

Self-Directed Services for the Long-Term Supports of Adults with Intellectual and
Developmental Disabilities:

A Propensity Score Matching Analysis

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Abstract

Through the civil rights movement, people with intellectual and developmental disabilities (IDD) gained rights that are often taken for granted by non-disabled individuals, including the right to live immersed in the larger community instead of institutional facilities. Self-directed services (SDS) are an option intended to promote the autonomy of people with disabilities to make their own decisions regarding services. It provides service management authority to the service participants, including budget authority. Ever since its implementation in 1993, however, little attention has been paid to the quantitative evaluation of the impact of this service, even though SDS has become a statewide community care option. Indeed, every state in the U.S. has one or more SDS programs.

This cross-sectional, observational study evaluated the effectiveness of SDS for people with IDD by comparing the quality of life and service satisfaction of participants and non-participants. Propensity score matching and multivariate regressions were applied to the 2018-19 National Core Indicators data (n=18,827) answered by 37 states' service users. All analyses were adjusted for gender, race/ethnicity, care type (home, facility, other), metro status, income, age, and disability severity. Findings were mixed with respect to the quality of life indicators, and no difference in service satisfaction was found between participants and non-participants. Overall, this study does not support the notion that SDS is superior to traditional agency-based services.

The implication of this study is that SDS deserves a higher level of scrutiny than it has thus far received. Its superiority over more traditional services should not be taken for granted. There are, however, two critical limitations of this study. First, the assignment to groups was not randomized. The second is that the survey was not

explicitly designed to track the effectiveness of SDS. The use of randomized designs and survey instruments more closely tailored to SDS would either validate the findings more conclusively or contradict them with more robust methods.

Table of Contents

List of Tables	vi
List of Figures	vii
Chapter One: Introduction	1
Problem Statement	6
Purpose of the Study	16
Research Questions	17
Hypotheses	17
Theoretical Perspectives: Self-Determination Theory	18
Chapter Two: Literature Review	23
Benefits of Self-Directed Service	28
Challenges of Self-Directed Service	33
Chapter Three: Methods	39
Data Source	39
Data Overview	40
Measures	43
Understanding Missing Data and Dealing with It	46
Analytic Strategies	47
Chapter Four: Results	50
Propensity Matching	50
Descriptive Analysis of our Populations	51
Multivariate Regression Results	54
Result of T-test for the Employment Variable	55
Result of T-test for the BMI Variable	55
Result of T-test for the Health Variable	55
Result of T-test for the Community Inclusion Variable on the Whole Population	56
Result of T-test for the Relationship Variable	56

Result of T-test for the Decision-Making Variable	56
Result of T-test for the Service Satisfaction Variable	57
Chapter Five: Discussion	57
Chapter Seven: Implications	63
Limitations of Study	68
Conclusion	69
References	70
Appendices	
Appendix A: Numerical Coding for Dependent and Independent Variables	84

List of Tables

Table 1. Responsibilities of stakeholders	14
Table 2. Description of studies	24
Table 3. Respondents per state	42
Table 4. Distribution of demographic characteristics and dependent variables across three study populations	51
Table 5. Multivariate regression results	55

List of Figures

Figure 1. Process of accessing and using CDCS	13
Figure 2. Self-determination theory	19
Figure 3. SDS Participation	41
Figure 4. Probability Distribution of SDS Participation by Participant Demographics	50

Chapter One

Introduction

This paper examines the effectiveness of participation in self-directed service (SDS) in the US, focusing on the intellectual and developmental disability (IDD) population. The IDD population is defined as those who have intellectual disability, or other developmental disabilities (National Institute of Health, 2021). For example, ADHD, autism, cerebral palsy, and down syndrome are considered as IDD. It usually presents at birth and affects an individual's physical, intellectual, and/or emotional development. SDS supports service participants' decision-making for their services for inclusion into the community and achieving an independent life. SDS consumer-centered service differs from traditional provider-centered service because consumer plans their own services rather than using ready-made services. In the US, SDS started in the flow of the civil rights movement, seeking rights for individuals living with disabilities. In this sense, SDS lies at the intersection of various topics in the disability area: the human right to choose their life, community inclusion and independent living, including employment and relationships issues, and person(consumer)-centered service balancing between what individuals want and need, and participants' and government's responsibilities.

The rights of people with disabilities have changed as society changes the perspective on disability from a medical point of view (e.g., deviation from normality, pathological, atypical) to a social model (social barrier, environmental modifications, individualized supports) (World Health Organization [WHO], 2001). Through policy implementation, legislation, revision of diagnostic standards considering contextual factors, or changing the name of a disability from mental retardation to intellectual disability, the effort to ensure the rights of people with disabilities has increased in the

last two decades. Thanks to political action, people with IDD have moved from medical institutions to community-based settings since deinstitutionalize movement. According to 2020 -2021 National Core Indicator (NCI) survey data on people with IDD, 16% live in their own homes, 42% live with a parent or relative's house, and 42% live in mid to small-size facilities within the community (National Core Indicators [NCI], 2023).

However, 'community presence' does not mean real social inclusion and acceptance by the community (Presnell & Keesler, 2021; Scior et al., 2020; Merrells, Buchanan & Waters, 2018; Lippold & Burns, 2009; Verdonschot, Witte, Reichrath, Buntinx & Curfs, 2009). Building community-based residential places for people with IDD is still considered a threat to that neighborhood and may be perceived as an obnoxious facility resulting in a 'not-in-my-backyard' attitude. Van Alphen, Dijker, Bos, Van den Borne, and Curfs (2012) asked participants to respond to a survey in which they imagine they would have a disability facility in their neighborhood and then answer questions about their emotions. The multivariate analysis indicated that the more severe the disabilities experienced by potential residents, and the larger the facility, the more negatively neighbors respond, for example, with anger and anxiety toward people with IDD (Van Alphen et al., 2012).

This research underscores that acceptance by community members is a critical factor in community inclusion. Community inclusion can increase self-esteem, quality of life and help consolidate the identity of individuals with IDD (Machin & Jeffries, 2017; Merrells, Buchanan & Waters, 2018). The absence of community inclusion can lead to social anxiety, embarrassment, sadness, and loneliness (Leary, 2022). Yet few resources are available to measure the attitudes toward people with IDD, increasing

the risk of continuous challenges such as stigma and discrimination (Scior et al., 2020).

Historically, people with IDD have been subjected to negative stereotypes, dehumanization, mistreatment, and neglect rooted in late nineteenth-century eugenics views (Luckasson & Schalock, 2020; Mackelprang & Salsgiver, 2015). However, this prejudice and abuse towards people with IDD still prevail after hundred years. Scior and colleagues (2020) asked 667 experts and representatives of ID field organizations in 88 countries about contextual information on attitude and environment to include people with IDD. They found that the public still perceived people with IDD as needy, dependent, incapable, incompetent, and negatively affecting their non-disability group's productivity. These psychological barriers prevent people with IDD from full inclusion in the community, limiting their capability, chance to decide their own opinions and reducing interaction with others to build relationships (Werner & Roth, 2014; WHO, 2011).

These prejudices and discrimination frame people with IDD as deprived of their rights to decide their life course. In the U.S., plenary guardianship, in which the court gives all life decisions to guardians, is more typical than limited guardianship, in which the guardians make only certain decisions (Shogren et al., 2021). Guardianship has been perceived as “a humanitarian response to the vulnerability of the incompetent” (Frolik, 1998, p.350). However, scholars say that this view is based on a deficit-based model, which is the belief that individuals with disabilities are unable to make decisions for themselves and therefore require someone to take care of them. It goes against individualized support and the rights of citizenship, that every person has the right to make a decision (Shogren et al., 2021).

The deficit frame on disability also affects employment. Having a job enhances self-confidence, self-esteem, self-efficacy, and a sense of belonging. Still, in the case of IDD, the help required-deficit lens over IDD restricts their capability, depriving opportunity to earn these benefits, focus on their potential rather than needs, and broaden their social network (Forrester-Jones, Jones, Heason & Terlizzi, 2004). Studies indicate that people with IDD have limited participation in social activities and tend to interact with others who also have intellectual disabilities (Lippold & Burns, 2009). Having friends who do not have disabilities often from caring relationships, but Green & Schleien (1991) suggested 'facades of friendship' could confuse people with IDD as the relationships are genuine. The authors stated that people with IDD living in community-based facilities often struggle to build meaningful relationships (Green & Schleien, 1991).

People with disabilities' right to choice is a universal human right that societies must create an appropriate environment to let people exercise their rights as others. The Convention on the Rights of Persons with Disabilities (CRPD) states equality, non-discrimination, and respect that society needs to promote for the disability's dignity as a human. Article 3 'general principle' (1) says, "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" (CRPD, 2006). In this regard, SDS is a service encouraging people with disabilities' supported decision-making over their services.

Self-directed services (SDS) are an alternative agency delivery model in which participants, or their representatives, have decision-making authority over services and take direct responsibility for managing their benefits (Benjamin, 2001). For example, they can recruit, hire, train (employer authority), and/or decide how much they want to pay for that service provider. They can also choose how they want to use

their assigned budget (budget authority) (“self-directed,” n.d.). SDS is also known as Cash and Counseling model in the US in the sense that people can use the assigned money as they need and want and receive counseling for planning and using the budget and assistance for fiscal management. Participants can designate representatives for decision making Dale et al., 2003). In 2015, 75% of states offered budget and employer authority, while eleven only offered employer authority (DeCarlo et al., 2017). According to the National Council on Disability, the central goal of self-directed services is to “maximize an individual’s opportunities to live independently in the most integrated community-based setting of his or her choice.”(National Council on Disability [NCD], n.d.)

In the 2019 National Inventory of Self-Direction Programs report, 267 self-direction programs are identified in the US, serving over 1.2 million individuals. These include older adults, veterans, and people with disabilities and traumatic brain injury. This report revealed that every state has at least one self-directed service (Edwards-Orr, Morris, DeLuca, Ujvari, & Sciegaj, 2020). SDS options and names vary depending on the state. Examples include veteran-directed care, development disabilities waiver, elderly waiver, home, and community-based waiver, personal assistance services, HIV/AIDS waiver, and mental health waiver (Edwards-Orr et al., 2020).

Although SDS programs are available to other population groups, people with disabilities constitute a majority of SDS service participants. According to data provided by the Applied Self-Direction, among 267 identified SDS programs, as many as 61% of programs offered help for adults with physical disabilities in 2019. Other categories with widespread support from these programs include adults age 65 and older (57% in 2019), adults with intellectual disabilities (32% in 2019), and

children with intellectual disabilities (28% in 2019). These percentages do not add up to 100% because 3 out of 4 programs serve multiple populations (Edwards-Orr et al., 2020).

Among 272 SDS programs, 157 were funded by the 1915(c) Home and Community-Based Services (HCBS) Waiver in 2014 (National Resource Center for Participant-Directed Services, 2014). Medicaid Home and Community-Based Services (HCBS) 1915(c) waivers are a type of Medicaid service. It allows states to provide community-based services, which enables SDS as an alternative to institutionalized services (U.S. Department of Health and Human Services, 2000; Provost & Hughes, 2000). It is called a ‘waiver’ because it allows states to waive formal Medicaid eligibility requirements for individuals who would otherwise receive care in a facility (Thompson and Burke, 2007). Developing mechanisms to use federal funds for community-based services laid the groundwork for achieving a person-centered service environment.

Problem Statement

Self-directed service was designed to enhance service by giving them greater control over their services. It’s been developed based on interests shared between service beneficiaries and the government. From the existing medical-oriented personal assistance services, SDS has evolved into a service that provides a broad scope of care, including medical assistance, daily tasks, and tasks supporting community integration, such as job training. This could happen with edified citizenship through the civil rights movement and the government’s mutual interest in improving the efficiency of the service.

Institutional Care

In the past, institutionalized care or family care of individuals with intellectual and developmental disabilities was considered non-optional. In the 1960s, people with developmental disabilities institutional treatment had raised issues as the number of people exceeded the capability of quality care. They lived apart from the rest of society and their family and spent their life in facilities with conditions that some deemed deplorable (“self-determination,” n.d.). Families continuously voiced their concerns about poor service and the inability to control their family members’ quality of life in the facility. For example, in Minnesota, in 1972, Richard Welsch filed a complaint with federal courts because of the deteriorated condition of the Cambridge State Hospital, where his daughter lived (The Minnesota Governor’s Council on Developmental Disabilities, 2018). The high cost of inpatient care was another issue that the government wanted to develop a cost-effective solution for while providing satisfactory service to service users. (RWJF, 2004). For example, in Los Angeles in 1953, the inpatient care cost was \$35 per day, while outpatient with personal attendant benefits was \$10 per day (CHSSCA, n.d.).

Independent Living Movement

Before the 1970s, when people with disabilities were equated to institutionalized patients, independent living was not even considered in their life. Inspired by the 1950s and 1960s civil rights movements, however, people with disabilities started raising their voices seeking accessibility to education, and required environment adjustments to get equal opportunities. One of the representative figures, Ed Roberts, led the independent living movement at the University of California at Berkeley. To attend the university, he sued the school in 1962 (Fleischer, D. & Zames, D., 2011). From there, his advocacy for a barrier-free campus spread to the community, and in 1972, the first Center for Independent Living (CIL) was

established by and for people with disabilities. The CIL was operated by people with disabilities and provided services, counseling, and training for living skills and job development to enhance their integration into the community. This approach was focused on a person's rights and the choice of their services to provide resources for better social integration. It differed from a medical model approach focusing on their medical conditions and limitations resulting from the disability (Fleischer & Zames, 2011; Gina & Mike, 2005). Roberts said:

“Most people never thought of independence as a possibility when they thought of us. But we knew what we wanted, and we set up CIL to provide the vision and resources to get people out and into the community. ... no longer would we tolerate being spoken for (p. 39)” (Fleischer & Zames, 2011).

This independent living movement paved the way for people with disabilities to seek their rights as human beings and citizens of society.

Deinstitutionalization

In 1981, Congress passed the Omnibus Budget Reconciliation Act (OBRA). It allowed states to support home and community-based waiver options for people with disabilities, mental illness, HIV, and aged people (Lindsey, Jacobson & Pascal, 1990). This waiver option was integrated with the Social Security Act in Section 1915 (c) (Duckett & Guy, 2000). In 1999 the Supreme Court's *Olmstead v L.C.* affirmed that community integration was an obligation of public programs under the Americans with Disabilities Act (ADA) Title (“self-determination,” n.d., p. 6). Over the years, the states' new obligations under the *Olmstead* decision and the preference that beneficiaries tend to have for home and community-based services have shifted services from an institutional setting to community-based services (Reaves & Musumeci, 2015).

De-institutionalization had led people from state-sponsored institutions to group homes and similar facilities from the 1960s to the 1990s. Services are designed for various levels of disabilities, offering preconfigured bundles. However, not every state had enough public resources to support deinstitutionalization, and their Medicaid spending was disproportionately huge compared to the number of recipients. These problems caused long waiting lists preventing them from receiving the support they needed, and they often became a target of budget cutters. For example, the total expenditures reached \$44 billion in 1998, accounting for 25% of all Medicaid expenditures. However, it corresponded to only 4% of Medicaid recipients (Provost & Hughes, 2000). For people with disabilities and their families receiving the service, these preconfigured fixed sets of services gave little control over their services because they could not decide the type of services, providers, or the time of the service (RWJF, 2004).

Evolution and Expansion of SDS

SDS has been developed from personal care/personal assistance services (PAS). In the mid-1970s, PAS required prescription and registered nurse supervision as the medical point of view prevailed against people with disabilities. Also, PAS was often provided through agencies, and it limited service users' choice of using service, having no authority to choose how and when to receive that service. For example, due to the agencies' working hours, people who need this service during non-business hours had difficulty receiving adequate care (Dale, Brown, Phillips, Schore & Carlson, 2003). PAS is also limited to personal assistance supporting routine activities (i.g., bathing, eating, getting in and out of bed), so it doesn't cover having assistive technologies or home modifications that they need for their independent life. Gradual

changes, however, started from the state level to the federal by removing medical regulatory requirements and relaxing the scope of personal care.

In 1993, federal legislation released the medical requirements and made methods to authorize the personal care service. The same year, the Robert Wood Johnson Foundation (RWJF) granted a three-year project to a non-profit organization called Monadnock Developmental Services to seek a solution for deinstitutionalized community integrated and cost-effective service. As a result, they reported it helped decrease the cost by 12 percent, increase recipients' quality of life, and cut down the waiting list for services because people could use generic services to meet their needs.

In 1995, RWJF awarded a \$5 million grant to help states' reform efforts and pilot programs based on the achievements of the Monadnock project. Nine states (Hawaii, Kansas, Maryland, Michigan, Minnesota, Ohio, Texas, Vermont, and Wisconsin) received \$400,000 over three years, \$200,000 to five states for the first step of reform, and \$100,000 to four states for building a foundation with detailed plans and public engagement (RWJF, 2004). This funding helped participating states expand their self-directed services. It evolved into Medicaid-funded programs under section 1915(c) HCBS waiver using matched federal funds (NCD, 2013).

In 1998, RWJF and the U.S. Department of Health and Human Services (HHS) collaborated to launch the Cash and Counseling Demonstration program in Arkansas, Florida, and New Jersey. According to Mathematica's Policy Research evaluation, the program reduced the unmet needs, improved quality of life (participants and their caregivers), and participants experienced positive health outcomes. Regarding the funds, personal care spending was higher than other Medicaid-funded PAS recipients due to their additional spending than the original assignment during the demonstration period. The report explained that the program

would not cost more than traditional service if states designed and operated carefully, considering the savings from institutional and other long-term care costs (Mathematica, 2006).

In 1999, the federal government, represented by the Centers for Medicare and Medicaid Services(CMS), stated in the State Medicaid Manual that personal care can be directed by the beneficiary for the first time in federal policy. Moreover, in this manual, the scope of care is revised, including ADLs and IADLs, and relatives were allowed to be paid personal care providers if they are not legally liable relatives (NCD, 2013). In 2002 CMS issued an ‘Independence Plus’ waiver application template allowing states to offer self-directed services under section 1915(c) waiver and section 1115 waiver program. In 2002-2004, CMS and RWJF supported states to make them grow in SDS services through Real Choice System Change grants and Cash and Counseling development grants (CMS, 2002).

Components of SDS

State by state, the SDS operating policies vary, but there are shared components: person-centered planning, individual service plan, Individualized budget, and financial management services. SDS can be designed with or without the assistance of a selected representative, but the process needs to be directed by the participants, including a selection of assistance. SDS plan reflects the individual’s preferences, needs, and assistance to meet their goals. For service implementation, states are responsible for individualized assessment, risk assessment (including backup plans), establishing individual budgeting methods, evaluating participants’ expenditures, and plans for adjustment cases. Also, providing support to operate SDS is an essential duty that states must provide. Some states have support brokers who help participants as an agent of the program. The financial management services

(FMS) act as agents to help participants and their representatives with financial-related responsibilities, such as distributing payroll based on collected work timesheets, arranging employee insurance, and monitoring expenditures. It is the state's duty to make FMS available for participants who choose to participate in SDS. (Medicaid, n.d.).

Example of SDS: CDCS in Minnesota

To understand SDS in more detail, I look closely at Minnesota's SDS program, also called Consumer-Directed Community Service (CDCS). Minnesota is one of the pioneering jurisdictions in SDS. In 1989, the Dakota County Voucher Project, which later became known as SDS, was launched. It was one of the first efforts in the US to examine the feasibility of SDS. Based on this previous experience, in 1997, Minnesota became one of the first nine states to receive a grant from the Robert Wood Johnson Foundation (RWJF) to develop and implement SDS ("Self Determination," n.d.; RWJF, 2004).

Overview of CDCS. The CDCS program was created as a waived service option for people with developmental disabilities in early 1998, in conjunction with Minnesota's Self Determination Project (Minnesota Department of Human Services [MNDHS], 2005). CDCS is currently available through the Home and Community-Based Services (HCBS) and is supported by Minnesota Statutes 256.476, a 'consumer support program' (Minnesota Statutes of 2019). Minnesota's CDCS program provides employer and budget authority, and participants can hire (and pay) their relatives to care for them (MNDHS, 2020).

Eligibility. If a person is enrolled in one of the following programs, he/she is eligible to use CDCS.

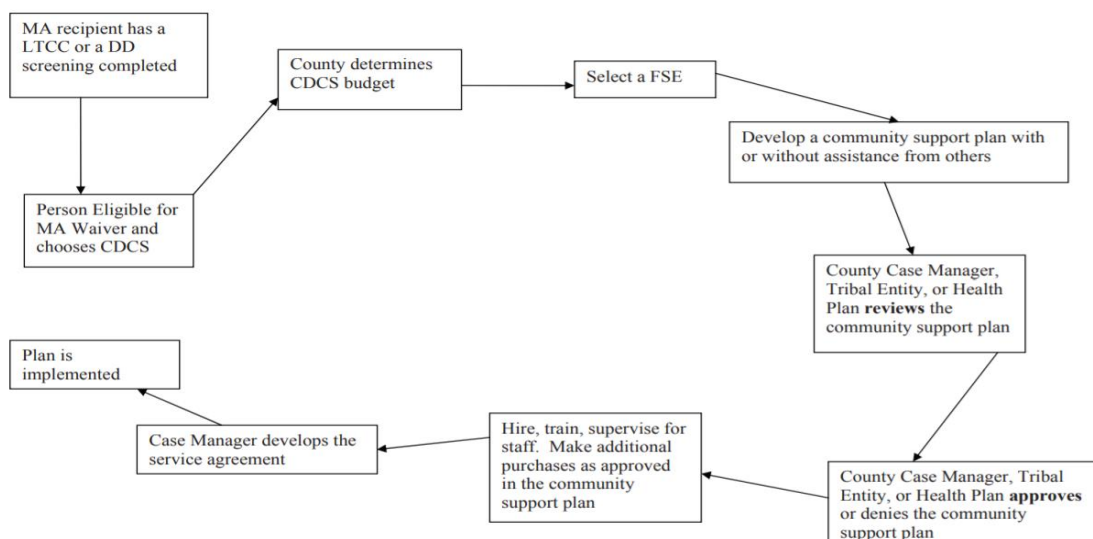
- Alternative Care (AC)

- Community Alternative Care (CAC) Waiver
- Community Alternatives for Disabled Individuals (CADI) Waiver
- Elderly Waiver (EW)
- Developmental Disabilities (DD) Waiver
- Minnesota Senior Health Options (MSHO)
- Traumatic Brain Injury (TBI) Waiver

Process of Using CDCS. People eligible for CDCS can make an informed choice about services that could meet their needs. A lead agency first provides information about self-direction and its roles and responsibilities, budget, available services, supports, and goods that can be purchased within a CDCS budget. After the person selects CDCS, the lead agency assigns a CDCS budget based on the assessment (“CDCS process,” n.d.).

Figure 1

Process of accessing and using CDCS



Source: The figure is adapted from “Consumer Directed Community Supports Consumer Handbook,” by MNDHS, 2005., p.22.

After a budget is decided, the person selects Financial Management Services (FMS) (Fiscal Support Entity (FSE) in the above figure). As previously discussed, participants must select an FMS to receive assistance. For example, FMS conducts background checks for the service providers hired by the participant.

Responsibilities of Stakeholders. During the process of the CDCS, participants, FMS providers, and the lead agency each have responsibilities.

Table 1

Responsibilities of stakeholders

Participant	FMS provider	Lead agency
<ul style="list-style-type: none"> • Communicate on an ongoing basis with the lead agency and FMS provider • Hire, train, monitor, and manage support workers • Monitor and evaluate services to ensure they are adequately meeting assessed needs • Make revisions to the CDCS Community Support Plan as needed (some modifications will require lead agency approval) • Review and monitor spending summaries • Review and submit support workers’ timesheets to the FMS provider. 	<ul style="list-style-type: none"> • Bill DHS or the managed care organization (MCO) • Provide monthly spending summaries to the person • Provide quarterly spending summaries to the lead agency • Provide monthly reports to the lead agency when over or under-spending occurs • Receive and process invoices for approved expenditures • Review and process support workers’ timesheets. 	<ul style="list-style-type: none"> • Help the person, as needed, succeed in the community and meet CDCS program and service requirements • Inform the FMS provider, support planner (if applicable), and person when it approves revision to the CDCS Community Support Plan • Meet with the person at a frequency outlined in his/her plan and according to his/her program requirements • Monitor and evaluate the plan’s implementation, including the person’s health, safety, and satisfaction, the plan’s effectiveness, and the possible need for revision • Review and monitor spending summaries.

Note. Contents of the table retrieved from “CDCS process and procedure” by the

MNDHS, 2021

The table above describes CDCS's view on distributing responsibilities between participants, providers, and agencies. The essential tasks such as hiring, managing, and monitoring support workers are participants' responsibilities. FMS manages the budget and billing between the lead agency and participants. Lead agencies help participants meet program requirements and review plans to secure their safety, satisfaction, and plan efficiency.

The goods and services must be categorized into the following service categories: (1) environmental modifications and provisions, (2) personal assistance, (3) self-direction support activities, and (4) treatment and training. *The environmental modifications* and provisions indicate services and goods to maintain a suitable physical environment. It helps the person live and participate in his community or support their health and safety. These include home modifications and assistive technology, among many others ("CDCS service," n.d.).

Personal assistance indicates services to help a person with her activities of daily living (ADLs), such as bathing or eating, and instrumental activities of daily living (IADLs), such as cooking or managing medication through hands-on assistance, prompts, and instruction. Personal assistance includes caregiver relief, help with mobility, skill-building, as well as help with ADLs and/or IADLs. People may also employ a personal care assistant (PCA), their spouse, or their parent (MNDHS,2005; "CDCS service," n.d.).

Self-direction support activities are another service category available under CDCS. This category concerns services or expenses incurred for administering CDCS, such as financial management services (FMS) provider fees or costs for worker recruitment. The person must choose Self-direction support activities outlined in the CDCS Community Support Plan ("Self-direction," n.d.). CDCS Community

Support Plan can be developed by participants or through CDCS support planning services which help a participant develop and implement CDCS Community Support Plan. This plan must identify all services, goods, and support to meet assessed needs, frequency and duration, price, backup services, desired outcome, and contact information (MNDHS,2005). FMS provides help with financial tasks for CDCS participants. FMS providers must be enrolled under Minnesota Health Care Programs (MHCP). Participants of CDCS must choose an FMS provider to bill the state for approved services (“Financial management,” n.d.).

The *treatment and training* category includes services that improve the person’s health and ability to live in the community. Treatment services are typically provided by people with specialized skills and credentials, such as nurses. In addition, caregivers, or even the participant, may receive funds under this category to pay for caregiving training. Training and education must be directly related to an identified need. County administrators monitor CDCS to ensure participants follow state and federal law and their health and safety (MNDHS, 2005).

Purpose of the Study

This study aims to evaluate and verify the SDS effectiveness using quantitative methods. Even though SDS programs have been around for decades, limited research has reported their outcomes to measure their effectiveness. Previous studies attest to SDS’s impact on people’s lives, but it needs to be updated continuously with recent data to verify the programs’ effectiveness. Also, sufficient data need to be used to conduct legitimate quantitative analysis.

My research aims to measure SDS's effect on the IDD population’s life and service experience using 2018-19 National Core Indicators data. I will conduct multivariate regression followed by propensity score matching analysis. Nine themes

were reclassified for better examination based on the literature review and variable availability (no data available for cost-saving).

Research Questions

The current research questions are:

1. Do participants with IDD age 18 or older who use SDS have a higher quality of life (employment, community inclusion, decision-making, relationship, and health) than those who do not?
2. Do participants with IDD age 18 or older who use SDS have higher service satisfaction than those who do not?

Hypotheses

The independent variable for the multivariate regression and propensity score matching analysis is whether a person participated in SDS. The dependent variables are quality of life (employment, community inclusion, decision-making, relationship, and health) and service satisfaction. The control variables are income, age, gender, race, the severity of a disability, rural/metropolitan, and type of residence, including interaction terms participation \times age and participation \times severity of a disability. A series of null hypotheses are as follows:

Hypotheses on Quality of Life (QoL).

H1. Among the IDD population age 18 or older, there is no significant difference between the participants of SDS and those who do not participate regarding

H1-1. employment,

H1-2. community inclusion,

H1-3. decision-making,

H1-4. relationships and

H1-5. BMI

H1-6. Health

Hypothesis on Service Satisfaction (SS).

H2. Among the IDD population age 18 or older, there is no significant difference between the participants of SDS and those who do not participate regarding service satisfaction in general.

Theoretical Perspectives: Self-Determination Theory

In this chapter, I will explain self-determination theory (SDT) as a theoretical framework to motivate self-directed services and explain why they are expected to improve the well-being of their participants. I will discuss different types of motivations and the basic psychological needs they require.

What is Self-Determination Theory?

Self-Determination Theory studies motivation and has contributed to understanding how individuals regulate their behavior. According to this theory, whether a particular behavior persists over time depends on motivation. Specifically, the type of motivation, and the rationale behind it, are believed to play a critical role. (Hagger et al., 2014). SDT focuses on the type and quality of the motivation rather than the amount, saying that type and quality are essential to predict outcomes such as psychological health, well-being, and effective performance (Deci & Ryan, 2008).

Types of Motivations: Autonomous, Controlled Motivation and Amotivation

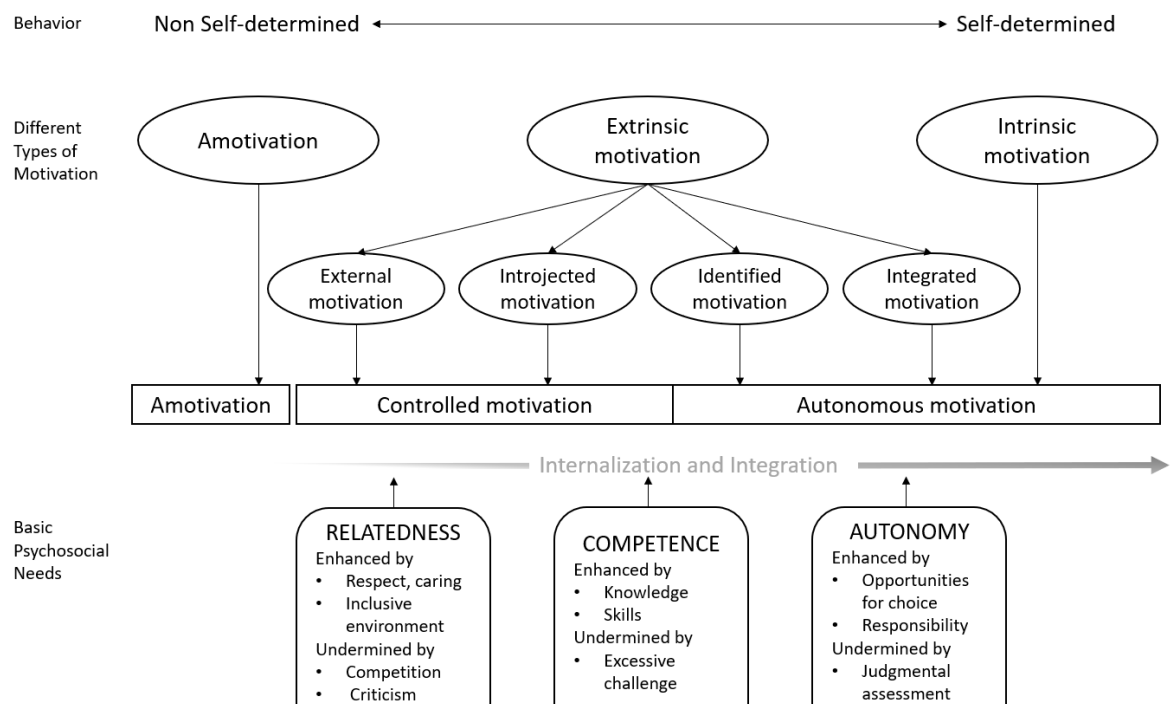
Understanding motivation is essential to understand the impact SDS can have on its participants. To begin, we will discuss three types of motivation: autonomous, controlled, and amotivation. According to Hagger et. al., *autonomous motivation is defined as engaging in a behavior because it is perceived to be consistent with intrinsic goals*; meanwhile, *controlled motivation reflects engaging in behaviors for externally referenced reasons such as to gain rewards or perceived approval.* (Hagger

et al., 2014). In contrast, Banerjee and Halder (2021) define amotivation as having a complete absence of self-determination because the subjects do not have any intrinsic or extrinsic reason to participate because the action does not produce desired outcomes. (Banerjee & Halder, 2021)

The following diagram provides a visual illustration of the different types of motivations, alongside their degree of self-determination, increasing to the right.

Figure 2

Self-determination theory



Source: Adapted from Kadir et al. (2020), Ryan & Deci (2000), and Cook & Artino (2016).

Types of Extrinsic Motivation

As we can see from the diagram, extrinsic motivation is the most complex, as it comes in four different forms, with increasing levels of autonomy as we move to the

right. These four types of extrinsic motivation emphasize the degree to which a value or rule has been internalized and possibly accepted by the individual. In the next paragraph, let's discuss each type, starting from the least autonomous.

First, external motivation pertains to behaviors performed due to external incentives, like a reward or punishment (Deci & Ryan, 2000), and has the lowest level of autonomy. Next on the list is introjected motivation, which drives people to partially internalize an action to get approval and avoid shame, guilt, or anxiety (Deci & Ryan, 2008). Third is identified motivation, in which an individual adopts a behavior because they recognize it as valuable. Fourth and last is integrated motivation, which exhibits the highest autonomy among extrinsic motivations. Integrated motivation means the behavior is driven by the individual's values and needs. The primary difference between integrated motivation and intrinsic motivation is that it is still driven by rewards rather than the act itself (Ryan & Deci, 2000).

Basic Psychological Needs: Autonomy, Competence, and Relatedness

Deci & Ryan (2000) found that autonomy, competence, and relatedness are prerequisites for intrinsic motivation, psychological well-being, and optimal functioning. In this context, autonomy means having the ability to make decisions free from judgment or control; competence means having the skills and knowledge to engage with their surroundings; and relatedness means having a sense of belonging with others, being cared for, and having the ability to care for others (Ryan & Deci, 2017). Fulfilling these basic psychological needs allows for intrinsic motivation to develop (Cook & Artino, 2016).

These psychological needs are relevant to self-determination because they impact motivation. For example, feelings of inadequacy or self-confidence can lead

people to believe their actions will not positively impact them, resulting in amotivation (Deci & Ryan, 2008; Ryan, 1995; Bandura, 1986; Seligman, 1975).

Previous Studies on Self-Determination and Its Impact

Motivation and its impact have been studied in many contexts, such as psychology and social work. These studies have shown that motivation with higher degrees of autonomy produces better outcomes for health and quality of life, among others.

For example, a study by DeCaro, Janessen, and Lee (2015) measured the impact of two significant interventions with regard to voting participation and enforcement. They enforced voting to different degrees and found that the group given the highest degree of autonomy cooperated the most. This result can be interpreted as saying that higher degrees of autonomy increase the likelihood a behavior will be accepted and integrated into their values. In fact, according to Ryan & Deci (2017), groups that feel they have no chance to express themselves are more likely to exhibit controlled motivation or amotivation.

The relationship between autonomy and positive health outcomes has also been studied. For example, Ng et al. (2012) used meta-analysis to show that a healthcare setting that fosters self-governance is positively associated with mental and physical well-being. Conversely, controlled forms of regulation were found to have a negative impact on mental health. This study's findings are significant in supporting empowering service users with authority to manage their services, promoting their overall well-being. In the case of sports, Kimberley et al. (2011) found that coaches who exhibit excessive control over athletes may harm their psychological well-being, resulting in burnout, depression, and physical symptoms. In contrast, athletes who are given autonomy tend to experience positive outcomes, such as increased vitality.

The relationship between interpersonal relationships and the three basic psychological needs required for self-determination was studied by Patrick, Knee, Canevello, and Lonsbary (2007). Their study found that people experience higher levels of relationship satisfaction when their basic psychological needs are fulfilled. Meanwhile, O'Shea, Isadore, and Galvan (2023) examined how the perceived level of support for the basic psychological needs related to the quality of life of college students with disabilities. They concluded that supporting students' psychological needs of autonomy, competence, and relatedness increased their likelihood of experiencing higher levels of personal satisfaction with their health and quality of life.

How is Self Determination Theory related to Self Directed Services?

Self-directed services offer participants greater control and authority over the services they receive – which naturally increases their autonomy and self-determination. The studies we have cited connect self-determination with positive outcomes in health, relationships, and quality of life. As a result, it is reasonable to expect that self-directed services could result in similar benefits, provided that the basic psychological needs listed above (competence, relatedness, and autonomy) are met. One crucial limitation worth discussing is that our study uses secondary data, which does not provide information about relatedness and competence. As a result, we cannot directly establish whether the basic psychological needs of SDT are satisfied.

It should also be noted that although SDS provides more autonomy, it still has policies that need to be adhered to, which can still limit participant's autonomy to some degree and possibly impact their motivation as well. In fact, previous studies have found that choice, acknowledgment, and opportunities for self-direction facilitate intrinsic motivation, while imposed goals, given directions, and pressured evaluation diminish intrinsic motivation (Ryan & Deci, 2000).

Chapter Two

Literature Review

The university's library search engine and Google Scholar were used to identify published studies using the keywords 'self-directed service' or 'consumer-directed services.' Fourteen studies were identified, both quantitative and qualitative, including empirical primary data collection studies, a secondary data analysis, and a literature review.

There are various assessments of the success of the SDS program. Previous research found that SDS increased decision-making opportunities, service satisfaction, quality of life, relationship with a service provider, empowerment, cost-saving, health and safety, community inclusion, and reduced unmet needs. However, due to its nature as a participant-managing service, SDS still has some ease of use issues, such as the burden of administrative tasks, a large amount of paperwork, and a lack of information to service participants or their guardians. These problems are also observed among administrative staff who supports participants. The policy guidelines changed frequently; many administrators found them unclear or subjective. The staff retention problems also affect the efficiency of service delivery and service satisfaction.

Table 2 summarizes the studies used in the following benefits and challenges sections. Although studies' focused topics are different, outcomes give us insights into the benefits and limitations of SDS. The description of the studies includes the benefits and challenges of SDS, including the method, findings, and research strengths and limitations.

Table 2

Description of studies

First author	Pub. Date	Study focus	Research method	Group studied	Data source	Findings		Strengths	Limitations
						Benefits	Challenges		
Hall-Lande	2012	Perspective on SDS	QUAL	33 Minnesota county administrators	Semi-structured interview	<ul style="list-style-type: none"> • Changes in philosophy • Improved quality of life • Increased quality of staff • Cost-saving 	<ul style="list-style-type: none"> • Lack of clear policy • Program changes • Monitor quality and outcomes 	Interview questions were reviewed by staff from the Department of Human Services, and two county administrators (high-content validity)	Lack of explanation on sample characteristics, since they disclose there was a significant variation in the number of service participants between counties
Kendall	2013	Impact of control and choice	QUAL	Six professionals from a local authority social care transformation team, 5 from a user-led organization, and Two national experts	Semi-structured interview	<ul style="list-style-type: none"> • Empowerment (power shift, and increased authority (control and choice)) 	<ul style="list-style-type: none"> • Struggle to exercise decision making (lack of practice, complexity, and too broad options) • Restriction prevent SDS from implementing its original intention (Approval required, low flexibility of using budget, and lack of trust) • Decreased autonomy by being managed by service participants' family members • The economic and political climate impact on SDS • Resistance to change 	Not only analyze the perspective of professionals, but also analyze in terms of individualism, and collectivism	<p>Focused negative nature of SDS</p> <p>Small scale study</p>
Foster	2003	Effects of SDS	QUANT	1,739 service enrollees (or their representatives)	Computer-assisted telephone survey	<ul style="list-style-type: none"> • Improved satisfaction • Reduced unmet needs • Contrary to common concerns, SDS was proved as safe (in terms of health status) as agency-directed care 		One of few quantitative study	The high rate of proxy (71% for the elderly and 29% for the nonelderly) could affect the results
Gross	2013	Catalysts for participating SDS as parents/guardians of adults with significant intellectual and developmental	QUAL	4 SIDD's support members: 22 people (guardian, parents, service providers, case managers, or program directors)	Three group interviews and three individual interviews	<ul style="list-style-type: none"> • Individualized supports and services • Service provider management • Individualized budget (flexibility of managing the service, and it allows obtaining high-quality service provider 	<ul style="list-style-type: none"> • Finding a reliable service provider 	Interview participants were the circle of support members who are working directly, compared to the county-level administrator	Among four interview participants, two participants' relatives with disabilities have overlapped support members This could limit case variety, sharing

Table 2

Description of studies

First author	Pub. Date	Study focus	Research method	Group studied	Data source	Findings		Strengths	Limitations
						Benefits	Challenges		
		disabilities (SIDD)				by paying more than agency paid) • Improved independent behavior and communication • Improved general well-being • Improved health and safety • Increased community participation and social inclusion		These groups of people are proper to discuss how SDS changes people with disabilities' life (benefits of SDS)	similar experiences
Vinton	2010	Caregivers' perceptions during SDS pilot program	QUANT+ QUAL	Quant: 50 caregivers and three project coordinators Qual: 44 individuals (caregivers, consumers , and support coordinators), three project coordinators	Survey (pre and post-experience after six months of participation), interview, and focus group interview (7 times)	• Survey participants reported that they experienced an increasing level of choice over services as well as the goodness of fit and satisfaction • Hiring service providers who are familiar with consumer and their family • Having flexibility by managing the service and budget • Family members could use the time for themselves (e.g., working or time off) by hiring and paying people who can care for their relatives with disabilities	• Caregivers' confidence in their relatives prevent a consumer from choosing what they want • Caregivers preferred to hire family members or friends instead of other service providers • Complicated and new systems require explicit instruction for parents and service providers	Pre and post-survey results (QUANT) were supported by focus group interviews and individual interviews (QUAL)	The Pre and post surveys for the quantitative analysis were conducted with a small number of people (53 people), and the term time between the 'pre' and 'post' survey was too short of understanding this new system
Mitchell	2015	Facilitators and barriers to choice in SDS	QUAL	Archived data: 6 young people with disability and their parents Primary interviews: stakeholders (policy maker, coordinator of a national transitions forum, support service manager,	Archived interview data + primary interviews	• In a rural area, having an individual budget and recruiting service provider was helpful to receive trustworthy cares • Having choice start from one's interests and aptitudes is expected to achieve a positive outcome	• Hard for young people with disabilities to make a decision without trusted people's help • Lack of accessible and trustworthy information • No clear pathway from child services to adult services • The choice needs to be approved by gatekeepers(social workers) • Individual's communication and cognitive abilities are	Main themes were saturated from data, including interviewees with disabilities	The archived interview data was not focused on SDS, but about choice and control in general, over the life, although the stakeholders for the primary interviews were sampled related to SDS

Table 2

Description of studies

First author	Pub. Date	Study focus	Research method	Group studied	Data source	Findings		Strengths	Limitations
						Benefits	Challenges		
				social worker, etc.)			important factors for decision making and need to be practiced		
DeCarlo	2019	Successes, challenges, and future direction of SDS	QUAL	58 program director and HCBS administrators (service directors, deputy directors, state Medicaid agency coordinators, waiver administrators, self-direction administrators, and state policy analysts, representing	Semi-structured interviews	<ul style="list-style-type: none"> • Opportunities for self-determination • Improved support relationship between the service provider and IDD 	<ul style="list-style-type: none"> • Restructuring case manager relationships • Balancing flexibility and monitoring of using public money 	Administrators from 34 of 42 states that operated SDS in 2019 participated in the interview	The perspectives of people with disabilities were missing
Timberlake	2014	Parents' perceptions of SDS	QUAL	14 families receiving SDS	Semi-structured interviews	<ul style="list-style-type: none"> • Choosing what they feel comfortable with and work with someone who had a prior relationship • Parent advocacy and empowerment was strengthened by having authority 	<ul style="list-style-type: none"> • Families reported anxiety about making good choices • Need some help to support families' decision making 	Parents' perspective of SDS	The perspective of people with disabilities was missing
Warfield	2014	Family well-being in SDS	QUANT	74 SDS participants' family members (experienced at least 6months)	Survey	<ul style="list-style-type: none"> • Low levels of parenting stress • Better health condition (parents) • Positive impact on family functioning 		One of few quantitative research Focused informal caregivers' well-being	Small sample size
Bogenschutz	2019	Fiscal perspective of SDS	QUAL	54 administrators	Semi-structured interviews	<ul style="list-style-type: none"> • Opportunity for self-determination • Cost-saving (removing middle money. Provider agency is not an intermediary administrator in SDS) 	<ul style="list-style-type: none"> • Balancing between flexibility and monitoring of using public money • Political environment affect SDS funding status 	Focused government administrator's point of view to understand perspective in terms of operating a person-centered	The perspective of people with disabilities and other support groups were missing

Table 2

Description of studies

First author	Pub. Date	Study focus	Research method	Group studied	Data source	Findings		Strengths	Limitations
						Benefits	Challenges		
						<ul style="list-style-type: none"> • SDS participants managed budgets more carefully to use efficiently than service agencies 	<ul style="list-style-type: none"> • Cost-saving (put annual caps to limit spending on certain goods and services) 	service	
Kim	2020	Person-centered service in SDS	QUAL	28 SDS stakeholders (assessor, case manager, support planner, fiscal management services)	Semi-structured interviews	<ul style="list-style-type: none"> • The flexibility that allows participants to create their plan • Family members can be hired as a service provider 	<ul style="list-style-type: none"> • Flexibility could be a problem by losing consistency, control and creating confusion. It makes case managers feel less confident about this services' policy • The budget is not sufficient as much as an adult can live, paying existing services 	Not just interviewed diverse stakeholders but identified and clarified the responsibility of each stakeholder	Although this study was published in 2020, the methods and results are redundant as previous studies which interviewed stakeholders
Spaulding-Givens	2019	Benefits and barriers of SDS	QUAL	18 SDS participants	Semi-structured interviews	<ul style="list-style-type: none"> • Financial help • Mental wellness and stability • Opportunities to experiences • Improved self-esteem by managing budget • Physical well-being 	<ul style="list-style-type: none"> • Lack of clarity and flexibility • Complex purchasing procedures • Budget management can be a burden for someone who has lack of support 	One of few studies which interviewed participants of SDS	18 participants of 200 individuals enrolled in SDS likely are not representative of the program experience
Harkes	2012	Research-based evidence in the UK	QUAL	17 papers	Literature review		<ul style="list-style-type: none"> • Lack of information to understand how it works for people with disabilities • Practitioner reluctance to promote SDS since presumed severity of help for participation or concerns posing them vulnerable to financial abuse • Complex and burden of paperwork 	Explored SDS service-related literature to identify existing barriers within the service The trend of studies focusing on people with intellectual disabilities	None of the reviewed papers studied only intellectual disabilities, which is the main subject of this article
Brown	2018	Parent perspectives on SDS	QUAL	24 parents of people with IDD who were enrolled in SDS	Semi-structured interviews		<ul style="list-style-type: none"> • Managing service provider is challenging • Burden of paperwork • Budget restrictions and approval processes prevent people from getting needs on time 	Reflexivity described the three authors' close experiences related to SDS	Focused negative side of the SDS

Benefits of Self-Directed Service

Individualized Services - Improving Quality of Life, Health, and Safety

Research on the benefits of SDS include self-determination as crucial to improving life quality, and it was the most commonly cited benefit among reviewed papers (Hall-Lande, Hewitt, Bogenschutz, & Laliberte, 2012; Foster, Brown, Phillips, Schore, & Carlson, 2003; Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2013; Vinton, 2010; Mitchell, 2015; Warfield, Chiri, Leutz, & Timberlake, 2014; Spaulding-Givens, Hughes, & Lacasse, 2019) A study conducted in 2019 provides supporting evidence for the claim that having authority over one's life is a way to achieve this self-determination (Abery et al., 2019). The 'President's New Freedom Commission on Mental Health' (2003) report recommended community-based service provisions. A consumer-directed approach was considered critical (Hogan et al., 2003). The improved life through SDS was measured quantitatively, examining survey data (using a logit model). They found it decreased unmet needs while health and safety metrics were unaffected.

Hall-Lande et al. (2012) found that many county directors described that introducing self-directed support encourages individualized service plans. They can meet the needs of people with intellectual disabilities effectively by improving their quality of life. Gross et al. (2013) conducted a case study about 'how the experiences of parents/guardians influence their decisions to participate in direct services for an adult with a significant intellectual and developmental disability (SIDD).' The authors found that people experienced individualized services through group and individual interviews. Compared to agency-directed services, which generally served larger groups, self-direction helped them receive services that reflected a person's particular needs. Gross et al. (2013) also identified that self-directed service improves health and safety for adults with significant intellectual and developmental disabilities. They found consistent,

individualized support from direct service providers ensures their health by making special diets for individuals and caring for oral health or hygiene through one-on-one support, compared to living in a group home (Gross et al., 2013).

Service Provider Management - Increased Satisfaction with Service

Participants identified service provider management as a benefit of SDS, increasing service satisfaction. Seven studies found that service provider management was reported as frequently as individualized services as increasing service satisfaction (Foster, Brown, Phillips, Schore, & Carlson, 2003; Gross et al., 2013; Vinton, 2010; Mitchell, 2015; DeCarlo, Bogenschutz, Hall-Lande, & Hewitt, 2019; Timberlake et al., 2014; Kim, 2020). Hall-Lande et al.(2012) indicated that administrators perceived participants and their families as having employee authority show a high level of satisfaction and authority in managing the staff. Timberlake, Leutz, Warfield, and Chiri (2014) explored parents' experiences with self-directed services, particularly the responsibilities of choice. Their qualitative analyses of the interviews of fourteen families receiving self-directed services found that they feel comfortable hiring someone they already knew or had a relationship with their child with disabilities. It revealed that family members are not just satisfied with the authority of staff management but also feel free from judging by unknown outsiders. Gross et al. (2013) study also mentioned that parents or guardians are trying to find service providers who feel comfortable and confident in caring for their children. Hence, the ability to hire familiar providers increases service satisfaction.

In many cases, the service providers had a lengthy relationship with their son/daughter with SIDD before providing services through a self-directed program (Gross et al., 2013). In both studies, Timberlake et al. (2014), and Gross et al. (2013), authors identified that parents prioritized the importance of interpersonal relationships. Warfield, Chiri, Leutz, and Timberlake (2014) surveyed families participating in self-directed

services focusing on coordination with providers, parenting stress, and the impact of services. In the regression analysis results, one of the main findings was a higher level of interpersonal relationships, measuring communication and relationship dimensions, and significantly lower levels of parenting stress.

Individualized Budget

The third most common benefit cited was having an individualized budget (Gross, 2012; Vinton, 2010; Mitchell, 2015; Bogenschutz, DeCarlo, Hall-Lande, & Hewitt, 2019; SpauldingGivens et al., 2019). Participants of self-directed services satisfied the individualized budget feature because it allows flexibility to meet their needs; “the level and type of support could be adjusted at any time the individual’s needs, or preferences changed” (Gross et al., 2013, p. 94). Gross et al. (2013) also remarked that with the flexibility of the budget, participants have more power to negotiate service providers’ wage rates. Interview participants, support members, and parents averred that they experienced minimal turnover of service providers through the self-direction program. One SIDD’s guardian said, “I’m able to pay our staff enough that makes it a real job. [At the sheltered workshop], by the time staff people get paid, you’re looking at such a low [pay rate]... you could go to McDonald’s and make better money... with a higher wage, you get better quality... You’re not going to get somebody at [the sheltered workshop] to stay there for long... at \$7.50 an hour” (p.94).

Choice-Opportunities for Self-Determination

Literature on SDS benefits emphasizes that support can improve self-determination and allow various service options. Vinton (2010) conducted a pre-and post-test survey to examine the perception of choice over agency-directed services. Caregivers were asked how much they agreed they had a choice over services. Compared to before participating in self-directed services, participants’ perceptions about ‘choice’ were improved,

indicating that they have a choice over service providers, types of services, or how services are provided. Mitchell (2015) explored archived interview data in the UK against young people with disabilities who participate in self-directed service to understand how to facilitate informed choice. One of the findings was the importance of support from trusted others. For example, informed choice works well in a rural setting where the individual has strong family networks (Mitchell, 2015).

DeCarlo et al. (2019) conducted a qualitative study, interviewing 34 state administrators out of 42 states that currently operate self-directed service options. A thematic analysis was applied to study how program administrators describe the strengths of self-direction service. They found opportunities for individuals with IDD and their family members to express self-determination. One participant said, “(self-direction) really opens the door to that menu of choices, [so] it’s really very comprehensive” (DeCarlo et al., 2019, p. 14). They also pointed out that participants agreed that ‘choice comes with the responsibility’ and described that responsibility decreases service issues (DeCarlo et al., 2019).

Change in the Service Philosophy - from Service Provider to Client

Research suggests that self-directed services have changed the prevailing service philosophy from provider-centered to participant-centered services. For example, Hall-Lande, Hewitt, Bogenschutz, and LaLiberte (2012) explored Minnesota county directors’ perspectives on benefits, challenges, and suggestions for Minnesota’s self-directed service based on semi-structured interviews. One of the benefits was a positive change in philosophy. As one county administrator said, “CDCS is all about the person... traditional services are all about the service provider” (p. 250). In Kendall and Cameron’s (2013) study, authors interviewed administrators to explore administrators’ perceptions of choice and control in self-directed service. Most participants described choice and control as an

empowerment factor facilitating a power shift. One of the participants explained, “Empowerment occurs when service users switch from being controlled to having control” (Kendall & Cameron, 2013, p.267).

Decreased Challenging Behaviors

Challenging behaviors of people with disabilities were reduced for those who participated in self-directed programs. Several administrators noted that problematic behavior was significantly reduced, allowing for increased time in the community (Hall-Lande et al., 2012). It might be because they can choose a service provider with a good relationship with their children. A parent said, “The boys love [provider] and wish he’d never leave” (Timberlake et al., 2014).

Parent Empowerment

Managing the self-directed service for their children, such as hiring, managing, and replacing support providers, described becoming more confident and empowered. In the Timberlake et al. (2014) study, parents said that they could grow their knowledge and confidence in choosing and managing services, saying, “I surprised myself as a parent... I’m proud that [the child]’s doing well. I think I’m a very good parent” (Timberlake et al., 2014). Similarly, Gross et al. (2013) also highlighted that many parents initially found directing the services challenging, but most felt it got easier as they became more experienced.

Community-Based Service

According to National Core Indicators (NCI) Consumer Survey data, which surveyed individuals with a developmental disability who received at least one service between 2002 and 2003, 34.7% of people who participated in a consumer-directed budget program lived with parents or relatives, while 21.3% lived independently. This data also indicated that participants of these consumer-directed programs were more likely to be in

control of their lives (NCI, 2004, pp. 2-4). One participant moved from agency-directed to participant-directed services. Previously he ran out from the group home and roamed the city alone, but now a service provider accompanies him to go out for his preferred community activities (Gross et al., 2013). Individualized, one-on-one support helps them live in the community much safer while pursuing their preferences.

Cost-Effectiveness

County administrators indicated that the county could save much money with the self-directed option, with service participants and their families greater awareness of their service budget (Hall-Lande et al., 2012). One county manager said, “Families direct their resources. They are good shoppers, very responsible with their own money. They monitor quality more closely and think of it as their own money, so they are more careful” (Hall-Lande et al., 2012). Another explanation will be the lower overhead and administrative costs. The self-direction program was observed to have cost savings over traditional agency-directed services because it can knock out some administrative costs and use those costs for program participants directly (Bogenschutz et al., 2019). Spending caps were among the most common cost-saving factors. It varies from state to state, but the concept limits spending for self-directed services. For example, there were annual caps for entire self-direction services in some states, and in other states, they have sub-caps to limit spending in specific categories of services (Bogenschutz et al., 2019).

Challenges of Self-Directed Service

Restriction on Choice

The most common challenge of self-directed services mentioned in the literature is the restriction on choice (Kendall & Cameron, 2013; Mitchell, 2015; DeCarlo et al., 2019; Bogenschutz, 2019; Brown, 2018). Under SDS, budget authority rests on the participant, but administrators are still responsible for approving a spending plan ensuring fair use of

taxpayer money. Bogenschutz et al. (2019)'s interviews with administrators also found the dilemma between securing the money and encouraging participants to make their choice based on their needs, saying: "it really initially started as a self-determination movement, not as a self-direction movement and when that term self-direction came about and really began to focus more on the fiscal authority we really struggled with that ... it took away from the person centeredness and ... really got us into just focusing on how was the money spent and were people doing it in ways that could be justified through the scrutiny of that public lens"(p.163).

Similarly, participants demonstrate that making choices is interrupted by a perceived disconnect between purchase and assessed needs, limiting responsiveness, flexibility, and creativity. Spaulding-Givens et al. (2019) interviewed 18 individuals enrolled in self-directed service to explore the barriers of choice. One participant explained, "Sometimes when they're saying 'no' to things but they're not realizing how it really connects to the goal" (p. 337). Another Mitchell's (2015) study participant also said, "If you want to go out for an evening... then you should be allowed to do so. You are still obstructed by gatekeepers [from social work] who say actually you can't just do that; we have to make sure it's done properly" (p. 196).

Need for a Clear Direction and Policy Guidelines

Another comment was the lack of clarity of SDS policy (Hall-Lande et al., 2012; Vinton, 2010; Michell, 2015; Spaulding-Givens et al., 2019; Harkes, Brown & Horsburgh, 2012). HallLande et al. (2012) found that county-level administrators perceive the current guidelines for self-directed service as unclear. The interview participants almost unanimously agreed that this unclear or continually changing policy affects the effective implementation of the program. Another challenge was the variation of implementation across counties. Among the counties implementing self-directed service, no uniform

guidelines about the program's operation existed. One participant described, "If it is a statewide program that is supposed to be uniform in all counties you can't have some counties doing one thing and others doing other things, there has to be some uniformity" (Hall-Lande et al., 2012, p. 252). Another said, "The difficulty in that was that each county tried to come up with their own policies and procedures and it was shifting ground all of the time, it was frustration for the workers. Suddenly we realized that the county could come up with its own policies and procedures and not pay attention to anything else... We kind of just did our thing until we got some direction" (Hall-Lande et al., 2012, p. 252). Kim's study (2020) states these inconsistent program policies still happen among Minnesota counties. The author pointed out that it could increase the confusion of program participants and discourage the staff from recommending this service.

Spaulding-Givens et al. (2019)'s study also observed this policy ambiguity problem. The authors interviewed 18 self-directed service participants to examine the purchasing decisions. They found that the lack of clarity in guidelines makes it difficult to make decisions. There is some ambiguity about the purchase frequency and list of permissible items. Participants said, "what is the one time? Is it really just one time forever?" (p.336), explaining that while some purchases are permitted on a one-time basis, many are not allowed as recurring purchases. This is not a context-reflected rule because these restrictive purchases are necessary to honor participants' perspectives (Spaulding-Givens et al., 2019).

The Burden of Administrative Tasks - Complicated Procedures Followed by a Volume of Paperwork

Several studies found that complicated purchasing procedures make it difficult for participants to manage self-directed services (Spaulding-Givens et al., 2019; Harke et al., 2012; Brown et al., 2018). Participants explained how hard it is to manage. For example,

they need to pay for services with their money and wait for reimbursement. For the purchase, they need approval by submitting multiple estimates and submit receipts within deadlines (Spaulding-Givens et al., 2019).

Brown et al. (2018) found that paperwork is a massive caregiver burden. “The paperwork is a huge thing. If I wasn’t in my full capacity, the paperwork is daunting” (p. 353). The other parents mentioned the process of submitting paperwork was particularly burdensome. “It’s not online. It’s all hand-done, and if you make an error... they call you, and you better get over to [the program office]... which is a 45-minute trip for us... and correct your timesheet” (p.353). The process was much more manageable for some parents whose states offer online submission channels. “I go on the computer and enter my time, then review all my staff time every two weeks. [If] I miss something, they’ll come back to me, and then I notify my employees... and they have to go back in and edit them themselves” (p. 353)

Lack of Information

A systematic review by Harkes, Brown, and Horsburgh (2014) explored literature on the UK's self-directed service to learn accessibility, barriers for people with intellectual disabilities, and strategies to overcome these barriers. One fundamental challenge was understanding the degree to which participants and social workers understand the policy. They first need to determine how participants understand self-determination and readiness as a decision-maker. In the case of social workers, it was reported that they need more training since they also don’t have a good awareness of the service as much as they can guide participants to the best use (Harkes et al., 2014).

Concerns Around Making “Good” Choices

Although some SDS participants or their guardians felt confident managing their service, others showed less confidence in directing the service. In Timberland et al. (2014)

study, all but three of fourteen answered that they needed help for this waiver-directing program or passively followed the professionals' opinion, such as a doctor, therapist, or service broker. One mentioned, "I like that [broker] takes care of it. It's overwhelming to me... stressful situations get me upset. I couldn't do it [waiver program] without help (Timberlake et al., 2014).

Another concern raised by administrators was planning for safety and health needs. Although participants have the authority to plan the services, individuals' essential requirements for safety and health are crucial. Vinton (2010) interviewed three project coordinators following the pre-and post-test survey about choice. They responded to open-ended questions about the program's strengths and weaknesses. Among the list of weaknesses, the author pointed out: "Families insisted on providing most of the care, but consumers needed other services" (p. 219).

Staffing and Management Issues

Participants or their parents also show concerns about finding a service provider they feel comfortable with. As discussed above, if they can hire close people, there are some expected benefits, but if they cannot, they are apprehensive about hiring and trusting an unfamiliar person (Gross et al., 2013). This issue also mentioned a study that interviewed county administrators who monitor the service to ensure safety. In traditional services, workers are required to attend some general training to support a service program. However, participants are responsible for hiring, training, or managing the schedule in self-directed service. Administrators said they tried to be more careful when approving the service plan (HallLande et al., 2012; DeCarlo et al., 2019). In rural areas, the lack of service providers was one of the difficulties (Mitchell, 2015).

Brown, Harry, and Mahoney (2018) interviewed 26 parents of adult children with IDD enrolled in a self-directed program in five US states to understand their experiences

navigating this program. Among the findings, one central theme was managing the service providers. Parents experienced finding, training, scheduling, and/or retaining service providers was challenging. They said that even though there are websites to search for providers, getting staff was the most challenging part, and it was primarily on their own. One parent said, “I think it’s finding people and training people that’s such a big thing. And then it’s that you’re repeating that a lot. I mean ... it’s not a lifetime job for most people... it’s just a lot of work and effort to do that” (Brown, Harry & Mahoney, 2018, p.353). Another difficult task was scheduling workers—some experienced difficulties finding backup help whenever staff changed the schedule. “If somebody doesn’t show up, I’m the backup person. And so that really cuts into my ability to be able to work in a typical work environment” (Brown, Harry & Mahoney, 2018, p. 353)

Another challenge was monitoring service providers. In traditional services, training, licensure, and background checks were more straightforward. Hall-Lande et al. (2012)’s interviews with county directors also showed these concerns, indicating that self-directed service providers do not receive the general training typically offered in traditional systems. The flexibility of this service makes social workers more careful in scrutinizing tasks because, under the self-directed service, family members and friends can be paid as a provider. It also raised issues about boundaries. As one county director noted, “...traditional boundaries are generally clear in licensed providers. It is different with parents as paid providers. Where does the staff role start and stop and being a parent begin and end?”

Ability to Make Decisions

Participation in SDS requires individuals to make difficult decisions. Yet some participants, for example, those with intellectual disabilities, have had limited experience in making decisions because their guardians have made most decisions for them

throughout their lives. Spaulding-Givens et al. (2019)'s participant interviews found that their symptoms negatively affect participants' decision-making process. Mitchell (2015)'s research similarly pointed out that individuals' ability to make their own decisions is essential for this program's success. The individual's communication and cognitive abilities were seen as factors that impact their choice. One administrator said, "...people need to have some choosing ability and I think a lot of young people with disability don't because somebody may be only able to choose what clothes to put on..." (p. 196)

Most research on SDS has focused on a qualitative analysis of SDS experiences, but the effectiveness of SDS policies, which could be measured quantitatively, has not received much attention. One of the data which scholars have frequently used is the Cash and Counseling Demonstration and Evaluation (1999-2003). This data was collected by Brown, Carlson, Dale, Foster, Philips, and Schore (2007) using random assignment, which is the best possible scenario for treatment outcome research since it allows control over any unexpected sources of variation (Shadish, Cook & Campbell, 2002). To follow up on these previous researchers' commitment to the outcome of SDS participation and evaluate SDS's up-to-date status, continuous research on the outcome of the service with recent data is necessary.

Chapter Three

Methods

Data Source

This dissertation used 2018-19 National Core Indicators (NCI) data for quantitative analysis, which was obtained through the Institute on Community Integration (ICI) at the University of Minnesota. NCI measures the outcomes of services for adults with IDD across the United States. The core indicators address key concerns such as employment, community inclusion, choice, relationships, and health, allowing the evaluation of the

outcome of the services. Indicators are measured by several survey questions. For example, the indicator ‘employment (“people have support to find and maintain community integrated employment” p.3 (NCI IPS Work, 2019)’ is measured by a series of survey questions about current employment. The NCI survey comprises in-person, family, and staff stability surveys.

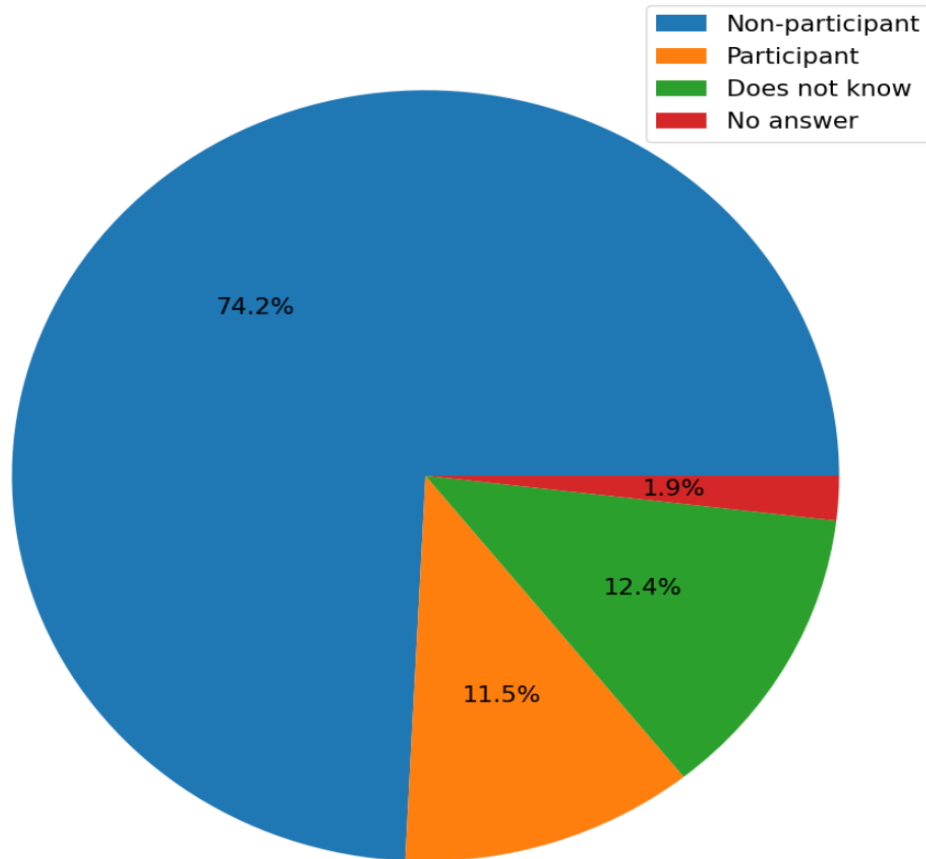
In this study, an in-person survey (IPS) was used to understand how SDS impacts the respondents’ quality of life and service satisfaction. In the 2018-19 NCI IPS, 37 states participated and submitted data by June 30, 2018. Broadly speaking, these questions can be divided into subjective questions and fact based questions. For the latter category questions, the survey allowed a third person (such as a parent) to answer the questions as a proxy if the subject was unable to do it. The questions cover various topics, including work, community inclusion, leisure activities, the ability to make decisions, and health, among other topics. The survey also includes a variety of demographic variables that can be used as control variables.

Data Overview

The 2018-2019 NCI IPS has a total sample of 22,008 individuals with IDD from 37 states. Random sampling was applied, targeting “individuals over the age of 18 who are receiving at least one publicly funded service besides case management (p.6 NCI IPS Overview, 2019).” Each state was asked to complete a minimum of 400 surveys, but some of them were unable to meet this requirement. Given that this study is intended to analyze SDS at a national level, without breaking down the effect by state, we keep data from all states, including those that did not manage to produce the desired number of responses. The following pie chart provides a breakdown of the dataset based on whether they are SDS participants or not, while Table 3 shows statistics by state.

Figure 3

SDS Participation



Note. As we can see from the pie chart above, only 11.5% of respondents are SDS participants, while a significant percentage either does not know, or did not respond to the question.

Table 3*Respondents per state*

State	Respondents	Participant	Non-Participant	Unknown
Overall	22008	2535	16333	3140
TX	2388	353	1822	213
MN	2140	135	2005	0
WI	961	457	504	0
FL	867	78	766	23
VA	807	128	647	32
IN	742	0	0	742
OH	732	24	682	26
CO	712	0	706	6
PA	710	47	615	48
MI	658	104	540	14
NC	651	5	625	21
NJ	514	149	348	17
AR	510	0	0	510
SC	501	1	463	37
GA	479	10	463	6
NY	448	4	444	0
WA	441	8	295	138
KY	429	74	324	31
OR	420	198	222	0
NE	418	52	361	5
AZ	413	23	388	2
KS	408	89	304	15
NV	408	0	0	408
TN	406	22	381	3
MO	403	40	363	0
ME	400	0	0	400
NH	400	93	301	6
OK	400	6	393	1
CT	391	57	291	43
AL	378	1	372	5
UT	372	93	274	5
HI	363	56	292	15
RI	358	53	301	4
SD	351	19	310	22
VT	346	122	224	0
DE	342	0	0	342
WY	341	34	307	0

Note. We can see the number of respondents per state and how many of them are SDS participants. The column *Unknown* counts those who did not provide a yes/no answer when asked about their SDS participation.

Measures

My objective is measuring the impact that SDS participation (independent variable) has on six dependent variables centered around quality of life and service satisfaction, while controlling for demographic variables. In this section I provide some detail on how each of these dependent and independent variables are defined and computed, while some of the finer details are relegated to Appendix A.

Quality of life maps to five dependent variables (each hypothesis is tested separately for each of these variables), while service satisfaction is measured with a single dependent variable. The following sections provide detail on how each of these variables is computed.

All six dependent variables are designed so that a higher score is a positive outcome, meaning that an increase in the score would correlate with a positive effect.

Dependent Variable: Employment

This variable describes whether survey participants have a paid job in the community or not. It was constructed using a single question, and has a score range between 0 and 1. More details are available in Appendix A.

Dependent Variable: Community Inclusion

The community inclusion variable was coded as a continuous value ranging from 0 to 1. This score is computed by averaging the coded responses to eight survey questions (missing responses are excluded from this average). Each of these questions measures the level of involvement the respondent has with their community. For example, a question may ask: *Are you able to do X as often as you want?*, and the responses get assigned a score between 0 (for *“No, I can’t do X at all”*), and 1 (for *“Yes, I can do X whenever I want”*), with

an intermediate response getting a score of 0.5 (e.g., “I can do X sometimes, but not as frequently as I would like”). For a list of the exact questions included in this variable, and the scores we assign, see Appendix A.

Dependent Variable: Decision-making

These questions can be answered by proxy respondents, such as family, friends, staff, or others. The decision-making variable was computed by aggregating the numerical values for nine survey questions. These questions inquired about service participants’ engagement in decision-making on their lives and services. For example, one of the questions was “*who decides daily schedule,*” and the alternatives were “*Person decides*” (gets a score of 1), “*Person has help deciding*” (gets a score of 0.5), and “*Someone else decides*” (which gets a score of 0). The decision-making variable (average of all responses, excluding missing responses) ranged from 0 up 1. Higher scores indicate that the individual has a higher ability to make their own decisions with regards to their schedule or treatment.

Dependent Variable: Relationship

This variable was computed by adding the numerical values corresponding to three survey questions (excluding missing responses). Questions ask about relationships of family and friends and loneliness. As an example, one of these questions asked whether the individual has friends. The available choices were: “*Yes, has friends who are not staff or family*” (I score this with 1 points), “*Yes, all friends are staff or family, or cannot determine*” (I score this with 0.5 point), and “*No, does not have friends*” (I score this with 0 points). The final relationships variable range is in the 0-1 range, where higher score indicates better relationships with friends and family.

Dependent Variable: BMI

This variable was computed by assigning a grade to each person’s BMI (computed

from the height and weight). The range was 0-2, with higher scores assigned to healthier BMIs.

Dependent Variable: Health

This variable was computed using a single response to a question on overall health. It is graded on a scale of 0-3, with a higher score indicating better health.

Dependent Variable: Service Satisfaction

This variable will be coded as a continuous value by averaging up to twelve numerical values to survey questions (missing values were excluded from the average). For example, one of the questions was “*Are you able to contact your case manager/service coordinator when you want to?*”, and the available choices were “*Yes*” (gets a score of 1), “*Sometimes/Maybe/In between*” (gets a score of 0.5), and “*No*” (gets a score of 0). The final service satisfaction variable ranges from 0-1. See Appendix A for a detailed breakdown of the 12 questions and their respective scoring methods.

Independent Variable: SDS Participation

Whether someone participated in SDS or not was determined based on a single question from the survey, and is coded with either 0 (non-participant), or 1 (participant), while respondents who missed this question had to be excluded from the entire data analysis, because it is the only independent variable in this study.

Control Variable: Income

This variable indicates the median income in the ZIP code of the respondent (i.e., the information is not specific to the respondent, only specific to their ZIP code). I coded this variable directly as a number corresponding to a bracket of size \$10,000, and used average imputation to fill in missing data.

Control Variable: Age

Age was reported as integer numbers, and these numbers were used without further

processing. Missing data was handled with average imputation.

Control Variable: Gender

Gender was coded using dummy variables. I assigned the choices “*Other*” and empty responses with the same dummy (i.e., treated as a third dummy/gender).

Control Variable: Race

The race variable was coded using dummy variables, where missing responses were all treated as a separate race and assigned their own dummy variable.

Control Variable: Severity of Disability

This variable was used to control for levels of intellectual disability, but people without intellectual disability gave a “Not applicable” response to this question. These levels were coded using dummy variables instead of numeric, because I had many types of missing responses (not applicable, does not know, empty), and I chose to code these with their own dummy variable as they mean different things.

Control Variable: Rural/Metropolitan

This variable was used to control for the kind of city environment they live in, whether it is a large city, or a small rural environment. Dummy variables were used, and missing data was treated as a separate category.

Control Variable: Type of residence

This variable is intended to control for the type of residence the subject lives in. While the questionnaire had over 10 possible choices for this response, I chose to simplify the coding by breaking it down into two broad categories, either (a) an institutional facility, or (b) a home setting (their own, or a family member’s). Overall, this variable was coded using dummy variables, and missing data was assigned its own category.

Understanding Missing Data and Dealing with It

When I wrote the original proposal for this research, I did not account for the fact

that most respondents would have missing data for at least some questions. This includes questions that were skipped, answered with “*don't know*”, or “*not applicable*”. This dissertation uses a total of 35 dependent variables (which get aggregated into 7 as listed above), as well as 7 control variables, and one independent variable. Overall, this dissertation requires 43 survey responses.

I dealt with missing responses as follows:

- Eliminated records missing all control variables (n=3181).
- For a given regression, compute the average of the outcome variables across all available responses (we do not drop a record just because it is missing 1-2 responses).
- For a given regression, drop records missing all responses for the outcome variable (because there would be nothing to average).

In the end, the size of the analysis samples ranges from 13,569 to 18,827, depending on the outcome.

Analytic strategies

Multivariate Regression

I will test the hypotheses using a multivariate linear regression approach using the following equation.

$$y_i = \beta_0 + \beta_1 SDS_i + \beta_2 X_i + \epsilon_i$$

where

- y_i = measure of the effectiveness (QoL, SS) of the treatment for individual i
- SDS_i = 1 if individual i **participate** SDS and 0, if not
- X_i includes **household income, rural/metropolitan residence, age, type of residence, gender, race, and severity of a disability.**

I used a t-test with a 95% confidence for each hypothesis.

Propensity Score Matching

I used propensity matching to better measure whether participating in the program has a causal effect on the outcomes. This is necessary because our data was not obtained through a randomized controlled trial. As a result, participation in the program depends on people's individual preferences, which means participants are different from non-participants. I will use demographic variables to estimate the propensity (the probability) of participating in the program using a logistic regression model. Then, I split the population into two subpopulations, based on their propensity. This process allowed me to have two populations with some shared characteristics (because they have a similar propensity). This allows controlling individual variability to substitute for conducting a randomized control experiment.

Then, I will repeat the multivariate regressions described in the previous section with the same null hypotheses. Suppose for a given outcome, the tests in a multivariate regression indicate a statistically significant result, but the test in propensity score matching does not. In that case, it will be interpreted that there is a correlation but no causal relationship.

Moreover, the results in the high propensity sub-sample will inform us about the effects of SDS in a sample of similar people all likely to enroll in SDS, but some chose to not enroll. In contrast, the results in the low propensity sub-sample will inform us about the effects of SDS in a sample of people unlikely to enroll in SDS, but a few did choose to enroll. Because we anticipate that the high propensity sub-sample will have different demographic characteristics than the low propensity sample, differences in the results across these two samples may indicate whether the effects of SDS may differ by certain characteristics.

Multiple Comparisons Test and the Bonferroni Correction

Testing multiple hypotheses on the same population increases the probability of incorrectly rejecting the null hypothesis (i.e., incorrectly claiming that a variable has a significant effect when it does not). This problem is known as the *multiple comparisons problem*, and there exist many approaches to solve it in order to reduce the probability of a false positive. In this thesis, I used the Bonferroni correction, which consists of multiplying the p-value given by the regression by the number of tests performed on the population. In this case, since I wanted to find a relationship with a confidence of 95%, the maximum p-value we should find is $0.05/7 = 0.00714$.

Chapter Four

Results

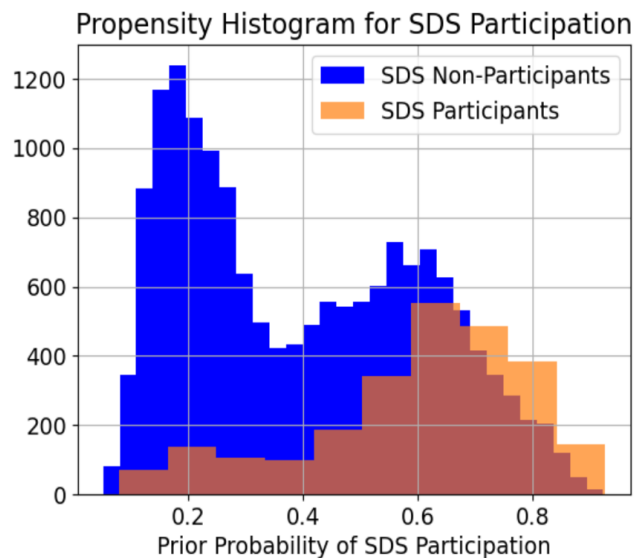
Propensity Matching

In order to obtain a propensity score, I used the control variables outlined in the previous chapter (race, gender, among others) to predict the participation variable `SDS_II_SDSUPPORTS`, using a logistic regression model. I excluded responses with a missing dependent variable, but used imputation on missing data for the independent variables (see Appendix A for more details).

The following histogram illustrates the distribution propensity scores I obtained:

Figure 4

Probability Distribution of SDS Participation by Participant Demographics



Note. The figure above shows the distribution of probabilities each participant had to participate in an SDS program based on their demographic information.

Figure 4 shows that the propensity scores are roughly distributed into two bell curves, one centered around propensity = 0.18, and another centered around propensity = 0.62 (approximately). Subsequent analysis used propensity = 0.4 as the division point

between these two bell curves. Going forward, I refer to the population with a propensity below 0.4 as the “low propensity” population, and the population with a propensity equal or higher to 0.4 as “high propensity”. The motivation for doing this is to create two subpopulations with some shared demographic characteristics, as a substitute for the ideal testing methodology (a randomized control trial). The multivariate regression results on these sub-populations are all reported in the next sections.

Descriptive Analysis of our Populations

To better understand the populations on which we are doing our regression, I summarized the characteristics of each population in the following table:

Table 4

Distribution of demographic characteristics and dependent variables across three study populations

	Full Sample (n=18,827)	Low-Propensity Sample (n=9,061)	High-Propensity Sample (n=9,766)
	N (%)	n (%)	n (%)
SDS Participation	2509 (13.32)	391 (4.31)	2118 (21.69)
Gender			
Male	10,724 (56.96)	5,241 (57.84)	5,560 (56.93)
Female	7,949 (42.22)	3,795 (41.88)	4,154 (42.53)
Other	77 (0.41)	25 (0.28)	52 (0.53)
Race			
White	13,008 (69.09)	6,444 (71.12)	6,784 (69.47)
Black	2,711	1,646	1065

	(14.40)	(18.17)	(10.90)
Latino	1,069 (5.68)	346 (3.82)	723 (7.40)
American Indian	220 (1.17)	175 (1.93)	45 (0.46)
Asian	376 (2.00)	139 (1.53)	237 (2.43)
Pacific	43 (0.29)	10 (0.11)	33 (0.34)
Other	1,180 (6.27)	301 (3.32)	879 (9.00)
Type Home			
Home	9,768 (51.88)	772 (8.52)	8,996 (92.11)
Facility	8,573 (45.54)	8,122 (89.64)	451 (4.62)
Other	177 (0.94)	109 (1.20)	68 (0.70)
Missing	309 (1.64)	58 (0.64)	251 (2.57)
Level of Intellectual Disability			
Mild	6,323 (33.58)	3,265 (36.03)	3,058 (31.31)
Moderate	5,172 (27.47)	2,742 (30.26)	2,430 (24.88)
Severe	2,209 (11.73)	1,268 (13.99)	941 (9.64)
Profound	1,389 (7.38)	1,091 (12.04)	298 (3.05)
Unspecified	1,647 (8.75)	410 (4.52)	1,237 (12.67)
Unknown	165 (0.88)	54 (0.60)	111 (1.14)
<hr/>			
N/A	1,677	141	1,536

	(8.91)	(1.56)	(15.73)
Missing	245 (1.30)	90 (0.99)	155 (1.59)
Region			
Metropolitan	13,208 (70.15)	6,169 (60.09)	7,039 (72.08)
Micropolitan	3,037 (16.13)	1,704 (18.81)	1,333 (13.65)
Small Town	1,560 (8.29)	780 (8.61)	780 (7.99)
Rural	738 (3.92)	279 (3.08)	459 (4.70)
Missing	284 (1.51)	129 (1.42)	155 (1.59)
	Mean (Std)	Mean (Std)	Mean (Std)
Median income coded	5.85 (1.86)	5.63 (1.72)	6.06 (1.97)
Age	42.88 (15.73)	49.98 (15.18)	36.30 (13.16)
Employment (0-1)	0.315 (0.464)	0.283 (0.450)	0.343 (0.475)
BMI (0-2)	0.950 (0.813)	0.984 (0.810)	0.918 (0.816)
Health (0-3)	1.825 (0.767)	1.807 (0.757)	1.842 (0.776)
Community (0-1)	0.520 (0.187)	0.495 (0.187)	0.542 (0.184)
Relationships (0-1)	0.815 (0.151)	0.809 (0.158)	0.822 (0.144)
Decision-making (0-1)	0.558 (0.143)	0.544 (0.162)	0.571 (0.120)
Service Satisfaction (0-1)	0.551 (0.048)	0.553 (0.047)	0.550 (0.048)

Note. This table summarizes the average values and distributions for each demographic and each dependent variable, across the three populations in my study. These numbers are used only as a point of reference to understand how large of an impact SDS participation can have.

On average, 13.3% of the sample enrolled in SDS. Fifty-seven percent of the sample are men and 69% are White. Fifty-two percent of the sample are living at home, where 46% reside in an institutional facility. Thirty-four percent of the sample have a mild disability, 27% have a moderate disability, and 19% have a severe or profound disability. Seventy percent of the sample live in a metropolitan area. The sample resides in a zip code with a medium income of \$58,000 on average. The average age is 43. Thirty-two percent are employed. The BMI score indicates the average person in the sample is overweight (BMI>25 but less than 30). The average health, community, decision-making, and service satisfaction ratings indicate that people rated their quality of life and service satisfaction slightly better than the middle rating.

The high and low propensity sub-samples were very similar on most dimensions with a few exceptions. Those in the high propensity sub-sample were much more likely to be living at home and much less likely to be living in a facility than those in the low-propensity sub-sample. The high propensity sub-sample was slightly more likely to live in a large metropolitan and were much younger on average than the low propensity sub-sample.

Multivariate Regression Results

Following the methodology outlined in the previous chapter, I conducted regressions for seven dependent variables for three populations a) the overall population, b) the population with a low propensity to participate in SDS, and c) the population with a high propensity to participate in SDS. For each of these 21 regressions, I conducted a t-test in order to determine the validity of the null hypotheses previously outlined. The results of

these t-tests are summarized in the following table.

Table 5

Multivariate Regression Results

	Overall Population	Low-propensity Population	High-propensity Population
Quality of Life			
Job	-0.004	-0.064	0.011
Health	-0.050***	0.108*	-0.090***
BMI	0.030	0.108	-0.008
Community Inclusion	0.011*	0.013	0.010
Relationships	-0.005	-0.001	-0.006
Decision Making	-0.008	-0.029***	-0.003
Service Satisfaction	0.0008	0.002	0.001

* $p < 0.05/7 = 0.007$, ** $p < 0.01/7 = 0.001$, *** $p < 0.001/7 = 0.0001$

Note: The p-values listed above must be divided by a factor of 7, due to the Bonferroni correction, because we have 7 dependent variables.

In the following sections, I explain some of the most interesting tests performed, including every test with a significant relationship, as well as tests that were rejected by a small margin.

Result of T-test for the *Employment* Variable

After Bonferroni adjustments, we did not find any evidence that SDS participation affects the job variable.

Result of T-test for the *BMI* Variable

Similarly, we did not find any evidence that SDS participation affects the BMI variable.

Results of T-test for the *Health* Variable

In the overall population, SDS participation has a negative and significant effect on health. Since the average health score on this population is 1.825, SDS participation is associated with a 2.75% decline in the health score. SDS participation is also significantly negatively associated with health for the high propensity sub-sample. Since the average

health score in this population is 1.842, SDS participation is associated with a 4.86% decline in the health score. This combination of results suggests that the relationship between SDS participation and health may be causal.

In contrast, in the low propensity sub-sample, SDS participation has a positive and significant effect on health. Since the average health score on this population is 1.807, SDS participation is associated with a 5.98% improvement in the health score. This result may indicate that people who are unlikely to opt for SDS (older adults in facilities) may benefit in terms of health from SDS participation. At the same time, it's worth noting that the health variable was constructed using a single response, making the health score more susceptible to fluctuation.

Result of T-test for the *Community Inclusion* Variable on the Whole Population

In the full sample, SDS participation is positively associated with community inclusion. Since the average community score on this population is 0.520, SDS participation is associated with a 2.19% increase in their score. However, the regressions on the low and high propensity populations indicate no significant relationship between SDS participation and community inclusion. Thus, this effect may not be causal.

Result of the T-test for the *Relationship* Variable

All three regressions for the relationship variable indicate no significant association between relationships and SDS participation.

Result of the T-test for the *Decision-Making* Variable

SDS participation is not significantly related to decision-making for the full sample or the high propensity sub-sample, but is negative and significant for the low propensity sub-sample. Specifically, SDS participation is associated with 0.0294, or 5.27%, decline in the decision-making score. This finding suggests that SDS participation may increase decision-making among those unlikely to be enrolled in SDS (older adults in facilities).

Still, it does not change decision-making among those more likely to be enrolled in SDS (young adults at home).

Result of the T-test for the *Service Satisfaction* Variable

There is no evidence to claim that SDS participation impacts service satisfaction.

Chapter Five

Discussion

People with disabilities started SDS to enhance their authority to plan and manage their types of services and providers. There are differences between states, but overall, SDS differs from traditional pre-planned, provider-oriented, agency-based service delivery because service users can plan, hire, train, and manage their providers and payment amount. Since SDS was implemented in the U.S., it has spread across the states. Indeed by 2019, every state in the U.S. had one or more SDS programs. There was high interest in SDS among scholars when it started in the 1980s, along with funding for laying the foundation to implement the new delivery service and conducting research to establish the quality and effectiveness of services that provide evidence-based practice. However, of the **60** studies identified through the university library database using “self-directed service,” only **13** used quantitative methods, and 9 used the Cash and Counseling demonstration data, which was collected in 1999-2003. Yet such quantitative policy evaluations are necessary to maintain or improve service quality. Furthermore, research efforts need to be balanced between quantitative and qualitative methods to expand our understanding of the impact of SDS on people with disabilities.

This cross-sectional study evaluated the effectiveness of SDS for people with IDD by comparing the quality of life and service satisfaction of participants and non-participants. Using the 2018-19 National Core Indicator data (n=18,827), multivariate and additional propensity-matching regressions were applied to ensure the reliability of the

results. Findings were mixed with respect to the quality of life indicators, and no difference in service satisfaction was found between participants and non-participants. Statistically significant but small differences were found in health, community inclusion, and decision-making in the quality of life theme. Among five quality of life dependent variables, health positively correlates with SDS participation when examined among the low propensity population and a negative association with the high-propensity population. Also, overall population regression results found a negative association with SDS participation. Community inclusion showed a positive association with SDS participation, but no statistical significance was observed when it tested with high and low-propensity populations. Low-propensity population regression on decision-making presented a negative impact. No significant difference in employment, relationships, and service satisfaction was found. The variable LEVELMR, which represents the severity of disability, shows a statistically significant negative effect for many outcomes. To take employment as an example, profound levels of intellectual disability is associated with a 22% decrease in the probability of having a job. This result is not surprising, because a more severe disability will certainly make it harder to secure employment, which is why this was a control variable. Overall, this study does not support the notion that SDS is superior to traditional agency-based services.

According to SDT, having more control and autonomy significantly increases intrinsic motivation, which can lead to enhanced well-being more than those without. Because they can choose services that are aligned with their preferences, and have competence by managing their own lives. However, in this study, shows that only with participation of SDS (having hiring/budget authority over their services) is not enough to lead to positive outcomes. Participants could not perform better compared to non-participants might be explained by external factors undermining intrinsic motivation and

discouraging the individuals' participation or involvement. Ryan and Deci (2017) explained that external factors such as controlling rewards, threats of punishment, evaluations, surveillance, deadlines, and imposed goals can negatively affect intrinsic motivation. Also, another possible explanation from the perspective of SDT is a lack of a supportive and empowering environment in meeting participants' basic psychological needs for autonomy, competence, and relatedness. To understand this non-positive impact of having a choice, a future study can measure participants' perceived competence, relatedness, and autonomy to see which needs are not satisfying to participants.

Quality of Life

BMI

Unlike most other variables in this study, BMI was computed directly based on observed quantities (the participant's height and weight). This study found no statistical differences in BMI scores between SDS participants and non-participants.

Health

The health status of participants was measured using a self-reported health condition variable. There were small statistical differences in subjective health condition and it varies depending on the tested population. Overall population testing showed a negative association of health condition and SDS participation. Among the low-propensity population, I found a positive association between health condition and SDS use (a gain of 5.98%). Interestingly, among the high-propensity population, SDS participation decreased the health score by -4.86%. Meanwhile, on the overall population, SDS participation produced a net effect of -2.75%. These results deserve substantial discussion. First, we can see that 2 out of 3 regressions yield a negative outcome, suggesting that SDS does more harm than good regarding health outcomes. On the other hand, the effects are small, which points to a lower significance level (i.e., the result is small; therefore, it could potentially

be a false positive).

Perhaps one of the most important driving factors in this finding is that the survey does not attempt to directly measure the quality of the service being received. While SDS is intended to improve services, there are no mechanisms to ensure the family caregiver has actually done their job, compared to an agency-based caregiver who would be more likely to be monitored.

One study supporting our findings was conducted by the U.K. Department of Health in 2006-2007. They used a randomized controlled trial pilot program, and measured health outcomes after six months. They found a negative association between having participated in SDS and self-reported health levels in people with IDD.

An older study conducted by Brown et al. (2007) using data from 1999-2002 demonstrated through a randomized controlled trial that SDS does not introduce negative health effects. While these results may seem to contradict our findings, in reality they are not so different. We found a small overall negative impact of less than 3%, while this study using older data found no effect. I believe these differences are small enough and may be within the standard noise levels of a quantitative study involving self-reported data.

Interpreting the current study's negative self-perceived health impact must be made with caution for the following reasons. First, although the results were statistically significant, the impact size was insufficient to guarantee the result, which implies a false positive finding is likely. It is possible that reproducing this study on a new sample, or changing the experimental design, could change the outcome into a null result. In fact, when the self-reported health measure was combined with the BMI score (a previous experiment), the null hypothesis could not be rejected on the overall population.

Further study is required to validate or negate this study's findings. The most

promising direction would be using a randomized design to better control for all the possible confounding variables. More importantly, it would be preferable to have a survey customized for SDS, rather than leveraging secondary data. An ideal SDS survey would cover certain SDS-specific issues in more detail. For example, when it comes to health outcomes, it would be desirable to know whether a family caregiver has received any training to address their needs, as the lack of preparation could easily pollute our findings by comparing a qualified health professional (in the case of agency-based service) against a well-intentioned, but ultimately unprepared, family member.

Community Inclusion

This study found a positive association between community inclusion and SDS participation in the overall population only. After applying propensity score to two groups (low propensity and high propensity population), there were no statistically significant results on each subpopulation. It is not a consistent result across samples (overall, low, and high-propensity population), so findings may not be entirely reliable. One potential reason for this discrepancy is confounding variables that are not equally present in the subgroups. This result is relatively consistent with previous quantitative findings that reported no significant difference (Harry et al., 2017; Glendinning et al., 2008; Gross, 2013) or found meaningful impact from qualitative research (Gendera, Fisher, Robinson, Clements & Eastman, 2011).

In this study, community inclusion includes questions about the frequency of going out to the community to do something participants want, such as religious activity, eating out, shopping, or meeting friends. Merells, Buchanan & Waters (2018) found key factors affecting people with IDD's social inclusion by conducting a systematic review: (1) levels of participation, (2) social interaction, (3) physical and social skill, and (4) cultural and societal factors. Since all eight community inclusion questionnaires used the 'go out'

phrase, this result focuses on physical inclusion in the society rather than inclusion requiring social interaction or social skills.

One previous study which found SDS participation had no effect on community inclusion was Harry et al. (2017). This study measured community inclusion based on employment, educational, recreational, cultural, religious, and social activities. Their study focused on younger people (ages 18-30) with IDD. Although this study found no difference in community inclusion between SDS participants and non-participants, they observed that SDS participants reported a higher level of satisfaction for help around the house or community, compared to agency-based care. One could infer from these results that improved help around the house or community do not translate into an overall improvement in community inclusion.

In contrast, a study by Gendera, Fisher, Robinson, Clements and Eastman (2011) did find that SDS participation had a positive effect on community inclusion. Their study was a qualitative pilot focused on children and young adults and their family members. One limitation the authors emphasized was the fact that this was a pilot study, and did not account for the long-term effect of participating in SDS. The authors explained that pilot study participants tend to prioritize their immediate needs instead of planning long-term, which means that the behaviors observed in this pilot may do not represent the same kinds of behaviors as my study attempted to measure. Another key difference between this study and mine is the fact that Gendera et al. used qualitative methods, making comparisons difficult.

Many other qualitative and quantitative studies have leveraged pilot data to study the impact of SDS. Some of these studies include Mahoney et al., (2019); Harry et al., (2017); Manthrope et al., (2015); Glendinning et al., (2008). Although using pilot data to assess SDS brings clear limitations, the lack of disability data has pushes scholars in this

direction. To achieve the best results, a program like SDS should be evaluated continuously, in order to understand the long-term effects of participating in it.

Decision Making

Results show a slight negative impact on decision-making only for the low-propensity population (-5.27%), while we fail to reject the null hypothesis for the high-propensity population and the overall population. This result contradicts previous studies like Glendinning et al., 2008; Vinton, 2010 had claimed SDS had a positive impact on decision-making ability. Meanwhile, a study by Murphy and Kelly (2017) which conducted a meta-synthesis using U.K., U.S., and Australian literature found that, even though this relationship is assumed to be positive throughout the literature, statistical evidence of it is limited.

Implications

This study is one of few quantitative studies evaluating SDS for people with IDD in the U.S. There are several policy implications from the outcome of this study. While many believe SDS may be superior to agency-based services, this study's results have failed to validate such optimistic expectations. Results underscore the importance of critically evaluating the impact of SDS in the U.S. in a recent qualitative study conducted in the U.K. (Biziewska, 2022), an interviewee criticized what he perceived to be an overly rosy picture of SDS:

I think direct payments can be sold in a very positive way because: 'it's your budget', 'your're in control'... but the reality is – Are you telling them about managing that money? Are you telling them how difficult it might be to get care at that rate?

The findings of this study can contribute to the SDS practice by providing new evaluation results which are different from the common belief on SDS. This new

perspective can allow stakeholders to reexamine the service practice to resolve existing concerns or problems or improve the service for a better experience and scholars to verify or contradict the results with better or more detailed data.

Health Implications of SDS

The safety of implementing SDS was one of the main concerns at its beginning. Through a demonstration study in 1999-2002 (Brown et al., 2007), scholars found comparable health status of SDS participation to traditional agency-based service; some results showed better conditions, and some showed no statistical differences. This study's positive outcomes have been used as quantitative empirical evidence until now. However, the current atmosphere around SDS is one in which their positive effects are taken for granted while relying on decades-old data. This attitude could prevent constructive criticism from improving the service quality. This is a problem that not only applies to health but also to other outcomes.

Unlike the existing literature, this study found that participating in SDS was associated with a decrease in self-reported health scores of 2.75% in the overall population. Meanwhile, a previous methodology I used (in which we had combined BMI and health) indicated that SDS did not affect that combined health + BMI score. Overall, given the small size of the effect (less than 3%), the fact that this variable is subjective, and the fact that a previous analysis showed no impact makes me believe this result is likely to be a false positive, meaning we have detected a statistically significant relationship. Still, future studies would be unlikely to reproduce this conclusion. Perhaps an area for future exploration would be measuring SDS's impact against more tangible health measures, such as BMI, cholesterol levels, blood pressure, or other more easily quantifiable measures.

Through years of implementation and research, a majority of participants have expressed their interest, and satisfaction with, hiring family members or close friends as

service providers (Mahoney, 2004; Wendel, 2022; Nadash, 2023). In fact, the largest SDS program in the U.S. reported over 71% of providers of SDS participants were family members in 2021 (California Department of Social Services, 2021). Since these caregivers support them with daily tasks, such as bathing or eating, people prefer to get assistance from someone they are already familiar with.

Despite participants' preferences, whether SDS leads to improved health outcomes is debatable. The conclusions of this study indicate that a slightly negative effect is more likely, in which case the caregiving provided under SDS may be a convenient alternative rather than one that produces health benefits.

According to Mahoney Simon-Rusinowitz, Loughlin, Ruben, and Mahoney (2019), service providers' "care literacy" is vital, which is why some SDS caregivers could benefit from receiving limited medical training to the condition of the person they are caring for. Future studies could focus on understanding in more detail whether health outcomes are in fact slightly negative, and whether the qualifications of caregivers is what drives this effect.

There exist cases however, in which having family members as caregivers for SDS is the best option available. One such example is rural areas, where it is difficult to receive more specialized care, and family members may be the only option. Another notable example was the COVID-19 pandemic, during which health care providers were in short supply across the nation. During the pandemic some states that had previously restricted SDS participants from hiring family members made an exception to protect beneficiaries and caregivers from the virus.

Community Inclusion

This study's results on community inclusion present an opportunity to question the effectiveness of SDS at its core. One of the primary purposes of creating SDS was

providing community-based services instead of institutional services, to allow participants to remain involved in their communities. Our study leveraged useful markers of inclusion, like participation in religious activities, going out or running errands. We found a small but positive effect on the overall population, but not the sub-populations (high and low propensity of participating in SDS). One possible explanation for this is that, while SDS can show a correlation with improved community inclusion, there exist other drivers that play a larger role. For example, if someone has very severe intellectual disabilities, even if they participate in SDS, and receive their care at home, they are unlikely to be able to attend a church or enjoy running errands. As one interviewee stated, “self-directed doesn’t necessarily mean they’re getting that community integration” (Bogenschutz et al., 2019).

Perhaps future studies on community inclusion should adjust questions to account for other limitations that might prevent inclusion, which go beyond whether the participant is living at a facility or not.

Supported Decision Making

Within the low propensity population (i.e., those who had a lower likelihood of joining SDS in the first place), this study found that actually participating in SDS had a small and negative impact on the decision. In a sense, 'self-directed' service has no better(positive) impact on decision-making and even a slightly negative impact on decision-making questions that cause the difference between an ideal picture and reality.

SDS administrative staff's limited understanding and knowledge could be a contributing factor, which has been reported in Irish and Canadian empirical studies (Fleming, McGilloway & Barry, 2016; Bahadshah et al., 2015). According to their study, when stakeholders have a limited knowledge of the policies they are supporting, it can negatively can affect clients' decision-making due to unclear, confusing guidelines and different regulations between agents, which frustrate users of SDS because it is difficult

for them to know in advance what services and/or requests will be approved or denied. In the U.S., since the demonstration study, this phenomenon was found along with practitioners' confusion about their role due to the transition from a provider-oriented perspective to a customer-oriented mindset. Some studies even found that staff even tried to avoid recommending SDS.

To make self-directed service users choose and direct their services as its name, service administrators' training is necessary to provide consistent and appropriate suggestions.

Limitations of Study

The limitation of this study is the data which was not explicitly designed to measure the effectiveness of SDS. However, this 2018-19 NCI data provides a public IDD system survey, including the SDS participation variable, so it was a good source to measure differences in participating SDS compared to others. Even though SDS participants and nonparticipants were not a randomized, which would eliminate selection bias, propensity-matching methods reduced some threats to internal validity. The use of randomization, as well as a new survey more closely designed for SDS would either validate the findings more conclusively, or otherwise contradict them with better or more detailed questions.

For future study, a dismantling study design would be a worthwhile alternative to better understand the effect of SDS. Unlike the current study, which measured the effectiveness of SDS using components that were found to be important through literature reviews, a dismantling study design can be a more scientifically sound way to identify factors are most effective in achieving its intended outcome. It breaks down a complex intervention in to parts and tests them separately to determine which ones are necessary

(Campbell, Stanley, & Shadish, 2002). Conducting such a study can help to better manage confounding factors, by isolating the effects of each component.

To obtain as much information as possible about services for IDD, proxy replies were allowed for some selected questions in each health, service satisfaction, and decision-making variable, mainly for objective questions. According to the NCI report, the survey was designed using accessible language and suggested rephrasing to help people with IDD's understanding. It has been revised based on feedback from states, self-advocates, families, and participants. A proxy respondent is allowed only when an individual with IDD cannot communicate effectively with the surveyor or when the participant requests to do so. However, the proxy responses could differ from the service recipients' responses. Although using proxy responses is unavoidable, it is important to be aware of this fact when interpreting the results.

Racial disproportionality is another significant problem that needs to be addressed in future research. To improve the representativeness of samples, future studies need to employ targeted recruitment strategies and partner with organizations that serve diverse populations. By doing so, researchers can ensure that their samples are more diverse and sensitive to capturing racial and ethnic representation. Moreover future research should also examine the differences in outcomes between different racial and ethnic groups by conducting subgroup analyses. Such analyses can provide valuable insights into how self-directed service can be tailored to meet the needs of diverse populations. Qualitative research that specifically focuses on this issue can also provide a deeper understanding of how racial factors affect participation in SDS as well as the effectiveness of the services provided. Overall, addressing racial disproportionality in future research is crucial for gaining a more comprehensive understanding of how SDS can effectively serve individuals from diverse racial and ethnic backgrounds. Fundamental social work values

around inclusion, elevating unheard voices, advancing equity, and social justice can only be properly served when the most vulnerable stakeholders are represented, and their experiences highlighted. Only then can truly effective policy and practice responses, whether in terms of legislative action, or evidence-informed interventions, be designed and implemented.

Conclusion

This cross-sectional, observational study evaluates the effectiveness of SDS for people with IDD using quality of life and service satisfaction outcome variables. The results of this study do not support the notion that SDS is superior to traditional agency-based services. This result does not mean that SDS is not working. As an option for community-based service, it provides a chance to manage their services, and broadly speaking it provides comparable service to agency-based service. The findings of this study can raise critical questions on the universality of prevailing positive beliefs in SDS, which must respond to the needs and aspirations of underrepresented vulnerable groups if it is to advance social justice and motivate efforts to redress both extant or anticipated structural, social, and institutional problems while also improving service users' experiences.

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Appendix A: Numerical Coding for Dependent and Independent Variables

A.1: Dependent Variable: Employment

The employment variable is computed based on a single question, coded under HAVEJOB15. The range for this variable is 0-1. Given this independent variable relies on a single question, I simply exclude missing answers (rather than using some kind of imputation).

HAVEJOB15: Do you have a paid job in the community?

Answer	Dataset Coding	My Coding
Yes	2	1
No	1	0
Don't know	99	Excluded
Missing Data	None	Excluded

A.2: Dependent Variable: Community Inclusion

The community inclusion variable is computed based on 8 questions coded under GOOUT15, GETPLACES15, GOOUTENOUGH15, SHOPPING15, ERRANDS15, ENTERTAIN15, EATOUT15, RELIGION15. The range for this variable is 0-1 (most included and capable of participating), and the lowest possible score is 0 (most limited in their ability to engage with the community). Missing answers are excluded, and the average is computed across the questions with answers. Records are excluded if none of the 8 questions has an answer.

GOOUT15: Are you able to go out and do the things you like to do?

Answer	Dataset Coding	My Coding
No, I don't get to do any of the things I like to do	1	0
Yes, I can go out and do the things I like to do	2	1
In between, I go out and do some things that I like, but there are things I like to do that I can't do	3	0.5
Not applicable – doesn't name things s/he likes to do	98	Excluded

Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

GETPLACES15: Are you able to get places when you want to do something outside your home, like going to see friends, for entertainment, or to do something fun?

Answer	Dataset Coding	My Coding
No, almost never	1	0
Yes, almost always	2	1
Sometimes	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

GOOUTENOUGH15: Are you able to go out and do the things you like to do as much as you'd like?

Answer	Dataset Coding	My Coding
No, I do go out and do some things that I like, but I'd like to do more.	1	0
Yes, I do the things I like to do as much as I like	2	1
Not applicable – doesn't name things s/he likes to do	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

SHOPPING15: How often did you go shopping in the past month?

Answer	Dataset Coding	My Coding
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0	1	0
1-2 times	2	1/3
3-4 times	3	2/3
Five times or more	4	1
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

ERRANDS15: How often did you go shopping in the past month?

Answer	Dataset Coding	My Coding
0	1	0
1-2 times	2	1/3
3-4 times	3	2/3
Five times or more	4	1
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

ENTERTAIN15: How often did you go out to entertainment in the past month?

Answer	Dataset Coding	My Coding
0	1	0
1-2 times	2	1/3
3-4 times	3	2/3

Five times or more	4	1
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

EATOUT15: How often did you go out to eat in the past month?

Answer	Dataset Coding	My Coding
0	1	0
1-2 times	2	1/3
3-4 times	3	2/3
Five times or more	4	1
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

RELIGION15: How often did you go to a religious practice in the past month?

Answer	Dataset Coding	My Coding
0	1	0
1-2 times	2	1/3
3-4 times	3	2/3
Five times or more	4	1
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

A.3: Dependent Variable: Decision-Making

The community inclusion variable is computed based on 9 questions coded under CHOSHOME15, HOUSEMATES15, SCHEDULE15, FREETIME15, CHOSJOB15, CHOOSDAY15, CHOOSBUY15, CHANGE16, CHOOSSTAF15. The highest possible score for this variable is 1 (if they answered that the individual makes their own decisions for every question), and the lowest possible score is 0 (if they answered that someone else makes decisions on every question). Missing answers are excluded, and the average is computed across the questions with answers. Records are excluded if none of the 9 questions has an answer.

CHOSHOME15: Who chose where the person lives

Answer	Dataset Coding	My Coding
Someone else chose	1	0
Person made the choice	2	1
Person had some input	3	0.5
N/A- Person lives in the family home	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

HOUSEMATES15: Who chose housemates

Answer	Dataset Coding	My Coding
Someone else chose	1	0
Person made the choice	2	1
Person had some input	3	0.5
N/A- Person lives in the family home	98	Excluded
Don't know, no response, unclear response	99	Excluded

Missing Data	None	Excluded
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SCHEDULE15: Who decides daily schedule

Answer	Dataset Coding	My Coding
Someone else decides	1	0
Person decides	2	1
Person has help deciding	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

FREETIME15: Who decides how to spend free time?

Answer	Dataset Coding	My Coding
Someone else decides	1	0
Person decides	2	1
Person has help deciding	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

CHOSJOB15: Who chose where you work?

Answer	Dataset Coding	My Coding
Someone else made the choice	1	0
Person made choice	2	1

Person had help making the choice	3	0.5
N/A- no job in community	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

CHOOSDAY15: Who chose day program or workshop?

Answer	Dataset Coding	My Coding
Someone else chose	1	0
Person made choice	2	1
Person had some input	3	0.5
N/A- no day program or workshop	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

CHOOSBUY18: Who chooses what to buy with spending money?

Answer	Dataset Coding	My Coding
Someone else chooses	1	0
Person chooses	2	1
Person had choosing what to buy or has limits	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

CHANGE16: Person can change case manager/service coordinator

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
N/A-No case manager/service coordinator	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

CHOOSSTAF15: Person chooses staff

Answer	Dataset Coding	My Coding
Someone else chose	1	0
Person chose staff	2	1
Staff are assigned but can be changed if requested by person	3	0.5
N/A	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

A.4: Dependent Variable: Relationships

The relationships variable is computed based on 3 questions coded under HASFRNDS15, LONELY15, SEEFAMILY15. The highest possible score for this variable is 1 if they answered positively to each question (have non-family/staff friends, can visit family as they please, and are not lonely). The lowest possible score is 0. Missing answers are excluded, and the average is computed across the questions with answers. Records are excluded if none of the 3 questions has an answer.

HASFRNDS15: Has friends

Answer	Dataset Coding	My Coding
No, does not have friends	1	0
Yes, has friends who are not staff or family	2	1
Yes, all friends are staff or family, or cannot determine	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

LONELY15: Ever feel lonely

Answer	Dataset Coding	My Coding
No, not often	1	1
Yes, often	2	0
Sometimes	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

SEEFAMILY15: Can see/communicate with family

Answer	Dataset Coding	My Coding
No	1	0
Yes, sees family whenever s/he wants to or chooses not to see family	2	1
Sometimes	3	0.5

Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

A.5: Dependent Variable: BMI

This variable is computed based on a single question coded under BMI. The BMI variable is actually computed, while the survey asks only about weight and height. Converting BMI into scores is slightly more challenging than other variables. It is easy to see why an obese BMI gets a lower score than overweight, but it is not easy to decide the score for an underweight BMI. I made the subjective decision to assign underweight BMIs with a score of 1, which means we assume underweight is as bad as overweight, but preferable to being obese. From a data analysis point of view, it would have been preferable if the survey had included an additional coding for BMI scores below 13, which would indicate serious cases of malnourishment requiring hospitalization. For simplicity, we ignore such scenarios, since only 0.2% of respondents (n=44) have a BMI < 13, which is probably why the survey did not code this as a separate category.

The range for this variable is 0-2 (higher means healthier). Since this independent variable relies on a single question, I exclude missing answers (rather than using some kind of imputation).

BMI: Person's BMI

This variable is calculated based on the person's weight and height. The coding is:

Answer	Dataset Coding	My Coding
Underweight	BMI < 18.5	1
Normal or Healthy	18.5 <= BMI < 25	2
Overweight	25 <= BMI < 30	1
Obese	BMI > 30	0
Missing Data	None	Excluded

A.6: Dependent Variable: Health

The health variable is computed based on only one question coded under HEALTH.

HEALTH13: Person's health

Answer	Dataset Coding	My Coding
Excellent	1	3
Very good	2	2
Fairly good	3	1
Poor	4	0
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

The range for this variable is 0-3 (higher means healthier). Since this independent variable relies on a single question, I exclude missing answers (rather than using some kind of imputation).

A.7: Dependent Variable: Satisfaction with Services/Supports

This variable is computed based on 12 questions coded under: KNOWSCM15, ASKIMPOR15, GETBACK15, SPLAN15, MSPLAN15, PLANUNDRSTND15, PLANPEOPLE15, PLANCHOOSE15, STAFHELP15, STAF15, SWORKCOME15, GOODLIFE15. The highest possible score for this variable is 1 (meaning a high level of satisfaction, engagement and probability to renew), and the lowest possible score is 0. Missing answers are excluded, and the average is computed across the questions with answers. Records are excluded if none of the 12 questions has an answer.

KNOWSCM15: Have you met your case manager/service coordinator?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1

Maybe	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

ASKIMPOR15: Case manager/service coordinator asks what you want?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
Sometimes	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

GETBACK15: Are you able to contact your case manager/service coordinator when you want to?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
Sometimes	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded

Missing Data	None	Excluded
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SPLAN15: Do you have a service plan?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
Maybe, not sure	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

MSPLAN15: Did you take part in the last service planning meeting?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
Had option to but chose not to	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

PLANUNDRSTND15: At the service planning meeting, did you know what was being talked about?

Answer	Dataset Coding	My Coding
No	1	0

Yes	2	1
In between	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

PLANPEOPLE15: Did the service planning meeting include the people you wanted to be there?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
In between	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

PLANCHOOSE15: Were you able to choose the services that you get as part of your service plan?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
Had some input	3	0.5

Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

STAFHELP15: Has staff who help you

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

STAF15: Staff are respectful

Answer	Dataset Coding	My Coding
No	1	0
Yes – all staff always	2	1
Sometimes or some staff	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

SWORKCOME15: Do staff come and leave when they are supposed to?

Answer	Dataset Coding	My Coding
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No	1	0
Yes	2	1
Maybe not sure	3	0.5
Not applicable	98	Excluded
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

GOODLIFE15: Are services and supports helping you to live a good life?

Answer	Dataset Coding	My Coding
No	1	0
Yes	2	1
In between	3	0.5
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

A.8: Independent Variable: SDS Participant

Whether a respondent is an SDS participant or not can be determined using the variable `S_II_SDSUPPORTS`, which we have coded as follows:

S_II_SDSUPPORTS: Is person identified as using self-directed supports?

Answer	Dataset Coding	My Coding
No	1	0

Yes	2	1
Don't know, no response, unclear response	99	Excluded
Missing Data	None	Excluded

Given that this variable is used as the target for the Logistic Regression model, it does not make sense to do any kind of imputation on it, therefore, we exclude missing data.

A.9: Control Variables: Demographics

Control variables in this experiment include demographic variables. Most of these variables are categorical, which means we cannot simply represent them as a number. Instead, I have used dummy variables, and have encoded missing data as a separate category. I abbreviate dummy variable using Dummy(3, 5) to mean: [0, 0, 1, 0, 0] (third entry out of five).

MEDINCOMECAT: Median income category based on zip code

For this variable, the numerical coding in the survey is sufficient, while average imputation is used for any missing data.

Answer	Dataset Coding	My Coding
\$0-\$9,999	1	1
\$10,000-\$19,999	2	2
\$20,000-\$29,999	3	3
\$30,000-\$39,999	4	4
\$40,000-\$49,999	5	5
\$50,000-\$59,999	6	6
\$60,000-\$69,999	7	7
\$70,000-\$79,999	8	8

\$80,000-\$89,999	9	9
\$90,000-\$99,999	10	10
\$100,000-\$109,999	11	11
... follow the same pattern
\$150,000-\$159,999	16	16
\$160,000-\$169,999	17	17
\$170,000-\$179,999	18	18
\$180,000-\$189,999	19	19
\$190,000-\$199,999	20	20
\$200,000-\$209,999	21	21
\$210,000-\$219,999	22	22
\$220,000 and up	23	23
Missing Data	None	5.8

GENDER: Gender of individual

Answer	Dataset Coding	My Coding
Male	1	Dummy (1,3)
Female	2	Dummy (2,3)
Other	3	Dummy (3,3)
Missing Data	None	Dummy (3,3)

AGE: Age in completed years to end of survey cycle (06/2019)

Answer	Dataset Coding	My Coding
18	N/A	18
19	N/A	19
... ages are copied without modification	N/A	...
107	N/A	107
Missing Data	None	43.798

METROCAT: Rural/Metro classification based on zip code.

Answer	Dataset Coding	My Coding
Rural	Rural	Dummy (1,5)
Small town	Small town	Dummy (2,5)
Metropolitan	Metropolitan	Dummy (3,5)
Micropolitan	Micropolitan	Dummy (4,5)
Missing Data	None	Dummy (5,5)

RACE: This variable is itself an encoding of more direct questions like “Race: Asian”.

Answer	Dataset Coding	My Coding
American Indian or Alaskan Native	1	Dummy (1,7)
Asian	2	Dummy (2, 7)
Black or African American	3	Dummy (3, 7)

Pacific Islander	4	Dummy (4, 7)
White	5	Dummy (5, 7)
Hispanic/Latino	6	Dummy (6, 9)
Other race not listed	7	Dummy (7, 7)
Don't know	8	Dummy (7, 7)
Don't know, no response, unclear response	99	Dummy (7, 7)
Missing Data	None	Dummy (7, 7)

LEVELMR: If person is diagnosed with intellectual disability, level:

Answer	Dataset Coding	My Coding
Mild ID	1	Dummy (7,7)
Moderate ID	2	Dummy (1,7)
Severe ID	3	Dummy (2,7)
Profound ID	4	Dummy (3,7)
Unspecified level of ID	5	Dummy (4,7)
ID Diagnosis unknown	6	Dummy (5,7)
Not applicable	98	Dummy (6,7)
Missing Data	None	Dummy (7,7)

Note: Even though the first four responses could have been represented with a number (since they are different levels of the same condition), I chose dummy variable encoding instead because a numerical scale couldn't represent the remaining responses well.

TYPEHOME18: Type of residence

Answer	Dataset Coding	My Coding
ICF/IID, 4-6 residents with disabilities	1	Dummy (1, 4)
ICF/IID, 7-15 residents with disabilities	2	Dummy (1, 4)
ICF/IID, 16 or more residents with disabilities	3	Dummy (1, 4)
Nursing facility	4	Dummy (1, 4)
Other specialized institutional facility	5	Dummy (1, 4)
Group living setting, 2-3 people with disabilities	6	Dummy (1, 4)
Group living setting, 4-6 people with disabilities	7	Dummy (1, 4)
Group living setting, 7-15 people with disabilities	8	Dummy (1, 4)
Lives in own home or apartment; may be owned or rented, or may be sharing with roommates or spouse	9	Dummy (2, 4)
Parent/relative's home (may include paid services to family for residential supports)	10	Dummy (2, 4)
Foster care or host home (round-the-clock services provided in a single- family residence where 2 or more people with a disability live with a person or family who furnishes services)	11	Dummy (1, 4)
Foster care or host home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services—sometimes called shared living.)	12	Dummy (1, 4)

Homeless or crisis bed placement	13	Dummy (3, 4)
Other	14	Dummy (3, 4)
Don't know	99	Dummy (4, 4)
Missing Data	None	Dummy (4, 4)

For this variable there were too many similar options, and I decided to consolidate them into broad categories, either (a) living in a care facility, or (b) living at home.