associated with improved access to medical care and control of chronic conditions (Christopher et al., 2016). The Affordable Care Act (ACA) of 2010 was implemented to expand Medicaid coverage for all U.S. residents with combined family incomes at or below 138% of the federal poverty level, including able-bodied adults without children who were previously not eligible for Medicaid (Han et al., 2015). The ACA was highly publicized resulting in unprecedented public knowledge and interest in the program. Opponents to the program sued and in 2012 the U.S. Supreme Court ruled states are not required to adhere to ACA verbiage requiring they expand Medicaid eligibility (Han et al., 2015). As of July 2022, twelve states including Georgia have not expanded Medicaid.

State poverty rate is the second control variable. Poverty rate was selected as a control variable due to the initial paradoxical nature of ACA expansion. Olson (2015) reports states with the greatest need to expand Medicaid under the ACA due to poverty and extreme rates of uninsured citizens were the first to reject the measure while several states with the least need expanded. It would stand to reason that states with the greatest poverty rates would also have the greatest need of federal funding to support costs associated with caring for individuals diagnosed with IDD.

The number of individuals diagnosed with IDD receiving services funded in whole or part by Medicaid and total IDD spending per state were selected to describe the costs states assume as they seek to fund services and provide care to the population. IDD services are typically one of the largest line items in most state budgets (Pollack, 2011). There is considerable variation between state populations, wealth, and size of their respective IDD populations. Therefore, these conditions combined may affect the availability of fiscal resources used to fund services to individuals diagnosed with IDD. The third control variable is the number of individuals diagnosed with IDD receiving services funded in whole or part by Medicaid. Advocates claim expanded services and increased public funding will produce better outcomes for the affected population. These claims are related to service provider's assertions Medicaid's reimbursement rates are much less than the actual cost of providing care and adversely impacts outcomes attained by individuals diagnosed with IDD (Walker & Osterhaus, 2010). Many states report fiscal deficits and have difficulty increasing funding in this area. The fourth control variable is total IDD state spending.

The fifth and sixth control variables are State GDP and per capita income respectively. They were selected as control variables to be indicators of wealth. State legislators and individuals with access to greater financial resources may vote differently than peers with fewer fiscal resources when responding to the challenge of funding services to individuals diagnosed with IDD. This chapter presents the results of a descriptive statistical analysis and a regression analysis of data for the 2015 review period.

The data is analyzed using Microsoft Excel 365 software which produces descriptive and linear regression statistics with ANOVA and coefficients output. One independent variable, six dependent variables, also referred to as quality-of-life outcomes, and six control variables have been identified. Model 1, Figure 5, requires each proposed hypothesis be studied in a one dependent variable to one independent variable manner. Model 2, Figure 6, requires the control variables be added to the regression analysis to account for confounding factors that may also affect the quality-of-life outcomes under consideration.

The following hypotheses are tested.

Hypothesis 1: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are more likely report not having someone to go to for help if they feel scared, but those individuals that receive greater funding will more often report having someone to go to for help if they feel scared.

Hypothesis 2: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are at risk for experiencing loneliness, but those individuals that receive greater funding will report lower levels of loneliness.

Hypothesis 3: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services report limited opportunity to develop friendships with non-caregivers, but those individuals that receive greater funding will report having more friends who are not paid staff or family members.

Hypothesis 4: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are less likely to have access to annual health examinations, but those individuals that receive greater funding are will more often report having received an annual health examination.

Hypothesis 5: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services are prone to be overweight or obese, but those individuals that receive greater funding will be less likely to report being overweight or obsess.

Hypothesis 6: Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services report limited opportunities to exercise 30 minutes three times weekly, but those individuals that receive greater funding will be more likely to report exercising 30 minutes three times weekly.

Figure 5:

Predictors of outcomes experienced by individuals diagnosed with IDD (Research Model 1)

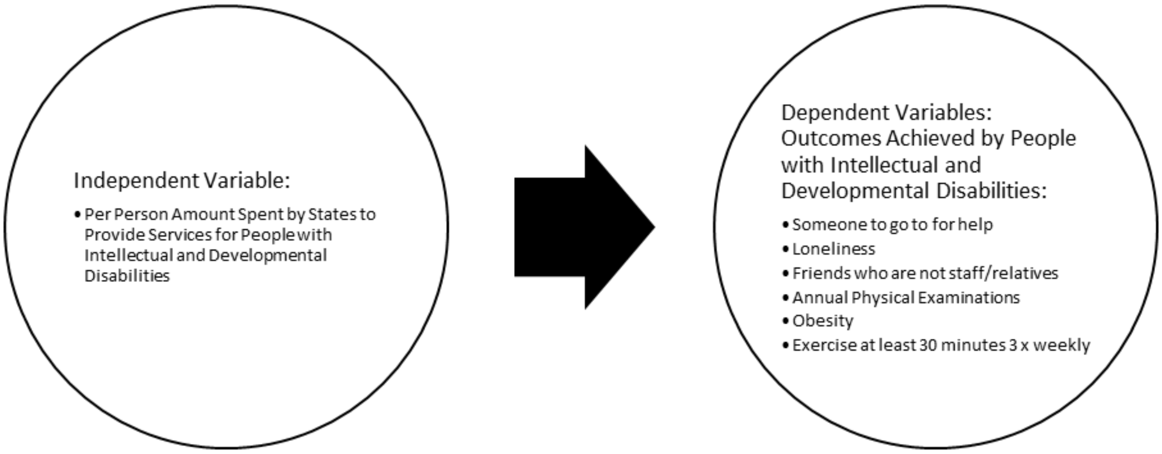
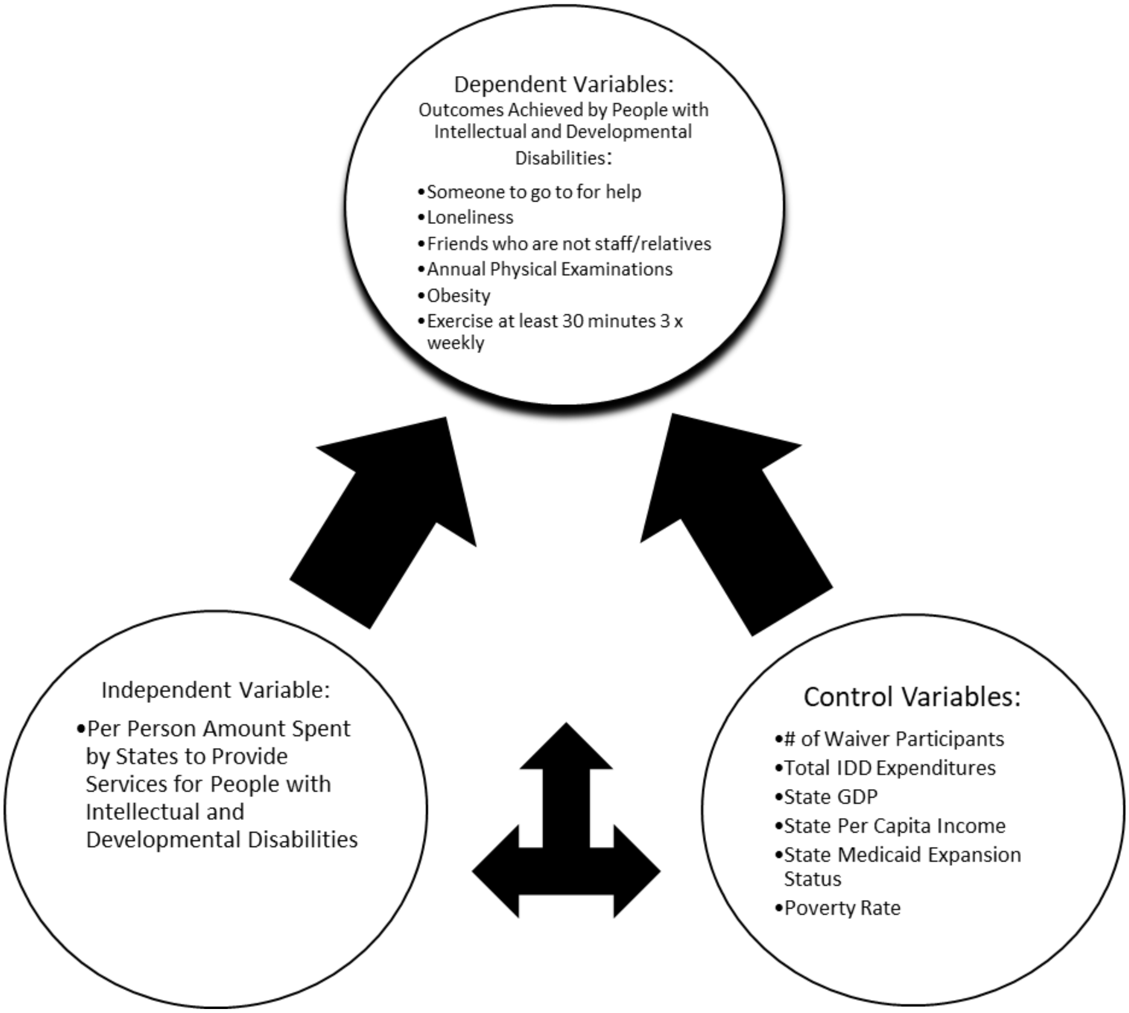


Figure 6:

Predictors of outcomes experienced by individuals diagnosed with IDD (Research Model 2)



The researcher relies on public sources due to the ethical considerations involved in directly studying individuals diagnosed with IDD and lack of access to the IDD population across states. The task was further confounded by limited reporting of public expenditures in the area of IDD spending. The researcher relies on data reported by the Coleman Institute for Cognitive Disabilities. The institute reported IDD per person spending data in the publication, The State of the State in Intellectual and Developmental Disabilities, during fiscal years 2011, 2013 and 2015.

The researcher was unable to obtain IDD per person spending data for years prior or subsequent to the reported period. The National Core Indicators produced by Human Service Research Institute data is limited to the states participating in the program during period concurrent with the data reported by the Coleman Institute for Cognitive Disabilities. The researcher was able to obtain data (N=72) for all variables except the dependent variable relating to exercise. For this variable, the researcher was able to identify a smaller sample size (N=57). The 15 entry difference is due to variations in states participating in the National Core Indicators during the limited review period. Although the sample size in both instances is less than 100, the researcher believes the study maintains merit and may be used to inform future studies of this nature.

Descriptive Statistics

Appendix C contains the dataset used for statistical analysis of independent variable. The first column indicates the year for which the data was collected. The second column lists the states and municipalities under review. The third column is a numerical representation of the average dollars spent per individual diagnosed with IDD. Appendix D contains the dataset used for statistical analysis of the five dependent variables. The first column indicates the year for which the data was collected. The second column lists the states and municipalities being reviewed. The third column reflects the outcomes experienced by individuals diagnosed with IDD as a percentage. Appendix E reports the same data for the sixth dependent variable. Appendix F contains the dataset for the covariables in fashion like that described for the independent and dependent variables. Appendix G describes descriptive statistics results for all variables including exercise.

The first independent variable, IDD Spending Per Person (N=72), reflects the averaged amount of fiscal resources states and municipalities allocate to fund services and supports for individuals diagnosed with IDD. The mean value of 51.03indicates states and municipalities spend a little more than $51,000 per person to fund services and supports for individuals diagnosed with IDD. The least amount of per person spending is 23.1 or $23,100 and maximum is 113.7 or $113,700. This indicates a variance of $90,600 between the state or municipality spending the least and most per person. The range is more noteworthy when you consider the minimum expenditure describes California, one of the most populous states while the maximum expenditure describes Delaware, one of the least populous states. The high standard deviation of 18.42, which is a measure of spread or how much the data set is spread about from the mean is consistent with the observed range of values described in the minimum and maximum. The observed spread is in part attributable to the inclusion of states or municipalities that had very different characteristics, e.g., population, demographics, economy, etc. for the year under review.

The first dependent variable, percent having someone to go for help if feeling scared (N=72), reflects the percentage of individuals diagnosed with IDD reporting having people or a social network to support them in the event they experience fear. The mean of 92.22 indicates 92 percent of individuals diagnosed with IDD report having someone to go to for help if they become afraid. The minimum reported for this variable was 84 percent while the maximum was 97 precent. The Standard deviation for this variable is 3.04.

The second dependent variable, feeling lonely (N=72), reflects the percentage of individuals diagnosed with IDD reporting a discrepancy between their desire for interpersonal relationships and actual existence of those relationships. The mean of 40 indicates 40 percent of individuals diagnosed with IDD are lonely. The minimum value of 27 percent is reported for Texas and the maximum value of 85 percent is recorded for Kentucky. These states significantly differ in both population and wealth. There is also a notable difference in seasonal changes and overall climate. The standard deviation for this variable is 8.02.

The third dependent variable, having friends who are not paid family or staff (N=72), reflects the percentage of individuals diagnosed with IDD reporting meaningful relationships with individuals who are not compensated caregivers or family members. The mean of 76.15 indicates overall 76 percent of individuals diagnosed with IDD reported maintaining relationships with people that are not paid staff or family members. Kentucky reported the minimum for this variable at 50 percent while the maximum is 91 percent for New Hampshire. The standard deviation for this variable is 7.15.

The fourth dependent variable, having a physical exam within the past year (N=72), reflects the percentage of individuals diagnosed with IDD that receive at a minimum an annual physical examination. The mean of 89.36 indicates 89 percent of individuals diagnosed with IDD report receiving an annual physical examination. The minimum reported for this variable is 61 precent and the maximum is 98 percent. The standard deviation for this variable is 6.93.

The fifth dependent variable, overweight or obese (N=72), reflects the percentage of individuals diagnosed with IDD who have Body Mass Indexes (BMI) that are considered overweight or obese. The mean of 62.58 indicates 63 percent of individuals diagnosed with IDD are reported to be overweight or obese. The minimum of 48 percent was recorded for Florida and the maximum of 74 was recorded for South Dakota. These states significantly differ in both population and wealth. There is also a notable difference in seasonal changes and general climate. The standard deviation for this variable is 5.10.

The sixth dependent variable, exercise at least 30 minutes three times weekly (N= 57), reflects the percentage of individuals diagnosed with IDD residing in states or municipalities reviewed in this study reporting at least 30 minutes of exercise no less than three times weekly. The mean of 22.64 indicates 23 precent of individuals diagnosed with IDD reported exercising at least 30 minutes three times weekly. The minimum of 0 percent was recorded for Florida and 42 percent was recorded for Wisconsin. The 0 percent reported for Florida is unlikely and may be an aberration or error in the National Core Indicators data. The descriptive statistics table reflecting the analysis of the dependent variable relating to exercise and other variables is located in Appendix E.

The first control variable, number of waiver participants, reflects the number of individuals diagnosed with IDD within a state or municipality receiving services and supports funded through a Medicaid waiver program. As described earlier in chapter two, Medicaid waivers allow states to waive some Medicaid program requirements to allow for the funding of services that would not normally be covered by the program. The mean of 16917.05 indicates on average a state or municipality reported 16,917 individuals receiving services and supports through a Medicaid waiver program. The minimum of 1,041 Medicaid waiver participants was reported by Delaware and the maximum of 116,232 participants was reported by California.

The second control variable, total IDD expenditure, reflects the total dollars spent by a state or municipality to fund supports and services to individuals diagnosed with IDD. The mean of 1171.66 indicates on average states and municipalities spent $1.172 billion to fund services and supports for individuals diagnosed with IDD. The minimum was reported for Mississippi with $88.5 million in expenditures and the maximum of $10.23 billion was reported for North Carolina.

The third control variable, gross domestic product, reflects the annualized total value of goods produced and services provided within a state or municipality. The mean of 433310.61

indicates states or municipalities average gross domestic product was $433,310,610,000. The minimum of $30.9 million was reported for Vermont and the maximum of $2.496 trillion was reported for California.

The fourth control variable, per capita income, reflects the average amount of money earned by individuals residing in a state. The mean of 45117 indicates residents of states or municipalities included in this study earned an average of $47,177. The minimum of $34,222 was reported for Mississippi and the maximum of $74,352 was reported for the District of Columbia.

The fifth control variable, Medicaid expansion, describes whether a state or municipality had decided to accept Federal funding to expand Medicaid access. The researcher assigned values to expansion status of 1.00 to indicate in 2015 a state had decided to expand Medicaid and 2.00 indicating a state had not decided to expand Medicaid. The mean of 1.76 is consistent with a visual review of the data available in Appendix E

The sixth control variable, poverty rate, reflects the percentage of individuals within a state with incomes at or below the federal poverty level. The mean of 14.06 reflects on average 14 percent of individuals within the states and municipalities included in this study had incomes at or below the federal poverty level. The minimum of 5.5 percent poverty was reported for New Hampshire and a maximum of 22 percent was reported for Kentucky.

Table 1. Descriptive Statistics All Variables Excluding Exercise

Variables	N	Mean	Std. Dev.	Min	Max
IDD Spending Per Person ($1,000)	72	51.0375	18.418242	23.1	113.7
Percent having someone to go to for help if feeling scared	72	92.222222	3.036038	84	97
Percent feeling lonely	72	40	8.02461	27	85
Percent reporting having friends who are not paid staff or family	72	76.152777	7.153566	50	91
Percent having physical exam in the past year	72	89.361111	6.926791	61	98
Percent overweight or obese	72	62.583333	5.095565	48	74
Number of Waiver Participants	72	16917.06944	19464.212	1041	116232
Total IDD Expenditure (millions of dollars)	72	1171.656944	1665.1576	88.5	10230
GDP (millions of dollars)	72	433310.6111	435204.53	30933	2479556
Per Capita Income (dollars)	72	45117	7945.2661	34222	74352
Medicaid Expansion Status (Y=1, N=2)	72	1.763888	0.427671	1	2
Poverty Rate (percent of people in poverty)	72	14.061111	3.492993	5.5	22

Bivariate Correlation Analysis

Table 2 describes the correlation between all variables excluding the dependent variable relating to exercise (N=72). A second table located in Appendix H describes the correlation between the dependent variable relating to exercise and all other variables (N=57). A score of 1.00 would be a perfect correlation. Scores of .50 or greater would suggest a strong correlation while scores of .30 to .49 would be considered a moderate correlation. Positive correlation suggests that as one variable increases, so does the other. Negative correlation suggests that as one variable increases, the other decreases. Significance, denoted by "p," will be indicated by asterisks. One asterisk indicates p<.10. Two asterisks indicate p<.05. Three asterisks indicate p<.01.

A moderate significant correlation (0.34*) is observed between the dependent variable, individuals diagnosed with IDD reporting having friends who are not paid staff or family, and the dependent variable, individuals diagnosed with IDD reporting having someone to go to for help when feeling scared. It would stand to reason that if these individuals have natural supports, people who are genuinely concerned about the person without a tie by blood or money, these people would be available to offer comfort when an individual diagnosed with IDD is feeling fear.

A moderate significant negative correlation (-0.36*) exists between the dependent variable, individuals diagnosed with IDD reporting having friends who are not paid staff or family, and the dependent variable, individuals diagnosed with IDD reporting feelings of loneliness. One would reason this relationship exists because natural supports, described in the previous paragraph, maintain relationships with the individual diagnosed with IDD and would be available to that person reducing the likelihood he or she would experience loneliness.

A statistically significant weak correlation (0.20***) exists between the dependent variable, individuals diagnosed with IDD experiencing obesity or being overweight, and the dependent variable, individuals diagnosed with IDD reporting loneliness. This correlation may be indicative of lonely people being less active resulting in obesity. It may also suggest that obese people experience social stigma and isolation resulting in feelings of loneliness.

A statistically significant weak negative correlation (-0.20***) exists for the dependent variable, individuals diagnosed with IDD experiencing obesity or overweight, and the dependent variable, individuals diagnosed with IDD having a physical exam in the last year. The correlation suggests that individuals diagnosed with IDD receiving routine medical care are less likely to be overweight. The relationship may also suggest that individuals diagnosed with IDD experiencing obesity have other health issues that encourage annual physical examinations.

A statistically significant weak negative correlation (-0.29**) exists between the covariable, number of Medicaid waiver participants, and the dependent variable, individuals diagnosed with IDD experiencing obesity or overweight. The correlation suggests that as more individuals receive Medicaid waiver services, fewer report obesity. Medicaid, a health insurance, is necessary to receive waiver funded services. The correlation implies access to Medicaid may improve overall health for individuals diagnosed with IDD resulting in a reduced incidence of obesity.

A statistically significant moderate negative correlation (-0.31**) exists between the covariable, total IDD expenditures, and the dependent variable individuals diagnosed with IDD experiencing obesity and overweight. The correlation suggests that as funding for IDD services increases individuals diagnosed with IDD are less likely to be obese or overweight. This may be due to the IDD expenditures being used to purchase services that increase activity or improve a person's overall condition reducing the incidence of obesity or overweight.

A statistically significant weak negative correlation (-0.29**) exists between the covariable, state or municipality gross domestic product, and the dependent variable, individuals diagnosed with IDD experiencing obesity and overweight. The correlation indicates as states wealth increases, individuals diagnosed with IDD are less likely to be overweight or obese. Other studies have found that obesity and wealth are related because of greater access to healthcare and ability to fund needed services.

A statistically significant weak negative correlation (-0.22***) exists between the covariable, state or municipality per capita income and individuals diagnosed with IDD reporting having someone to go to for help if feeling scared. The correlation suggests as wealth increases, individuals diagnosed with IDD are less likely to report experiencing fear. This relationship may be explained by the improved certainty one experiences as they acquire wealth which could result in improved capacity to access safe housing and fund needed services.

A statically significant moderate negative correlation (-0.33**) exists between the covariable, state or municipality per capita income and individuals diagnosed with IDD reporting loneliness. The correlation indicates as wealth increase, individuals diagnosed with IDD are less likely to experience loneliness. This relationship may be indicative of the increased access to resources that may be utilized toward recreation and other community-based activities thereby increasing the person's access to other people and reducing feelings of loneliness.

A statistically significant weak positive correlation (0.25**) exists between the covariable state or municipality per capita income and the covariable state or municipality gross domestic product. The correlation demonstrates as would be generally expected that if state or municipality revenue from goods and services increase, personal wealth of the residents of the state or municipality will also increase.

A statistically significant weak positive correlation (0.29**) is evident between the covariable, state Medicaid expansion status, and dependent variable, IDD per person spending. The correlation suggests that as funding allocations for individuals diagnosed with IDD increases due to the cost of services and factors unique to their region, states and municipalities may be increasingly willing to expand Medicaid accepting the funding match offered by the federal government to offset costs incurred.

A statistically significant weak positive correlation (0.21***) exists between the covariable, state or municipality poverty rate, and the dependent variable, individuals diagnosed with IDD experiencing obesity or overweight. The relationship is expected due to the breadth of information regarding the incidence of obesity among people experiencing poverty due to lack of access and education about nutrition.

A statistically significant weak positive correlation (0.29**) exists between the covariable state or municipality poverty rate, and the covariable Medicaid expansion status. The correlation may be related to states with high rates of poverty being more willing to consider the financial benefits offered through Medicaid expansion.

A statistically significant weak negative correlation (-0.29**) exists between individuals diagnosed with IDD reporting exercise at least 30 minutes three times weekly and the independent variable, state and municipality IDD spending. The correlation suggests that as individuals are afforded increased IDD funding, they are more likely to exercise. This may be due to exercise being an activity encouraged by state and municipality funders which encourages providers of services to individuals diagnosed with IDD to ensure the activity occurs.

A statistically significant weak positive correlation (0.26***) exists between the dependent variable, individuals diagnosed with IDD reporting exercise at least 30 minutes three times weekly, and the dependent variable, individuals diagnosed with IDD having a physical exam in the last year. The correlation suggests that individuals diagnosed with IDD that receive annual physicals are more likely to exercise. This behavior may be related to instructions given by physicians aimed at mitigating adverse health conditions or obesity.

Table 2. Bivariate Correlations: Dependent, Independent and Control Variables Excluding Exercise (N=72)

	Variable	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*
1	**IDD Spending Per Person ($1,000)**	1											
2	**Percent having someone to go to for help if feeling scared**	0.01	1										
3	**Percent feeling lonely**	-0.13	-0.19	1									
4	**Percent reporting having friends who are not paid staff or family**	-0.01	0.34*	-0.36*	1								
5	**Percent having physical exam in the past year**	0.03	0.16	-0.00	0.13	1							
6	**Percent overweight or obese**	0.09	-0.03	0.20***	-0.07	-0.20***	1						
7	**Number of Waiver Participants**	-0.09	0.02	-0.10	-0.07	-0.02	-0.29**	1					
8	**Total IDD Expenditure (millions of dollars)**	0.12	0.05	-0.09	-0.07	0.02	-0.31**	0.89	1				
9	**GDP (millions of dollars)**	-0.14	-0.18	-0.19	-0.11	0.03	-0.29**	0.78	0.59	1			
10	**Per Capita Income (dollars)**	0.51	-0.22***	-0.33**	-0.03	-0.07	-0.07	0.14	0.20	0.25**	1		
11	**Medicaid Expansion Status (Y=1, N=2)**	-0.29**	0.08	0.19	0.18	0.17	-0.08	-0.02	-0.09	-0.08	-0.51	1	
12	**Poverty Rate (percent of people in poverty)**	-0.18	0.09	0.19	-0.18	-0.04	0.21***	0.11	0.04	0.09	-0.51	0.29**	1

* p<.10, ** p<.05, ***p<.01

Regression Analysis

Linear regression produces several useful outputs. Appendix I contains the table describing the summary output regression statistics by dependent variables for models 1 and 2. The researcher will review the Pearson R and the coefficient of determination (R Square) to determine goodness of fit between variables. The Pearson R describes the strength and direction of relationships between variables with scores ranging from -1.00 to 1.00. A score close to zero suggests a weak relationship while scores near -1.00 and 1.00 are considered stronger relationships. The coefficient of determination statistic allows the researcher to identify how much of the variability observed in the dependent variable can be attributed to the variability observed in the independent variable(s). It describes the percentage of observed points that fall within the regression line and how well the model fits the observed data. The higher the coefficient the better the fit. The researcher will evaluate the Significance F produced by ANOVA. This statistic is indicative of associated risk and reveals the probability that a null hypothesis in a regression model cannot be rejected. For the purposes of our study, the Significance F statistic must be less than .10. Beta will be considered. This variable reflects the degree of change in the dependent variable for every one-unit increase of the independent variable. Values range from 0-1 with higher values indicating stronger associations between variables. Finally, the standard error will be reviewed. This statistic indicates how different the population mean is from the sample mean. Smaller values indicate less spread denoting the sample population means are close.

Individuals diagnosed with IDD reporting having someone to go to for help if they feel scared

Table 3 describes the analysis the hypothesis related to the dependent variable, individuals report having someone to go to for help if they feel scared. Model 1 demonstrates an analysis of the relationship between the independent variable, IDD spending per person, and dependent variable, individuals diagnosed with IDD reporting having someone to go to for help if they feel scared. The analysis produced a Pearson R of 0.01, a weak relationship and a correlation coefficient (R Square) of 0.00 suggesting none of the observed variance in the dependent variable can be attributed to IDD spending per person. The Beta value of 0.00 is consistent with the Pearson R denoting no relationship between the dependent and independent variables. Further, the Significance F of 0.92 exceeds the 0.10 level of acceptable risk. Therefore, this model is rejected, and the researcher accepts the null hypothesis.

Model 2 demonstrates an analysis of the relationship between the independent and dependent variables studied in Model 1 and the six control variables. When the control variables are included, the Pearson R improves to 0.37 which reflects a weak to moderate relationship between all variables. The R Square improves to report 14 percent of the observed variance in the proportion of individuals diagnosed with IDD reporting having someone to go to for help if they feel scared is related to IDD spending and the control variables. Of the independent and covariables reviewed, with the exception of gross domestic product, all had Beta results at or near zero. The value of the gross domestic product covariable exceeded 1.00 casting doubt on the reliability of statistic. The covariable produced a p-value of 0.06 indicating a statistically significant relationship between it and the dependent variable that is not likely due to random effects. The Model produces a Significance F of 0.20 which is above the less than 0.10 maximum level of acceptable risk. Were this model a hypothesis, the null would be accepted indicating there is no relationship between all the variables under review.

Table 3. Regression Analysis: Dependent Variable: Feeling Scared (N=72)

	Spending Model 1 ß	Spending & Covariables Model 2 ß
Spending (R^2 0.0001)		
IDD Spending	0.00(0.02)	
Spending & Covariables (R^2 0.1365)		
IDD Spending Per Person ($1,000)		0.02 (0.03)
# of Waiver Participants		0.00 (0.00)
Total IDD Expenditure (millions of dollars)		0.00 (0.00)
GDP (millions of dollars)		-2.86 (1.48)*
Per Capita Income (dollars)		0.00 (0.00)
Medicaid Expansion Y=1 N=2		-0.28 (0.96)
Poverty Rate (percent of people in poverty)		-0.03 (0.12)

*p<.10, **p<.05, ***p<.01
Standard Error is denoted by parenthesis
Note R^2 is the variance explained by block

Individuals diagnosed with IDD reporting loneliness

Table 4 describes the analysis the hypothesis related to the dependent variable; individuals diagnosed with IDD reporting loneliness. Model 1 demonstrates an analysis of the relationship between independent variable, IDD spending per person and dependent variable, individuals diagnosed with IDD reporting loneliness. The analysis produced a Pearson R of 0.13 suggesting a weak relationship between the variables. The R Square is 0.02 suggests almost none of the observed variance in the dependent variable can be attributed to the independent variable. The Beta value of -0.06 is consistent with the Pearson R indicating a weak relationship between the independent and dependent variables. The Model produced a Significance F of 0.28 which is well beyond the less than 0.10 level of acceptable risk. Therefore, this model is rejected, and the null hypothesis accepted.

Model 2 describes an analysis of the relationship between independent and dependent variables described in Model 1 and the six control variables. The Pearson R improves to 0.36 which reflects a relatively weak relationship between all variables. The R Square improves to reflect 13 percent of the observed variance in the dependent variable is related to the independent variable and the control variables. The Beta values, with the exception of the covariables Medicaid expansion status and gross domestic product, are all at or near zero indicating a weak relationship between the independent, dependent and covariables. The model produced a Significance F of 0.24 which exceeds the less than 0.10 maximum level of acceptable statistical risk. Therefore, were this model a hypothesis, the null would be accepted.

Table 4. Regression Analysis: Dependent Variable: Loneliness (N=72)

	Spending Model 1 ß	Spending & Covariables Model 2 ß
Spending (R^2 0.0167)		
IDD Spending	-0.06 (0.05)	
Spending & Covariables (R^2 0.1279)		
IDD Spending Per Person ($1,000)		0.00 (0.07)
# of Waiver Participants		0.00 (0.00)
Total IDD Expenditure (millions of dollars)		0.00 (0.00)
GDP (millions of dollars)		-4.00 (3.94)
Per Capita Income (dollars)		0.00 (0.00)
Medicaid Expansion Y=1 N=2		0.73 (2.56)
Poverty Rate (percent of people in poverty)		0.16 (0.33)

*p<.10, **p<.05, ***p<.01
Standard Error is denoted by parenthesis
Note R^2 is the variance explained by block

Individuals diagnosed with IDD reporting having friends who are not paid staff or family

Table 5 describes the analysis the hypothesis related to the dependent variable, individuals diagnosed with IDD reporting having friends who are not paid staff or family. Model 1 demonstrates an analysis of the relationship between the independent variable, IDD spending per person, and dependent variable, individuals diagnosed with IDD reporting having friends who are not paid staff or family. The analysis produced a Pearson R of 0.01 suggesting a minimal relationship between the variables. The R Square is 0.00 suggesting none of the observed variance in the dependent variable can be attributed to the dependent variable. The reported Beta of 0.00 also indicates a weak relationship. The model produced a Significance F of 0.94 which is well beyond the 0.10 level of acceptable risk. Therefore, this model is rejected, and the null hypothesis accepted.

Model 2 demonstrates an analysis of the relationship between variables reviewed in Model 1 and the six control variables. When the control variables are included, the Pearson R improves to 0.32 which reflects weak to moderately strong relationship between all variables. The R Square improves to indicate 10 percent of the observed variance in the dependent variable, individuals diagnosed with IDD reporting having someone to go to for help if they feel scared, is related to the dependent variable, IDD per person spending, and the control variables. The model produced a Significance F of 0.42 which is above the less than 0.10 maximum level of acceptable risk and indicates were this model related to a hypothesis, the null would still be accepted. The covariables, Medicaid expansion status and poverty rate, produced statistically significant p-values. The Medicaid expansion status covariable produced a Beta of 4.01 which exceeds the typical range of 0-1 for the statistic. The covariable, poverty rate, produced a Beta of -0.55 which suggests a moderate association with the dependent variable. Both covariables, Medicaid expansion status and poverty rate, produced p-values less than 0.10 suggesting the associations observed are likely not random.

Table 5. Regression Analysis: Dependent Variable: Friends (N=72)

	Spending Model 1 ß	Spending & Covariables Model 2 ß
Spending (R^2 0.0001)		
IDD Spending	0.00(0.05)	
Spending & Covariables (R^2 0.1007)		
IDD Spending Per Person ($1,000)		0.02 (0.06)
# of Waiver Participants		0.00 (0.00)
Total IDD Expenditure (millions of dollars)		0.00 (0.00)
GDP (millions of dollars)		-1.57 (3.57)
Per Capita Income (dollars)		0.00 (0.00)
Medicaid Expansion Y=1 N=2		4.01 (2.32)*
Poverty Rate (percent of people in poverty)		-0.55 (0.30)*

*p<.10, **p<.05, ***p<.01
Standard Error is denoted by parenthesis
Note R^2 is the variance explained by block

Individuals diagnosed with IDD reporting receiving annual health examinations

Table 6 describes the analysis the hypothesis related to the dependent variable; individuals diagnosed with IDD reporting receiving annual health examinations. Model 1 demonstrates an analysis of the relationship between the independent variable, IDD spending per person, and the dependent variable, proportion of individuals diagnosed with IDD reporting receiving annual health examinations. The analysis produced a Pearson R of 0.32 suggesting a weak to moderate relationship between the independent and dependent variables. The R Square is 0.00 indicating none of the observed variance in the dependent variable can be attributed to variance observed in the independent variable. The Beta of 0.01 describes a weak relationship between variables. The Significance F of 0.79 is well beyond the less than 0.10 level of acceptable risk. Therefore, the null hypothesis is accepted.

The second model describes an analysis of the relationship between the variables reviewed in Model 1 and the six control variables. The Pearson R worsens to 0.29 which reflects a weak relationship between all variables. The R Square improves to reflect 8 percent of the observed variance in individuals diagnosed with IDD reporting receiving annual health examinations is related to IDD per person spending and the control variables. The model produced multiple Beta that were near or at 0.00 indicating little to no relationship between the variables. The model also produced Beta values that exceed the expected range of 0-1. The model produced a Significance F of reported as 0.55 which is well above the less than 0.10 level if acceptable risk. Were this model a hypothesis, the null hypothesis would be accepted.

Table 6. Regression Analysis: Dependent Variable: Annual Health Examination (N=72)

	Spending Model 1 ß	Spending & Covariables Model 2 ß
Spending (R^2 0.0010)		
IDD Spending	0.01(0.04)	
Spending & Covariables (R^2 0.1365)		
IDD Spending Per Person ($1,000)		0.04 (0.06)
# of Waiver Participants		0.00 (0.00)
Total IDD Expenditure (millions of dollars)		0.00 (0.00)
GDP (millions of dollars)		4.98 (3.48)
Per Capita Income (dollars)		0.00 (0.00)
Medicaid Expansion Y=1 N=2		3.36 (2.26)
Poverty Rate (percent of people in poverty)		-3.32 (0.29)

*p<.10, **p<.05, ***p<.01
Standard Error is denoted by parenthesis
Note R^2 is the variance explained by block

Individuals diagnosed with IDD reported to be overweight or obese

Table 7 describes the analysis the hypothesis related to the dependent variable, individuals diagnosed with IDD reported to be overweight or obese. Model 1 provides an analysis of the relationship between the independent variable, IDD spending per person, and dependent variable, individuals diagnosed with IDD reported to be overweight or obese. The analysis produced a Pearson R of 0.09 suggesting a weak relationship between the variables. The R Square is 0.01 suggests only one percent of the variance observed in the dependent variable can be attributed to variance in the independent variable. The model produced a Beta of 0.01 indicating a minimal relationship between the independent and dependent variables. The *Significance F* is 0.44, which is well beyond the less than 0.10 level of acceptable risk. Therefore, the null hypothesis is accepted.

Model 2 demonstrates an analysis of the relationship between the variables reviewed in Model 1 and the six control variables. When the control variables are included, the Pearson R improves to 0.47 which reflects a moderately strong relationship between all variables. The R Square improves to report 23 percent of the observed variance observed in the dependent variable is attributable to the independent variable. With the exception of the covariables Medicaid expansion status and poverty rate, the model produced Beta values at or near 0.00 suggesting little to no association between variables. The covariable Medicaid expansion status produced a value of -2.04 which exceeds the expected values for the statistic. The covariable poverty rate, produced a value of 0.49 indicating a moderate to strong association between it and the dependent variable. Further, the covariable produced a p-value of 0.02 which is statistically significant and tells us the result is not likely due to chance. The model produced a Significance F of 0.02 which is well below the less than 0.10 maximum level of acceptable risk. Were this model a hypothesis, the null hypothesis would be rejected in favor of the alternative hypothesis.

Table 7. Regression Analysis: Dependent Variable: Obesity (N=72)

	Spending Model 1 ß	Spending & Covariables Model 2 ß
Spending (R^2 0.0083)		
IDD Spending	0.03 (0.03)	
Spending & Covariables (R^2 0.2303)		
IDD Spending Per Person ($1,000)		0.03 (0.04)
# of Waiver Participants		0.00 (0.00)
Total IDD Expenditure (millions of dollars)		0.00 (0.00)
GDP (millions of dollars)		0.00 (2.34)
Per Capita Income (dollars)		0.00 (0.00)
Medicaid Expansion Y=1 N=2		-2.04 (1.53)
Poverty Rate (percent of people in poverty)		0.49 (0.20)**

*p<.10, **p<.05, ***p<.01
Standard Error is denoted by parenthesis
Note R^2 is the variance explained by block

Individuals diagnosed with IDD reporting exercise 30 minutes three times weekly

Table 8 describes the analysis the hypothesis related to the dependent variable; individuals diagnosed with IDD reporting exercise 30 minutes three times weekly. Model 1 provides an analysis of the relationship between the independent variable, IDD spending per person, and dependent variable, individuals diagnosed with IDD reporting exercise 30 minutes three times weekly. The analysis produced a Pearson R of 0.29 which suggests weak to moderate relationship between the variables. The R Square indicates 9 percent of the variance observed in the dependent variable can be attributed to variation in the independent variable. The model produced a Beta of -0.13 which indicates a weak association between the variables. The model produced a Significance F of 0.03, which is well below the less than 0.10 level of acceptable risk. Therefore, the null hypothesis is rejected in favor of the alternative hypothesis.

Model 2 demonstrates an analysis of the relationship between the variables considered in Model 1 and the six control variables. When the control variables are included, the Pearson R improves slightly to 0.38 which reflects a moderately strong relationship between all variables.

The R Square improves to report 15 percent of the observed variance in the dependent variable is attributable to the independent variable. With the exception of the covariables gross domestic product and Medicaid expansion status, the model produced Betas at or near 0.00 suggesting minimal association between the covariables and the dependent variable. The covariable poverty rate produced a relatively strong Beta value of -0.63. The covariables, gross domestic product and Medicaid expansion status, produced Beta statistics that exceed expected values. The model produced a Significance F of 0.31 which is well above the less than 0.10 maximum level of acceptable risk. Were this model a hypothesis, the null hypothesis would be accepted.

Table 8. Regression Analysis: Dependent Variable: Exercise (N=57)

	Spending Model 1 ß	Spending & Covariables Model 2 ß
Spending (R^2 0.0856)		
IDD Spending	-0.13 (0.06)**	
Spending & Covariables (R^2 0.1477)		
IDD Spending Per Person ($1,000)		-0.14 (0.09)
# of Waiver Participants		0.00 (0.00)
Total IDD Expenditure (millions of dollars)		0.00 (0.00)
GDP (millions of dollars)		3.11 (4.56)
Per Capita Income (dollars)		0.00 (0.00)
Medicaid Expansion Y=1 N=2		-1.23 (2.98)
Poverty Rate (percent of people in poverty)		-0.63 (0.41)

*p<.10, **p<.05, ***p<.01
Standard Error is denoted by parenthesis
Note R^2 is the variance explained by block

In summary, statistical significance was only found for the sixth alternative hypothesis demonstrating a relationship between IDD per person spending and individuals diagnosed with IDD reporting exercise 30 minutes three times weekly. This finding is an original contribution to literature and offers valuable insight into the relationship between state and municipality spending to fund services and outcomes achieved by individuals diagnosed with IDD. All other alternative hypotheses were rejected in favor of the null hypotheses. Other relationships were found in the data. Specifically, statistically significant relationships between (1) the dependent variable, individuals diagnosed with IDD reporting having someone to go to for help if they feel scared, and the covariable, gross domestic product. (2) the dependent variable, individuals diagnosed with IDD reporting having friends who are not paid staff or family, and the covariable, Medicaid expansion status, (3) the dependent variable, individuals diagnosed with IDD reporting having friends who are not paid staff or family, and the covariable, poverty rate, and (4) the dependent variable, individuals diagnosed with IDD reported to be overweight or obese, and the covariable, poverty rate. Finally, the study found that the relationship between the independent variable, IDD and per person spending, the dependent variable, individuals diagnosed with IDD reported to be overweight or obese, and the covariables produced a result indicating 47 percent of the observed variation in the dependent variable was attributable to the independent variable and covariables.

Chapter V

CONCLUSION

Advocates for IDD services and supports have historically and consistently called for increased funding allocations. Advocates claim increased funding will produce better outcomes for the affected population. These claims are related to service provider's assertions Medicaid's reimbursement rates are much less than the actual cost of providing care and adversely impacts outcomes attained by individuals diagnosed with IDD (Walker & Osterhaus, 2010). Unfortunately, the researcher found a dearth of information available to address the research question. The researcher found no comparable studies linking quality of life outcomes, described in this study as dependent variables, to economic factors, described in this research as the independent variable and covariables. The lack of research means there are no preexisting data to which the researcher may compare the results of this study. Therefore, the researcher will utilize this chapter to discuss the study findings, make inferences about what those findings may suggest, address the study limitations, and propose future research.

Summary of Findings

The hypotheses are concerned with determining whether fiscal resources allocated to purchase supports and services for individuals diagnosed with IDD will produce a calculable impact on outcomes achieved by the group members. The first hypothesis sought to determine whether spending to purchase supports and services for individuals diagnosed with IDD is related to how often individuals report having someone to go to for help if they feel scared. The analysis produced results indicating no measurable relationship or significance. When the economic covariables were added, the outcome remained essentially unchanged. The results suggest that funding for services and supports are not quantifiably correlated to individuals diagnosed with IDD reporting they have someone to go to for help if they feel scared.

The second hypothesis sought to identify whether a relationship exists between funding to purchase supports and services for individuals diagnosed with IDD and these individuals reporting loneliness. The analysis did not find a relationship and the addition of economic covariables did not improve the results. The results suggest funding is not related to individuals diagnosed with IDD reporting loneliness.

The third hypothesis sought to determine whether a relationship exists between funding to purchase supports and services for individuals diagnosed with IDD and these individuals reporting having friends who are not paid staff or family. The analysis did not find a relationship and when the covariables were added, the results remained essentially the same. The results suggests funding is not related whether individuals diagnosed with IDD report friends who are not paid staff or family.

The fourth hypothesis sought to identify whether a relationship exists between funding to purchase supports and services for individuals diagnosed with IDD and these individuals reporting receipt of annual health examinations. The analysis did not find a relationship between the variables. When the covariables were added, the results did not significantly change. The results suggest funding is not related to individuals diagnosed with IDD reporting access to annual health examinations.

The fifth hypothesis considers whether a relationship exists between funding to purchase supports and services for individuals diagnosed with IDD results in these individuals reporting being overweight or obese. The analysis did not find a significant relationship between the variables, but when the economic covariables were added a statistically significant result was attained suggesting that together the economic variables contribute to individuals diagnosed with IDD reporting obesity or being overweight. This finding is not entirely unexpected due to it being common knowledge that wealth and health are related, and economic factors affect obesity rates. Individuals diagnosed with IDD experience higher rates of poverty (Havercamp, Scandlin & Roth, 2004) and poverty is also associated with increased incidence of obesity (Levine, 2011).

The sixth and final hypothesis sought to determine whether funding to purchase supports and services is related to individuals diagnosed with IDD exercising at least 30 minutes three times weekly. The analysis found that these conditions are related. The researcher speculates the relationship may be due to state and municipality funders requiring day support providers to ensure individuals are exercising. The relationship may also be due to individuals diagnosed with IDD receiving health recommendations from healthcare providers that would normally not be available to the person were they not participating in a Medicaid waiver program. Adding the economic covariables worsened the results suggesting for this study the only economic factor contributing to the outcome is the amount of money spent per person to fund IDD services.

Recommendations

Only the sixth hypothesis, Individuals diagnosed with intellectual and developmental disabilities who receive publicly funded supports and services report limited opportunities to exercise 30 minutes three times weekly, but those individuals that receive greater funding will be more likely to report exercising 30 minutes three times weekly, was found to be true. The other five hypotheses were rejected in favor of their null hypotheses because they did not produce results indicating a significant relationship. This finding suggests that per person IDD spending does not in itself equate to desirable outcome achievement. These findings further challenge the existing status quo that essentially fund IDD services based on fee for service with categorically undifferentiated expectations regarding outcomes which in the case of this study could be considered return on investment.

Annually, billions of dollars are allocated to provide social service programs that are not empirically validated and ineffective (Peters, 2015). States and municipalities may wish to consider requiring service providers adopt evidence-based practices which require the identification of approaches that have been shown to produce desired outcomes which may be replicated and independently monitored to assure quality (McGrew, Johannesen, Griss, Born, & Katuin, 2007). The practice assumes and studies have generally confirmed that if a provider adopts an approach that has been proven effective, they should be able to replicate the results with the individuals they serve (McGrew & Griss, 2005). Many disciplines have adopted evidence-based practices; however, it is unclear whether application of the practice will be a viable option for the IDD population due to the wide-ranging presentation of disability and varied settings in which individuals receive services. Further, the services provided are akin to care in the case of individuals diagnosed with IDD care is inherently subjective and value driven which may when implemented look very different from case to case.

States and municipalities may elect to use Pay for Success which a targeted funding apparatus that would attach IDD funding to outcomes demonstrated by program participants. The Pay for Success program has been around since 2010 and was first adopted in a limited manner by the British government as a means of paying for outcomes achieved by education programs instead of services rendered (Golden, 2014). The program appeared in the United States in 2014 when the New York City implemented the strategy to fund programs aimed at reducing recidivism among juveniles (Golden, 2014). The Pay for Success approach requires the government or funder to identify quality indicators or outcomes for which funding will be attached. This approach hinges current or future funding on the achievement of the stipulated outcomes (Morrison, 2003). Benefits of this approach are unlike evidenced based practice in that it allows providers to be innovative in their efforts to achieve the desired outcomes (Morrison, 2003). Utilizing the Pay for Success approach does not require all funding received by a provider me delivered in this manner (Fox & Morris, 2021). If it were, the practice would not likely be a tenable because few providers have sufficient resources to front funding with a promise to pay for results that may or may not materialize.

Study Limitations

Due to ethical considerations and other challenges associated with conducting research with the population of individuals diagnosed with IDD, the researcher chose to use aggregated numerical data from credible secondary sources within the public realm that have a history of gathering and documenting information related to the study population. The use of secondary data means the study may be replicated, reanalyzed, or reinterpreted allowing peer or future researchers opportunities to test their own ideas, models and theories (Johnston, 2014). The researcher acknowledges aggregate data is generally less desirable due to a general loss of information when data is moved between micro to macro level evaluation (Clark & Avery, 1976). However, the data being utilized in this research is considered unique in that comparable resources are either unavailable or unidentifiable.

Employing secondary data, particularly in the area relating to the dependent variables allowed the researcher to access to a sample much larger than would typically be attainable using conventional methods and other resources at the researcher’s command. The larger sample will make the data more representative of the target population and in most instances allow greater validity and generalizability of the findings (Smith et al., 2008). Unfortunately, the data is analyzed in aggregate by year. Therefore, the sample size is directly related to the number of years of data available across all studied variables. The sample size is less than 100. Although not ideal, the sample represents the entirety of data points available from all sources that would produce a viable dataset. The sample was limited to the three years of reported IDD spending per individual reported by the Coleman Institute for Cognitive Disabilities. It was further limited by the varied participation of states in the National Core Indicators project produced by Human Services Research Institute. Ultimately, the sample size was limited to 72 for five of the six dependent variables. The sixth variable had a sample size of 57. Due to these limitations the results of the study will likely not be generalizable to the population of individuals diagnosed with IDD.

The method by which the data was collected, and its initial intended purpose may impact or influence how well the data relates to the research questions under review or how well the results of analysis will generate new knowledge (Doolan & Froelicher, 2009). Clearly, it is most desirable for researchers to participate in the data collection process and reliance on secondary data results in the researcher forfeiting some of his understanding of how well the data was collected and whether there were respondent problems that may impact data quality (Johnston, 2014). The researcher believes the data used is a good match to the research questions and employed a careful evaluation to avoid the limitations of using aggregated data from a secondary source.

Future Research

Research is currently hampered by state and federal government laws that in some instances prevent capable service providers from conducting research using individuals diagnosed with IDD as a studied population. It is suspected these laws may have been created as a deterrent in part due to the historic atrocities that were for decades systematically perpetrated against the population while states routinely housed these individuals in state run hospitals and other institutions. While the past is important, progress is needed if we are to better serve the IDD population.

Advocacy organizations are encouraged to work with state and federal entities to empower the IDD population to become advocates for inclusion in research. Efforts in this area would promote research while working to remove the stigma associated with studying the IDD population. A movement in this direction is feasible when one considers that grassroots efforts have essentially led to the closing of state-run hospitals and normalized the development of community-based supports and services for the population.

Research would benefit from improved transparency around fiscal reporting at both the state and federal level. Most states have public dashboards already in existence which could be utilized to report a variety of statistics about individual budgets, services and supports funded, and metrics used to determine how budgets are generated. Medicaid generally requires states using Medicaid waivers to conduct quality assurance activities with providers. The results of these activities could be shared in public dashboards to report data appropriate for research.

Unfortunately, individuals diagnosed with IDD are not usually considered appropriate participants for research due to communication challenges and difficulty understanding complex concepts. Research would benefit from providers partnering with state and federal organizations with the aim of empowering individuals diagnosed with IDD to self-promote their participation in studies about their care, needs and circumstance. Ideally, individuals diagnosed with IDD would be provided information in a manner that accommodates their preferred method of communication and learning style.

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Appendix A

Institutional Review Board Approval

Institutional Review Board (IRB)
For the Protection of Human Research Participants

PROTOCOL EXEMPTION REPORT

Protocol Number: 04024-2020 **Responsible Researcher:** Timothy Coons

Supervising Faculty: Dr. Diane Holliman

Project Title: *Analysis of the Relationship between Spending Per Person Outcomes Achieved by Intellectually and Developmentally Disabled Americans.*

INSTITUTIONAL REVIEW BOARD DETERMINATION:

This research protocol is **Exempt** from Institutional Review Board (IRB) oversight under Exemption **Category 4**. Your research study may begin immediately. If the nature of the research project changes such that exemption criteria may no longer apply, please consult with the IRB Administrator (irb@valdosta.edu) before continuing your research.

ADDITIONAL COMMENTS:

- *Upon completion of this research study all data must be securely maintained (locked file cabinet, password protected computer, etc.) and accessible only by the researcher for a minimum of 3 years.*

☒ ***If this box is checked, please submit any documents you revise to the IRB Administrator at irb@valdosta.edu to ensure an updated record of your exemption.***

Elizabeth Ann Olphie 03.31.2020
Elizabeth Ann Olphie, IRB Administrator

Thank you for submitting an IRB application.
Please direct questions to irb@valdosta.edu or 229-253-2947.

Revised: 06.02.16

Appendix B:

National Core Indicators (NCI) Demographic Data by Year

NCI Demographic Data for Year 2011: Age

State	**Mean**	**Min**	**Max**	**SD**	**Median**	**N**
AL	46	18	87	14	47	436
AR	39	18	77	15	37	396
AZ	37	18	84	15	33	394
CT	44	18	86	16	44	402
GA	40	18	80	13	38	547
HI	44	19	89	16	42	434
IL	42	20	87	14	42	357
KY	42	19	82	14	42	474
LA	40	18	78	14	39	429
MA	47	19	89	15	47	503
ME	46	20	94	16	44	347
MEORC	46	19	90	17	47	387
MI	44	18	88	15	45	422
MO	45	19	87	15	45	501
NC	40	18	91	15	38	931
NJ	47	22	24	12	48	431
NY	45	18	101	16	46	2584
OH	43	19	93	15	43	462
PA	44	18	92	16	44	1253
SC	44	21	88	14	44	407
NCI Average	**43**	**19**	**84**	**15**	**44**	**12097**

Note. Data compiled from National Core Indicators (2013)

NCI Demographic Data for Year 2011: Race

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Other Race Not Listed	Two or More Races	Don't Know	N
AL	0	0	38	0	61	1	1	0	434
AR	1	1	21	0	77	1	1	0	396
AZ	8	1	5	0	76	6	0	4	390
CT	1	1	13	0	78	4	0	3	399
GA	0	1	47	0	51	1	0	0	544
HI	1	43	1	18	16	3	18	1	434
IL	1	2	22	0	73	2	1	1	357
KY	0	0	13	0	84	1	1	0	472
LA	1	1	39	0	58	1	0	0	430
MA	0	1	6	0	89	2	0	1	503
ME	2	1	0	0	97	0	0	0	348
MEORC	1	1	3	0	94	0	0	2	384
MI	1	1	19	0	75	3	1	1	421
MO	0	0	14	0	84	1	0	0	502
NC	1	1	36	0	60	1	1	0	930
NJ	0	1	22	0	71	3	1	1	431
NY	1	1	17	0	70	7	1	3	2585
OH	0	0	13	0	84	2	0	0	462
PA	1	1	7	0	90	1	0	1	1239
SC	0	0	48	0	52	0	0	1	409
NCI Average	**1**	**3**	**19**	**1**	**72**	**2**	**1**	**1**	**12070**

Note. Data compiled from National Core Indicators (2013)

NCI Demographic Data for Year 2011: Level of Intellectual Disability

State	No ID	Mild	Moderate	Severe	Profound	Unspecified	Unknown	N
AL	0	21	32	15	32	0	0	435
AR	6	29	27	16	20	1	1	394
AZ	8	39	35	12	3	2	2	392
CT	1	41	33	14	11	0	1	402
GA	1	31	35	15	9	9	2	544
HI	1	15	38	22	21	2	2	424
IL	1	35	33	17	13	1	1	355
KY	0	42	25	17	10	5	1	467
LA	9	30	25	13	22	2	1	425
MA	4	34	23	7	2	9	22	495
ME	4	39	26	14	9	4	3	340
MEORC	3	46	28	12	6	3	3	366
MI	2	40	22	17	15	4	1	401
MO	9	41	20	16	11	3	1	496
NC	1	31	29	18	19	2	1	870
NJ	5	38	20	5	2	13	16	423
NY	1	38	28	13	16	1	2	2500
OH	0	43	33	11	11	1	0	433
PA	1	44	30	11	10	3	1	1229
SC	3	29	33	19	12	1	4	397
NCI Average	**3**	**35**	**29**	**14**	**13**	**3**	**3**	**11788**

Note. Data compiled from National Core Indicators (2013)

NCI Demographic Data for Year 2011: Other Disabilities

State	**Autism Spectrum Disorder**	**Cerebral Palsy**	**Brain Injury**	**Seizure Disorder or Neurological Problem**	**Chemical Dependency**	**Down Syndrome**	**Prader-Willi Syndrome**
AL	7	13	1	33	0	8	0
AR	10	29	4	33	0	11	5
AZ	13	20	2	26	0	11	1
CT	16	13	2	29	1	10	0
GA	10	10	2	21	0	11	1
HI	11	15	3	37	0	9	1
IL	13	17	1	25	1	15	0
KY	12	12	3	27	1	9	0
LA	12	22	4	33	0	9	0
MA	12	13	4	26	0	14	0
ME	20	13	3	25	1	11	1
MEORC	7	11	4	21	0	6	1
MI	14	18	2	22	1	7	1
MO	9	13	3	26	0	7	1
NC	16	16	3	31	0	7	1
NJ	16	15	2	27	0	13	1
NY	13	13	2	25	1	11	0
OH	9	19	4	27	0	10	2
PA	4	10	1	9	0	10	2
SC	n/a	n/a	n/a	n/a	n/a	n/a	n/a
NCI Average	**12**	**15**	**3**	**26**	**0**	**10**	**1**

Note. Data compiled from National Core Indicators (2013)

NCI Demographic Data for Year 2013: Age

State	**Mean**	**Min**	**Max**	**Standard Deviation**	**Median**	**N**
AL	45	21	82	13	45	402
AR	40	18	82	15	39	397
CT	45	19	89	16	45	405
FL	38	18	82	14	36	676
GA	43	20	84	13	42	481
HI	45	19	89	16	44	405
IL	42	20	85	14	41	325
IN	39	18	89	14	38	719
KY	40	18	85	15	38	460
LA	43	18	88	15	42	491
MD	42	18	93	15	39	349
MEORC	45	18	91	16	45	449
MO	44	19	90	15	42	487
MS	40	18	81	12	37	411
NC	41	18	92	16	39	866
NH	43	22	86	16	40	406
NJ	44	18	91	14	44	487
NY	49	18	92	14	50	548
OH	43	18	96	14	43	453
OR	45	18	81	16	46	397
PA	43	19	93	16	43	1397
SC	44	18	90	14	44	424
TX	40	24	84	13	38	401
UT	38	18	90	15	36	407
VA	43	18	90	15	41	429
WI	38	18	82	16	33	352
NCI Average	**42**	**18**	**93**	**15**	**41**	**13024**

Note. Data compiled from National Core Indicators (2014)

NCI Demographic Data for Year 2013: Race

State	**American Indian or Alaska Native**	**Asian**	**Black or African American**	**Pacific Islander**	**White**	**Other Race Not Listed**	**Two or More Races**	**Don't Know**	**N**
AL	0	0	35	0	65	0	0	0	402
AR	1	1	17	0	80	1	1	0	398
CT	1	0	13	0	79	4	1	1	403
FL	0	0	24	0	70	3	1	1	674
GA	0	0	46	0	53	1	1	0	479
HI	0	41	1	24	14	1	18	1	405
IL	1	1	22	0	72	3	1	0	328
IN	0	0	9	0	89	1	1	0	717
KY	1	0	10	0	87	1	1	0	459
LA	0	0	37	0	60	1	1	1	491
MD	1	2	30	0	59	3	2	3	359
MEORC	0	0	2	0	96	0	0	1	450
MO	0	0	15	0	83	1	1	0	487
MS	0	0	48	0	50	0	0	0	413
NC	1	0	38	0	59	0	1	0	866
NH	0	0	1	0	95	1	1	1	406
NJ	0	2	20	0	71	4	1	2	482
NY	1	1	18	0	70	7	1	1	548
OH	0	0	15	0	83	1	1	0	453
OR	1	2	2	0	89	1	2	3	397
PA	0	1	5	0	92	0	0	1	1370
SC	0	0	56	0	42	0	1	0	422
TX	0	1	15	0	58	22	1	3	383
UT	1	0	1	1	91	2	0	2	405
VA	0	1	34	0	63	1	1	1	428
WI	2	1	3	0	92	1	1	1	351
NCI Average	**1**	**2**	**20**	**1**	**72**	**2**	**1**	**1**	**12974**

Note. Data compiled from National Core Indicators (2014)

NCI Demographic Data for Year 2013: Level of Intellectual Disability

State	**No ID**	**Mild**	**Moderate**	**Severe**	**Profound**	**Unspecified**	**Unknown**	**N**
AL	0	28	39	17	15	0	0	402
AR	8	28	27	14	18	1	4	399
CT	0	50	23	16	10	0	0	409
FL	11	24	34	12	6	5	8	632
GA	2	29	36	20	10	4	0	477
HI	3	17	35	23	20	1	1	405
IL	1	40	30	15	13	0	1	324
IN	6	49	22	8	7	6	2	718
KY	9	40	28	13	6	4	2	457
LA	8	31	20	17	19	4	0	493
MD	9	28	29	12	8	3	11	352
MEORC	11	43	28	10	5	2	2	449
MO	11	30	25	20	9	4	1	485
MS	2	36	28	13	15	4	2	411
NC	1	27	33	18	21	1	0	803
NH	3	43	24	9	5	8	7	405
NJ	20	33	16	7	4	16	5	483
NY	3	35	29	14	17	1	1	547
OH	8	35	33	12	9	1	1	453
OR	7	38	33	10	10	2	1	391
PA	1	43	28	13	11	2	1	1349
SC	6	32	30	11	7	0	13	416
TX	10	25	23	21	15	2	4	401
UT	7	40	24	12	14	2	1	405
VA	2	32	38	20	7	1	0	414
WI	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
NCI Average	**6**	**34**	**29**	**14**	**11**	**3**	**3**	**12474**

Note. Data compiled from National Core Indicators (2014)

NCI Demographic Data for Year 2013: Other Disabilities

State	Autism Spectrum Disorder	Cerebral Palsy	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome
AL	6	11	2	21	0	8	1
AR	11	22	3	29	0	12	1
CT	18	12	3	25	0	10	0
FL	12	19	2	20	0	8	1
GA	8	11	1	16	0	9	0
HI	11	15	2	36	0	8	1
IL	12	16	3	25	1	14	0
IN	17	19	2	24	0	11	1
KY	13	14	3	27	9	11	0
LA	12	17	2	29	0	8	0
MD	15	16	4	25	0	10	0
MEORC	6	13	2	23	0	9	0
MO	16	14	3	26	1	7	0
MS	8	15	2	26	0	11	0
NC	17	17	3	30	0	8	0
NH	13	12	6	26	0	13	0
NJ	23	12	4	26	0	12	0
NY	14	15	3	28	0	8	0
OH	10	19	3	26	0	11	0
OR	16	17	6	25	1	5	1
PA	3	9	0	8	0	5	0
SC	9	8	1	14	0	5	1
TX	13	17	3	30	0	9	0
UT	12	5	4	24	0	8	1
VA	11	15	2	25	1	6	0
WI	17	18	9	34	1	11	1
NCI Average	**12**	**14**	**3**	**25**	**0**	**9**	**0**

Note. Data compiled from National Core Indicators (2014)

NCI Demographic Data for Year 2015: Age

State	**Mean**	**Min**	**Max**	**Standard Deviation**	**Median**	**N**
AL	46	18	87	14	47	436
AR	39	18	77	15	37	396
AZ	37	18	84	15	33	394
CT	44	18	86	16	44	402
GA	40	18	80	13	38	547
HI	44	19	89	16	42	434
IL	42	20	87	14	42	357
KY	42	19	82	14	42	474
LA	40	18	78	14	39	429
MA	47	19	89	15	47	503
ME	46	20	94	16	44	347
MEORC	46	19	90	17	47	387
MI	44	18	88	15	45	422
MO	45	19	87	15	45	501
NC	40	18	91	15	38	931
NJ	47	22	24	12	48	431
NY	45	18	101	16	46	2584
OH	43	19	93	15	43	462
PA	44	18	92	16	44	1253
SC	44	21	88	14	44	407
NCI Average	**43**	**19**	**84**	**15**	**44**	**12097**

Note. Data compiled from National Core Indicators (2015)

NCI Demographic Data for Year 2015: Race

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Other Race Not Listed	Two or More Races	Don’t Know	N
AR	0	1	21	0	77	1	0	0	398
CA	0	7	10	0	49	31	1	0	8396
CO	1	0	5	0	78	11	0	5	414
CT	0	1	11	1	80	4	0	3	437
DC	0	0	90	0	6	3	0	0	334
DE	0	0	34	0	62	2	1	1	442
FL	0	1	26	0	67	4	1	1	1415
GA	0	1	48	0	50	1	0	0	481
HI	0	57	1	20	16	3	4	0	398
IL	0	1	25	0	68	5	0	0	366
IN	0	1	6	0	91	1	1	0	740
KS	0	1	10	0	85	3	1	1	373
KY	1	0	9	0	88	1	1	0	411
LA	0	0	37	0	60	1	0	0	415
ME	1	1	1	0	95	1	0	2	398
MEORC	0	0	3	0	96	0	1	1	399
MI	0	1	17	0	79	1	1	1	408
MN	2	2	3	0	90	1	0	2	410
MO	0	1	1	0	86	0	0	0	404
NC	1	0	36	0	60	2	0	0	762
NH	0	0	1	0	96	0	0	1	409
NJ	0	1	18	0	76	4	0	0	417
NY	1	2	22	0	61	10	2	2	586
OH	0	0	15	0	82	1	2	0	457
OK	7	0	13	0	77	2	1	0	400
PA	1	1	11	0	82	2	1	2	682
SC	0	0	52	0	46	1	0	1	400
SD	16	1	1	0	80	1	1	1	338
TN	0	0	26	0	73	0	1	0	465
TX	3	1	17	0	69	6	1	3	1910
UT	1	1	2	1	91	3	1	1	426
VA	0	1	29	0	54	1	0	15	1061
VT	1	3	1	0	92	1	0	2	327
NCI Average	**1**	**3**	**19**	**1**	**72**	**3**	**1**	**1**	**25679**

Note. Data compiled from National Core Indicators (2015)

NCI Demographic Data for Year 2015: Level of Intellectual Disability

State	NO ID	Mild	Moderate	Severe	Profound	Unspecified	Unknown	N
AR	3	29	25	16	19	4	5	394
CA	13	38	23	14	9	3	0	8381
CO	0	39	27	10	6	10	7	414
CT	2	41	30	14	13	0	1	439
DC	1	28	36	19	13	0	3	336
DE	4	45	25	11	7	2	7	433
FL	15	24	32	13	8	2	6	1416
GA	1	35	37	12	9	6	0	480
HI	3	18	42	19	16	1	2	400
IL	1	39	32	15	11	1	1	367
IN	7	44	24	6	3	9	8	729
KS	4	42	27	12	8	5	2	366
KY	4	43	30	12	6	5	1	411
LA	9	32	24	15	17	2	1	414
ME	1	41	32	10	6	3	7	395
MEORC	9	43	28	9	3	4	3	397
MI	3	37	31	13	11	4	2	397
MN	0	42	28	15	7	9	0	410
MO	11	37	19	14	14	5	0	405
NC	4	26	32	17	15	3	3	760
NH	5	42	23	7	4	7	11	410
NJ	17	21	16	10	5	26	5	412
NY	4	40	33	12	7	2	1	585
OH	9	43	30	8	5	2	3	457
OK	0	44	28	11	16	1	0	400
PA	1	43	31	11	9	2	4	678
SC	5	29	30	13	8	1	14	393
SD	12	51	18	7	9	3	1	334
TN	0	33	30	14	11	3	8	465
TX	8	26	26	16	20	1	3	1886
UT	13	40	19	13	14	1	0	425
VA	5	17	27	19	21	1	9	987
VT	7	51	24	7	3	6	2	323
NCI Average	**5**	**36**	**28**	**12**	**10**	**4**	**4**	**25499**

Note. Data compiled from National Core Indicators (2015)

NCI Demographic Data for Year 2015: Other Disabilities

State	Autism Spectrum Disorder	Cerebral Palsy	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome
AR	17	26	7	39	3	11	1
CA	18	21	7	27	2	11	1
CO	12	16	4	28	0	112	1
CT	21	14	3	32	1	11	0
DC	10	8	1	18	2	7	0
DE	16	12	2	23	1	8	1
FL	18	23	3	28	1	8	1
GA	13	9	2	28	0	7	0
HI	15	16	2	35	0	12	1
IL	19	17	3	30	1	15	1
IN	22	14	4	26	1	14	2
KS	19	15	3	27	1	13	1
KY	18	25	5	40	3	13	2
LA	18	19	5	33	1	7	2
ME	19	12	6	27	3	10	2
MEORC	7	17	7	30	1	12	1
MI	20	18	5	31	2	7	0
MN	14	17	1	16	1	6	0
MO	18	11	7	31	2	6	2
NC	23	16	7	32	2	8	1
NH	17	13	14	30	3	14	1
NJ	22	13	2	34	0	17	1
NY	18	11	3	23	1	9	1
OH	10	16	5	26	1	9	1
OK	9	18	1	35	1	11	1
PA	14	11	3	28	1	11	1
SC	11	9	3	18	1	5	1
SD	14	19	7	29	3	6	0
TN	12	19	6	41	2	8	1
TX	17	20	14	32	2	10	1
UT	17	12	6	31	3	10	1
VA	17	13	5	32	2	7	1
VT	22	12	4	22	3	10	1
NCI Average	**16**	**15**	**5**	**29**	**2**	**10**	**1**

Note. Data compiled from National Core Indicators (2015)

Appendix C:

Independent Variable: IDD Spending Per Person

Independent Variable: IDD Spending Per Person ($1,000)

Year	State	IDD Spending Per Person ($1,000)	Year	State	IDD Spending Per Person ($1,000)
2011	Alabama	46.2	2013	Mississippi	45.1
2013	Alabama	51.1	2011	Missouri	41.5
2011	Arkansas	38.4	2013	Missouri	52.0
2013	Arkansas	43.5	2015	Missouri	57.5
2015	Arkansas	49.8	2011	New Hampshire	45.2
2015	California	23.1	2013	New Hampshire	45.8
2015	Colorado	37.5	2015	New Hampshire	44.0
2013	Connecticut	81.5	2013	New Jersey	73.1
2015	Connecticut	76.8	2015	New Jersey	82.5
2015	Delaware	113.7	2011	New York	75.1
2015	D.C.	109.2	2013	New York	69.4
2011	Florida	28.1	2015	New York	69.6
2013	Florida	29.5	2011	North Carolina	46.8
2015	Florida	30.1	2013	North Carolina	54.5
2011	Georgia	31.2	2015	North Carolina	68.2
2013	Georgia	35.7	2011	Ohio	40.4
2015	Georgia	41.1	2013	Ohio	41.5
2013	Hawaii	38.3	2015	Ohio	40.8
2015	Hawaii	39.1	2011	Oklahoma	54.1
2011	Illinois	31.5	2015	Oklahoma	56.1
2013	Illinois	33.8	2013	Oregon	33.4
2015	Illinois	36.0	2011	Pennsylvania	59.9
2013	Indiana	55.8	2013	Pennsylvania	67.0
2015	Indiana	46.9	2015	Pennsylvania	72.4
2015	Kansas	30.5	2013	South Carolina	29.9
2011	Kentucky	41.3	2015	South Carolina	34.1
2013	Kentucky	36.7	2015	South Dakota	30.7
2015	Kentucky	57.3	2015	Tennessee	85.0
2011	Louisiana	49.7	2013	Texas	37.2
2013	Louisiana	62.1	2015	Texas	29.7
2015	Louisiana	61.9	2013	Utah	37.3
2011	Maine	66.8	2015	Utah	38.5
2015	Maine	69.7	2015	Vermont	58.9
2013	Maryland	56.2	2013	Virginia	62.2
2015	Michigan	47.0	2015	Virginia	63.9
2015	Minnesota	67.9	2013	Wisconsin	36.4

Note. Data compiled from Coleman Institute for Cognitive Disabilities (2014,2015,2017)

Appendix D:

Dependent Variable Data by State and Year Excluding Exercise (N= 72)

Dependent Variable Data by State, Municipality and Year: Someone to go to for Help if Scared

Year	State	% have someone to go to for help if feeling scared
2011	Alabama	93
2013	Alabama	97
2011	Arkansas	91
2013	Arkansas	97
2015	Arkansas	93
2015	California	91
2015	Colorado	91
2013	Connecticut	92
2015	Connecticut	93
2015	Delaware	87
2015	D.C.	90
2011	Florida	92
2013	Florida	94
2015	Florida	93
2011	Georgia	91
2013	Georgia	91
2015	Georgia	96
2013	Hawaii	84
2015	Hawaii	95
2011	Illinois	90
2013	Illinois	89
2015	Illinois	88
2013	Indiana	94
2015	Indiana	95
2015	Kansas	88
2011	Kentucky	86
2013	Kentucky	90
2015	Kentucky	96
2011	Louisiana	96
2013	Louisiana	95
2015	Louisiana	95
2011	Maine	96
2015	Maine	95
2013	Maryland	92
2015	Michigan	95
2015	Minnesota	93
2013	Mississippi	87
2011	Missouri	94
2013	Missouri	93
2015	Missouri	95
2011	New Hampshire	91
2013	New Hampshire	94
2015	New Hampshire	95
2013	New Jersey	87
2015	New Jersey	88
2011	New York	95
2013	New York	89
2015	New York	86
2011	North Carolina	94
2013	North Carolina	93
2015	North Carolina	94
2011	Ohio	93
2013	Ohio	94
2015	Ohio	91
2011	Oklahoma	86
2015	Oklahoma	93
2013	Oregon	88
2011	Pennsylvania	96
2013	Pennsylvania	94
2015	Pennsylvania	92
2013	South Carolina	92
2015	South Carolina	97
2015	South Dakota	93
2015	Tennessee	96
2013	Texas	91
2015	Texas	89
2013	Utah	94
2015	Utah	92
2015	Vermont	92
2013	Virginia	93
2015	Virginia	93
2013	Wisconsin	92

Note. Data compiled from National Core Indicators (2013, 2014, 2015)

Dependent Variable Data by State, Municipality and Year: Feeling Lonely

Year	State	% feels lonely	Year	State	% feels lonely
2011	Alabama	46	2013	Mississippi	37
2013	Alabama	43	2011	Missouri	36
2011	Arkansas	35	2013	Missouri	33
2013	Arkansas	34	2015	Missouri	46
2015	Arkansas	44	2011	New Hampshire	33
2015	California	35	2013	New Hampshire	34
2015	Colorado	43	2015	New Hampshire	40
2013	Connecticut	36	2013	New Jersey	39
2015	Connecticut	28	2015	New Jersey	41
2015	Delaware	39	2011	New York	35
2015	D.C.	30	2013	New York	44
2011	Florida	37	2015	New York	42
2013	Florida	34	2011	North Carolina	45
2015	Florida	37	2013	North Carolina	36
2011	Georgia	39	2015	North Carolina	44
2013	Georgia	45	2011	Ohio	42
2015	Georgia	46	2013	Ohio	44
2013	Hawaii	46	2015	Ohio	42
2015	Hawaii	29	2011	Oklahoma	42
2011	Illinois	34	2015	Oklahoma	47
2013	Illinois	40	2013	Oregon	37
2015	Illinois	37	2011	Pennsylvania	35
2013	Indiana	41	2013	Pennsylvania	36
2015	Indiana	35	2015	Pennsylvania	32
2015	Kansas	42	2013	South Carolina	45
2011	Kentucky	63	2015	South Carolina	40
2013	Kentucky	85	2015	South Dakota	35
2015	Kentucky	30	2015	Tennessee	38
2011	Louisiana	34	2013	Texas	37
2013	Louisiana	37	2015	Texas	27
2015	Louisiana	41	2013	Utah	45
2011	Maine	39	2015	Utah	49
2015	Maine	50	2015	Vermont	49
2013	Maryland	39	2013	Virginia	43
2015	Michigan	37	2015	Virginia	33
2015	Minnesota	42	2013	Wisconsin	45

Note. Data compiled from National Core Indicators (2013, 2014, 2015)

Dependent Variable Data by State, Municipality and Year: Friends Who are Not Staff or Family

Year	State	% individuals reporting having friends who are not paid staff or family
2011	Alabama	71
2013	Alabama	84
2011	Arkansas	85
2013	Arkansas	71
2015	Arkansas	78
2015	California	71
2015	Colorado	69
2013	Connecticut	77
2015	Connecticut	70
2015	Delaware	72
2015	D.C.	72
2011	Florida	77
2013	Florida	85
2015	Florida	76
2011	Georgia	76
2013	Georgia	72
2015	Georgia	85
2013	Hawaii	73
2015	Hawaii	81
2011	Illinois	76
2013	Illinois	84
2015	Illinois	76
2013	Indiana	77
2015	Indiana	81
2015	Kansas	77
2011	Kentucky	54
2013	Kentucky	50
2015	Kentucky	58
2011	Louisiana	82
2013	Louisiana	80
2015	Louisiana	81
2011	Maine	80
2015	Maine	86
2013	Maryland	69
2015	Michigan	66
2015	Minnesota	85
2013	Mississippi	77
2011	Missouri	71
2013	Missouri	74
2015	Missouri	76
2011	New Hampshire	82
2013	New Hampshire	91
2015	New Hampshire	80
2013	New Jersey	77
2015	New Jersey	78
2011	New York	77
2013	New York	70
2015	New York	65
2011	North Carolina	78
2013	North Carolina	76
2015	North Carolina	75
2011	Ohio	78
2013	Ohio	89
2015	Ohio	78
2011	Oklahoma	80
2015	Oklahoma	75
2013	Oregon	73
2011	Pennsylvania	75
2013	Pennsylvania	76
2015	Pennsylvania	77
2013	South Carolina	75
2015	South Carolina	87
2015	South Dakota	74
2015	Tennessee	86
2013	Texas	80
2015	Texas	69
2013	Utah	81
2015	Utah	71
2015	Vermont	76
2013	Virginia	70
2015	Virginia	80
2013	Wisconsin	79

Note. Data compiled from National Core Indicators (2013, 2014, 2015)

Dependent Variable Data by State and Year: Had Physical Exam in the Past Year

Year	State	% had physical exam in the past year
2011	Alabama	90
2013	Alabama	87
2011	Arkansas	97
2013	Arkansas	97
2015	Arkansas	98
2015	California	86
2015	Colorado	91
2013	Connecticut	92
2015	Connecticut	92
2015	Delaware	89
2015	D.C.	71
2011	Florida	91
2013	Florida	91
2015	Florida	94
2011	Georgia	91
2013	Georgia	86
2015	Georgia	93
2013	Hawaii	91
2015	Hawaii	90
2011	Illinois	86
2013	Illinois	89
2015	Illinois	89
2013	Indiana	91
2015	Indiana	90
2015	Kansas	73
2011	Kentucky	91
2013	Kentucky	86
2015	Kentucky	86
2011	Louisiana	93
2013	Louisiana	95
2015	Louisiana	95
2011	Maine	96
2015	Maine	95
2013	Maryland	83
2015	Michigan	61
2015	Minnesota	86
2013	Mississippi	63
2011	Missouri	96
2013	Missouri	95
2015	Missouri	95
2011	New Hampshire	93
2013	New Hampshire	90
2015	New Hampshire	92
2013	New Jersey	92
2015	New Jersey	94
2011	New York	91
2013	New York	93
2015	New York	90
2011	North Carolina	89
2013	North Carolina	89
2015	North Carolina	92
2011	Ohio	81
2013	Ohio	85
2015	Ohio	80
2011	Oklahoma	97
2015	Oklahoma	98
2013	Oregon	86
2011	Pennsylvania	94
2013	Pennsylvania	92
2015	Pennsylvania	93
2013	South Carolina	89
2015	South Carolina	86
2015	South Dakota	96
2015	Tennessee	90
2013	Texas	94
2015	Texas	93
2013	Utah	80
2015	Utah	93
2015	Vermont	85
2013	Virginia	90
2015	Virginia	85
2013	Wisconsin	91

Note. Data compiled from National Core Indicators (2013, 2014, 2015)

Dependent Variable Data by State, Municipality and Year: Individuals Overweight or Obese

Year	State	% of Individuals overweight or obese
2011	Alabama	68
2013	Alabama	71
2011	Arkansas	62
2013	Arkansas	60
2015	Arkansas	63
2015	California	58
2015	Colorado	60
2013	Connecticut	63
2015	Connecticut	58
2015	Delaware	62
2015	D.C.	68
2011	Florida	58
2013	Florida	57
2015	Florida	48
2011	Georgia	65
2013	Georgia	61
2015	Georgia	65
2013	Hawaii	50
2015	Hawaii	56
2011	Illinois	66
2013	Illinois	66
2015	Illinois	62
2013	Indiana	63
2015	Indiana	67
2015	Kansas	66
2011	Kentucky	67
2013	Kentucky	68
2015	Kentucky	70
2011	Louisiana	65
2013	Louisiana	60
2015	Louisiana	60
2011	Maine	66
2015	Maine	64
2013	Maryland	60
2015	Michigan	60
2015	Minnesota	61
2013	Mississippi	70
2011	Missouri	57
2013	Missouri	62
2015	Missouri	60
2011	New Hampshire	64
2013	New Hampshire	54
2015	New Hampshire	67
2013	New Jersey	67
2015	New Jersey	66
2011	New York	62
2013	New York	60
2015	New York	60
2011	North Carolina	60
2013	North Carolina	58
2015	North Carolina	50
2011	Ohio	65
2013	Ohio	63
2015	Ohio	70
2011	Oklahoma	64
2015	Oklahoma	66
2013	Oregon	65
2011	Pennsylvania	61
2013	Pennsylvania	62
2015	Pennsylvania	66
2013	South Carolina	72
2015	South Carolina	61
2015	South Dakota	74
2015	Tennessee	66
2013	Texas	60
2015	Texas	56
2013	Utah	60
2015	Utah	59
2015	Vermont	73
2013	Virginia	65
2015	Virginia	57
2013	Wisconsin	60

Note. Data compiled from National Core Indicators (2013, 2014, 2015)

Appendix E

Dependent Variable Data by State and Year: Exercise (N= 57)

Dependent Variable Data by State, Year and Municipality: Individuals Who Exercise At Least 30 Minutes Three Times Weekly

Year	State	% of individuals who exercise at least 30 minutes three times weekly
2013	Alabama	35
2013	Arkansas	29
2015	Arkansas	23
2015	California	34
2015	Colorado	32
2013	Connecticut	16
2015	Connecticut	15
2015	Delaware	17
2015	District of Columbia	8
2013	Florida	0
2015	Florida	28
2013	Georgia	25
2015	Georgia	30
2013	Hawaii	33
2015	Hawaii	37
2013	Illinois	19
2015	Illinois	17
2013	Indiana	17
2015	Indiana	23
2015	Kansas	22
2013	Kentucky	14
2015	Kentucky	16
2013	Louisiana	23
2015	Louisiana	23
2015	Maine	22
2013	Maryland	16
2015	Michigan	14
2015	Minnesota	36
2013	Mississippi	16
2013	Missouri	26
2015	Missouri	32
2013	New Hampshire	32
2015	New Hampshire	31
2013	New Jersey	24
2015	New Jersey	9
2013	New York	19
2015	New York	26
2013	North Carolina	0
2015	North Carolina	26
2013	Ohio	13
2015	Ohio	16
2015	Oklahoma	30
2013	Oregon	30
2013	Pennsylvania	15
2015	Pennsylvania	16
2013	South Carolina	21
2015	South Carolina	13
2015	South Dakota	16
2015	Tennessee	18
2013	Texas	39
2015	Texas	34
2013	Utah	26
2015	Utah	22
2015	Vermont	33
2013	Virginia	24
2015	Virginia	18
2013	Wisconsin	42

Note. Data compiled from National Core Indicators (2014, 2015)

Appendix F

Covariables by State and Year

Covariable: # of Waiver Participants

Year	State	# of Waiver Participants
2011	Alabama	5663
2013	Alabama	5848
2011	Arkansas	4055
2013	Arkansas	4147
2015	Arkansas	4,120
2015	California	116,232
2015	Colorado	10,538
2013	Connecticut	9,346
2015	Connecticut	9,602
2015	Delaware	1,041
2015	D.C.	1,703
2011	Florida	30,043
2013	Florida	29,068
2015	Florida	30,858
2011	Georgia	11,366
2013	Georgia	12,065
2015	Georgia	12,106
2013	Hawaii	2,695
2015	Hawaii	2,741
2011	Illinois	18,000
2013	Illinois	18,545
2015	Illinois	21,542
2013	Indiana	13,727
2015	Indiana	19,740
2015	Kansas	9,089
2011	Kentucky	7,754
2013	Kentucky	12,773
2015	Kentucky	14,869
2011	Louisiana	10,492
2013	Louisiana	11,611
2015	Louisiana	11,724
2011	Maine	4,156
2015	Maine	4,506
2013	Maryland	13,407
2015	Michigan	24,045
2015	Minnesota	20,978
2013	Mississippi	1,961
2011	Missouri	10,140
2013	Missouri	12,110
2015	Missouri	12,110
2011	New Hampshire	4,128
2013	New Hampshire	4,637
2015	New Hampshire	4,960
2013	New Jersey	10,740
2015	New Jersey	10,972
2011	New York	73,317
2013	New York	78,325
2015	New York	4,610
2011	North Carolina	10,939
2013	North Carolina	10,985
2015	North Carolina	73,815
2011	Ohio	29,227
2013	Ohio	32,492
2015	Ohio	34,886
2011	Oklahoma	5,096
2015	Oklahoma	5,421
2013	Oregon	14,335
2011	Pennsylvania	26,766
2013	Pennsylvania	26,589
2015	Pennsylvania	29,107
2013	South Carolina	9,414
2015	South Carolina	10,157
2015	South Dakota	3,593
2015	Tennessee	7,826
2013	Texas	29,620
2015	Texas	31,821
2013	Utah	4,423
2015	Utah	4,828
2015	Vermont	2,919
2013	Virginia	10,282
2015	Virginia	11,358
2013	Wisconsin	23925

Note. Data compiled from Coleman Institute for Cognitive Disabilities (2014,2015,2017)

Covariable: Total IDD Expenditures

Year	State	Total IDD Expenditure (millions of dollars)
2011	Alabama	261.7
2013	Alabama	298.6
2011	Arkansas	155.9
2013	Arkansas	180.3
2015	Arkansas	595.8
2015	California	7,150.0
2015	Colorado	624.5
2013	Connecticut	761.4
2015	Connecticut	1,279.1
2015	Delaware	216.4
2015	D.C.	347.4
2011	Florida	844.9
2013	Florida	856.2
2015	Florida	1,751.7
2011	Georgia	354.1
2013	Georgia	431.1
2015	Georgia	994.3
2013	Hawaii	103.3
2015	Hawaii	155.9
2011	Illinois	566.4
2013	Illinois	627.4
2015	Illinois	1,727.2
2013	Indiana	765.3
2015	Indiana	1,528.8
2015	Kansas	429.1
2011	Kentucky	320.4
2013	Kentucky	468.8
2015	Kentucky	1,163.4
2011	Louisiana	521.6
2013	Louisiana	723.7
2015	Louisiana	1,436.4
2011	Maine	277.7
2015	Maine	448.2
2013	Maryland	753.4
2015	Michigan	1,560.3
2015	Minnesota	1,903.8
2013	Mississippi	88.5
2011	Missouri	421.1
2013	Missouri	629.5
2015	Missouri	1,081.0
2011	New Hampshire	186.5
2013	New Hampshire	212.5
2015	New Hampshire	298.9
2013	New Jersey	785.1
2015	New Jersey	1,964.2
2011	New York	5,505.7
2013	New York	5,433.2
2015	New York	401.1
2011	North Carolina	512.3
2013	North Carolina	598.2
2015	North Carolina	10,230.0
2011	Ohio	1,179.7
2013	Ohio	1,349.1
2015	Ohio	3,370.0
2011	Oklahoma	275.5
2015	Oklahoma	509.9
2013	Oregon	479.0
2011	Pennsylvania	1,603.6
2013	Pennsylvania	1,781.6
2015	Pennsylvania	3,290.0
2013	South Carolina	281.4
2015	South Carolina	695.0
2015	South Dakota	189.5
2015	Tennessee	977.6
2013	Texas	1,102.9
2015	Texas	2,800.0
2013	Utah	164.9
2015	Utah	313.8
2015	Vermont	196.2
2013	Virginia	640.0
2015	Virginia	1,355.8
2013	Wisconsin	871.5

Note. Data compiled from Coleman Institute for Cognitive Disabilities (2014,2015,2017)

Covariable: GDP (Millions of Dollars)

Year	State	GDP (millions of dollars)
2011	Alabama	183917
2013	Alabama	194787
2011	Arkansas	105768
2013	Arkansas	113227
2015	Arkansas	117,787
2015	California	2,479,556
2015	Colorado	320,721
2013	Connecticut	241,517
2015	Connecticut	259,488
2015	Delaware	71,914
2015	D.C.	124,605
2011	Florida	755,240
2013	Florida	811,752
2015	Florida	908,520
2011	Georgia	431,654
2013	Georgia	464,753
2015	Georgia	521,008
2013	Hawaii	74,555
2015	Hawaii	81,230
2011	Illinois	692,881
2013	Illinois	741,122
2015	Illinois	799,931
2013	Indiana	312,139
2015	Indiana	331,946
2015	Kansas	154,958
2011	Kentucky	171,587
2013	Kentucky	184,524
2015	Kentucky	193,413
2011	Louisiana	229,945
2013	Louisiana	230,833
2015	Louisiana	235,114
2011	Maine	52,576
2015	Maine	58,131
2013	Maryland	340,578
2015	Michigan	474,983
2015	Minnesota	335,530

Year	State	GDP (millions of dollars)
2013	Mississippi	102,371
2011	Missouri	262,067
2013	Missouri	280,571
2015	Missouri	296,929
2011	New Hampshire	66,153
2013	New Hampshire	70,476
2015	New Hampshire	76,478
2013	New Jersey	534,178
2015	New Jersey	563,234
2011	New York	1,247,606
2013	New York	1,365,529
2015	New York	1,487,628
2011	North Carolina	431,723
2013	North Carolina	462,269
2015	North Carolina	508,929
2011	Ohio	528,190
2013	Ohio	566,532
2015	Ohio	611,020
2011	Oklahoma	166,236
2015	Oklahoma	186,816
2013	Oregon	179,528
2011	Pennsylvania	624,820
2013	Pennsylvania	668,569
2015	Pennsylvania	714,203
2013	South Carolina	185,009
2015	South Carolina	205,817
2015	South Dakota	48,070
2015	Tennessee	325,294
2013	Texas	1,515,196
2015	Texas	1,573,498
2013	Utah	135,450
2015	Utah	149,153
2015	Vermont	30,933
2013	Virginia	457,641
2015	Virginia	483,787
2013	Wisconsin	284271

Note. Data compiled from U.S. Bureau of Economic Analysis Interactive Data Application (2022)

Covariable: Per Capita Income (Dollars)

Year	State	Per Capita Income (dollars)
2011	Alabama	35,101
2013	Alabama	36,258
2011	Arkansas	34,253
2013	Arkansas	36,605
2015	Arkansas	39,842
2015	California	54,632
2015	Colorado	52,222
2013	Connecticut	62,900
2015	Connecticut	67,761
2015	Delaware	47,997
2015	D.C.	74,352
2011	Florida	40,482
2013	Florida	41,069
2015	Florida	45,493
2011	Georgia	36,849
2013	Georgia	37,813
2015	Georgia	41,974
2013	Hawaii	44,378
2015	Hawaii	48,566
2011	Illinois	44,279
2013	Illinois	47,285
2015	Illinois	51,864
2013	Indiana	39,829
2015	Indiana	42,778
2015	Kansas	47,527
2011	Kentucky	34,826
2013	Kentucky	36,131
2015	Kentucky	39,360
2011	Louisiana	39,131
2013	Louisiana	41,396
2015	Louisiana	43,146
2011	Maine	39,737
2015	Maine	43,888
2013	Maryland	52,576
2015	Michigan	43,655
2015	Minnesota	52,229
2013	Mississippi	34,222
2011	Missouri	38,536
2013	Missouri	40,576
2015	Missouri	43,334
2011	New Hampshire	49,184
2013	New Hampshire	51,010
2015	New Hampshire	54,935
2013	New Jersey	55,599
2015	New Jersey	60,551
2011	New York	51,167
2013	New York	54,117
2015	New York	58,743
2011	North Carolina	36,839
2013	North Carolina	38,225
2015	North Carolina	41,778
2011	Ohio	39,287
2013	Ohio	41,373
2015	Ohio	44,641
2011	Oklahoma	39,777
2015	Oklahoma	44,785
2013	Oregon	39,787
2011	Pennsylvania	44,300
2013	Pennsylvania	46,456
2015	Pennsylvania	50,352
2013	South Carolina	36,005
2015	South Carolina	39,698
2015	South Dakota	49,040
2015	Tennessee	42,648
2013	Texas	44,745
2015	Texas	47,345
2013	Utah	36,628
2015	Utah	40,668
2015	Vermont	49,662
2013	Virginia	48,654
2015	Virginia	52,379
2013	Wisconsin	43,194

Note. *Data compiled from U.S. Bureau of Economic Analysis Interactive Data Application (2019)*

Covariable: Medicaid Expansion Status

Year	State	Medicaid Expansion Y=1 N=2
2011	Alabama	2
2013	Alabama	2
2011	Arkansas	2
2013	Arkansas	2
2015	Arkansas	1
2015	California	1
2015	Colorado	1
2013	Connecticut	2
2015	Connecticut	1
2015	Delaware	1
2015	D.C.	1
2011	Florida	2
2013	Florida	2
2015	Florida	2
2011	Georgia	2
2013	Georgia	2
2015	Georgia	2
2013	Hawaii	2
2015	Hawaii	1
2011	Illinois	2
2013	Illinois	2
2015	Illinois	1
2013	Indiana	2
2015	Indiana	1
2015	Kansas	2
2011	Kentucky	2
2013	Kentucky	2
2015	Kentucky	1
2011	Louisiana	2
2013	Louisiana	2
2015	Louisiana	2
2011	Maine	2
2015	Maine	2
2013	Maryland	2
2015	Michigan	1
2015	Minnesota	1
2013	Mississippi	2
2011	Missouri	2
2013	Missouri	2
2015	Missouri	2
2011	New Hampshire	2
2013	New Hampshire	2
2015	New Hampshire	1
2013	New Jersey	2
2015	New Jersey	1
2011	New York	2
2013	New York	2
2015	New York	1
2011	North Carolina	2
2013	North Carolina	2
2015	North Carolina	2
2011	Ohio	2
2013	Ohio	2
2015	Ohio	2
2011	Oklahoma	2
2015	Oklahoma	2
2013	Oregon	2
2011	Pennsylvania	2
2013	Pennsylvania	2
2015	Pennsylvania	1
2013	South Carolina	2
2015	South Carolina	2
2015	South Dakota	2
2015	Tennessee	2
2013	Texas	2
2015	Texas	2
2013	Utah	2
2015	Utah	2
2015	Vermont	1
2013	Virginia	2
2015	Virginia	2
2013	Wisconsin	2

Note. Data compiled from Kaiser Family Foundation (2022)

Covariable: Poverty Rate (Percent of People in Poverty)

Year	State	Poverty Rate (percent of people in poverty)
2011	Alabama	15
2013	Alabama	18.5
2011	Arkansas	18.7
2013	Arkansas	13.9
2015	Arkansas	16.1
2015	California	13.9
2015	Colorado	9.9
2013	Connecticut	10.9
2015	Connecticut	9.1
2015	Delaware	11.1
2015	D.C.	16.6
2011	Florida	14.9
2013	Florida	14.8
2015	Florida	16.2
2011	Georgia	18.4
2013	Georgia	18.5
2015	Georgia	18.1
2013	Hawaii	10.6
2015	Hawaii	10.9
2011	Illinois	14.2
2013	Illinois	13.6
2015	Illinois	10.9
2013	Indiana	16.5
2015	Indiana	13.5
2015	Kansas	14.2
2011	Kentucky	16
2013	Kentucky	22
2015	Kentucky	19.5
2011	Louisiana	21.1
2013	Louisiana	21.2
2015	Louisiana	18.6
2011	Maine	13.4
2015	Maine	12.3
2013	Maryland	10.5
2015	Michigan	12.8
2015	Minnesota	7.8
2013	Mississippi	19.1
2011	Missouri	15.4
2013	Missouri	17.5
2015	Missouri	9.8
2011	New Hampshire	7.6
2013	New Hampshire	5.5
2015	New Hampshire	7.3
2013	New Jersey	9.9
2015	New Jersey	11.2
2011	New York	16
2013	New York	17.3
2015	New York	14.2
2011	North Carolina	15.4
2013	North Carolina	14.7
2015	North Carolina	15.3
2011	Ohio	15.1
2013	Ohio	14.9
2015	Ohio	13.6
2011	Oklahoma	13.9
2015	Oklahoma	14.2
2013	Oregon	14
2011	Pennsylvania	12.6
2013	Pennsylvania	11.2
2015	Pennsylvania	12.3
2013	South Carolina	19.3
2015	South Carolina	14.3
2015	South Dakota	13.9
2015	Tennessee	14.7
2013	Texas	16.9
2015	Texas	14.7
2013	Utah	12.2
2015	Utah	9.3
2015	Vermont	10.7
2013	Virginia	9.8
2015	Virginia	10.9
2013	Wisconsin	13.5

Note. Data compiled from U.S. Center for American Progress (2022)

Appendix G

Descriptive Statistics: All Variables Including Exercise

Descriptive Statistics All Variables Including Exercise

Variables	**N**	**Mean**	**Std. Dev.**	**Min**	**Max**
IDD Spending Per Person ($1,000)	57	52.254385	19.479119	23.1	113.7
Percent having someone to go to for help if feeling scared	57	92.2105263	3.016246	84	97
Percent feeling lonely	57	40.087719	8.183783	27	85
Percent reporting having friends who are not paid staff or family	57	76.157894	7.200668	50	91
Percent having physical exam in the past year	57	88.736842	7.366735	61	98
Percent overweight or obese	57	62.38596	5.486198	48	74
Percent who exercise at least 30 minutes three times weekly	57	22.649122	9.089812	0	42
Number of Waiver Participants	57	16962	19955.1814	1041	116232
Total IDD Expenditure (millions of dollars)	57	1252.14	1741.33592	88.5	10230
GDP (millions of dollars)	57	442947.386	461031.222	30933	2479556
Per Capita Income (dollars)	57	46397.82456	8107.31882	34222	74352
Medicaid Expansion Status (Y=1, N=2)	57	1.701754	0.061134	1	2
Poverty Rate (percent of people in poverty)	57	13.766666	3.56898	5.5	22

Appendix H

Correlations: All Variables

Bivariate Correlations: Dependent, Independent and Control Variables Including Exercise (N=57)

	Variable	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*13*
1	**IDD Spending Per Person ($1,000)**	1												
2	**Percent having someone to go to for help if feeling scared**	-0.06	1											
3	**Percent feeling lonely**	-0.14	-0.11	1										
4	**Percent reporting having friends who are not paid staff or family**	-0.03	0.34**	-0.26**	1									
5	**Percent having physical exam in the past year**	0.03	0.19	0.03	0.13	1								
6	**Percent overweight or obese**	0.11	0.01	0.18	-0.06	-0.21	1							
7	**Percent who exercise at least 30 minutes three times weekly**	-0.29**	0.02	0.07	0.10	0.26***	-0.19	1						
8	**Number of Waiver Participants**	-0.17	-0.05	-0.07	-0.09	0.02	-0.30**	0.07	1					
9	**Total IDD Expenditure (millions of dollars)**	0.05	-0.01	-0.07	-0.08	0.06	-0.32**	0.04	0.89	1				
10	**GDP (millions of dollars)**	-0.18	-0.26***	-0.18	-0.13	0.09	-0.29**	0.10	0.76	0.56	1			
11	**Per Capita Income (dollars)**	0.51	-0.32**	-0.33**	-0.08	-0.01	-0.04	-0.09	0.08	0.12	0.22	1		
12	**Medicaid Expansion Status (Y=1, N=2)**	-0.28**	0.08	0.23***	0.21	0.13	-0.12	-0.01	-0.02	-0.07	-0.08	-0.48*	1	
13	**Poverty Rate (percent of people in poverty)**	-0.16	0.08	0.22	-0.22	-0.09	0.23***	-0.16	0.13	0.06	0.10	-0.48*	0.28**	1

* p<.10, ** p<.05, ***p<.01

Appendix I

Summary Output Regression Statistics: Dependent Variable: Exercise

Summary Output Regression Statistics by Dependent Variables (Models 1 and 2)

	Model	Pearson R	R Square	Significance F
1	Scared and IDD Spending Per Person	0.0114	0.0001	0.9242
2	Scared, IDD Spending Per Person and Control Variables	0.3694	0.1365	0.2032
1	Loneliness and IDD Spending Per Person	0.1291	0.0167	0.2798
2	Loneliness, IDD Spending Per Person and Control Variables	0.3577	0.1279	0.2459
1	Friends who are not paid staff or family and IDD Spending Per Person	0.0085	0.0001	0.9436
2	Friends who are not paid staff or family, IDD Spending Per Person and Control Variables	0.3173	0.1007	0.4235
1	Annual Health Examinations and IDD Spending Per Person	0.3178	0.001	0.791
2	Annual Health Examinations, IDD Spending Per Person and Control Variables	0.2898	0.084	0.5596
1	Overweight or Obese and IDD Spending Per Person	0.0916	0.0084	0.4442
2	Overweight or Obese, IDD Spending Per Person and Control Variables	0.47	0.2304	0.015
1	Exercise 30 Minutes Three Times Weekly and IDD Spending Per Person	0.2925	0.0856	0.0272
2	Exercise 30 Minutes Three Times Weekly, IDD Spending Per Person and Control Variables	0.3842	0.1476	0.3141