Evaluation of Consumer Directed Community Supports for People with Intellectual and Developmental Disabilities in Minnesota

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Dedication

To my parents, David and Peggy
For showing me the value of education
For creating community for people with disabilities
And for encouraging me to explore

Thank you.

Abstract

Self directed support options for individuals with intellectual and developmental disabilities (IDD), such as the Consumer Directed Community Supports (CDCS) Program in Minnesota, have become increasingly viable and common in recent years. Despite the fact that such programs continue to grow, systematic, independent study of their uses and effectiveness has remained sparse.

Using an extant data set that includes data from a survey of 112 randomly selected CDCS users from across the state and 29 county developmental disabilities services administrators, this dissertation offers a comprehensive study of Minnesota's self directed supports program for people with IDD. Specifically, this study looks at CDCS usage patterns, including the testing of a model that aims to explain why some individuals remain on the self directed program, while others depart, presumably in favor of traditional service models. In addition, this study examines the characteristics of the direct support workforce that supports persons with IDD in self directed supports.

Two main hypotheses were tested in this research, both using binary logistic regression, with additional descriptive analysis coming from chi-squared analyses and descriptive statistics. Binary logistic regression analysis suggests that CDCS users are more likely to be current users when they are under the age of 22, living in the metropolitan area of the state, and have higher than average individualized budgets. This is an important finding since it supports findings from the initial study using this data set, which descriptively found discrepancies in CDCS usership that may be linked to paternalistic attitudes among county administrators in non-metropolitan areas of the state. The second hypothesis, which tested the predictive utility of wage rates, fringe benefit provision, training opportunities, and worker relationship to the CDCS user on the length of worker tenure, did not yield statistically significant results, leaving questions about the character of the direct support workforce in CDCS.

These findings, as well as others from this study, suggest implications for policy development, future research, and social work practice, which are discussed at some length, as are the limitations of this research.

Table of Contents

List of Tables

List of Figures

Evaluation of Consumer Directed Community Supports for People with Intellectual and Developmental Disabilities in Minnesota

Introduction & Problem Statement

Since the movement towards deinstitutionalization began in the late 1960s, people with intellectual and developmental disabilities, along with their families and advocates, have pressed for progressively more community inclusion and personal choice in daily living. While great strides have been made, enabling about 92% of individuals with intellectual and/or developmental disabilities (IDD) who use residential services to receive such services in community settings that serve fewer than 16 individuals (Lakin, Larson, Salmi & Scott, 2009), true inclusion and self determination have remained elusive goals. While much work remains to achieve true community inclusion for individuals with IDD, steady progress is being made towards deinstitutionalization. In hopes of continuing this progress towards community inclusion, policy innovations aimed at promoting self determination for people with IDD continue to emerge.

One such innovation is the emergence of self directed services and supports for people with intellectual and developmental disabilities. As defined by U.S. Code in the Developmental Disabilities Act, people with developmental disabilities are defined as those individuals with a mental or physical impairment that is manifested before the age of 22, that is likely to continue indefinitely, and results in substantial limitation in three or more specifically defined areas of living. People with intellectual and developmental disabilities are the primary focus of this study.

The Centers for Medicare and Medicaid Services (CMS) offer a four-component definition of self directed services that involves (a) person-centered planning, (b) individualized budgeting, (c) self-directed support, and (d) quality assurance and improvement (Department of Health and Human Services, 2003). In addition, the CMS conceptualization of self directed programs states that these programs are state-run and enable individuals receiving services to live in their own homes (Department of Health and Human Services, 2003). Similarly, a definition proposed by the National Resource Center on Participant Directed Services (2009) describes self directed services as, "A philosophy and orientation to the delivery of services whereby informed consumers assess their needs, determine how these needs should be met, determine who can best meet them and monitor the quality of services received. The consumer exercises substantial control over the resources available to meet their needs."

Often referred to as consumer directed services or participant directed services, these approaches emerged with the 1991 Monadnock self determination project in New Hampshire, and have become increasingly common in the fields of IDD and aging. In the IDD field, at least 13 states had implemented full self directed services options as of 2006, while an additional 11 states offered self directed services in a pilot program, and eight more anticipated launch of a self direction option for people with disabilities by the end of 2007 (Walker, Hewitt, Bogenschutz & Hall-Lande, 2009), indicating that this policy approach has gained wide acceptance nationwide. However, self directed funding options for people with IDD remain in the formative stages with frequent policy changes and wide variation in implementation across states and within states. In addition, there has been little systematic study of self directed support options for people with intellectual and developmental disabilities, particularly from the perspective of program users. As such, much remains unknown about how these programs work, how they are implemented, and what benefits and drawbacks they have for the people who choose this form of assistance.

It is this lack of evaluation of self directed programs, particularly accounting for the views of program users that this work seeks to address by offering a comprehensive evaluation of Minnesota's self directed services option for people with IDD, called Consumer Directed

Community Supports (CDCS). This work will offer a comprehensive independent evaluation of Minnesota's CDCS program to directly account for the viewpoints of multiple stakeholders, and will contribute significantly to the early understanding of the implementation, usage, and outcomes of self directed services for people with IDD.

This dissertation considers several vital aspects of self directed supports using an extant data set with quantitative and qualitative components. In addition to eliciting information from multiple stakeholder groups, including service users and their families as well as county Developmental Disability Services administrators, the study is designed to provide insights into the status of the direct support workforce under Minnesota's CDCS option. This study provides new insights into the workforce outcomes that will be central to the long term stability of self directed service options. In addition to workforce outcomes, the dissertation investigates how CDCS users expend their funds, as well as factors that promote individuals to continue using CDCS or opt for traditional agency-based services. Finally, analysis of interviews conducted with county DD Services directors are used to frame and inform the testing of quantitative research hypotheses and add a measure of richness to the analysis and understanding of this model of supports. Before beginning an examination of the study's methods, findings, and conclusions, however, the study will be contextualized within the current literature on self directed supports and direct support workforce issues, as well as the historical and theoretical background that has led to the enablement of self directed services for individuals with IDD.

Chapter I

Literature Review

The literature pertaining to self directed service options for people with intellectual and developmental disabilities continues to emerge along with evolving self directed policies throughout the United States. Because self directed programs have only emerged since 1991, and have diffused more widely just since the late 1990s, the literature on the outcomes, benefits, and challenges of self directed services is limited. Nevertheless, an initial body of literature has emerged, and will be presented in this section to provide the necessary context on the current status of self direction. Description of the historical and theoretical bases of self direction will be offered, as this will assist in framing the remainder of the discussion. This portion of the paper will begin with contextual information about community services for people with disabilities in Minnesota and nationally, in order to provide the necessary context for understanding self directed community supports.

Community Supports for People with IDD

The initial section of this review of literature will examine the current status of community supports for people with intellectual and developmental disabilities, both nationally and in Minnesota. This is an important piece of contextual knowledge for understanding self directed supports, particularly since institutionalization of people with disabilities was normative until the movement towards deinstitutionalization began in the end of the 1960s. Community supports, broadly conceptualized, are those supports and services that are provided within an individual's community, rather than in segregated settings where integration of people with and without IDD is unlikely.

The National Residential Information Systems Project on Residential Services (RISP) report is published annually, and provides a wealth of national and state-specific data about the status of residential services for people with intellectual and developmental disabilities. The 2009 publication of this report, based on 2008 data and edited by Lakin, Larson, Salmi & Scott (2009), provides the basis for this entire section of the literature review.

Beginning with Minnesota-specific data, RISP reveals that the population of Minnesota's large residential settings for people with disabilities (those with 16 or more residents) has dropped to 415 in 2008, down from 4985 thirty years earlier. Over the same time span, the overall population of the smallest residential settings (those with six or fewer residents) expanded dramatically from only 286 in 1977 to 12,273 in 2008. This reversal in the distribution in living settings for people with disabilities is in line with deinstitutionalization trends. As seen in Figure 1.1, the general trend in Minnesota over the past thirty years has been strongly towards smaller residential settings. Minnesota tends to be ahead of national trends in its move towards deinstitutionalization, though some large institutional residential settings do remain in the state.

Of particular interest in terms of self directed supports, the RISP report identifies the populations of individuals who receive residential support in Intermediate Care Facilities for Mental Retardation (ICF/MR) and through the Home and Community Based Services Medicaid waiver (HCBS). In Minnesota, the number of people receiving services through the HCBS waiver far outpaces the number using ICF/MRs, which do not require a waiver but typically have larger numbers of individuals with disabilities living in the same facility. In 2008, the number of individuals using the HCBS waiver to obtain residential services was reported at 14,563, down slightly from the high of 14,735 in 2002, during a time of open enrollment in the HCBS program in many Minnesota counties. By contrast, only 1,832 individuals received residential services in

ICF/MR settings. Because users of CDCS must be enrolled in the HCBS waiver program and since HCBS enrollments are currently slow with long waiting lists in the state's most populous counties, this may mean declining or stagnant enrollments in CDCS in coming years.

National trends to emerge from the RISP data portray a similar progression towards smaller residential settings and increased reliance on the HCBS waiver, though vast differences across states remain. As of June of 2008, 99.4% of state-operated or licensed residential settings for people with IDD had 15 or fewer residents, and 95.4% had six or fewer residents, meaning that less than 1% of all state-run or state-licensed residential facilities were in the largest category of institution. Only eight states (plus the District of Columbia) had closed all of their large state institutions as of 2008. Nationally, in 2008, about 72% of people with intellectual and developmental disabilities who received residential services lived in settings with six people or less, whereas Minnesota's proportion of individuals in small residential sites was higher than the national trend, at about 86%, suggesting that Minnesota may be somewhat more progressive than the national trend in the provision of residential services to individuals with disabilities in smaller community settings. Also of interest, states reported that about 57.4% of people who use residential support services receive those services within their family home. This segment of the population likely includes many users of self directed supports.

It is important to place these national trends in residential situations for people with IDD in context of state patterns, however, as states vary widely in their residential outcomes. Figure 1.1 shows the national trend for individuals with IDD living in small residential settings (those with six of few residents) as well as trends for selected states. This figure indicates the variation between states such as Vermont, New Hampshire, and Hawaii, which have made great strides towards deinstitutionalization, and states at the opposite end of the spectrum (Mississippi, Illinois, and Arkansas), which continue to have high rates of institutionalization. In contrast to eight states (plus the District of Columbia) that have closed all large institutions, Mississippi continues to have 60.8% of people with IDD in the state living in the largest category of institution (those with 16 people or more). While Minnesota does continue to have a notable institutional population (415 people), the state tends to be among the best in utilizing small residential sites, with 92.6% of individuals with IDD in Minnesota residing in residential settings of six people or less.

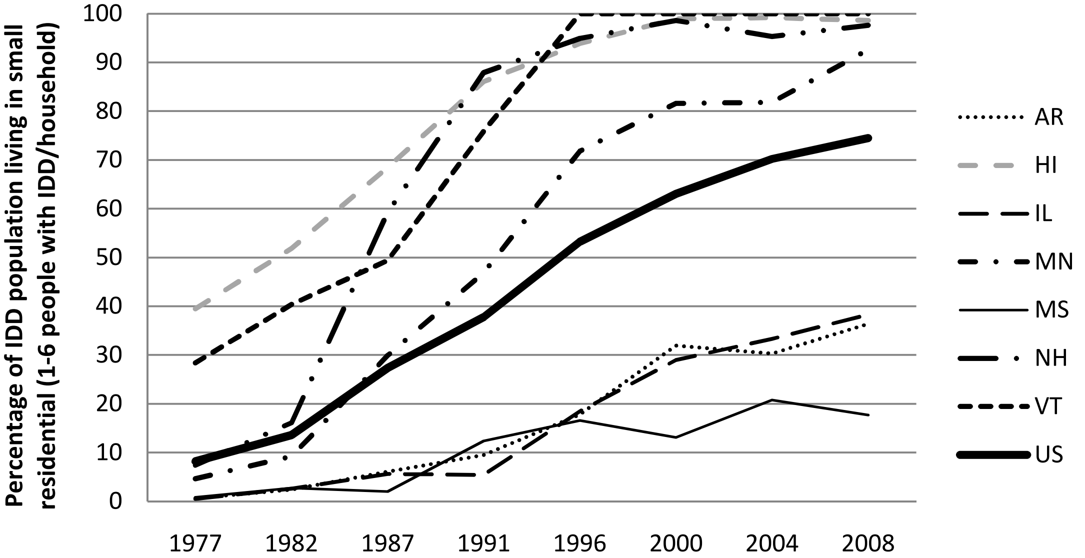


Figure 1.1. Percentage of IDD Population Living in Small Residential Sites by Year (U.S. and Selected States)

Adapted from Lakin, Larson, Salmi & Scott (2009)

Nationally, as seen in Figure 1.2, in 2008 74.5% of individuals with IDD live in settings with 6 or fewer people, whereas 12.2% live in settings of 7-15 people, and 13.3% of people with IDD remain in the largest category of institution, suggesting that trends towards deinstitutionalization nationally have made strong strides, but much progress remains to be made. In Minnesota, deinstitutionalization is still not complete, although the state is ahead of national trends, with 92.6% of people with IDD living in small settings, and the remaining population being split between large and medium-sized facilities.

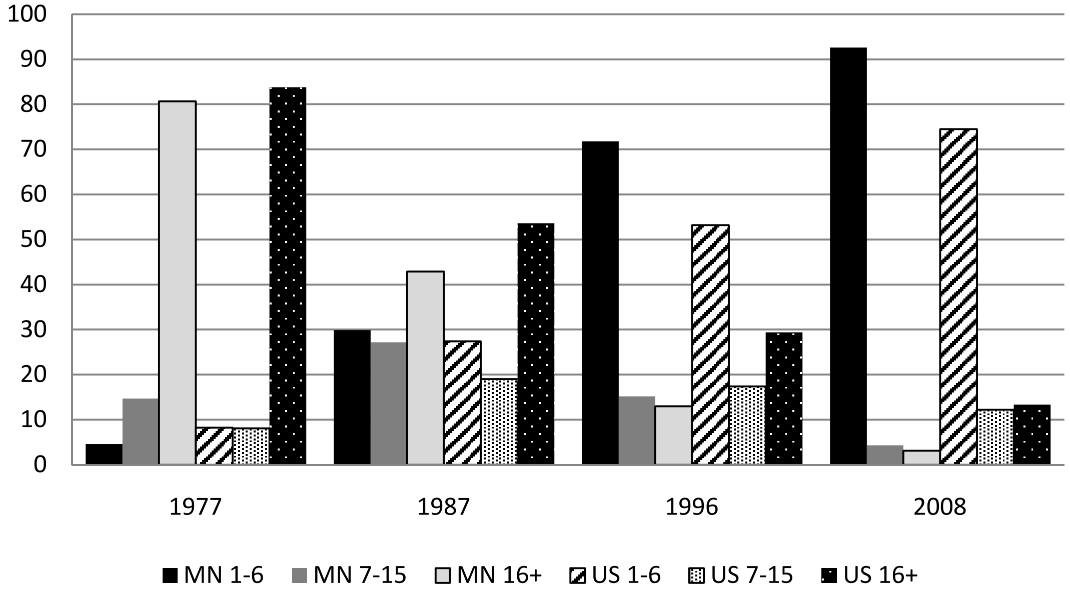


Figure 1.2. Percentage of People with IDD Living in Small, Medium, and Large Residential Sites by Year (U.S. and Minnesota)

Adapted from Lakin, Larson, Salmi & Scott (2009)

Finally, the growth in the number of people with disabilities receiving residential supports through the HCBS waiver continues on a national level with the number of people using HCBS growing by 4.7% since 2006 (to a total of 501,489 in 2007), with all states now offering HCBS. HCBS is used by about five times more people than ICF/MRs nationally, and by almost six times as many people in Minnesota, reinforcing the notion that Minnesota relies heavily on community services funded through the waiver. It is important to note, however, that HCBS is managed at the county level in Minnesota, resulting in some inconsistencies in access and usage throughout the state. Of particular interest in the national trend for people receiving services through the HCBS waiver to use services while residing in their family home, supporting the need to investigate the utility of self directed supports more thoroughly, as this trend indicates the potential for considerable growth in this service delivery method. This progression towards smaller community residential settings led the way to a policy environment in which self directed supports for people with IDD may be a reality.

Policy and Legal Milestones

Since the early 1970s, a series of public policy and legal milestones have promoted systematic changes in the integration of individuals with intellectual and developmental disabilities within American society as well as how their support needs are met. These changes have not evolved rapidly, but the gradual improvements that have come about due to a number of key legal actions have led to today's environment in which self direction of individual supports, based on individually set budgets for support through public funds, has become a viable policy option. This section will present the policy and litigation that has opened the opportunity for self directed supports for individuals with disabilities by describing key legal milestones, and presenting their importance to self direction. This review will proceed chronologically, beginning in 1970. Prior to 1970, institutionalization or family care of individuals with intellectual and developmental disabilities was normative, though high profile advocates such as the Kennedy family had begun to take steps towards destigmatizing IDD (MNDDC, 1998), thus setting the stage for future policy.

It is also essential to understand that the policy and legal milestones discussed in this section were enabled, in large part, by the advocacy of the independent living movement, often associated with the leadership of Ed Roberts in Berkeley, California. Occurring against the backdrop of the Civil Rights Movement, the independent living movement began with protests about the inaccessibility of dorms at the University of California, which resulted in several students with physical disabilities being forced to reside at the university health center. Eventually leading to the establishment of Centers for Independent Living (CILS), this self-advocacy movement was instrumental in raising the profile and the power of the voices of people with physical disabilities that were instrumental in promoting the policy and legal milestones below, as well as improvements in accessibility of buildings and transportation. While the advocacy of people with physical disabilities and the creation of CILS did not directly serve to improve living conditions and community integration for people with intellectual and developmental disabilities, the independent living movement did set a precedent for self-advocacy and service improvement that would be key to the progression of policy and service improvements for people with IDD a few years later.

Developmental Disabilities Services and Facilities Construction Act of 1970. The passage of the Developmental Disabilities Services and Facilities Construction Act of 1970 (PL 91-517) marks the beginning of significant IDD-related legislation in the United States and is remarkable for several reasons. First, the law offered the first definition of developmental disabilities in U.S. Code, specifying that developmental disabilities are those conditions that manifest prior to age 18, cause a substantial handicap, and are expected to continue indefinitely. Mental retardation, cerebral palsy, epilepsy, and neurological conditions are specifically mentioned.

PL 91-517 was also significant in that it created the authority for the formation of a developmental disability council in each state. These councils, which have been reauthorized by subsequent amendments and reauthorizations of the DD Services and Facilities Construction Act, play a vital role in state-level planning and service implementation for people with disabilities. The establishment of the state councils in 1970 represented a significant step since people with intellectual and developmental disabilities, parents, and advocates gained a voice in policy making, a vital step in the empowerment of people with IDD.

The DD Services and Facilities Construction Act of 1970 was also significant in that it represented the first steps towards deinstitutionalization, as it authorized funding for the construction of smaller, more localized residential centers where people with IDD could live and receive supports. Since there was a partial focus on relocating individuals to the regional facility closest to their home, the regional centers enabled, in many cases, the reestablishment of closer family relationships, and a greater degree of family oversight of support provision (MNDDC, 2001).

The DD Services and Facilities Construction Act of 1970 is notable to self direction primarily because it represented an initial move towards deinstitutionalization and because it authorized the creation of the state-level developmental disability councils, which have been instrumental in advocating for progressively more inclusive policy alternatives for people with IDD in many states, including Minnesota. Deinstitutionalization remains incomplete, with 42 states operating at least one large residential facility for people with disabilities (Lakin, Larson, Salmi & Scott, 2009). Nevertheless, vast strides have been made in providing community support options which now comprise over 99% of licensed residential facilities for individuals with disabilities in the United States (Lakin, Larson, Salmi & Scott, 2009). This is significant for self direction, since the existence of a variety of community residential options allows greater opportunities for self direction than would be afforded by institutional settings. The DD Services and Facilities Construction Act of 1970 is also significant because it is the basis upon which amendments were added to arrive at the 2000 reauthorization of the Developmental Disabilities Act described later in this section.

Wyatt vs. Stickney. In 1970 in the case of *Wyatt vs. Stickney*, a group of employees of an Alabama state hospital included a patient in their suit to contest their layoffs, claiming that the layoffs adversely impacted the quality of the patient's care. Judge Frank M. Johnson did not allow the employee's suit to move forward, but did agree to hear the case of the patient, Ricky Wyatt, who alleged that he had the right to receive mental health treatment, a claim that was upheld by the judge. In his decision, Judge Johnson ruled that patients of state hospitals indeed held the right to treatment. Since state treatment facilities were unable to meet the court's standards for treatment, the *Wyatt vs. Stickney* decision effectively marked the beginnings of large scale deinstitutionalization for individuals with mental health diagnoses, as well as similar effects for people with intellectual and developmental disabilities (TAC, nd). *Wyatt vs. Stickney* was also notable since it was the highest profile incident to date in which litigation was successful in bringing about significant structural changes, illustrating the power of litigation in advocating for additional movement towards inclusion of individuals with intellectual and developmental disabilities in the American mainstream (MNDDC, 1998). Litigation building on the *Wyatt vs. Stickney* ruling has been instrumental in guiding lawsuits regarding the reduction of waiting lists for Medicaid waiver services in some states (e.g.: *Makin vs. Hawaii, Fisher vs. Oklahoma, Boulet vs. Cellucci, Doe vs. Chiles*), and in gaining mandates for person centered planning in other states; both of which are key components of policy for self directed supports.

Omnibus Budget Reconciliation Act of 1981. Among the most important policy landmarks that has cleared the way to the development of policy for self directed supports for individuals with IDD is the Omnibus Budget Reconciliation Act of 1981 (OBRA; P.L. 97-35). Backed by the power of the deinstitutionalization movement and other legal milestones including the *Wyatt vs. Stickney* decision, OBRA addressed the need for community supports for people with disabilities by establishing the 1915(c) Home and Community Based Medicaid waiver program.

OBRA was a hallmark of Ronald Reagan's social service agenda, as it combined 57 separate federal grant programs into only nine loosely defined state block grant programs which allowed for great control over program design by individual states (Guttmacher Institute, 1996). In addition to representing a significant shift in how policy for social services is designed at the federal level, OBRA also represented a major turning point in the manner in which services are provided to people with IDD. Pertaining to self direction of services, most notable among the block grants is the Home and Community Based Services Medicaid Waiver (HCBS), which allowed states to use federal matching funds to reimburse the provision of services to individuals with intellectual and developmental disabilities living at home or in the community, rather than only in cases in which individuals resided in institutional residential settings.

The HCBS waiver program has several noteworthy provisions that have impacted the program throughout its existence. First, states are allowed to specify specific populations or geographic areas that may be funded through the 1915(c) waiver. This effectively limits the degree to which states must extend financial resources to fund the waiver, since eligibility criteria may be managed. Secondly, OBRA language specifies that states may cap the number of individuals who may utilize the HCBS waiver at a single time, thus providing another fiscal control mechanism. In many states, this has resulted in a waiting list for waiver services, since states are unable to adequately meet the growing demand for community services due to budget constraints (Kitchener, Ng, & Harrington, 2004). However, states have received mounting pressure to provide support to individuals with disabilities who are on the waiting list for HCBS waiver services, and some have turned to self-directed options for support to fill this need (Walker et al., 2009). Additionally, cost neutrality provisions for OBRA dictate that HCBS expenditures cannot exceed the per capita expenditures that would be anticipated with institutional provision of care.

The HCBS provisions of OBRA have several main components that are pertinent to an understanding to self directed supports. First, HCBS waivers provided a tool by which individuals with IDD could receive financial support to pay for services without institutionalization, thus strongly reinforcing the move towards community supports. Secondly, the HCBS dramatically expanded options for service provision for individuals with intellectual and developmental disabilities to include the possibility of federally funded supports that could be provided in one's own home or in a community setting that more readily represented the ideals of normalization, which will be discussed below. Finally, the skeleton of the HCBS waiver program has served as the basis for future funding possibilities, including those that support self direction of supports, such as the emerging Cash and Counseling model authorized by section 1915(j) of the Social Security Act.

Tax Equity and Fiscal Responsibility Act. The highly controversial Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA; P.L. 97-248) is most notable in that it repealed previous income tax cuts from the Economic Recovery Tax Act of 1981. TEFRA was implemented by the Reagan administration on the understanding that Congress would reduce government spending by three dollars for every dollar of increase in taxes, theoretically leading to large revenue increases for the federal government. While the main provisions of TEFRA related to taxation, additional provisions related directly to individuals with IDD.

Most specifically, TEFRA allowed for Medicaid waiver eligibility for the families of children with intellectual and developmental disabilities, even if the family's income was above the cap specified for Medicaid eligibility, provided that the duration of services exceeded 30 days and the child was identified to have a known disability (Bazelon, n.d.). While typically not associated with disability policy, TEFRA is significant to self direction of supports for individuals with IDD, since it set the precedent for families at higher income levels to be able to secure waiver funds to provide needed supports for their (young or grown) children who have intellectual and developmental disabilities, as is often the case in policies that allow for the self direction of supports.

Americans with Disabilities Act. The Americans with Disabilities Act of 1990 (ADA; P.L. 101-336, amended as P.L. 110-335 in 2008) is the main civil rights legislation protecting the rights of individuals with disabilities in the United States, and is far reaching in its scope. While the Rehabilitation Act of 1973 (P.L. 93-112) established the rights of people with disabilities in employment with federal agencies and contractors of the federal government, the ADA was the first legislation to establish civil rights protections for individuals with disabilities throughout American society. As the world's first example of anti-discrimination legislation for people with disabilities, the ADA has served as a model for the adoption of similar policies throughout the international community.

The ADA contains five titles, each with a specific focus area for establishing basic rights and accommodations for people with disabilities. Title I deals with employment, and prohibits employers from discriminating against qualified employees and potential employees on the basis of disability. Additionally, Title I requires employers to make reasonable accommodations to enable employees with disabilities to perform essential job functions. Title II requires that all public services, including education, public transit, programs and services of federal, state, and local government, and parks and recreational opportunities be made accessible to people with disabilities. Title III stipulates that private enterprises that do business with the public (e.g.: restaurants, shops, theaters) be accessible to people with disabilities, including the removal of physical barriers and providing written materials in alternate formats, although provisions are made for small employers, which are not required to make accessibility-related changes if they pose undue financial hardship. Title III also requires all newly constructed buildings to comply with building codes that enable full accessibility. Title IV requires telecommunication firms to provide relay services for individuals with hearing or speech impairments. Finally, Title V provides basic guidelines for administration and implementation of ADA.

While the ADA is generally regarded as the centerpiece of American disability policy it is not without criticisms. It has been argued that the ADA lacks proper oversight and enforcement which allows employers and business owners to easily claim economic hardship rather than make accommodations for employees or potential patrons, and that the ADA has done little to improve access to quality employment and true social integration (Switzer, 2003). Another emerging concern is that technological advances are often inaccessible to individuals with disabilities, since physical impairments may make the use of standard technologies related to computers and cell phones difficult (Carey, Friedman, & Nelson, 2005). Despite these criticisms, the ADA has made major contributions towards self directed programs, since it established a standard for determination of discrimination on the basis of disability. This has most notably opened the door to litigation such as *Olmstead vs. L.C. and E.W.*, which has been significant in the development of community services and have set the stage for self directed programs and policies.

Olmstead vs. L.C. and E.W. In this landmark ruling of a lawsuit premised on the ADA, the United States Supreme Court found, in what is commonly known as the *Olmstead Decision* (Olmstead et al. vs. L.C. et al., 1999), that individuals with disabilities, including IDD, physical disabilities, mental health disabilities and the elderly, have the right to care in the least restrictive environment possible, given the individual’s support needs. In 1995, a suit was filed by the Atlanta Legal Aid Society on the behalf of Lois Curtis and Elaine Wilson. Curtis and Wilson resided in a Georgia institution, and were unable to move into community living arrangements, despite holding the capability to do so, because no community residential options were available at the time (Atlanta Legal Aid, 2007). Asserting that forcing an individual to remain institutionalized after he or she was judged ready to move to a more integrated setting constituted discrimination based on the ADA, the *Olmstead Decision* marked the first application of ADA language mandating integration. Following the *Olmstead Decision*, by way of Executive Order 13127 (June 2001), the New Freedom Initiative ordered states to abide by the findings of the court by providing support options for people with disabilities that would offer the lowest degree of restriction feasible for the individual. Each state is required to maintain a plan of action on how the principles of *Olmstead* will be implemented and to evaluate progress, based on guidelines set forth by the Centers on Medicare and Medicaid Services.

In relation to these state plans, it is notable that there is a large degree of variability in if and how states have developed and implemented plans. As of August of 2009, 31 states had filed a formal plan outlining how they would comply with the *Olmstead Decision's* ruling, while 13 states (including Minnesota) had filed an alternative plan in lieu of a formal *Olmstead* plan. Six states and the District of Columbia had not filed an *Olmstead* plan or an alternative plan as of 2009 (Ng, Wong, & Harrington, 2009). In addition, the content of *Olmstead* and alternative plans is variable across states, with some states focusing most strongly on aging and mental health services, since community supports for individuals with physical disabilities and IDD tend to be more community focused in many states.

While the direct impact of the *Olmstead Decision* is large, the related events that have followed from the court's ruling have been equally significant. In the years following the *Olmstead Decision*, a cascade of related lawsuits have been successful in advocating for the expansion of community support options for individuals with intellectual and developmental disabilities, as well as the other populations covered by the ruling (physical disabilities, mental illness, the elderly), throughout the nation. The principles and precedent established by *Olmstead*, focusing on the pursuit of integration, community inclusion, and an end to discrimination based on disability status have underscored many subsequent suits that have moved individual states closer to achieving integrated services.

The impact of *Olmstead* on the development of self directed policy options to support individuals with IDD is significant. Advocates argue that the ability to control one's own finances and to select the supports one needs to pursue one's own goals may represent the ultimate manifestation of integration. The integration mandate established by the ADA and put into force by *Olmstead* has resulted in a continuation of deinstitutionalization and a rapid expansion of community services, which have grown by over 500% since 1992 (Kitchener, Ng, & Harrington, 2004). Self directed supports for people with IDD are premised on the notion that individuals are capable of living in the community with proper supports, which is the same notion that underlies *Olmstead*.

Developmental Disabilities Assistance and Bill of Rights Act of 2000*.* Building on the original Developmental Disabilities Services and Facilities Construction Act of 1970, and undergoing amendments in several years in the interim, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the DD Act) provides the basis for much of the civic participation, decision making, and service innovation that occurs in the area of intellectual and developmental disabilities. The DD Act was responsible for the original formation of Developmental Disabilities Councils in each state, and the continued funding of these bodies, which provide an official venue for people with disabilities, family advocates, and other concerned parties to strategize about issues related to IDD and to advocate for service innovations that are important in each state. The DD Councils are among the most important forums for individuals with IDD and their advocates to participate in civic life, and advocate for their needs from within the political system.

The DD Act is also responsible for the establishment of University Affiliated Programs (renamed University Centers for Excellence in Developmental Disabilities [UCEDD] in 2000). These centers exist in each of the states, with some states having more than one center. They are charged with providing specialized training, research, and outreach on issues relating to intellectual and developmental disabilities. While the research and training that is conducted via the UCEDD network is of vital importance in promoting progress for service systems for individuals with IDD, another key aspect of the UCEDD mission is to provide pre-service training to students who will work in the field. This critical mission was supported by the original DD Act in 1975, and continues to receive high priority in the 2000 reauthorization.

Finally, the DD Act is instrumental in providing funding for progressive projects of national significance and establishing systems for protection and advocacy for individuals with IDD. Together, these four components of the DD Act have been instrumental in bringing about self directed systems of support, particularly since the DD Councils and the UCEDDs have been consistent in advocating for more individual choice and control in the provision of services.

With this understanding of the major federal-level policy and litigation that has led to deinstitutionalization, the expansion of community support programs, and civil rights protections for people with intellectual and developmental disabilities now established, attention may turn to an examination of the theoretical movements that have shaped today's policies for self directed supports for people with IDD.

Theoretical Basis of Self Direction

Of primary theoretical importance to an understanding of self direction are theories of normalization and self determination, which have been dominant since the 1970s in guiding the evolution of disability policy. In addition, the theory of social capital, while not often associated with IDD-related policy and services, plays an important implicit role in the progression of self directed supports. The contribution of each of these theories will be outlined in this section.

Normalization/Social Role Valorization. Normalization is a theory, later revised as social role valorization, with formal origins dating back to the work of Bengt Nirje, President of the Swedish Parents Association for Mentally Retarded Children, who formally proposed the Normalization Principle in the late 1960s. Since Nirje's Normalization Principle was initially widely disseminated to the American audience in the 1969 President's Report on Mental Retardation, its merits have been updated a critiqued by a number of theorists, most notably Wolf Wolfensberger, whose 1972 work in *The Principle of Normalization in Human Services* remains the classic work on normalization theory. In this section, the work of Nirje and Wolfensberger will be summarized, critiques of normalization will be offered, and the theory's contribution to self direction of supports will be discussed. This conversation will also cover social role valorization, which grew out of normalization.

Normalization has taken various definitions over the past three decades, leading Baldwin (1985) to claim that there are a series of normalizations, rather than a single concept. While definitions have varied, all have focused generally on the notion of individuals with disabilities living typical lives within the context of their culture. In Nirje's (1970) conceptualization of normalization, concern was placed on the rhythm of life for a person with a disability being similar to that of an average person matched for gender, age, and culture, while leaving room for individual variations in behavior and preferences. In his later work, Nirje (1980) noted that society must also play a role in normalization by accepting people with disabilities into mainstream society, underscoring the egalitarian underpinnings of the Nirjian approach.

Partially developed as a critique of Nirje's early work, Wolfensberger's (1972) approach to normalization theory posited that a devalued group such as people with disabilities could not hope to gain equal status within society easily, and as such, proposed that people with disabilities be assisted in upholding their status in society which should be as good as the average citizen. As Wolfensberger's model of normalization evolved, it became more concerned with the notion of unacceptable differences if people with disabilities were not permitted to normalize, leading him to determine that the social roles of individuals with disabilities may be marginalized if they were to resist integration with the mainstream community. Wolfensberger (1983) formally presented these thoughts as a theory of Social Role Valorization, replacing his former theory of normalization, and proposing that the creation of socially valued roles for individuals with disabilities was the key to true integration.

Normalization theory is often credited with starting a discussion that has ultimately resulted in improved community integration and the development of valued social roles for individuals with disabilities, though the direct impact of normalization theory is difficult to assess due to variation between strands of the theory as exemplified by the preceding discussion on Nirje and Wolfensberger. In addition, critics of normalization theory have proposed that normalization assumes an assimilationist stance, in which people with disabilities are expected to conform to the norms of the dominant culture, rather than embracing the cultural uniqueness that may be promoted by the presence of a disability (Darling, 2003). Other critics (Culham, 2003) argue that normalization should be deconstructed, since the semantic disagreements that have clouded the normalization movement run the risk of slowing the move towards inclusion and away from marginalization of people with disabilities (Race, Boxall, & Carson, 2005). Normalization theory has been embraced differently among different disability groups, with individuals with physical disabilities following the ideas of normalization to a lesser extent than people in the IDD community. Finally, and perhaps most strongly, empirical research indicates that the normalization principle has fallen short of its aims since people with disabilities continue to experience less daily choice in where they live, work, and play than would be expected for people in the mainstream population (Smith, Morgan, & Davidson, 2005).

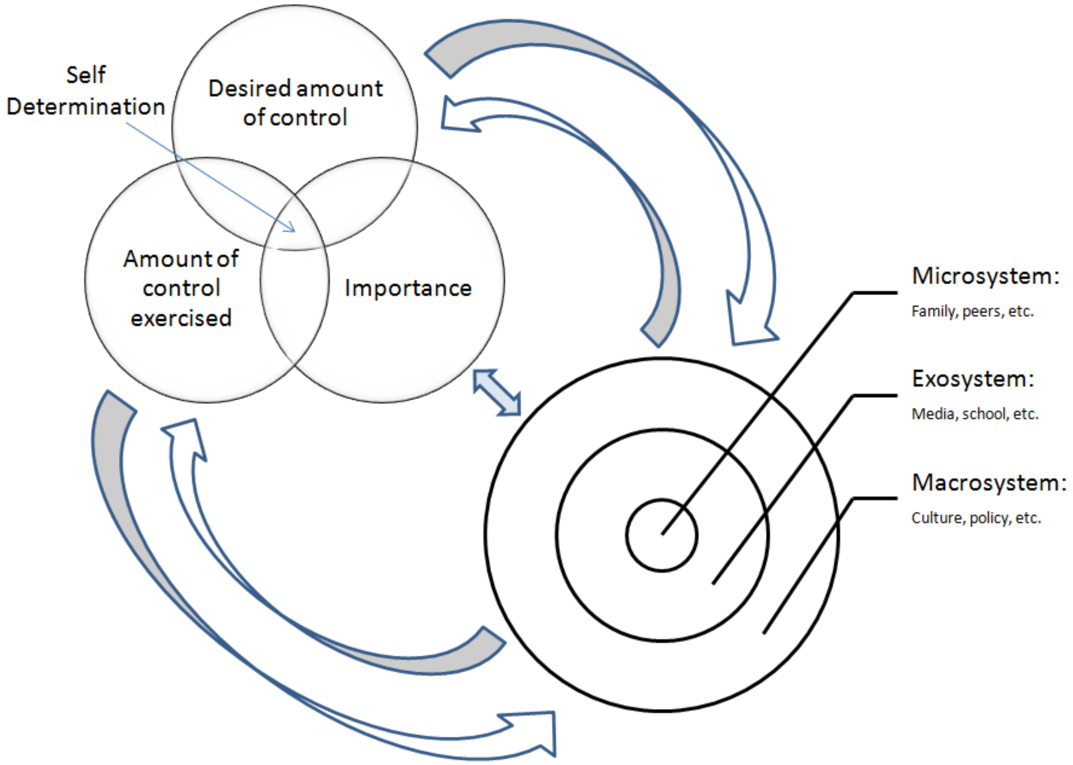
Despite these weaknesses, however, normalization theory has played a significant role on a number of fronts in the move towards self-direction of services and supports by people with intellectual and developmental disabilities. First, normalization theory was a driving force behind the deinstitutionalization movement which brought many people with IDD out of institutional care settings and into more normalized community residential and vocational settings. Secondly, the principles of normalization are evident in litigation, most notably the *Olmstead Decision*, which stipulate that services for individuals with disabilities be provided in the least restrictive (i.e.: most normalized) environment. Third, the legacy of normalization, particularly as conceptualized by Wolfensberger, is partially responsible for raising the civil rights profile of individuals with intellectual and developmental disabilities, leading to the signing of the ADA and recognition of the right of people with IDD to live and work for themselves with the same civil status as any other member of American society. In addition, normalization and social role valorization theory holds the notion that individuals with IDD must be allowed to lead lives that are as similar as possible to their cultural counterparts: a notion with the underlying assumption individuals with intellectual and developmental disabilities are capable and entitled to make decisions and direct their supports in their own interests.

Self Determination. Much like normalization, the construct of self determination is one that has been confused by multiple meanings in recent years. Michael Wehmeyer, one of the foremost scholars in self determination theory as it applies to people with disabilities, has theorized that self determination is based on the individual’s ability to act in accordance with his or her free will, absent of external compulsion (Wehmeyer, 2003, 2005). In earlier work, Wehmeyer (1996, 1999) focused on issues of empowerment, autonomy, and self-regulation. In common interpretation, both in the academy and in practice, this conceptualization of self determination is defined as personal control over decisions and events, though this interpretation has come under fire by Wolfensberger (2002), who argues that many people with more severe disabilities may be further marginalized by practitioners and researchers who equate self determination with control, since the notion of control creates an uneven power dynamic that disempowered individuals with IDD cannot hope to overcome. As a response to this criticism, Wehmeyer (2005) reiterates that self determination is indeed about volition or free will over one's decisions and not about a particular behavior or means of control.

An alternate view of self determination is offered by Abery and Stancliffe (2003), who set forth an ecological model of self determination, in which the individual's environment influences his or her opportunities for self determination and his or her actions, in turn, influence the environment. Self determination in this model comes about when an individual considers his or her desired level of personal control, the importance of the issue to be decided, and the degree of personal control that would need to be exercised. While markedly more complex than the dominant version of self determination as proposed by Wehmeyer, Abery and Stancliffe's (2003) ecological model of self determination attempts to account for the nuances of life, which sometimes require the ceding of personal control, or compromise in self determination, as in a relationship with an intimate partner or a work supervisor. It is similar to Wehmeyer's work, however, in that it holds volition as a key to self determination.

The application of Abery and Stancliffe's (2003) ecological model of self determination warrants further description because of its theoretical proximity to Urie Bronfenbrenner's (1979) ecological systems theory, which is often adopted in social work practice, research, and education. In Bronfenbrenner's model, an individual is an agent within a multi-tiered system, in which the individual's decisions and actions may influence, and be influenced by, elements of the microsystem (family, peers, classroom, etc.), mesosystem (interactions and communications between agents in the microsystem), exosystem (community, media, school, etc.), and macrosystem (governments, economics, history, culture, etc.). Although originally envisioned as a theory of child development (Bronfenbrenner, 1979), the ecological model eventually evolved to explain environmental influences on human development over the lifespan (Bronfenbrenner, 2000), much as Abery and Stancliffe's (2003) tripartite ecological model of self-determination suggests that a person's experiences with self determined action may inform future choices later in life, based on the influence of personal and environmental factors. Abery and Stancliffe (2003) also investigated the complex interrelations between their three-component model of self determination and the influence of the multiple systems suggested by Bronfenbrenner, noting, for instance, that cultural influences from the macrosystem may regulate the degree to which an individual may make decisions and exercise self-determination based on factors such as age or sex. Likewise, a child or a person with an intellectual disability may cede some control for decision making and self-determination to a family member in his or her microsystem, based on the notion that the family member's greater experience in making decisions in certain areas may result in optimal outcomes. Thus, influences from all levels of the ecological systems model developed by Bronfenbrenner, and widely applied in social work, may influence the self determination of an individual with an intellectual or developmental disability. The simple representation of some of the many interactions between the ecological systems theory and Abery and Stancliffe's theory of self determination are illustrated in Figure 1.3, and lend important insights into the nature of self determination in the context of self directed supports. It is notable, however, that this conceptualization of self determination remains controversial, as individualized notions of the exercise of choice and control, as proposed by Wehmeyer (2003) continue to dominate conversations about self determination.

Figure 1.3: Abery and Stancliffe's (2003) Self Determination Model and Bronfenbrenner's (1979) Ecological Systems



In addition to the differences in conceptualizing self determination, other challenges to self determination theory have also emerged. Foremost among these critiques is that self determination among individuals with intellectual and developmental disabilities is not expanding, despite heavy theoretical concentration on the construct. Explanations for the lack of expansion of self determination range from arguments about ingrained structural issues that perpetuate traditional roles and power differentials (Powers, 2005) to a lack of real choices in life's large decisions that undermines the opportunity for real self determination for people with disabilities (Storey, 2005). Furthermore, the majority of studies in the disability field still do not account for issues of self determination (Shogren, Wehmeyer, Buchanan, & Lopez, 2006), and those that do address self determination often provide inconclusive results about how self determination is promoted and interventions that may assist in expanding the scope of self determination (Chambers et al., 2007). Thus, the impact of self determination theory on the lives of people with disabilities, including IDD, remains in question, though it is clear that self determination theory has had a direct impact on the enablement of policy for self directed disability services.

Self determination theory has been a high profile part of the movement towards self directed policies enabling individuals with intellectual and developmental disabilities to direct their supports. Choice and volition are at the heart of all conceptualizations of self determination, as they are the central elements of self directed policy. In addition, the initial work towards self directed policy, as outlined in the policy section, involved self determination projects funded by the Robert Wood Johnson Foundation. Thus, in the policy arena, self determination theory has been a driving force in the development of policy for self direction of supports by individuals with intellectual and developmental disabilities. Ironically, self determination at the policy level has largely been left out of the debate about self determination theory, which has focused primarily on micro level applications of the theory. Nevertheless, self determination theory has been influential in raising the profile of the need for self directed policy and funding options for people with IDD.

Social Capital. The theory of social capital was first proposed by French educational sociologist Pierre Bourdieu in 1986, when he published a chapter that differentiated among cultural and social capital. Social capital, Bourdieu proposed, was based on relationships within social networks, in which patterns of expectation and obligation formed in the context of group norms to create conditions under which group members could accumulate social capital that could be redeemed at a time when it would most benefit the individual possessing it. The theory was revised by Coleman (1988) who refined the conditions under which social capital could be accumulated, and the nature of the obligations and expectations that govern social capital. Coleman (1988) also extended the conceptualization of social capital by contrasting it with human capital and the more traditional materialist definition of capital that equates with monetary capital or the means control material production. While the complexity of the nuances of social capital are outside the scope of this review, it is important to understand that social capital is based on the qualities of the relationship between actors, rather than traits of the actors individually. This is particularly true in Coleman's conceptualization, which is the basis of most applications of social capital theory.

Of particular interest to the study of self directed supports for individuals with IDD is the differentiation between two distinct forms of social capital: bonding and bridging. According to Putnam (1993) bonding social capital is present within tightly knit homogeneous groups, while bridging social capital is useful for interactions within the broader community and across social groups. While the specific interrelations between bonding and bridging sub-types of social capital have not been studied in relation to self directed support models, it is possible that reliance on family members to provide support services (indicating the need for bonding social capital), may reduce the application of bridging social capital. It is unknown to what extent this may serve to limit or promote greater social inclusion of individuals with IDD in their communities, where bridging social capital would be primary.

Although not a theory that is typically associated with the disability movement, social capital is gaining a foothold in disability studies and services, particularly as a result of the Council on Quality and Leadership's promotion of integrated communities as a central component to quality service provision and accreditation (CQL, 2009). Though just now growing in disability studies, the social capital concepts developed by Bourdieu and Coleman may hold a key to developing a deeper understanding of the underlying assumptions of self directed programs of support, as well as the ramifications of these programs.

The existing literature examining the importance of social capital among individuals with disabilities, while it does not address self directed services directly, provides some background on the application of social capital theory with this population. For instance, Bates and Davis (2004) suggest that social capital and social inclusion are best understood in tandem, as they have complimentary roles in supporting community services for individuals with learning disabilities in the British context. Further suggestion of the importance of social capital in developing social inclusion comes from Australia, where Chenowith and Stehlik (2004) contend that people with disabilities and their families have been excluded from the application of social capital development, and suggest that mindful program development is necessary to bring the benefits of increased social capital to people with disabilities. The importance of using social integration, as opposed to physical integration, as a means for building social capital for people with disabilities is underscored by Cummins and Lau (2003) who contend that efforts to extend social capital through physical inclusion may be stressful, rather than useful. Other authors (McKeever & Miller, 2004) explicitly use Bourdieu’s rendering of social capital to illustrate that the study of parents of children with disabilities, who are often studied in terms of their stress and presentation of psychosocial symptoms, actually act in ways that optimize their physical, cultural, and social capital in order to provide optimal opportunities for their children, bringing the important role of social capital in family systems to the forefront of conversation.

Within family systems, social capital may be more limited for individuals with intellectual disabilities than would be expected for people without IDD. In a Swiss study, researchers found that people with intellectual disabilities felt less connection to their families, and less ability to leverage within-family social capital (Widmer et al., 2008). Widmer and colleagues (2008) also note that the within-family social capital available to individuals with intellectual and developmental disabilities is likely to remain limited across the lifespan, as people with IDD are less likely than people without IDD to have long term partners and children. Trainor (2008) contends that this difficulty in establishing family social capital and the related difficulties that families face in utilizing their accumulated capital, may translate to sub-optimal outcomes when youth with disabilities transition into the adult service system and work opportunities, leading to the notion that educational systems should develop curriculum that seeks to build social capital among individuals with IDD and their families.

As applied to self directed policy options for people with intellectual and developmental disabilities, social capital theorists would note that self direction assumes some degree of social capital, particularly concerning the hiring of support staff by people with IDD or their primary support people. The ability to hire and manage staff assumes that the individual receiving supports is adequately empowered to create obligations and expectations in the relationship with the support staff, thus assuming the presence of social capital, as would be the case in any relationship between an employer and employee. This indicates a fundamental shift in the power dynamic between the person with IDD and his or her support staff, since, as the employer, the individual with IDD is in the position to assert more power in the formation of social capital.

Another particularly interesting application of social capital theory to the study of self directed services is how the ability to hire family members and close friends to provide support services for pay will change the traditional tendency for such supports to be provided without charge. Traditionally, family members or close friends would assist in supporting individuals with IDD at no charge, as a part of the social capital arrangement which would suggest that providing supports would be repaid with other favors in the future. With payment for support services becoming more normative with the expansion of self directed programs, it is unclear if the existing social capital arrangements that enable free support services will remain intact.

This is potentially of concern since the proportion of paid to unpaid support remains unclear among individuals who self direct supports, as does the strength of social capital obligations and expectations that govern unpaid support if paid support becomes more normative.

Current Literature on Self Direction

With the policy and theoretical backdrop to self direction established, attention may turn to the current state of knowledge on implementation of self directed programs in the United States. Although the current state of knowledge on the promising practices, benefits, challenges, and cost-benefit ratio of self directed programs is largely undeveloped due to the fact that self directed services are still newly emerging and undergoing rapid transformations, a small amount of literature has emerged. In this section, the literature will be examined to gain a sense of the findings of the earliest studies of self directed programs. Because the literature is limited in this area, policy for people with disabilities and for the elderly will be examined together in order to develop stronger themes from early implementation.

Promising Practices in Self Direction*.* Although a significant amount of variation exists in implementation of consumer directed supports from state to state, there are several common elements. Generally speaking, and in line with the previously presented CMS definition of self directed services, self directed supports may be viewed as those in which people with disabilities, their families, and their allies directly manage and direct their services and supports. In this service option, people with disabilities and their families use individually set and controlled budgets to select, purchase, and manage their own supports within an established framework of guidelines (Alliance for Self Determination, 1999; Nerney & Shumway, 1996; Scala & Nerney, 2008). Finally, regular evaluation of outcomes is necessary (Mosely, 2004). Typically, among individuals with IDD, a family member or other key advocate will be central in helping to coordinate and evaluate self directed supports in the individual’s behalf.

Research reveals several common elements reflecting promising practices in self direction. These features include individual budgets, support coordination, and the use of fiscal intermediaries (Nerney, 2001; Scala & Nerney, 2008). These supports are thought to be essential to the effective implementation and long-term usage of self directed services.

Individual budgets are financial plans developed, managed, and controlled by the individual with IDD and his or her support circle (Scala & Nerney, 2008). These budgets are based on the individual's unique needs and ambitions with individualized supports needed to meet these goals. The process of individual budgeting involves components to guarantee control by the individual with the intellectual or developmental disability and his or her family. These components include the development of a person-centered plan that reflects the goals and dreams of the person the ability of the person receiving supports to continually oversee and manage his or her staff. Finally, individual budgets must be flexible enough so that the person can shift funds across budget line items, create new items, and eliminate old ones as long as the basic supports and services are preserved (Agosta, 1999/2000; Scala & Nerney, 2008, Nerney, 2001).

Independent support coordination (also referred to as independent brokering or personal agents) is another promising practice in self direction. This involves creating support mechanisms such as a support coordinator to facilitate the types of supports needed and to help people navigate the system. This approach relies on two important assumptions: the support coordination role must be independent from service provider system and the support coordinator must have authority from the state or other sanctioned authority to represent the person with IDD and his or her family. The support coordinator is a person who assists the person with an intellectual or developmental disability with the development of the individualized plan, helps coordinate resources and supports, and assists with ongoing evaluation of progress and quality of supports. Support coordinators have similar roles to case managers, but they are employed by the individual not by the agency providing supports or the county or state funding the program, an important separation of duties that has emerged from early implementation (Walker et al., 2009). Support coordinators serve as intermediaries to broker services and supports (Wehmeyer & Stancliffe, 2003).This role of the independent support coordinator removes the conflict of interest inherent in many traditional models of support. Supports and services are coordinated based on what is best for the individual, as determined by the individual and his or her closest allies (Scala & Nerney, 2008, Nerney, 2001).

Fiscal intermediaries are another key component of best practices in assisting people with intellectual and developmental disabilities with management of their individual budget. Fiscal intermediaries are community organizations where the funds of the individual budget are deposited and managed. The fiscal intermediary is employed by the individual receiving supports to monitor and ensure compliance with all federal and state laws and regulations in the management of funds and personnel. Simply stated, fiscal intermediaries help individuals with IDD and their families with the practical management and organization of the individual budget (Wehmeyer & Stancliffe, 2003). Fiscal intermediaries must be independent of the services provided, and have no other jobs or responsibilities that would present a conflict of interest. Specific duties of the fiscal intermediary include financial tasks such as writing checks for all expenses, payroll, and withholding taxes. Further, fiscal intermediaries ensure that budgets are monitored and accounted for to both the individual with IDD and the public funding agency (Scala & Nerney, 2008; Nerney, 2001).

In addition, a recent national study by Walker and colleagues (2009) promotes a number of promising practice recommendations for strong self directed program options. In addition to agreement with the factors already stated, this study recommends that states update information technology systems to more readily track budgets and spending, build in variable levels of assistance within the self directed program, and adapt quality assurance systems to meet the needs of individuals who use self directed supports. In addition, the importance of providing adequate training and informational support and emphasizing accountability are identified by this study.

Benefits of Self Direction*.* Since the earliest attempts at initiating large scale implementations of consumer directed support programs, there have been indications that increased self determination that comes from self direction of supports is related to higher consumer satisfaction and service outcomes. Among the earliest evaluations of consumer satisfaction with consumer directed supports, Beatty, Richmond, Tepper, and DeJong (1998) found that individuals with physical disabilities were significantly more satisfied with their services when they were enrolled in a consumer directed personal assistance option, compared with control group subjects who were on a waiting list for such services. As self directed supports gained popularity in the 1990s, further evaluations were conducted to assess outcomes.

Cash and Counseling demonstration projects, which began in four states in 1996-1997, provide the initial large scale efforts at implementing self-controlled budgets. As one of the first states to implement a Cash and Counseling program, Arkansas has been a common state to consider for researchers seeking evaluating the outcomes of consumer-directed options. In Arkansas, reports suggest that Cash and Counseling was successful in raising consumer satisfaction with services (Foster, Brown, Phillips, Schore, & Carlson, 2003).

The Arkansas program, known as *Independent Choices*, was also shown to reduce consumers' unmet needs, while maintaining consumers' personal safety (Foster et al., 2003).

Additionally, the Arkansas program was successful in reducing nursing home stays for both elderly and non-elderly recipients (Dale & Brown, 2005).

In Florida, another of the pilot states, consumer interest in cash programs remained strong compared to interest in traditional agency-based options (Loughlin et al., 2004), possibly indicating satisfaction and a desire to expand services among consumers. Between 85 and 95 percent of consumers who participated in the Cash and Counseling demonstration projects reported that they would recommend the program to others who wished to have more control over their care (Schore, Foster, and Phillips, 2007). Similarly, well over 90 percent of participants in Washington's Consumer Directed Care plan for the elderly expressed satisfaction with their experience with the program, emphasizing particular satisfaction with their increased ability to control important decisions related to their care (Young & Sikma, 2003). It is important to note, however, that each of these studies seeking satisfaction-oriented data may be skewed by the fact that service users are typically prone to rate satisfaction highly, often out of concern that that their services may be cut if low satisfaction is reported (Parker & Kroboth, 1991; Williams, Coyle, & Healy, 1998), suggesting that overall contentment with these early efforts at self direction may have been overstated.

Funds from Cash and Counseling programs, as well as other self directed funding options, are most often used to pay workers who provide support to the recipient. Even in situations where hiring and retaining staff is identified as a challenge, users of self directed programs report that being able to exercise control over staffing decisions is a benefit, based on results from an evaluation of Washington's aging program (Young & Sikma, 2003).

In a study of Cash and Counseling recipients in the three RWJ demonstration states (New Jersey, Arkansas, and Florida), Schore, Foster, and Phillips (2007) found that between 80 and 90 percent of beneficiaries used part or all of their Cash and Counseling allowance to pay workers, though rates were somewhat lower in Florida. In general, consumers have expressed high levels of satisfaction at being able to hire family members as paid caregivers (Matthias & Benjamin, 2008). Arkansas consumers who hired family members under Cash and Counseling also indicated similar or more positive health outcomes than consumers who hired non-family workers (Simon-Rusinowitz, Mahoney, Loughlin, & DeBarthe Sadler, 2005), suggesting the effectiveness of family staffing arrangements.

Workers who are related to recipients of self directed services report high levels of satisfaction, although they also indicate a desire for more respect from the person employing them, levels of emotional strain comparable to agency-based workers, and less formal training than agency staff (Dale, Brown, Phillips, & Lepidus Carlson, 2005). As the traditional pool of direct support workers continues to narrow, some authors have suggested that the flexibility in hiring friends and family members that is afforded by self directed support models may become a more necessary strategy in addressing the critical shortage of workers in the direct support workforce (Hewitt & Larson, 2007; Matthias & Benjamin, 2008).

Challenges of Self Direction*.* Implementation of self directed initiatives has been a challenge for many states, which has limited the efficiency and effectiveness of programs. New York, which had been selected to run one of the four initial Cash and Counseling demonstration projects, failed to implement a self directed program due to a combination of the transfer of the program within the state bureaucracy, an inability to gain the support of local social service districts, and redundancy with another version of a self directed support scheme (Sciegaj, Mahoney, & Simone, 2008). In another instance, the complexities of designing and implementing a new program resulted in delays and inefficiencies that slowed the self direction initiative’s launch in Minnesota (Schmitz, Luxenberg, & Eustis, 2005). Such difficulties in implementation have led to recommendations that states work to clarify why self directed personal care options are necessary, and to carefully evaluate the feasibility of implementation, given a particular authority structure, since this will determine the finances, training, and support that will be necessary to develop a strong service delivery system (Sciegaj, Mahoney, & Simone, 2008).

Educating and informing individuals and families about self directed models continues to be a challenge in implementation. Although the support of traditional agency service providers is necessary for effective implementation of Cash and Counseling programs, educational outreach about self directed programs works best when it is directly targeted to individuals with IDD and their representatives (Phillips et al., 2003). Additional outreach concerns have been raised about differentials in attitudes towards and use of Cash and Counseling among members of differing racial and ethnic communities (Sciegaj, Capitman, & Kyriacou, 2004; Simon-Rusinowitz et al., 2002). In a study of elderly individuals who were eligible to choose between self directed or traditional services, Sciegaj, Capitman, and Kyriacou (2004) found a tendency among Chinese, Latino, and African American service users to seek more control over their staffing, corroborating assertions by Simon-Rusinowitz and colleagues (2002), who suggest that Latino and African American families may prefer self direction due to their strong access to large family and friend support networks, and the ability to level in-group social capital easily.

Critics of self directed services sometimes cite concerns over the personal safety of recipients, who may be more vulnerable to financial exploitation and medical neglect with the less structured support system that is seen in self directed models. These critics were more likely to be policy experts than service users or their representatives (Simon-Rusinowitz et al, 2002). There has been evidence to suggest that these concerns may not be well grounded, as the personal security of individuals who self direct are similar to those using traditional services (Schmitz, Luxenberg, & Eustis, 2005; Young & Sikma, 2003).

Costs of Self Direction. The costs of offering self directed service options have been a closely observed issue during the initial phases of program implementation across states. Cost evaluations of the original three demonstration states provided the first insights into the financing of self directed supports, generally indicating similarities in cost between individuals who used the self directed option and those who used traditional services. In Arkansas, one of the original demonstration states, personal care expenditures were higher for the self directed option than for traditional services, mainly because individuals using the self directed model utilized a higher portion of their allotted funds than did people using traditional services (Dale & Brown, 2005). Savings in other Medicaid costs for nursing home stays, home health services, and other Medicaid services lowered over the first two years, helping to offset the higher costs for personal care services among Arkansas Cash and Counseling participants (Dale & Brown, 2005).

New Jersey's self directed model, which, like Arkansas, was funded directly through the state's Medicaid program, showed personal care costs that were about 16 percent higher for people using the self directed option than for people using traditional services (Dale & Brown, 2005). Unlike in Arkansas, however, New Jersey saw an increase in total Medicaid costs over time, since personal care services increased substantially, while savings from lower costs for other expenses, such as nursing home stays, eroded over the first two years post-implementation(Dale & Brown, 2005).

Florida, which financed its Cash and Counseling through a waiver rather than through Medicaid directly, saw significantly higher costs in its self directed program, especially among the non-elderly, perhaps because of higher assessed needs for individuals in the self directed group (Dale & Brown, 2005). A number of other states that have evaluated their early attempts at implementing self directed supports have not yet reported on whether costs under self direction are similar to costs with traditional services.

It is possible that service authorization and utilization may be key elements to understanding the fiscal impacts of self directed programs in comparison with traditional programs. In Minnesota, for instance, an interim report on the state's Consumer Directed Community Supports program reported that participants may have been going back to traditional services because they can gain authorizations for more services by doing so (Schmitz, Luxenberg, & Eustis, 2005). Conversely, in Arkansas, personal care service costs were higher under self direction because consumers were more able to spend their allotted funds on staffing needs (Dale & Brown, 2005). Finding a balance between allocation and utilization, then, may be a central concern in establishing cost neutrality for future efforts at implementing self directed services.

Direct Support Workforce

Shortages of direct support professionals (DSPs) to support the needs of individuals with IDD have emerged since the early 1980s (Lakin & Bruininks, 1981; Lakin et al., 1983), and have become increasingly acute as community residential arrangements for individuals with IDD have supplanted institutional settings (Hewitt & Larson, 2007; Prouty, Alba, & Lakin, 2008). A number of factors, including the continuing move towards community support, longer life expectancy for people with IDD, and the aging of the population have combined to raise the projected demand for direct support workers by 37% from 2003 to 2025 (Hewitt et al., 2008; Office of the Assistant Secretary for Planning and Evaluation, 2006). Further complicating the increased projected need for DSPs is the fact that the traditional pool of workers who support people with IDD is shrinking (Hewitt & Larson, 2007; Larson, Hewitt, & Knoblauch, 2005). A number of more specific interrelated factors are contributing to the current and looming shortages of DSPs, including wages and benefits, turnover, and training.

Wages for direct support workers are generally low, and many DSPs are not offered fringe benefits. In the most recent study to compare wages of both community-based (private) and institutional (public) DSPs, Polister, Lakin, and Prouty (2003) found average national hourly wage rates to be $11.67 for DSPs in public settings and $8.68 for those DSPs working in the private sector, making full time wages for work as a DSP roughly equal to the poverty line for a family of three (Lakin, Polister, & Prouty, 2003). As suggested by these findings, it is typical for DSPs in public settings to receive higher wages than their peers working in private settings, leading to further concerns about wages as the move towards community-based residential settings continues.

Fringe benefits are available to DSPs with varying frequency according to results of several studies compiled by Larson, Hewitt, and Knoblauch (2005). According to the ten state-level studies compiled between 1998 and 2003, between 30-98% of organizations that employ DSPs offer health insurance, 26-82% offer dental coverage, 21-81% provide retirement savings programs, and 30-87% provided DSPs with paid leave time. It is important to note, however, that many DSPs who work in agencies that offer benefits may not actually be eligible, since many agencies that offer benefits do so only for full-time employees, while many DSPs work on a part-time basis. Low wages and poor benefits may be primary reasons for high turnover rates among DSPs.

Turnover rates for DSPs working in community settings have not been systematically studied on a nationwide basis. However, state-level studies have emerged in the last ten years to indicate that annual turnover rates range from 24% for full-time DSPs in Wisconsin to 109% among staff in North Carolina’s adult care homes (Harmuth & Dyson, 2005). Adding further challenge, roughly 45% of DSPs who leave their positions do so within the first six months of employment (Larson, Lakin, & Bruininks, 1998). Hewitt and Larson (2007) estimate that it may cost roughly $784 million annually to replace staff due to DSP turnover, based on the average national turnover rate and the mean cost of training a new DSP, which is estimated at $2,413. Thus, it is clear that turnover is not only a problem in terms of continuity of quality care to people receiving supports, but also a major financial burden on agencies and individuals that provide such services. Related to turnover rates, DSP tenure rates are also of concern, as about 45% of all individuals who left their organization did so within six months of employment initiation, and an additional 23% left within 6-12 months, according to a longitudinal study by Larson, Lakin, & Bruininks (1998). This suggests that the greatest turnover occurs within the first year after hire, meaning considerable inconsistency in the people providing supports in the lives of individuals with IDD.

Finally, training of DSPs has long been acknowledged as a challenge to direct support workforce development. As the move towards community support has continued, DSPs have been required to obtain more independence and a larger skill set to adequately support individuals with IDD. The Community Support Skill Standards (Taylor, Bradley, & Warren, 1996) validated a set of 144 specific skills that are needed by DSPs, supporting the need to provide training beyond the 40 hours of pre-service training that is generally offered to DSPs (Hewitt & Larson, 2007). DSPs and administrators sometimes disagree on which topics require additional training, as indicated by a North Carolina study in which administrators indicated the need for more DSP training in the areas of documentation, communication, and crisis intervention, while the DSPs surveyed preferred more training on crisis intervention, education, self development, advocacy strategies, and community living skills (Test, Flowers, Hewitt, & Solow, 2004).

Original Study Background

The data for this study were originally collected at the University of Minnesota's Research and Training Center on Community Living as part of the Center's core activities grant from 2003 to 2008.The activities were funded by the United States Department of Education through the National Institutes on Disability and Rehabilitation Research. The original study was one of several distinct research projects supported by the grant, and was conducted by a multidisciplinary research team that included the author of this dissertation for the last year and a half of the project.

The original study aimed to gain an initial level of understanding about how individuals with IDD and their families in Minnesota gained access to needed services using the Consumer Directed Community Supports model, including benefits and challenges of using the model. In addition, staffing patterns for users of CDCS were to be examined to determine how workforce issues with CDCS compared with traditional services. Finally, a national survey was conducted to gain the most comprehensive assessment to date of the use of self directed supports nationally, as well as the challenges and promising practices that states encountered in their early experiences implementing self directed support options.

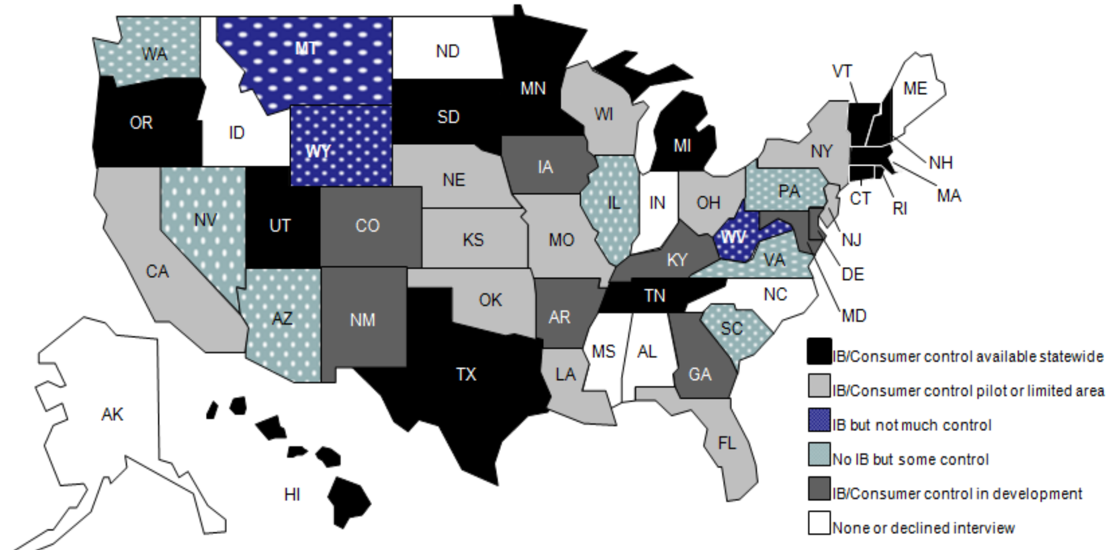
A mix of qualitative and quantitative data were collected in the original study. Data collection procedures for the survey of CDCS users in Minnesota and semi-structured interviews with county developmental disabilities services administrators are described in the methods section above, as these two sources of information were used in completion of this dissertation. Additionally, individual interviews were conducted with individuals and families who used CDCS and focus groups were conducted with CDCS users. The findings from these two data sources have not been systematically analyzed, and were primarily useful in guiding the development of the survey for CDCS users. Finally, a national study was conducted to ascertain the current status of self directed services for people with IDD throughout the United States. To gather data for this component interviews were conducted by a contracted member of the research team from Syracuse University with the director of developmental disabilities services (or their designee) in each state.

Rather than analyzing the results of the original study in an integrated manner, different sections of the original study's findings were considered individually to develop topically clustered analyses that informed the overall status of self directed supports nationally, and in Minnesota in the form of CDCS. The results of each component of the original analysis will be considered individually below.

National Study. The study of the national status of self directed supports revealed that the majority of states, 34 in total, had implemented some degree of self directed services for individuals with IDD who used the HCBS waiver as of early 2006. However, only 13 states (including Minnesota) had fully implemented a program of self direction on a statewide basis. Other states were recognized for developing various degrees of individual control or individualization of the budgeting process. The national status of self direction for individuals with IDD and their families is summarized in the national map available in Figure 1.4.

In addition to determining the status of self direction, the national study's final report (Walker, Hewitt, Bogenschutz & Hall-Lande, 2009) also described the variations within self directed models and precipitating factors that led to the implementation of self direction from the perspective of the people in charge of implementation at the state level, before making recommendations for future implementation and revision of self directed services. Robert Wood Johnson self determination grants were cited by several states as the main factor that promoted the launch of self direction, while other states reported that legal action aimed at reducing wait lists for waiver services led to the creation of their self directed service option. Variation was found in rules pertaining to eligibility, hiring and management of direct support professionals,

Figure 1.4. National Status of Self Direction for People with IDD as of 2006



Adapted from Walker, et al. (2009)

budgeting, and the level of assistance in management of services built into the self directed model. Finally, a list of recommendations was made to guide future implementation and revision of self directed support models. Among the recommendations, suggestions were made to keep support coordination independent from traditional case management, provide adequate training and support to service users, prepare information technology systems in advance, and to prepare for a reduction in flexibility when moving from a pilot to statewide implementation. Collaboration with multiple stakeholders in the implementation process, building systems for accountability and monitoring and taking a broad perspective on cost analysis were also recommended at the completion of the national study.

County Administrator Interviews. A semi-structured interview was conducted with 29 county-level developmental disabilities service administrators throughout Minnesota to gauge the benefits and barriers associated with CDCS implementation and use. The initial results of this portion of the original study indicate both challenges and promising practices.

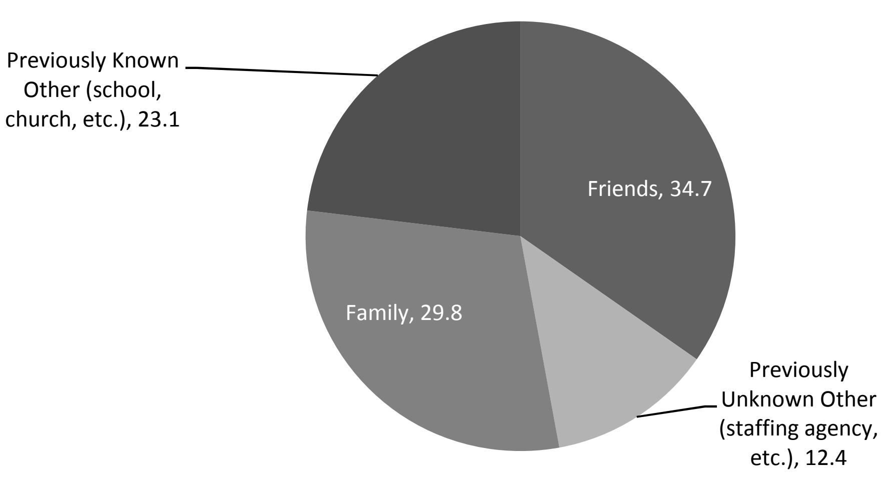
County administrators identified many challenges in early implementation, including changing program rules and a perceived lack of clear direction on implementation procedures from the state. As a result, many counties looked to leading counties in the metropolitan area to suggest paths towards building systems and structures that would enable successful self direction. This resulted in delays in implementation in many outstate counties, as they waited for metropolitan leaders to clarify vague implementation directives given by the state. Many administrators had concerns about abuse of the program, with potential for individuals with IDD and their families to use their individualized budgets for what were deemed to be inappropriate expenditures. Monitoring of services and shifting roles and attitudes for traditional case managers were also identified as challenges.

County administrators reported that one of the greatest strengths of using CDCS was that it promoted changes in thinking throughout the county's service provision system, towards greater desire for self-determination for service users with IDD and their family advocates, resulting in better quality of life and community integration for many CDCS users. Some county administrators also noted that there were improvements in the quality of the direct support workers who provide services under CDCS, as compared with traditional agency-based services. This included comments about the improved ease of finding direct support workers who matched the CDCS user's cultural preferences. It was also noted by some administrators that CDCS resulted in more cost efficient service delivery, since reduced costs compared with traditional services are built into the budgeting methodology for CDCS.

CDCS User Survey. Finally, previous results from the original study come from the initial descriptive analysis of the statewide survey of current and past CDCS users and their families. The survey has been analyzed in two distinct sections: one portion pertaining to direct support workforce status in CDCS, and the other about service usage patterns, both before and after the state changed CDCS rules about budgeting and by creating a list of what expenses were allowed or disallowed. While each of these topics has made significant contributions to understanding of CDCS, and of self directed services generally, these two sections of analysis have not yet been integrated, so they will be described separately here.

Workforce status. Perhaps the most important findings in the original study pertain to the status of the direct support workforce that supports CDCS users with IDD. The analysis of this segment of the original study was descriptive in nature, and examined selected associations between variables with a series of standard chi-square tests. Having the freedom to hire direct support workers that were known to the CDCS user and being able to set staff wages were the most frequently cited staffing benefits, each reported by 82% of respondents. Having better-trained staff was the least often cited staffing benefit, indicated by only 34% of the sample. Troubles finding staff (51%) and difficulties in performing payroll duties (31%) were the most commonly cited challenges of CDCS related to staff management. The relationship of the DSP to the CDCS user is summarized in Figure 1.5, which indicates that nearly 84% of all direct supports workers reported in the survey were previously known to the service recipient when they were hired, in sharp contrast to traditional services, where it is quite rare for a person with IDD to know a DSP before they begin employment.

Figure 1.5. Relationship of DSW to CDCS User (by percentage)



Only 63% of survey respondents indicated providing staff training of any kind. The training that was provided most often was training on the specific support needs of the individual receiving supports, which was provided directly by the individual or his or her family. Table 1.1 shows common types of training and training delivery sources, as reported in the original study (Bogenschutz, Hewitt, Hall-Lande & LaLiberte, in press).

Table 1.1. Types and Delivery Formats of Training Offered by CDCS Users

Type of Training	n	%	Delivery Format	n	%
Specific Needs of Consumer	61	88.4	Self-Delivered	49	70.0
First Aid	27	39.1	Consultant/Outside Agency	22	31.4
Cardio-Pulmonary Resuscitation (CPR)	22	31.9	Conference/Workshop	25	35.7
Fiscal Support Training	10	14.5	Family/Friends Deliver	23	32.9
Medication Administration	31	44.9	Medication Admin. Consultant	7	10.0

Finally, and perhaps most importantly, the original study found marked differences between the wages, rates of fringe benefit provision, and tenure of direct support workers in CDCS when compared with traditional agency-based services. Wage rates reported by CDCS users and their families who responded to this survey ranged from $5.00 to $28.50 per hour, with a mean hourly wage of $12.76. This is higher than would be expected in community agency-based services. Length of service reported for direct support workers were also substantially longer than would be expected in traditional service formats, with the mean tenure reported at about 34 months for DSPs reported in this survey. This compares to a study by Larson, Lakin and Bruininks (1998) that found about 68% of DSPs leave their work in community agencies within one year after hire. These positive findings from the original study were offset by concerning findings concerning the provision of fringe benefits, which were offered by only 20% of respondents. Perhaps of greatest concern, health insurance was offered by just over 8% of all respondents, a rate that compares unfavorably with a previous finding that suggests up to 98% of community agencies in Minnesota offer fringe benefits to at least some direct support workers (Larson, Lakin, & Bruininks, 1998). DSPs who were previously unknown to the CDCS user (such as workers from staffing agencies, professional nursing or occupational therapy services, etc.) were more likely than expected to be paid at the upper end of the wage distribution ($\chi 2$ (12, n=173) =21.37, *p*=.045). Additionally, direct support workers with longer tenures were more likely than expected to have higher wages ($\chi 2$ (12, n=151) =21.46, *p*=.044).

Service usage. The final portion of the original study's analysis descriptively investigated the use of selected services with CDCS. A key element of this analysis was examination of how expenditures changed after the state initiated a standardized budgeting methodology (budgeting was previously done by counties) and applied lists of allowable and disallowable expenditures for CDCS funds. Both of these policy changes occurred after the initial implementation of CDCS, and often resulted in lower individualized budgets and more restrictive, less creative ways of constructing services. As seen in Table 1.2, almost all categories of expenditure were reduced after the state's policy changes took effect, making CDCS an effective program option mainly for individuals who utilize only direct, person-to-person

Table 1.2. Change in utilization of key services before and after state-set budgets

Service Type	% using before	% using after	χ^2
Adaptive equipment	59.6	23.3	3.48
Remodeling	17.3	9.7	16.88***
House cleaning	42.3	37.9	50.37***
Mileage	66.3	42.7	14.37***
Organization memberships	51.9	8.7	0.91
Respite	75	64.1	18.33***
Technology	53.8	22.3	9.11**
Transportation	43.3	20.4	15.18***
Utilities	11.5	13.6	4.15*
Chore services	41.3	29.1	33.56***
Staffing provider agencies	47.1	42.7	42.64***
Staff training	43.3	22.3	18.93***
Staff wages	58.7	71.8	18.27***
Staff benefits	16.3	7.8	23.87***
Staff health coverage	18.3	8.7	6.24*
Staff paid vacation	17.3	9.7	4.94*
Staff sick leave	8.1	1.9	2.36
Summer camp	51.9	31.1	25.40***
Movies	66.3	12.6	4.50*
Restaurants	48.1	8.7	3.77
Sporting events	42.3	9.7	1.76
Travel	32.7	5.8	3.61
Plays/Theater	33.7	3.9	4.61*
Alternative therapies	30.8	16.5	20.83***
Behavioral therapies	20.2	12.6	15.34***
Therapeutic classes	34.6	11.7	4.26*
Crisis intervention	6.7	3.9	18.60***
Physical therapy	18.3	3.9	9.78**
Relaxation therapy	9.6	2.9	5.93*

* significant at $p < .05$

** significant at $p < .01$

*** significant at $p < .001$

All $\chi 2$ values are reported using the Yates correction

supports such as staff wages, respite services, and staffing agencies. Recreational expenditures, therapeutic services, and other types of expenditure that may serve to increase capacity for social inclusion were seriously reduced after state policy changes. These reductions were statistically significant based on a series of chi-square tests that tested association between use of particular services before and after the policy changes, as seen in Table 1.2. The Yates correction was applied to each of these tests, as this provides a more conservative assessment of association when only binary variables are included in the analysis (Garson, 2009).

Chapter II

Methods

This section will present the methods that were used in the implementation of this study, including the methods that were involved in the original portion of this investigation, which yielded the data source for this study's secondary analysis. Within this section, the study design, sampling procedures, operationalization of variables, instrumentation and data collection plan, and procedures for data analysis will be explained. This section will begin with an examination of the broad research questions and specific hypotheses tested in this research.

Research Questions & Hypotheses

Based on the literature presented above and within the context of community services for people with disabilities on the whole, it is clear that there is a building body of knowledge about self directed services for people with IDD in the United States. The work to date, however, must be considered provisional, as the nature of self directed programs is constantly changing and the expanse of knowledge generated to date is far from complete. Some of the most important gaps in the literature pertain to the benefits and drawbacks of self directed supports from the perspective of program users and the direct support workforce outcomes related to self directed services. It is these factors that will be of primary interest in this study. In addition, little research has been conducted to determine the factors that may promote individuals with intellectual and developmental disabilities to continue use of self directed supports, and what factors may be predictive of their departure, presumably in favor of traditional agency based services.

Two specific research questions are directly addressed in this dissertation, building on the original study that resulted in the data set to be used. The results of the original study are described in the preceding section, and were instrumental in informing the main research questions for this study.

The current study seeks to answer two main research questions, by testing related hypotheses as seen in Table 2.1. Generally, these research questions seek knowledge about the factors that lead CDCS users to either continue use of the program or leave the program in favor of other service options and the factors that promote longer tenures among DSPs in self directed supports. These questions were answered primarily using survey results, with findings from interviews with county IDD service administrators providing important supporting data to enrich quantitative findings and inform the variables to be tested in logistic regression analyses. In answering these questions, this dissertation makes an important contribution to the field of social work by illuminating important factors in individuals' perceptions of self directed services that were previously unexamined. Extending our knowledge about perceived benefits and drawbacks of self directed supports enables social workers, particularly those who design and implement policy, to design more user friendly forms of programming for people who wish to self direct their supports.

The hypotheses shown in Table 2.1 were derived based on the professional literature, the original analysis of the data set used in this study, and additional examination of the qualitative data, which lend support for the potential contribution of each of the hypotheses provided below. Additional explanation of the logic behind the construction of each research question and its component hypotheses is contained later in this section, as well as in the results section to follow.

Table 2.1. Primary Research Questions & Hypotheses

I. Why do some users remain on CDCS while others leave the program?
  a. Hypothesis I: Children are more likely to be current users of CDCS than adults.
  b. Hypothesis II: CDCS users with lower individualized budgets are more likely to be past users of CDCS.
  c. Hypothesis III: CDCS users who indicate that CDCS usage resulted in more community inclusion will be more likely to report being current CDCS users.

II. Why do some DSPs working in self directed supports remain employed longer than others?
  a. Hypothesis I: DSP tenures will be higher when pay rates are higher.
  b. Hypothesis II: Family members who work as DSPs will remain employed longer than friends or people with other relationships to the service user.
  c. Hypothesis III: DSPs who receive fringe benefits will have longer tenures than those who do not get fringe benefits.

Design

Using an extant data set, this study combines descriptive, exploratory, and explanatory methods to conduct an examination of the implementation, use, and workforce outcomes of Minnesota's program for self directed services for people with IDD, Consumer Directed Community Supports. The study involves multiple data collection methods that yielded different forms of data, both quantitative and qualitative. Since self direction of supports remains in the initial stages of implementation with a high degree of fluidity remaining in the implementation, and because CDCS has not been systematically and studied from a multi-stakeholder point of view, exploration and description are necessary and appropriate as first steps in research on the topic (Rubin & Babbie, 2008). Although the exploratory and descriptive sections of the dissertation will be integrated within the analysis in order to present a balanced view of CDCS, the contributions of each will be presented separately below.

The qualitative data, which are exploratory, consist of semi-structured qualitative interviews with county-level administrators of developmental disability services in several

Minnesota counties. These interviews were conducted with administrators in counties that had implemented CDCS and those that had not implemented the program, providing a cross section of county experiences, which provides insights into the barriers and successes in the early attempts at self directed services in Minnesota. This collection of qualitative data consists of verbatim transcripts of interviews containing information about the strengths and limitations of CDCS from the perspective of program administrators. Processes of implementation are also explored, since these may provide insights into the attitudes that underlie implementation of CDCS. The exploratory data will primarily be used to inform the hypotheses to be tested in quantitative analyses, and to add a measure of authenticity to the findings, coming from quotes by county DD Services directors.

Descriptive and explanatory data come from an eight page survey of CDCS users or their legal representatives (see Appendix B). Although only individuals with an identified intellectual or developmental disability are permitted to be a recipient of CDCS under Medicaid waiver rules, family members are often the legal representative of individuals with IDD, so they were permitted as proxies for the completion of the survey in this study. Surveys were randomly distributed in 2007 and were returned by 112 recipients. Random selection of participants helps to improve the generalizability of findings to a wider population, and is therefore desirable in survey research (Henry, 1990). The survey elicits information in four broad categories, which are described more thoroughly in the instrumentation section to follow. The majority of response categories are at the categorical level of measurement, which is appropriate for an initial descriptive study (von Eye & Clogg, 1996). Descriptive data provide the basis for the majority of the findings to be presented from the initial study using this data set, while the survey data were tested in an explanatory manner to bring additional understanding to the analysis of this study. While categorical variables provide limited options for statistical analysis, the available sample size and the presence of dozens of variables will provide enough relevant data for a robust analysis.

While descriptive and explanatory methods will be used in working with the survey data, it important to note that this study is exploratory in nature, overall. As this is an initial examination of the perceptions of service users and direct support workforce outcomes of self directed services. Initial exploration in the form of focus groups and case studies informed the creation of the survey, so while the results of the survey will be presented descriptively, the etiology of the survey and the situation of the results within the larger context of self directed services for people with IDD is very much exploratory. In addition, as this is an early investigation into this topical area, the results of the study, even those that are explanatory or descriptive, will need to be viewed as an initial exploration, which is subject to revision as consumer directed services continue to evolve.

Sampling

This study uses an extant data set, so this section will outline the sampling procedures that were used in the procurement of the original data. The county director interview data that are briefly described in the section above were obtained from selected counties in Minnesota, some of which had implemented CDCS and others that had not. In total, 29 of Minnesota’s 87 counties were selectively sampled to gain a cross section of the state that would enable detection of a range of experiences and responses regarding CDCS implementation. At the time of data collection, CDCS was being implemented actively by 41 counties, though the number of CDCS participants and the number of counties implementing CDCS has fluctuated remarkably since 2004, with the number of enrollees in CDCS declining while the number of counties offering CDCS has risen. While not to scale in order to show both service user numbers and counties, Figure 2.1 shows the decline in CDCS usage since 2004, along with the increase in the number of counties implementing CDCS on an ongoing basis.

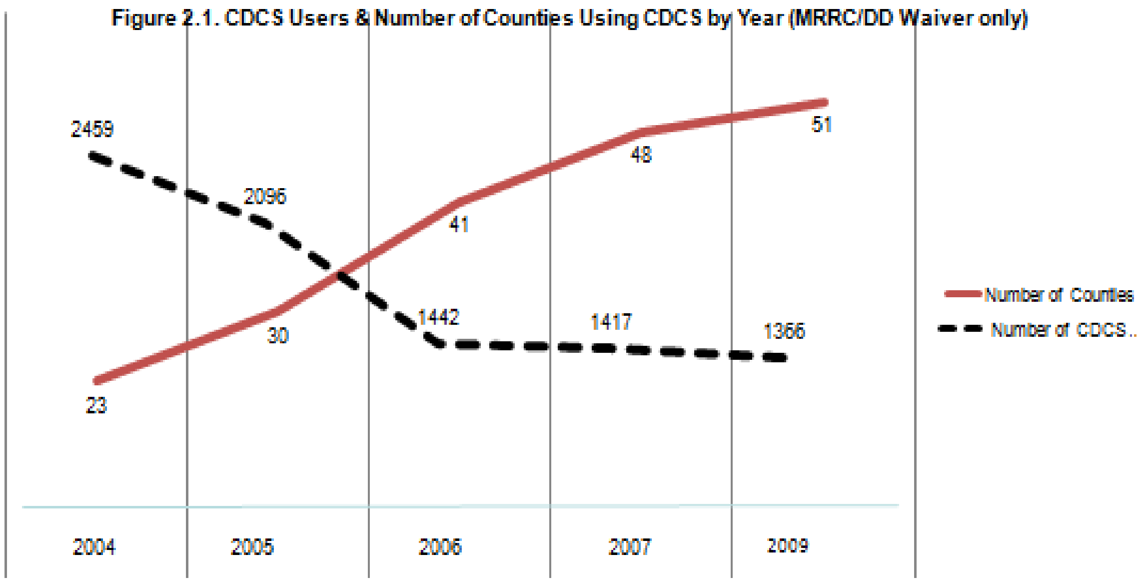


Figure 2.1. CDCS Users & Number of Counties Using CDCS by Year (MRRC/DD Waiver only)

For the CDCS consumer survey, administrators from counties that had implemented CDCS with individuals using the HCBS waiver were asked if they would be willing to distribute a survey to a sample of CDCS users in the county, making a sampling frame of 22 counties from across the state. Of these 22 counties, 20 agreed to participate in the distribution of surveys to service users. In order to maintain anonymity for potential survey recipients, a researcher assisted the county worker through the sampling process, but did not directly handle any list of CDCS users at any time while conducting the study.

A disproportionate stratified random sampling process was implemented within each county in order to obtain more even representation from the state's most populous urban county, other counties in the metropolitan area, and non-metropolitan counties. This even representation was considered important since different parts of the state had implemented CDCS somewhat differently due to the wide latitude afforded by loosely defined program rules for the first years of CDCS's existence. All county administrators were instructed to construct an alphabetized list of all individuals using the HCBS waiver who were using CDCS on September 1, 2004, whether they were currently utilizing CDCS or not. Once a county administrator assembled an alphabetized list, they were instructed to select individual CDCS users. Counties in the metropolitan area selected every tenth person on the alphabetized list and outstate counties selected every second person on the list to comprise the sample. This disproportionate sampling was conducted in order to account for much higher rates of CDCS usage in metropolitan counties. The worksheet that was used to guide the sampling process may be seen in Appendix A. Although some sampling error may have been introduced by sampling beginning with the first individual on the alphabetized list and then at specified intervals rather than the preferred method of using a random number generator or randomly selecting the starting point (Rubin & Babbie, 2008), the amount of potential error introduced was likely justifiable in return for a sampling method that was easier for county personnel to follow. In addition, selection in this manner from an alphabetized list would likely introduce less sampling error than would be anticipated if the list had been constructed in other ways, for example, based on date of enrollment in CDCS (Rubin & Babbie, 2008). What error may have been introduced may be particularly present in non-metropolitan counties, where the numbers of CDCS users were small.

Because slightly different versions of the survey were distributed to current and past users of CDCS, the county administrator was asked to identify the number of current and past users, so that the appropriate number of each survey could be delivered to the county. Surveys were color coded for the three regions of the state (Hennepin County, other metro-area counties, and non-metropolitan counties). Finally, surveys were packaged with the consent and assent forms necessary for each individual, based on information provided by the county administrators. The appropriate numbers of each survey format were packaged by the researchers and sent to each county's worker, who addressed the envelope and mailed the survey to CDCS participants. A cover sheet explaining the survey and its aims and informed consent forms were included in the package. As county administrators who assisted in sampling and distribution noted that there were families selected who did not speak English, the cover sheet was translated into Spanish and Hmong, with instructions to contact a linguistically competent disability advocate to complete the survey, if participation was desired. No surveys were completed through this mechanism. A full accounting of the sampling frame used in the survey portion of this study is available in Table 2.2.

Excluding those returned as undeliverable, a total of 369 surveys were distributed statewide in the first round of survey distribution. The researcher received 112 completed surveys for a total response rate of 30.4%, representing roughly eight percent of all CDCS users in Minnesota at the time of sampling, according to Minnesota Department of Human Services data. It is also notable to mention that Hennepin County selected an additional sample of 100 CDCS recipients after their original sampling. This was done because the disproportionate sampling strategy that was initially utilized did not yield enough returned surveys for robust analysis. The total number of surveys distributed listed above reflects this additional input from Hennepin County, which, by a wide margin, had the most CDCS users of any Minnesota County, accounting for 884 or 42% of the total CDCS users in Minnesota at the time of sampling.

Since this sampling method included all but two of the Minnesota counties that had regularly implemented CDCS, and because a random selection process was employed within each county to obtain a sample of potential respondents from each county, it can be assumed that this survey reached a representative cross section of CDCS users (Engel & Schutt, 2005). As such, the findings should have good generalizability regarding the experiences of CDCS users in Minnesota. It should be noted, however, that the Minnesota experience may be significantly different that what users of self directed services in other states have experienced, since program designs and implementation strategies do differ widely from state to state (Walker et al., 2009).

Table 2.2. Sampling Breakdown by County for CDCS User Survey

County	CDCS Users (on 9/1/04)	Number Sampled	Current Users	Current Users-Guardian	Past Users	Past Users-Guardian
Anoka*	151	15	0	11	0	4
Brown	5	3	0	2	0	1
Carleton	5	3	0	2	0	1
Carver*	13	2	0	2	0	0
Cass	1	1	0	0	0	1
Clay	3	2	0	0	0	2
Crow Wing	22	11	0	11	0	0
Dakota*	496	49	4	28	1	16
Goodhue	1	1	0	0	0	1
Hennepin^	1049	203	0	106	8	89
Itasca	4	2	0	1	1	0
Morrison	11	5	4	0	1	0
Mower	2	1	0	1	0	0
Olmsted	4	2	2	0	0	0
Ramsey*	393	40	1	23	0	16
Rock	4	2	2	0	0	0
St. Louis	19	10	0	5	0	5
Sherburne	5	3	0	2	0	1
Steele‡						
Todd‡						
Washington*	151	15	0	7	1	7
Wright	22	11	0	5	0	6
Total	2361	381	13	206	12	150

* Denotes county designated as metropolitan

^ Hennepin County was considered separately in analysis & sampled twice

‡ Steele & Todd Counties were in the sampling frame but did not participate

This study and its sampling method were reviewed and approved by the Institutional Review Board (IRB) at the University of Minnesota. Risks and benefits are clearly stated in the consent documents that accompany the survey, and no potential participant is required to complete the survey. Participation was entirely voluntary. In addition, the researchers were unaware of which service users were selected for participation in the survey. The fact that potential participants were drawn by someone outside of the research team helps to ensure that no participant was unfairly targeted for exclusion or inclusion in the sample, and also minimizes the potential for coercion (Sales & Folkman, 2000).

Variables & Operational Definitions

A total of 217 variables are involved in the survey portion of this study. The vast majority of these are categorical variables. With the presence of so many variables, it becomes practical to consider variables in clusters, which may be more readily operationalized. This section will first outline main concepts that are represented by clusters of variables in the survey. The operationalization of selected variables that will be central in this study's analysis will also be presented in this section. Because the qualitative data were examined inductively, meaning that variables may only be fully operationalized after analysis occurs (Engel & Schutt, 2005), this section will focus only on the survey portion of the study.

Source of Variable Clusters. The first category of variables to be considered is contained in the first portion of the survey (items 1-4), and pertains to the respondent's status on CDCS. These items give a general idea of the service user's current status with CDCS, including his or her allotted budget (before the state took control of individualized budgeting procedures from the counties in October of 2004 and, if applicable, at the time of CDCS termination), the types of services the individual uses, and the reason why the individual left CDCS, if a past user.

The next segment of variables is used to provide a sense of how current and past users spend their allotted CDCS funds. To gain this information, the variables in items five and six will be investigated. Of particular interest will be any differences in the binary variables in item five and item six, as these indicate how service usage changed for users of CDCS after the state took control of the budgeting process and introduced more restrictive spending rules. It is also important to note that the variables under consideration in items five and six are sub-categorized into categories of expenditure, including good and services, staffing, recreation and leisure, and therapies. Some of these sub-categorizations will be instrumental in constructing a composite variable that indicates the degree to which individualized budgets were spent on services that are likely to increase community inclusion, an important concept in segments of the explanatory analysis. Of particular interest are the recreational variables (items 5c and 6c) which suggest services that would likely integrate individuals with IDD into community events, thus increasing inclusion.

General benefits and challenges of CDCS use will be considered in the next set of variables. This set includes the individual variables in survey items seven and eight, which offered respondents several commonly cited challenges and benefits of using self directed services, based on previous focus groups and the existing literature on self directed programs. Examples of common benefits include the ability to hire family members as staff, improved quality of life, and increased flexibility. Some of the challenges that respondents could identify were changes in rules, paperwork, and managing payroll. Taken together, these variables provide information about the perceptions of service users about the pros and cons of self directing services.

Items 9-18 on the survey relate to the status of the direct support workforce in Consumer Directed Community Supports. The variables in this broad section provide the most comprehensive results of any published survey to date regarding workforce issues in self directed supports from the perspective of service users. This section may be further subdivided into categories related to staffing benefits and challenges, training, recruitment, and general workforce outcomes.

Staffing benefits and challenges are found in survey items 16 and 17. Examples of staffing benefits are the ability hire family or friends, the flexibility to set staff wages, and the ability to offer staff training. Potential challenges that could be identified by respondents included difficulty finding staff, disciplinary challenges, and difficulty training staff.

One of the most interesting categories, training variables are contained in items 10, 13, 14, and 15. The bulk of information for analysis among these variables comes from items 14 and 15. Survey question 14 contains items seeking information about the training topics that have been offered by each respondent while item 15 seeks feedback about the method of training delivery. While these variables are not exhaustive, they provide interesting and important insights as to the extent of DSP training that is offered by individuals who use CDCS, an area that has not been investigated previously.

Recruitment practices are briefly covered in items 9 and 12. Recruitment is the most generally covered of all the workforce status indicators, but will provide a beginning idea of where individuals who use CDCS find direct support workers among the categories that include friends, immediate family, extended family, and staffing agencies.

Finally, the grid in item 18 provides a comprehensive picture of important workforce outcomes. It is this section that provides highly useful information about the status of the direct support workforce in Consumer Directed Community Supports.

The last section of the survey provides demographic factors about the CDCS user, which may be used as independent variables. These demographic factors include sex, race, age, living situation, and geographic location.

While these categories of variables provide a general guide to the types of information that will be examined in this study, it is important to bear in mind that not only the descriptive nature of individual variables, but also the relationships between variables, will provide the basis for analysis. It is also worth noting that the vast majority of variables are categorical. While this did facilitate the collection of a great deal of information quite efficiently, it does not lend to higher level quantitative analysis. The analysis plan is detailed completely below.

Operationalization of Key Variables. A number of variables were of particular importance to this study, as they were used to test the specific research questions indicated earlier in this chapter. Operationalization will follow the three step process proposed by Rubin & Babbie (2008). This process begins with conceptualization, or identifying the general concepts that will be under consideration. This is followed by the development of a nominal definition, which is a dictionary-type definition of each construct. Finally, operationalization puts the nominal definition into a measurable, testable form. Following this stepwise process advocated by Rubin and Babbie (2008), the operationalization of several of the key variables for this analysis is contained in Table 2.3.

Table 2.3. Operationalization of Key Variables.

Concept	Nominal definition	Operational definition
CDCS status	CDCS status refers to whether an individual currently uses CDCS or if they used CDCS in the past but are no longer enrolled in the program.	The variable STATUS from the survey (indicated on front page as "current user" or "previous user" will be utilized to measure this variable. A code of 0 has been assigned to current users, and a code of 1 has been assigned to previous users.
Age	This variable refers to the age of the CDCS user at the time the survey was completed.	This variable will be operationalized based on a conversion of the age categories in item 21 on the survey into a binary variable. A code of 1 has been assigned to individuals age 21 and younger (referred to as children), and a code of 2 has been assigned to people indicating age 22 or older (adults). This is based on legal definition of the age of transition from school-based services to adult services.

Budget	This will be used to measure the size of the survey respondent's individualized budget for CDCS services.	Based on the initial descriptive analysis, the mean budget for CDCS users in the survey is $40,900. In order to convert this to a binary variable for analysis, reported budgets of $40,900 or less will be considered low budgets (coded 1) and reported budgets of $40,901 will be considered high budgets (coded 2).
Location	This will refer to whether the respondent is from Hennepin County, other counties in the metropolitan area, or a non-metropolitan county.	Original surveys were color coded to indicate location. Corresponding to this, yellow surveys indicate Hennepin County (coded 0), blue surveys indicate other metro-area counties (coded 1), and cream colored surveys indicate non-metro respondents (coded 2).
Social Inclusion	Social inclusion refers to the extent to which an individual with IDD is included in the activities and social life of his or her community.	Survey item 7G asks whether CDCS use resulted in greater social inclusion. A checked box will indicate improved social inclusion (coded 1) and an unchecked box indicates that social inclusion did not improve (coded 0).
DSP tenure	DSP tenure refers to the length of time that a direct support worker remains in his or her position, from the time of hire to the time of departure or survey completion (for those DSPs who were still employed).	DSP tenure will be measured in months, based on the respondents' reports in the fourth column of the staffing status grid in item 18. The mean tenure discovered in the descriptive analysis was 34 months. Tenures of 34 months or less will be considered shorter tenure (coded 1) and tenures of 35 months or longer will be considered longer tenures (coded 2).
DSP wage	DSP wage is the amount of pay per hour that is reported for a particular DSP.	Wages were originally reported as a continuous, ratio level variable in the last column of the grid in survey item 18. For measurement in this study, this will be converted to a binary variable based on the mean wage of $12.76. Wages up to and including $12.76 will be considered low wages (coded 1) and those wages higher than this mark will be high wages (coded 2).
Relationship	This variable indicates the relationship of the DSP to the CDCS recipient.	Relationships were originally qualitatively entered in the second column of the grid in survey item 18. These were then categorized into several response categories. For use in this dissertation, categories have been further narrowed to include family (parents, siblings, aunts, etc.; coded 1), other previously known individuals (friends, neighbors, church members, etc.; coded 2), and previously unknown people (staffing agencies, advertisements, etc.; coded 3).

Instrumentation

The instruments used in this study consist of a qualitative phone interview protocol and a quantitative mail-based survey, both of which were utilized previous to this study to create an extant data set that is being analyzed for this research. Combined, the data from these instruments provide a well rounded portrait of Minnesota's Consumer Directed Community Supports program. The phone interview protocol may be seen in Appendix C, while a coded version of the survey is attached as Appendix B.

The qualitative phone interview guide was developed by members of the original research team to elicit general information about counties' early experiences with the implementation, challenges, and successes of CDCS. It is a semi-structured interview containing 11 defined questions, with latitude to pursue appropriate follow up topics as needed. All but one question are designed to be used to seek information from informants in counties that had implemented CDCS, though the first question did seek information about the reasons why some counties had not implemented CDCS.

The concepts that were included in the mail based survey originally emerged from the earliest literature on self directed programs for people with IDD as well as a series of case studies and focus groups that were conducted with users of CDCS and their family members. Multiple perspectives were sought to gain a wide ranging perspective on the important features of CDCS to include in the survey, the language to use, and how topics might be organized. In particular, the focus groups were instrumental in helping the original research team to identify the strengths and challenges of using CDCS from the point of view of program users. These data about benefits and challenges, along with specific service usage categories make up the first half of the survey (items 5-8), which is very much situated within the experiences of service users. Usage data was collected for each individual for their experiences both before and after October of 2004, since it was at this time that the state took primary control of the individualized budgeting process and imposed a set of allowable and disallowable expenses which widely reshaped the utility of CDCS. This information provides what is perhaps the best available resource for understanding these programmatic changes and how they impacted CDCS users, an outcome of this study that may have particularly important implications for policy design in the future.

The second half of the survey, starting with item 9 and going through item 19, was developed based primarily on the literature on the development and status of the direct support workforce. Questions may be categorized into question sets about training of direct support workers (DSWs), recruitment practices, and participants' perceptions of the benefits and challenges of managing DSWs as part of CDCS. Additionally, information about the provision of fringe benefits was sought. Finally, a grid format (question 18) was used to guide survey respondents in identifying the relationships, wages, and tenure of DSWs that were hired using funds from CDCS. This section of the survey provides rich data that can be used to help place the workforce outcomes in CDCS tangibly within the context community services for people with IDD more generally.

In addition to the sections of service usage and workforce outcomes, an initial section of the survey elicited information about the individualized budget that was available to the respondent, his or her date of initiation (and termination of CDCS usage for past users) and reasons for ceasing CDCS use for people who no longer used CDCS at the time of survey. These items are labeled 1-4 on the survey. Finally, a demographic section (items 20-24) was placed at the end of the survey to gain information about the respondent's sex, age, race, location, and living situation. These demographic and general usership variables are useful as independent variables to help give context to the relationships that may be observed among other variables.

Aligning with the suggestion of Babbie (2006), the demographic section was placed at the end of the survey since it was thought to be less interesting to complete than other sections for the majority of respondents.

Reliability & Validity. Although this survey instrument had not been used previously, measures were taken to strengthen the reliability and validity of the instrument before its use in the original study.

Reliability. Reliability checks come in the form of internal consistency, since other forms of reliability (inter-rater reliability, test-retest, and alternate forms) do not apply to the research design that was used. However, internal consistency may be established by examining the statistical similarity in responses on theoretically similar survey items (Babbie, 2006).

For example, there are a number of similar items in the sections of the survey on benefits and challenges of CDCS use generally and in terms of workforce outcomes. The benefit of having staff stay longer appears in item 7d and in item16f. Having more reliable staff as a benefit of CDCS is a response option in items 7h and 16a. Challenge in managing payroll is a response option for 8b and 17d. Internal consistency may be established by looking at the relation of each of the items that are theoretically related as described above. If the participants' responses on both items in the set are strongly correlated, internal reliability may be considered strong. In addition, the ability to hire family members as paid staff can be investigated in a number of ways. First, the ability to hire family members is a choice of benefits of CDCS in items 7a and 16c. In addition to investigating the relationship between these two variables, items 12b and the staffing grid in item 18 on the survey could be used to provide reliability in terms of whether the respondent actually hired a family member to work.

To establish internal consistency, Kendall's tau-B was computed for four sets of variables that were theoretically similar within the survey. Kendall's tau-B (τ_β) was utilized since it provides reliable correlation estimates for non-parametric data (Chen & Popovich, 2002). In each case, significant correlations were found, indicating strong internal consistency for this instrument. In this analysis, the general benefit of having more reliable staff (BENRELY) and the staffing benefit of having more reliable staff (SBRELY) were correlated, as were general benefits (BENPAY) and staffing benefits (SBFAM) of being able to pay family members as DSPs, the general benefit (BENSTAY) and staffing benefit (SBSTAY) of having staff stay longer, and the general challenge (CHPYRL) and staffing challenge (SCPYRL) of doing staff payroll. These findings support the reliability of this survey instrument. Results of the internal consistency check are seen in Table 2.4.

Table 2.4. Internal Consistency of Selected Survey Items

	SBRELY	SBFAM	SBSTAY	CHPYRL
BENRELY				
β	0.444	-	-	-
p	<.001	-	-	-
n	107	-	-	-
BENPAY				
β	-	0.605	-	-
p	-	<.001	-	-
n	-	107	-	-
BENSTAY				
β	-	-	0.555	-
p	-	-	<.001	-
n	-	-	107	-
CHPYRL				
β	-	-	-	0.551
p	-	-	-	<.001
n	-	-	-	54

Validity. Validity of this survey has been established through both face validity and content validity. Face validity of the instrument was established by having county developmental disabilities administrators from selected Minnesota counties with highly developed CDCS programs evaluate the survey and provide feedback about its contents, presentation, readability, and exhaustiveness. Feedback from these reviews was incorporated into the final survey. The external reviewers' comments and the survey revisions that were made as a result end to the face validity of the instrument. Additionally, the reviewers shared the survey-in-development with CDCS users and conducted a pilot implementation to gain additional feedback.

Content validity has been established for the survey in two main ways. First, the list of goods and services in items 5a-d and 6a-d is comprehensive, reflecting a wide range of meaning of CDCS uses. While this list is not entirely exhaustive, it does represent a wide array of meaning for CDCS users and helps to establish the content validity of the instrument. Additionally, content validity of the second portion of the survey, dealing with workforce development outcomes, contains content related to recruitment, training, retention, and compensation of DSWs. These categories are consistently the focus of workforce development literature. The presence of survey items investigating all of these factors leads to further content validity of the instrument, as the various meanings of DSW workforce development are all examined.

Data Collection

Data for this project had been collected previously, before initiation of this dissertation, so this study is a secondary data analysis. As such, this section will outline the data collection procedures that have already occurred in the procurement of data, following the sampling procedures that were outlined previously.

Collection of the phone interview data from county developmental disabilities services administrators occurred first. Phone calls to the individual listed as the administrator of DD services in each county were placed by two members of the original research team, who had divided the list of counties to be contacted. Follow up calls were placed until contact was made, with a log of call attempts and outcomes kept for each county.

When the appropriate person from each county was reached, the researcher described the study and gained verbal consent to proceed with the interview with the informant. The University of Minnesota approved implied consent for the interviews, with consent implied if the interviewee gave verbal consent and continued with the interview conversation. The first question asked the respondent whether CDCS had been implemented in the county. If CDCS had been implemented, the interview proceeded with the remaining 10 questions, with follow up probes as needed. If CDCS had not been implemented, the reasons for this were examined, and the interview concluded.

All interviews were audio recorded, with the permission of the informant. The audio recordings were transcribed verbatim from audio to Microsoft Word format by a support worker at the Research and Training Center on Community Living. Verbatim transcription produced a more readily usable form of data, while maintaining the full integrity of the original recording. Following the completion of interviews, surveys were distributed.

After sampling for the survey was completed, the appropriate surveys for each county’s sample were compiled and distributed. Slightly different versions of the survey were used for previous and current users of CDCS, and these were accompanied by the appropriate consent forms. Recipients who were their own legal representative were given a consent form to read and sign prior to beginning the survey. Individuals who had a legal representative were given a consent form for the legal representative to complete and an assent form to be completed by the CDCS user. Additionally, the surveys were color coded according to location, with yellow representing Hennepin County, blue being used for other counties in the metropolitan area, and a cream colored survey being used for those counties outside of the Twin Cities metropolitan area.

The appropriate surveys were packaged in envelopes that included a stamped return envelope and sent to county administrators for mailing. The county worker addressed the envelopes and placed the survey packet in the mail. County administrators also sent a follow up postcard reminding potential respondents to complete the survey, following the suggestion of Dillman, Smyth and Christian (2008) that follow up cards may improve response rates for mail-based surveys. The postcard was mailed about two weeks following the date when the original mailing was made. The follow up postcard was translated into Hmong and Spanish to accommodate the identified language needs of some respondents, who were given the option of contacting linguistically competent disability advocates to complete the survey. The deadline for returning surveys was set about three weeks following the original mailing by county administrators. Due to an initially low response rate, this procedure was followed again to mail the survey to the same recipients again a month later. The initial low response rate was likely due to the surveys being mailed around the same time that annual recertification paperwork was due for CDCS recipients, adding to an already high volume of paperwork around the same time. In the second mailing, the follow up postcard was not included. Finally, Hennepin County followed the sampling procedure outlined above to draw an additional sample of potential respondents, who also received the survey. The additional sampling of respondents from Hennepin County helped to make the final sample more geographically representative of CDCS users in Minnesota, and the increase in surveys received provided sufficient statistical power to conduct the original quantitative analysis.

In all cases, surveys were returned directly to a member of the original research team, who compiled results. An option to call a member of the research team by phone was also presented as a way for potential respondents to complete the survey. This option was pursued by three individuals. In total, 112 completed surveys were received out of a total of 369 that were mailed (excluding those that were returned as undeliverable by the post office), resulting in a 30.4% response rate, which is in line with expectations for mail based surveys (Dillman, Smyth & Christian, 2008).

Data Analysis

Qualitative and quantitative data in this study were analyzed separately. The data were used in tandem to report on the findings of this study. Although mixed methodology research is viewed as a distinct form of research (Greene, 2008), specific forms of data must be analyzed individually. This section will outline the methods that were used to analyze both portions of the data for this study.

Qualitative Data Analysis. Qualitative data were loaded into NVivo8, a computer assisted qualitative analysis software package that assists in coding and organizing data. A directed qualitative content analysis approach to data analysis was employed. This approach began with an initial pass through the data to conduct first level coding (Miles and Huberman, 1994). From this first level coding, initial themes emerged from the data, and the strongest of these themes provided the basis for the remainder of the analysis. Since the investigator had some familiarity with the data and with the subject matter, a directed content analysis approach may be seen as appropriate since an entirely neutral approach to the data could not be assured (Hseih & Shannon, 2005). Once a set of strong themes emerged, each of these themes was taken under individual consideration in a subsequent pass through the data to examine additional possible meanings of each emergent theme (Hseih & Shannon, 2005). When the initial list of themes was developed, they were then clustered with similar themes resulting in a fairly small amount of central themes that emerged from the qualitative data. As the qualitative data analysis is meant to be instrumental in informing the direction of model formation for the quantitative analysis, coding did not require as much interpretation as would be expected in a strictly qualitative analysis, as meanings were ascribed based on surface level readings of the qualitative texts (Huberman & Miles, 2002).

This approach had a number of benefits. First, for a topic such as implementation of self directed supports which is in the earliest stages of study, conducting directed content analysis enabled a basic understanding of the central themes, which could then be tested by quantitative procedures. This provided an opportunity to understand multiple perspectives on a similar concept, which may serve to deepen the level of understanding of the challenges and benefits of this approach to service delivery, while enabling efficiency in analysis (Grbich, 2007). Next, a directed content analysis approach to qualitative data analysis holds the potential for identification of themes that were not uncovered in previous analyses. Finally, this approach allowed for an open approach to the data throughout the analysis, perhaps to a greater extent than with other qualitative approaches since dimensions of the emergent themes were investigated throughout the analysis. The main role of the qualitative analysis was to develop themes that would inform the quantitative findings derived from the data analysis described in the next section.

Quantitative Data Analysis. Quantitative data were loaded into SPSS 17, where the data were cleaned and checked for data entry errors. Data entry was conducted by a professional data entry firm as part of the initial study. As stated previously, categorical variables predominate in this survey. Frequency distributions were obtained to check for errors in the data, questionable data were checked for accuracy against the original surveys, and any errors were corrected. In addition, segments of randomly selected surveys were spot checked for accuracy of data entry using the original surveys. These spot checks were conducted with four surveys, with only one error detected across all variables.

Once data were cleaned, variables of interest were descriptively summarized. Descriptive summaries focus on frequencies for categorical variables and measures of central tendency and dispersion for interval level variables, such as budget allotments. While not sophisticated statistical analysis, frequencies and simple statistics provide important insights, particularly considering the exploratory nature of this research.

In addition to the strictly descriptive findings, a series of chi-square tests were conducted to provide additional insights into the relationships between variables. Chi square is appropriate for this analysis for several reasons. First, as a non-parametric test, chi square is appropriate for this data set, as many variables are unlikely to follow a normal distribution (Garson, 2009). Secondly, the reliance on categorical variables suggests that crosstabulation of variables may provide the greatest degree of statistical insight possible within this data set, which may not be robust for more complex analysis, given the total number of respondents and categorical nature of most variables (Greenwood & Nikulin, 1996). Finally, since understanding of self directed supports, and CDCS in particular, remains in the formative stages, conducting higher level statistical analyses may be presumptuous, as it may be inappropriate to make assumptions about complex interactions when the simple relationships between variables remain poorly understood.

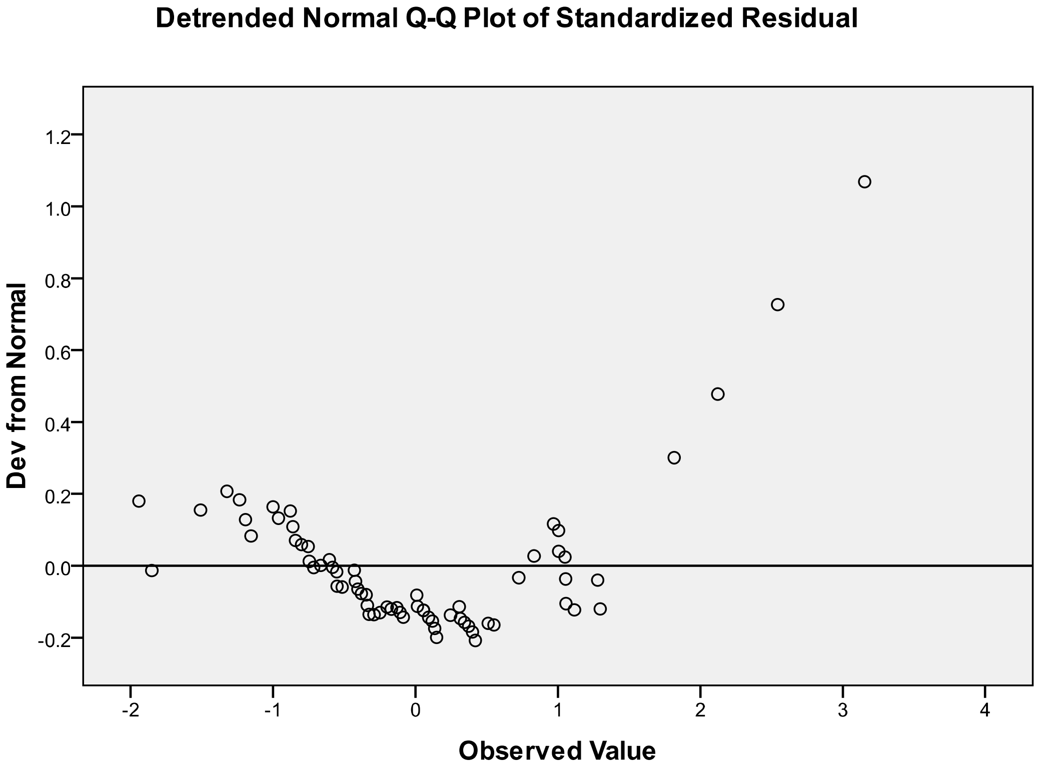
Finally, a series of tests of binary logistic regression were executed to further examine the relationships between key variables, as laid out in the research questions above. Logistic regression allows for the modeling of the effects of multiple predictor variables that may explain variation in a binary outcome variable, which may prove useful in establishing suggestions of explanation (Hosmer & Lemeshow, 2000). Logistic regression modeling seeks to find the most parsimonious fit between the predictive covariates and a single outcome variable, enabling stronger predictive insights than are permitted by simple chi-square tests of association (Pampel, 2000).

Binary logistic regression is based on use of a dichotomous outcome variable. In the first research question, testing the effect of four predictors on CDCS usage status, the outcome variable was originally dichotomous, so binary logistic regression is an appropriate choice. In the second research question, which examines the effect of selected predictors on DSP tenure, the choice to use logistic regression requires more explanation, as tenure was originally a continuous variable.

First, when tests of the assumptions of linear regression were conducted, it was found that normality of the error distribution for DSP tenure was not normal, suggesting the need for a non-parametric statistical alternative to standard linear regression (Garson, 2009a). The detrended Q-Q plot of standardized residuals displayed in Figure 2.1 reveals that there are spikes and valleys in the distribution of error terms, suggesting the possibility of bimodality. With this being the case, a non-parametric test such as logistic regression is indicated (Garson, 2009a; Hosmer & Lemeshow, 2000). Results of the Shapiro-Wilk test (W=.964, $p<.05$), used to test normality when sample sizes are relatively small (Garson, 2009a), corroborate the finding that the assumption of normal distribution of error terms is violated, as indicated by statistical significance.

With the determination made that linear regression is not appropriate for testing the second hypothesis due to the lack of normality in distribution of residuals for DSP tenure, a decision must be made in how to dichotomize DSP tenure so that binary logistic regression may be performed. Dichotomization of DSP tenure from a continuous variable may result in attenuation of variance, meaning that there is a decreased likelihood of finding significant results (Hosmer & Lemeshow, 2000). Nevertheless, in order to test the second research question dichotomization occurred. While tenure could have been dichotomized based on a number of factors, most notably 28 months, the known average tenure length for DSPs in traditional service settings for individuals with IDD (Larson, Lakin & Bruininks, 1998), the decision was made to use the mean point for DSP tenure from the original study. In justifying this dichotomization decision, it should be noted that the current dissertation and the preceding original study are initial investigations into the nature of the DSP workforce in self directed supports for people with IDD. As such, it may not be assumed that tenures in self directed services mimic those in traditional services, especially since many DSPs in self directed services are family members, friends, and neighbors to the service recipient, suggesting that stability in

Figure 2.2. Detrended Normal Q-Q Plot of Standardized Residuals: DSP Tenure



staffing may increase. Thus, tenure was broken into two categories: above the mean (35 months or more) and below the mean (34 months or less). Thus, in the testing of the second research question, predictor variables will be tested for their predictive ability in suggesting DSP tenures that are below or above the established mean point from the original study using this data set.

Chapter III

Results

The findings of this study bring new insight to the factors that enable self directed supports to be a viable service option for some individuals and to the status of the direct support workforce in self directed supports. In this section, the major findings of this study will be examined.

Sample Characteristics

A total of 112 users of CDCS completed and returned the mailed survey. It important to note that all CDCS users who received this survey were using the Mental Retardation and Related Conditions Medicaid waiver (MRRC; now known as Developmental Disabilities waiver). Respondents in this study may have been the actual user of CDCS or that individual's family member or other proxy person. According to Medicaid program rules, only the person with IDD may be considered the recipient of CDCS services and funds. However, due to the fact that many CDCS users involved in the sample were either minors or had a guardian/conservator who held legal responsibility for the individual, it is highly likely that many of the surveys were completed by family members or other proxies on the behalf of the individual with IDD who was using CDCS. In this regard, CDCS is often viewed as a family support program.

Of the respondents, 58.9% (n=66) were currently using CDCS, while the remaining 41.1% (n=46) had used CDCS in the past. Among those who answered a question about racial background, just over 87% (n=87) of the sample was Caucasian, with African Americans (4.6%, n=5) and Asian Americans (3.7%, n=4) comprising the largest shares of other racial groups in the sample. Geographically, slightly over half of all respondents came from the state's most populous urban county (54.5%, n=61), with the remainder from suburban (32.1%, n=36) and non-metropolitan (13.4%, n=15) parts of the state, roughly reflecting the distribution of all CDCS users, as reported by the state, which suggests greater utilization in urban and suburban counties. Respondents predominantly lived with family members (80.7%, n=88). The demographic composition of the sample is summarized in 3.1.

3.1. CDCS Survey Respondent Demographics

Age of Recipient	n	%	*Race*	*n*	%
0-4 years	3	2.8	European American/White	95	87.2
5-15	42	38.9	Asian American/Asian	4	3.7
16-21	14	13.0	Hawaiian/Pacific Islander	1	.9
22-64	47	43.5	African American/Black	5	4.6
65 +	2	1.9	Multiracial	3	2.8
			Other	1	.9
Living Situation	n	%			
Independent	5	4.6	*Location*	*n*	%
With Roommate	7	6.4	Hennepin County	61	54.5
Group Home (1-4 bed)	4	3.7	Other metropolitan	36	32.1
Semi-independent	4	3.7	Non-metropolitan	15	13.4
With Family	88	80.7			
Other	1	0.9	*CDCS Status*		
			Currently Use	66	58.9
			Past User	46	41.1

Qualitative Results

As an initial step in this analysis, the data from interviews with county level directors of developmental disabilities services from selected Minnesota counties were analyzed. Generally, the results of this analysis support findings from the original study utilizing this qualitative data set, which are summarized in Chapter I.

The county administrator interviews suggest that CDCS may be an appropriate program option only for certain users. First, several county administrators indicated that the users in their county were almost all children, and that restrictive budgets prohibit enrollment in day training and habilitation programs that are used by many adults with IDD in Minnesota, effectively excluding adults from CDCS usage since their service needs cannot be met.

Administrators were also critical of the state’s decision to change budgeting methodology after CDCS had been implemented, and suggested that the resulting confusion may have prompted some users to leave the program. Another theme to emerge, corroborating original study findings, was that of paternalism, which was most pronounced in non-metropolitan counties. Administrators in rural areas stated that they did not know why taxpayers should pay for CDCS services, and that did not feel it was worthwhile to invest time in learning how to implement CDCS since potential users may not be capable of managing their own service budgets, for example. Metropolitan county administrators, on the other hand, sometimes noted that CDCS users spent very carefully and were able to get more out of their money than would be expected with traditional services. These themes related to usage among children, people in the metropolitan area, and with higher budgets were quite salient, and will be quantitatively tested in the first research question.

Another major theme to emerge was lack of centralized direction in implementation, also in line with the original analysis of the qualitative data. County administrators expressed frustration that the state did not provide clear implementation guidelines for CDCS, leaving individual counties to develop their own systems. Further, the state change significant program rules after implementation, causing further inconsistency and difficulty in program implementation and oversight. These difficulties led several counties to delay implementation until leading counties, particularly a few large counties in the metropolitan area, developed systems that smaller counties could replicate.

Descriptive Analysis

Building on findings from the initial study, the first portion of this analysis seeks to add integrated descriptive findings to the initial base of knowledge derived from segmented analyses of the survey data. This integrated descriptive analysis will bring insights to how workforce status, service usage, and perceived benefits and challenges of CDCS are associated, and will inform the testing of the three main research questions outlined in the methods sections.

Association of Quality of Life and Social Inclusion with Recreation. The survey solicited information about the types of benefits that service users experienced with CDCS overall. The results for this section of the survey are displayed in 3.2. Perhaps of most interest in this portion of the analysis is the examination of which categories of expenditures in CDCS were related to user perceptions of higher quality of life and increased social inclusion. Since the results were of particular interest for recreation-related expenditures, which may be most indicative of community inclusion, these are discussed below.

Table 3.2. Overall Benefits of Using CDCS.

Benefit	*n* reporting benefit	percent reporting benefit
Paying family members	82	73.2
Improved family life	73	65.2
More friendships	51	45.5
Able to keep staff longer	68	60.7
Provided flexibility	81	72.3
Better quality of life	75	67.0
Increased social inclusion	66	58.9
Staff more reliable	56	50.0
Increased functioning	45	40.2
Promoted independence	73	65.2

It should be noted, however, that attitudes about community inclusion in general, and use of CDCS funds to promote community inclusion more specifically, were somewhat mixed among county administrators who were interviewed. While some county administrators suggested that CDCS was useful in increasing independence and choices in community life, others were more skeptical. For instance, one administrator from a non-metropolitan area remarked, “I don’t think I need to be paying for [social activities]. I just thought there was way too much potential for abuse…” This theme of careful public stewardship and caution in making decision about what expenditures would be in the approved CDCS service plan emerged strongly from the analysis of county DD Services Directors, and was most pronounced among non-metropolitan administrators. Nevertheless, other administrators, mainly from the metropolitan area, suggest that, as a result of CDCS, “Individuals are significantly more integrated into communities without the provider entity making it so formatted and unnatural.” Thus, the link between social inclusion and quality of life with recreation is somewhat controversial, making it a good topic for further quantitative exploration. Variables about use of recreational activities were considered important in this portion of the analysis because recreation permits individuals to gain interaction with their community members and can be logically linked with higher quality of life.

Quality of Life. Increased quality of life was associated with participation in a number of recreation and leisure activities in statistically meaningful ways. For example survey respondents who reported use of CDCS funds for travel ($\chi2$ (1, n=104) =5.51, p=.019), going to camp ($\chi2$ (1, n=103) =6.83, p=.009), and attending sporting events ($\chi2$ (12, n=151) =21.46, p=.029) were all more likely than expected to report an increase in quality of life with CDCS use as well. Of interest is the fact that these three categories of recreational and leisure expenditure were among the more costly of the categories tested, while less expensive types of recreation such as attending movies or going to dances were not associated with higher quality of life in a statistically significant way, possibly because they were within financial reach without CDCS funds, while CDCS funds actually enabled some users to travel and go to camp when they could not have afforded to do so without CDCS.

A number of non-recreational services and expenditure categories were also associated with better quality of life while using CDCS. For instance, people who purchased adaptive equipment (χ2 (1, n=104) =5.73, *p*=.017), technological equipment (χ2 (1, n=104) =8.28, *p*=.004), and respite (χ2 (1, n=104) =4.43, *p*=.035) services were all more likely than anticipated to report higher quality of life.

Social Inclusion. Among the most important potential benefits of use of Consumer directed Community Supports is the potential to increase social inclusion of individuals with intellectual and developmental disabilities in their communities. Not surprisingly, reports of increased social inclusion were found to be associated with recreational activities in a statistically significant way, since people with IDD may feel more included in their communities when they are able to choose ways in which to interact with others in leisure activities. For instance, people who reported increases in social inclusion also reported that they used CDCS funds to go to camps, and this finding held true both before (χ2 (1, n=104) =4.51, *p*=.034) and after (χ2 (1, n=103) =7.88, *p*=.005) policy changes in allowable expenses and budgeting, suggesting that camp may be a particularly important way in which individuals with IDD may be able to gain inclusion with peers. Additionally, associations were found between social inclusion and the expenditure of CDCS funds on travel (χ2 (1, n=104) =7.50, *p*=.006) and going to dances (χ2 (1, n=104) =4.99, *p*=.025), with a relationship between greater social inclusion and higher likelihood to spend CDCS resources on the activity in each case. Being able to spend CDCS funds on transportation costs was also significantly related to higher reports of better social inclusion (χ2 (1, n=104) =5.45, *p*=.020), plausibly because of the need to pay for transit expenses in order to get to and from events where social interactions may occur.

Predictive Analysis: Research Question 1

The first main research question under consideration in this study tests factors that may be associated with whether an individual with IDD continues use of the CDCS program option, or returns to traditional services. Based on descriptive findings from the initial study, it is hypothesized that the age of the service user, the allocated individualized budget, the service user's geographic location, and the perception of increased social inclusion will be predictive of CDCS usage status. This section will present findings that test the first hypothesis in Table 2.1. This hypothesis will be tested through the construction of a binary logistic regression model. Before testing begins, however, it is necessary to explain how the variables to be included in this model were chosen.

First, it has been observed that the number of enrollees in CDCS has been in steady decline (see Figure 2.1). This decline suggests the need to ascertain specific predictors that promote individuals to remain on the CDCS program option or move to traditional service options. Four potential predictors have been identified through careful consideration of the qualitative data analyzed for this project. First, age has been selected as a potentially important variable because some county administrators indicated that CDCS usage was almost exclusively among children. For instance, one administrator explained that CDCS users are "… all young children in [the county]. Adults in our county get what they need in other ways, but the CDCS participants in our county are young children. It seems to work best for educated, sophisticated families [with children] who know how to navigate the systems." Next, geographic location was chosen for consideration because of disparities in how administrators viewed the program, as indicated in the section above. In addition, the interviews suggested that some counties were reticent to implement CDCS because of the program's administrative complexities, waiting to see how the large counties implemented before trying it in smaller counties. This is exemplified by a comment from a rural administrator who said, "Honestly, we don't do many waivers, just two or three per year, so we don't understand it enough to then turn around and teach it." In addition, an administrator expressed frustration with inequities in how counties implemented CDCS: "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…" The importance of including social inclusion, another variable in this binary logistic regression analysis, is outlined in the descriptive section above, with the logic being that people who perceive more social inclusion may be more likely to remain on the CDCS program. Finally, the amount of the individualized budget was included in this analysis because county administrators suggested that decreasing budgets with state control of the budgeting methodology may have constricted the utility of CDCS for some users. In support of this notion, one county DD Services administrator stated, "The biggest access issue is resource allocation based on the state formula. The amount of service may not be able to meet people's needs." With the source and importance of each of the variables for this analysis established, the procedure for testing the first hypothesis may now proceed.

Variable Correlation. This first step in testing this hypothesis is examination of the bivariate correlations that are present among the variables to be considered in the regression equation. Spearman rank correlations are the most appropriate method to conduct this correlation analysis for a number of reasons. First, Spearman's rho (ρ) does well in accommodating nominal level data, while other correlation methods are better suited for interval or ratio level analysis. In this analysis, continuous variables were collapsed into ordinal categorizations to facilitate interpretation of findings. Since the variables to be tested in this model are at the nominal or ordinal level, Spearman rank correlation is appropriate. Second, due to the relatively small sample size, all variables may not be evenly or linearly distributed. The nonparametric Spearman method is also robust for this breach of usual parametric correlation assumptions (Hosmer & Lemeshow, 2000). Correlations of variables associated with this research question are displayed in Table 3.3.

As seen in Table 3.3, the dependent variable, CDCS status, is correlated with two of the independent variables in a statistically significant way, with significance established at $p<.05$. CDCS status was significantly positively correlated with the age of the CDCS user ($\rho=.494$) and negatively correlated with geographic location ($\rho=-.246$). Both of these findings are consistent with the results of chi-square tests displayed in the section about the results of the original

Table 3.3. Spearman Rank Correlation of Variables Related to Research Question 1.

		CDCS Status[1]	User's Age[2]	Geographic Location[3]	CDCS Individualized Budget[4]	Increased Social Inclusion[5]
CDCS Status						
	ρ	-	-	-	-	-
	n	-	-	-	-	-
User's Age						
	ρ	-.488**	-	-	-	-
	n	108	-	-	-	-
Geographic Location						
	ρ	.246**	-.032	-	-	-
	n	112	108	-	-	-
CDCS Individualized Budget						
	ρ	.124	.109	-.172	-	-
	n	88	85	88	-	-
Increased Social Inclusion						
	ρ	.004	.219*	-.090	.050	-
	n	112	108	112	88	-

Note: [1]Reported status in CDCS Usage (1=current CDCS user, 0=past CDCS user); [2]Reported age of the CDCS user (0=child age birth to 21, 1=adult age 22+); [3]Reported location in the state of Minnesota (0=Hennepin County, 1=Other metropolitan counties, 2=Non-metropolitan counties); [4]Individualized budget through CDCS reported as a binary variable (0=equal to or less than $40,900, 1=$40,901 or higher); [5]Self report of whether CDCS use led to greater social inclusion for the recipient (0=social inclusion not increased, 1=social inclusion increased).
*$p<.05$, **$p<.01$, ***$p<.001$

study, which found associations between CDCS usership with children and among people in the metropolitan areas of the state, including Hennepin County. Significant relationships between the dependent variable and social inclusion and CDCS budget were not found, however. Although this finding may suggest that these variables will not contribute significantly to a logistic regression model, they will be tested in the next stages since both variables may theoretically explain why some individuals continue use of CDCS while others leave the program. Two of the independent variables, age of the CDCS user and increased social inclusion were also positively correlated (ρ=.226). This is a logical finding given that children with IDD may spend more time with their peers in the normal course of the day (through integrated classrooms at school for instance) than would be expected with many adults with IDD, who often spend much of their time in segregated living and day activities.

Binary Logistic Regression. A binary logistic regression model was tested to determine how CDCS status is affected by participant age, geographic setting, CDCS budget, and perceived increases in social inclusion. Since the outcome variable in this case is dichotomous, logistic regression is the appropriate test, since it is designed for use with dependent variables that are binary in nature. The predictor variables in this case were converted to either dichotomous or categorical variables. Age was dichotomized based on the age at which an individual transitions to the adult service system (after age 21), CDCS budget, which was originally a ratio-level variable, was dichotomized based on the mean budget found in descriptive analysis (thus low budgets are $40,900 or lower and high budgets were $40,901+). Social inclusion was a dichotomous variable from the onset, and geographic location was categorized based on the participant's location in Hennepin County, other metro-area counties, or non-metropolitan areas of Minnesota. After removal of cases with missing data, the total sample for this test was

85, making for a small sample size for this test. An alpha level of .05 was established as the cutoff point for significance throughout analysis.

Based on the above variables, the full model hypothesized to predict the probability that an individual would be a current user of CDCS was as follows:

$$Probability\ of\ being\ a\ current\ CDCS\ user = \frac{e^{Model\ logit}}{1 + e^{Model\ logit}}$$

In this case the model logit portion of equation is equal to:

$$z = \beta_0 + \beta_1(User\ age) + \beta_2(Geographic\ location) + \beta_3(CDCS\ budget) + \beta_4(social\ inclusion)$$

Because all variables in this binary logistic regression equation are dichotomous or at the categorical level of measurement, dummy coding is used to designate values of categorical variables. This coding scheme is seen in Table 3.4.

Table 3.4. Categorical Data Coding for Independent Variables in Research Question 1.

			Parameter Coding	
Variable	Code	Frequency	1	2
User's Age	Child (0)	46		
	Adult (1)	39		
Geographic Location	Hennepin (0)	49	0	0
	Other metro (1)	23	1	0
	Non-metro (2)	13	0	1
CDCS Budget	$0-40,900 (0)	48		
	$49,001+ (1)	37		
Social Inclusion	Did not improve (0)	32		
	Improved (1)	53		

The first step in testing this hypothesis is assessing the fit of the data to the model. The Hosmer and Lemeshow test will be utilized to assess model fit since this procedure remains robust even when sample size is small (Garson, 2009a). A non-significant finding indicates an adequate fit between the data and the hypothesized model. As seen in Table 3.5, the result of the Hosmer and Lemeshow test for this model is not significant, suggesting adequate fit to proceed to next steps in the analysis. This finding is corroborated by the additional model fit test results (Cox & Snell R^2 = 0.327, Nagelkerke R^2 = .444) which, while not the preferred method for interpreting model fit, do provide additional credence to the Hosmer & Lemeshow findings (Garson, 2009a). These goodness of fit findings indicate that a significant amount of variation in CDCS usership status is explained by the independent variables under consideration in the model.

Table 3.5. Hosmer & Lemeshow Test for Research Question 1

Step	χ^2	*df*	*Sig.*
1	6.683	8	0.571

All of the predictor variables (user's age, geographic location, CDCS budget, and social inclusion) were entered into a regression model in a single block. This block of variables was found to have a significant relationship with CDCS status (χ^2 = 33.218, p<.001). In comparing the test model with the null hypothesis, which does not include any of the independent variables in the regression equation, the predictive accuracy of the model in predicting CDCS status was increased from 61.9% in the null hypothesis to 76.2% in the model including all independent variables in a single block. This suggests that the test model can accurately predict CDCS status 76.2% of the time, more often than a model not including the independent variables. The classification table in Table 3.6 displays this finding.

Table 3.6. Classification Table for Full Model in Research Question 1.

	Predicted		
	CDCS Status		
Observed	Past user	Current User	Percentage Correct
Past User	21	11	65.6
Current User	9	43	82.7
Overall Percentage			76.2

Three of the independent variables (age of user, geographic location, and CDCS budget) were found to be significant, unique predictors of CDCS status when put into the full block model. Perceptions of social inclusion did not add significantly to the understanding of CDCS status in this model. Table 3.7 offers a comprehensive view of the unique contributions of each of the independent variables in the understanding of CDCS status.

Table 3.7. Variable Summary: Block Entry Testing of Research Question 1.

						95% CI for Exp(B)	
Variable	Log Odds	Wald	*df*	*Sig.*	Exp(B)	Lower	Upper
Age (adult)	-3.111	20.532	1	.000	0.045	0.012	0.171
Location		6.375	2	.041			
Henn. v. Metro	1.721	5.626	1	.018	5.592	1.348	23.178
Henn. v. non-metro	1.277	2.449	1	.118	3.585	0.725	17.739
Budget (high)	1.303	4.32	1	.038	3.679	1.077	12.568
Soc. Incl. (increased)	0.75	1.458	1	.227	2.117	0.627	7.151
Constant	0.43	0.536	1	.464	1.538		

In interpreting the findings of this binary logistic regression model, it may be noted that age (OR = .045, *p*<.001), location (OR = 5.592, *p*=.018), and CDCS budget (OR = 3.679, *p*=.038) all significantly predict CDCS status, when other factors in the model are held constant. Since binary logistic regression always predicts the “1” condition of the binary dependent variable

(Garson, 2009a), this interpretation is based on prediction of being a current user of CDCS, rather than prediction of previous use of the program.

Since the odds ratio (Exp(B)) for age is less than one, this indicates that adults are less likely than children to be current users of CDCS, with other factors in the model held constant. Other findings suggest that location is a predictor of CDCS status, with odds of being a current user rather than a previous CDCS user increasing by a factor of 5.592 based on metropolitan residence rather than living in Hennepin County. The odds associated with current CDCS enrollment at the time of the survey administration were not significantly affected when comparing Hennepin County versus non-metropolitan residence, suggesting that metropolitan area residence may be the strongest predictor of ongoing CDCS usage among individuals with intellectual and developmental disabilities. Although not directly associated with CDCS usership status when considering covariation, this model suggests that having a higher CDCS budget may also be predictive of ongoing CDCS usage as compared with lower reported CDCS funding allotments. Perception of social inclusion does not contribute significantly to understanding of CDCS usage status (*p*=.227).

Predictive Analysis: Research Question 2.

The second research question investigates potential predictors of the length of tenure for DSPs working in CDCS. Based on literature on workforce development in the human service industry, much of which has been outlined in the literature review, it is hypothesized that staff who are paid higher wages and staff who receive fringe benefits will be more likely to remain employed for longer periods of time. Because CDCS offers recipients the flexibility to hire family members and friends, rather than mainly strangers as in traditional services, it is also hypothesized that people who have a family or friend relationship to the CDCS user will remain as DSPs for longer than strangers. Finally, based on the previous finding that training for DSPs is not offered as frequently as might be expected, and because the literature on workforce development in community human services indicates that better trained employees stay in their jobs longer, it is hypothesized that DSPs who have received staff training will have longer tenures than those who have not.

While the formulation of the variables in this research question was derived primarily from the professional literature, the qualitative analysis also provides some basis to the derivation of this quantitative research question. One metro-area county administrator stated, “families cut out the middle man as well as increase longevity of staff,” suggesting that family members who serve as paid DSPs may be more likely to have longer tenures in the perception of this administrator. Another county DD Services director concurred, noting that CDCS produced, “consistency in services, less [DSP] turnover, and improved satisfaction for both family and staff.” Administrators also suggested that lower levels of training may be attributable to family relationships between DSPs and CDCS users.

Variable Correlation. As with the first research question, this analysis begins by examining the bivariate relationships between key variables that are under consideration in this model. As previously, the Spearman rank correlation method was chosen for this procedure due to its robustness in handling nonparametric variables that may not be linearly related and because it accepts binary variables more readily than Pearson’s *r* or Kendall’s tau-B.

As may be seen in Table 3.8, statistically significant bivariate Spearman rank correlations were not present between the independent variable, DSP tenure, and any of the predictor variables. The only statistically significant Spearman correlations among any of the variables involved with the second research question are the relationship of the DSP to the CDCS recipient with the provision of fringe benefits (ρ=-.197) and between the provision of fringe benefits and offering training to DSPs (ρ=-.221). The presence of a positive correlation between relationship and fringe benefits suggests that individuals who are not direct family members (i.e.: who are friends or previously unknown at the time of hire) may be more likely to receive fringe benefits. Likewise, the positive relationship between fringe benefits and training may indicate that DSPs who receive staff training also receive fringe benefits.

It is typically assumed that relationships between the independent and dependent variables must be observed in correlation analysis in order to find useful results in logistic regression analysis (Hosmer & Lemeshow, 2000). Although a significant relationship between

Table 3.8. Spearman Rank Correlation of Variables Related to Research Question 2.

		DSP Tenure	Relationship to User	DSP Wage	DSP Fringe Benefits	DSP Training
DSP Tenure[1]						
	ρ	-	-	-	-	-
	n	-	-	-	-	-
Relationship to User[2]						
	ρ	-.037	-	-	-	-
	n	260	-	-	-	-
DSP Wage[3]						
	ρ	.012	.051	-	-	-
	n	261	260	-	-	-
DSP Fringe Benefits[4]						
	ρ	.044	.197**	.046	-	-
	n	261	260	261	-	-
DSP Training[5]						
	ρ	.084	.020	.086	.221**	-
	n	261	260	261	261	-

Note: [1]Reported length of DSP tenure (0=short tenure- 34 months or less, 1=long tenure- 35 months or more); [2]Relationship between CDCS user and DSP (0=direct family member, 1=previously known- friend, neighbor, etc., 2=previously unknown- staffing agency, etc.); [3]Reported DSP hourly wage rate (0=low wage- $12.76 or less/hr., 1=high wage- $12.77 or more/hr.); [4]Are fringe benefits available to the DSP (0=no, 1=yes); [5]Did the CDCS user offer staff training (0=no, 1=yes). **p*<.05, ***p*<.01, ****p*<.001

the predictors and the outcome variable have not been observed in this case, the full analysis proceeded in order to investigate any predictive capacity of the model that may not be anticipated from these preliminary results.

Binary Logistic Regression. The binary logistic regression test for this research question tested a model with DSP tenure as the dependent variable. The independent variables that were tested for their predictive power in explaining longer DSP tenures were the hourly wage the DSP is paid, his or her relationship to the CDCS user, whether or not fringe benefits were offered to the DSP, and whether the DSP received job training. DSP tenure is a dichotomous variable derived from the ratio level variable from the survey. Tenure was broken into high and low levels, delineated by the observed mean of 34 months from the descriptive analysis. Similarly, DSP wage was dichotomized based on the wages above and below the observed mean of $12.76 per hour. Relationship between the CDCS user and the DSP was originally a categorical variable which was collapsed into three categories for (a) direct family; (b) previously known individuals such as friends, neighbors, and church members; and (c) previously unknown individuals such as people from staffing agencies. Both of the final two independent variables, provision of fringe benefits and offering of staff training were originally dichotomous in the survey, and remain so in this analysis. The categorical variable coding scheme employed in this logistic regression analysis is displayed in Table 3.9.

Table 3.9. Categorical Data Coding of Research Question 2

Variable	Code	Frequency	Parameter Coding 1	 2
DSP Wage	Low (0)	120		
	High (1)	140		
Relationship to User	Family (0)	92	0	0
	Friend (1)	114	1	0
	Stranger (2)	54	0	1
Fringe Benefits	No (0)	216		
	Yes (1)	44		
Offer Training	No (0)	76		
	Yes (1)	184		

Based on this conceptualization of variables in this model, an equation for the logistic regression model may be laid out as:

$$z = \beta_0 + \beta_1(DSP\ Wage) + \beta_2(Relationship) + \beta_3(Fringe\ benefits) + \beta_4(Offer\ training)$$

Model fit for this combination of variables yielded mixed results. Findings from the Hosmer and Lemeshow test, shown below is Table 3.10, find non-significant results, indicating that there is adequate fit between the data and this model. This suggests that there may be statistically important findings among the predictor variables. However, indications of goodness of fit derived from the Cox & Snell (R^2 = .039) and Nagelkerke (R^2 = .053) tests suggest borderline or unacceptable goodness of fit. Because the Hosmer and Lemeshow model is typically deemed the most reliable for data such as these, and because the findings from Cox & Snell and Nagelkerke were in the borderline area for assessing goodness of fit, the analysis may continue to investigate the role of individual variable in predicting DSP tenure.

Table 3.10. Hosmer & Lemeshow Test of Research Question 2.

Step	χ^2	*df*	*Sig.*
1	11.019	8	0.201

The independent variables were entered into the regression model in a single block using the enter method. SPSS output indicates that this block of variables does not predict changes in DSP tenure in a statistically significant manner (χ^2 = 10.346, *p*=.066). Block 0, which tests the null hypothesis of there being no relationship between the independent block of variables and the single outcome variable, indicates that a model without any of the predictor variables can accurately predict DSP tenure 59.2% of the time. When the test block containing wages, relationship, training, and fringe benefit provision is entered into the regression equation, accurate prediction of DSP tenure may occur 61.2% of the time (Table 3.11), only slightly better than in the null model. This supports the findings from the correlation analysis that indicated no significant bivariate relationships between the predictors and DSP tenure.

Table 3.11. Classification Table for Full Model in Research Question 2.

	Predicted		
	DSP Tenure		
Observed	Short	Long	Percentage Correct
Short	117	37	76.0
Long	64	42	39.6
Overall Percentage			61.2

The final stage in this analysis is examination and interpretation of the contribution of wages, relationship of the DSP to the CDCS user, fringe benefit provision, and availability of training in the explanation of DSP tenure. This model tested the “1” condition of DSP tenure, so it is the prediction of longer tenures that is the concern of this model. As seen in Table 3.12, none of the predictor variables in this model offer unique and significant contributions to the understanding of DSP tenure. The constant is the strongest predictor, indicating that there is not substantial addition to the explanation of DSP tenure through the addition of any of the independent variables, leading to the conclusion that wage rates, the relation of the DSP to the CDCS user, staff training, and fringe benefit provision are not predictors of longer tenure based on the results of this sample of CDCS users with intellectual and developmental disabilities in Minnesota.

Table 3.12. Variable Summary: Block Entry Testing of Research Question 2.

						95% CI for Exp(B)	
Variable	Log Odds	Wald	*df*	*Sig.*	Exp(B)	Lower	Upper
Wage (High)	-0.012	0.002	1	0.964	0.998	0.594	1.646
Relationship		7.868	2	0.02			
Family v. Friend	0.447	2.409	1	0.121	1.564	0.889	2.753
Family v. Stranger	-0.546	2.025	1	0.155	0.579	0.273	1.229
Fringe Benefits (yes)	0.269	0.564	1	0.453	1.309	0.649	2.64
Training (yes)	0.388	1.716	1	0.19	1.474	0.825	2.633
Constant	-0.788	5.998	1	0.014	0.455		

Chapter IV

Discussion

The findings from this study illuminate a number of important points that expand the current state of knowledge about CDCS in Minnesota, with potential application to self directed services for individuals with intellectual and developmental disabilities nationwide. This study's findings inform a number of areas for discussion.

Usership Status

This study's results suggest that substantial segments of the population may not have equitable access to CDCS, consistent with earlier reports that program viability is sometimes a challenge with relatively new self directed programs such as CDCS (Sciegaj, Mahoney, & Simone, 2008; Schmitz, Luxenberg & Eustis, 2005). The first research question tested in this dissertation found that children, metropolitan area residents, and people with higher than average CDCS budgets were all factors associated with current usership status. These findings are potentially important since they suggest trends towards ongoing usership among children in the metropolitan area of the state. This finding is consistent with previous findings from the original study. What is new to the understanding of CDCS usership is the potential role of individualized budget size, as this is the first indication to date that supports the assumption that higher individualized budgets may enable individuals to continue using CDCS, whereas smaller budgets may inhibit long-term use of the program.

What is absent in this analysis is explanation of why former CDCS users leave the program. The professional literature indicates high rates of satisfaction with self directed programs (Beatty, Richmond, Tepper, & DeJong, 1998; Foster et al., 2003), but does not suggest reasons why users may discontinue use of self directed programs. While the reasons for program departure are an important area for future study, some reasons may be discerned from a combination of CDCS policy stipulations and the findings of this study.

This study indicates that individuals who have not yet transitioned to adult services and those with higher budgets are more likely to be current users of CDCS. A partial explanation for this may come from the fact that services often used by adults with IDD are either disallowed or too expensive to purchase with CDCS budgets. In the case of adult foster care, which is the mechanism by which most group home stays are paid, the state will not permit expenditure of CDCS funds, under the logic that CDCS is meant to help people stay in their family homes (Minnesota Department of Human Services, 2010). While adult day training and habilitation programs are permitted under CDCS rules, these services, which are used by many adults with IDD in Minnesota, are quite costly, and are out of reach for most people who have typical CDCS budgets. These two factors, related to adult foster care and day training and habilitation programs, effectively rule out CDCS use for most adults with IDD, helping to explain why adults and people with lower budgets tend to refrain from CDCS use. The state may be wise to consider funding alternatives, such as providing enough budget to pay for day training and habilitation, while still building in cost savings in other areas, which may make CDCS a viable option for more adults.

The finding that metropolitan area users are most likely to remain on CDCS, while non-metropolitan users may be more likely to depart is potentially explained by qualitative findings that suggest less knowledge and greater paternalism in attitudes among IDD service administrators in non-metropolitan areas. It is also possible that individuals in these areas perceive that there is less support for management of CDCS than there may be in the metropolitan area of Minnesota, where fiscal support entities and parent networking and advocacy organizations are more plentiful.

Workforce Factors

The lack of significant explanatory findings about the direct support workforce is somewhat surprising, based on established findings in the professional literature about the importance of wages, training, and fringe benefit provision of direct support worker retention (Hewitt & Larson, 2007). Further, the association that might be expected with family caregivers having longer tenures than people who are strangers at the time of hire did not hold true in this analysis. While these findings may be due to sampling error or the relatively small number of individuals who completed this specific portion of the survey that gathered DSP-related status data, they may also indicate differences in the nature and mechanisms by which the direct support workforce functions in self directed service options. Ultimately, further conclusions are not possible within the scope of this research, but may be a wise area for investigation in future studies.

Low levels of DSP training were offered by respondents to the survey in this study, with only 62% of people indicating that they provided staff training of any kind, and just 63% of those reporting that they provided training also reporting that using CDCS made training staff easier, whereas these numbers are substantially higher in traditional services (Larson, Hewitt, Knoblauch, 2005). This leaves well over a third of individuals using CDCS who did not provide any type of training to their DSPs. By a large margin, when training was offered, it was about the specific needs of the individual using CDCS, and was most often delivered by the individual or the user's family member. Some of this low rate of training may be due to the fact that many DSPs who provide support in CDCS are the family members of the individual using the program. However, even accounting for the familiarity that may be afforded by paid familial support providers, training levels remain low, and appear to be confined to a very narrow range of topics, which suggest the need for policy-level solutions that will enable expanded training opportunities for users of the self directed support option.

Since training in traditional service delivery settings is usually provided by the agency employing the DSP (Hewitt & Larson, 2007), there may be more training resources in such settings than are available to individual CDCS users who must self direct the majority of training. It is possible that locations which are highly invested in consumer direction of services may need to offer a menu of training opportunities to users of consumer directed supports and their staff in order to satisfy the training needs inherent in any relationship with a direct support professional. Trainings that are specifically targeted at how to find, choose, and retain quality DSPs would be of particular benefit, as would those that are based on the development of staff management skills, not just procedures for operating within the system.

Wages of DSPs in this study also did not successfully predict whether the worker would have tenure that was longer than average among the sample. It is possible that this finding is related to the relationship of the DSP to the CDCS enrollee. The original study using this data set established that over 87% of DSPs in this sample were previously known to the CDCS user at the time of hire (Bogenschutz, Hewitt, Hall-Lande & LaLiberte, in press). As this is the case, it is possible that the relationship between the support provider and the service user may be able to mediate some of the importance of wages in self directed supports, since family members, friends, and neighbors may be willing to work for a longer time at low pay than would a stranger with no previous connection with the service user.

The relationship of the DSP to the service user may also be useful in explaining why the provision of fringe benefits was not a significant predictor of DSP tenure, as would be expected in traditional services (Hewitt & Larson , 2007). A family member or neighbor, who likely provided supports with no compensation without CDCS, may see payment alone as suitable benefit. In line with previous findings that the majority of self directed funds are spent on person-to-person support services (Young & Sikma, 2003), CDCS may be seen largely as a family support program, rather than a program of individual support as it is defined by statue. Family members of people with IDD are able to receive compensation for their time as caregivers, and it is likely that this compensation is adequate to retain a family worker, in contrast to strangers who work in traditional services, who are likely to move jobs if compensation does not meet their expectations.

These issues suggest that the direct support workforce in self directed services may be fundamentally different than the workforce in traditional services. Since the self directed workforce is viewed as a potential source of relief for the upcoming shortage in direct support workers (Office of the Assistant Secretary for Planning and Evaluation, 2006), it will become increasingly vital to gain a fuller understanding of the nature of DSPs in self directed services, as this group has not been systematically studied. In future studies, comparison of workers in self directed supports with DSPs in traditional service environments will be necessary, as this study suggests that there may be differences between the two groups. It is also necessary to point out, however, that the lack of similarity between the DSPs in this study and what is known from previous studies of the traditional workforce may simply be due to sampling error and the relatively small sample of DSPs included in this study. Therefore, it cannot be said with certainty that the nature of the self directed DSP workforce is different than what is expected in traditional community services for people with IDD, only that additional study is important.

Implications

While this project was primarily a policy study, results have implications not only for policy, but for practice and future research as well. Implications for each of these areas are addressed individually below.

Policy Implications

There are a multitude of policy implications that arise from this study. In general, these implications fall into three main categories: (a) those that related to staff management by individuals with IDD and their families, (b) those related to more systematic staffing issues pertaining to wages, fringe benefits, and workforce stability, and (c) those policy implications related to availability and usage of self directed program options for people with IDD.

Workforce Stability Implications. Perhaps the most important policy implications to arise from this research are those related to the direct support workforce. As seen in the results section, staff wages are marginally higher than would be expected in traditional agency-based services, but rates of fringe benefit provision are quite low when compared to what is expected in agency-based services, though neither wages nor fringe benefits appear to predict longer tenure, based on logistic regression results. While staff tenures are much longer in self directed services than they are in traditional services, the long term sustainability of this extension in tenure is yet to be determined, as many direct support workers in self directed services may not be able to remain in employment that does not offer fringe benefits, particularly health insurance, over the long term, especially as they age and require more medical care themselves. These findings lead to a number of questions that will face policy makers, as well as suggestions of potential solutions.

DSP Wage Increases. First, the findings of this study suggest that workers in self directed services do receive marginally higher wages than would be expected in traditional services, but that pay increases are inconsistent. Findings suggest that people who self direct services who have higher budgets are more likely to provide raises to their DSPs. This also leads to the assumption that DSPs working for individuals with lower state-set individualized CDCS budgets may receive less pay raises.

These findings lead to the conclusion that, over time, inequities may arise in the wage rates for DSPs based on the CDCS budget of their employer, following the supposition that pay raises for DSPs working for people with high CDCS budgets will continue, while wage rates will stagnate for employees of CDCS users with lower budgets. This has potential consequences for both service users and policy. For service users, particularly those who do not rely exclusively on family members as paid supporters, this inequity in the provision of pay increases may result in uneven access to quality staff, with individuals who are able to provide wage increases that keep up with inflation being able to attract and retain high quality DSPs, while those individuals whose budgets do not allow for consistent wage increases may experience more difficulty finding and retaining DSPs. In this way, an erosion of the benefits of being able to recruit from non-traditional pools of DSPs, such as neighbors and friends, may occur for individuals with lower budgets, if wage rates are not adequate to attract DSPs to work. Wage inequities may not only be a problem for recruitment of staff directly, but also for turnover, and the training costs associated with recruiting and orienting replacement DSPs to the support needs of the CDCS user and other essential work tasks.

On the policy level, these findings are quite significant. CDCS (and self directed programs in other states) are often valued by policy makers for their potential benefit in relieving part of the crisis in staffing supply that is expected to affect the direct support profession in coming years. However, if wages stagnate for a portion of CDCS users, it will be uncertain whether the potential benefit in reducing the staffing crisis will be actualized.

Solutions to this problem may come in different forms. One part of the solution may be the implementation of more systematic training for CDCS users and their families about the general elements of staff management. If CDCS users are able to obtain more information about best practices in DSP management, they will be more likely to develop staffing patterns and compensations schemes that will lead to greater performance and tenure among their DSPs. States and counties may be able to develop such training curricula relatively cheaply and efficiently. Delivering this training at regular intervals at no or low cost to CDCS users is likely to improve staffing outcomes systemwide for users of self directed supports.

In Minnesota, increases in DSP wages for users of CDCS are mandated at any time when increases are provided in traditional provider-based services. Furthermore, these wage rate increases are stipulated to be at the same percentage of pay increase in both traditional services and CDCS. This parallel increase structure for DSP wages is important, and should be maintained in Minnesota and adopted in other states. It is also possible that the service plan that each CDCS user is required to file could help to target increases in budget allotment that are specifically related to staff wages. In this way, highly targeted funds for staff wage increases could be built into individualized budgets.

Innovative Fringe Benefit Provision. Findings of this study show that only about a fifth of all CDCS users offer any type of fringe benefits to their direct support workers. Perhaps most concerning, only about 8% of CDCS users provide their DSPs with health care coverage. This study also found a positive correlation between provision of fringe benefits and longer DSP tenures, suggesting that the relationship between DSP retention and the availability of fringe benefits may be important. Since the relatively small amount of funds available in individualized CDCS budgets may make the provision of fringe benefits unfeasible for many CDCS enrollees and their families, innovative policy options for the provision of fringe benefits may be necessary to promote the long term stability of the workforce in self directed supports.

One such policy innovation may be the development of a Medicaid buy-in option for DSPs working in consumer directed supports. Such an option would enable the CDCS user to provide a stipend to the DSP to be used towards buy in to a Medicaid health insurance option at a reduced rate to be negotiated by the state. Since the states administer both the Medicaid program and consumer directed service options, synergy between the two would likely make this an administratively feasible option. Furthermore, because of the very large risk pool already involved with Medicaid, health insurance could be provided at a very low cost relative to the private insurance market for individual plan subscribers. In Minnesota, it may be feasible to enable DSPs to buy into Minnesota Care at a reduced rate in order to gain access to consistent health care insurance.

Another option for promoting greater rates of health insurance provision may be for the state to provide a financial incentive or addition to the individualized CDCS budget for program users who offer health insurance to all or a portion of their direct support workers. Such a policy innovation would incentivize health care provision, making a more feasible option for CDCS users who wish to provide an option for health care coverage to their employees.

The primary challenge of this approach would be the high cost of health insurance on the private market, meaning that the size of the financial incentive to be offered by the state would need to be sizeable. However, if used in conjunction with the Medicaid buy-in option noted previously, an adequate method for promoting provision of health care coverage might emerge. The fiscal feasibility of this approach may be bolstered by the potential cost savings from emergency room care or health care through other public programs, which are often used by DSPs who do not receive health care insurance through their employers. While it is unlikely that cost savings in these areas would provide a complete offset to the need for increases in individualized budgets, it is possible that policymakers may find this option acceptable in light of the overall cost savings that is built into the CDCS option when compared to traditional service delivery models. The impact of the 2010 Patient Protection and Affordable Care Act may help to facilitate health benefit provision for DSPs in self directed services, though the full impact of this recently passed legislation will not be realized for several years.

In addition to innovations in the delivery of health insurance, policy creativity is also needed to create a system for paid time off and retirement plan contributions in order to make direct support work in consumer directed supports an attractive option for top candidates over the long term. As is the case for the potential Medicaid buy-in option, it may be feasible to develop a system whereby DSPs could pay into a retirement plan sponsored by the state or by another organization, such as the provider of fiscal intermediary or support broker services. Particularly if the retirement savings plan was sponsored by the fiscal intermediary entity, it could reach many users of CDCS at once (who could then offer the option to their workers), and would fit naturally into the financial management duties that the fiscal intermediary already performs, with payroll processing, recordkeeping for taxes, and so on. Individual CDCS users could determine the amount of their contribution for the DSP retirement plan based on their individualized budget, and DSPs could make individual contributions, just as in a conventional 403(b) plan. Such an option would likely be a strong incentive for retention of quality DSPs who would see high value in retirement savings as a part of their compensation for employment that is a long-term career and not simply a job. The state’s sponsorship of a similar plan could serve as a centralized policy option for improving DSP retention in self directed services such as CDCS for individuals with intellectual and developmental disabilities. By taking steps such as these, policy innovations may play a significant role in providing much needed fringe benefits that are quite likely to stabilize the direct support workforce in CDCS both at present and in the future, as the shortage of DSPs becomes more acute.

Relationship between DSP work in traditional services and CDCS. An unknown element in the evaluation of self directed supports generally, and Minnesota’s CDCS program for people with IDD specifically, is how the expansion of self directed supports may result in competition for direct support workers with traditional services. While CDCS users rely heavily on individuals who were previously known to them to be direct support professionals, there is a notable percentage of DSP in CDCS who are not previously known to the individual using supports. It is assumed that these individuals chose to work directly for the CDCS user over opportunities to work in traditional agency-based settings. It is also logical that some of the previously known DSPs may be interested in working in traditional service settings if the work fits their professional preferences or if the compensation would be favorable.

As the shortage of direct support professionals becomes more acute, it is plausible that individuals who self direct supports may find it increasingly more difficult to offer compensation that may be competitive in attracting the highest quality of DSPs, particularly among the potential worker pool that is not composed of family members or close personal friends. While it is seen as a strong benefit of CDCS that individuals with IDD may pay family and friends to provide direct support, it is likely that some need for workers who are either casual acquaintances or previously unknown at the time of hire will continue to exist. It is primarily in recruitment among this segment of the DSP workforce in self directed services that competition with traditional services may come to be an issue. Since wages in self directed services appear to be only marginally higher than in traditional services, and because traditional services offer fringe benefits at a much higher rate, many potential direct support workers may be drawn to work in agency-based services because of stronger overall compensation packages.

In light of this, the innovative options for fringe benefit provision, as delineated above, may take additional importance. In addition, it may be useful for the state to develop a training module that would be strongly suggested for all individuals who choose the CDCS option. This module could assist the individual (or their family advocate as needed) develop a tangible plan for DSP recruitment and retention. In addition, a DSP recruitment and management toolkit could be developed, including materials for targeted marketing, which could help individuals who self direct to attract high quality DSPs. These steps may help to close the competitive gap between CDCS users and traditional service provider agencies in the ability to attract and retain top DSPs.

DSP Training Implications. Related to policy, this study also has implications for systems of DSP management for individuals with IDD and their families who self direct services. Policy implications are particularly present related to staff training.

One option for improving access to and utilization of training opportunities for the DSPs working for people who self direct would be the establishment of regional training cooperatives that could pool resources to offer trainings that were targeted to the needs indicated by substantial numbers of CDCS users. By pooling training resources, people using CDCS would likely be able to gain access to a larger array of training topics at lower cost, since training could be delivered to more CDCS users at the same time. It is also possible that CDCS users could partner with traditional service provider agencies, which are able to provide a larger array of training topics, both those that are specifically designed to innovate in service delivery and those that are aimed at health and safety training (such as first aid, CPR, and medication administration), which are often mandated for DSPs working in agency settings. Many of the fiscal support entities in Minnesota provide such training opportunities to CDCS users. Partnering with traditional provider agencies could also allow DSPs working in self directed services to network with other DSPs to build their professional identities and to exchange ideas. The establishment of state-sponsored training seminars would also be a positive policy option that would enable people with IDD who self direct their services to extend training options to their direct support workers. These seminars could be offered regionally on a periodic basis throughout the year and could focus on central issues of importance in the DSP workforce, from the perspective of the state and service users. State sponsorship of CPR and first aid courses would also be a positive way to provide easily accessible and free/low cost training on basic health and safety issues.

Perhaps the most promising policy solution that could be implemented to enable better access to and utilization of high quality training for DSPs would be purchase of a statewide contract for an online, competency-based training curriculum such as the *College of Direct Support.* Competency-based training content that is rooted in the validated set of skills essential to work as a DSP as identified in the Community Support Skill Standards (Taylor, Bradley & Warren, 1996), may play a central role in helping direct support workers to develop the skills and behaviors required to perform their duties adequately. Online training has advantages over other forms of competency-based training.

First, online training is accessible at any time and in any place where internet access is available, reducing scheduling difficulties and travel costs associated with traditional classroom-based training. Second, content may be continuously updated, to reflect trends in best practices, knowledge innovations, terminology changes, and pedagogy. Particularly when paired with in-vivo, on-the-job training components that bring online learning into practice in real life, online training can provide state of the art content quite efficiently. Additionally, online training is standardized, assuring that all learners receive the same content, which cannot necessarily be assured in classroom-based training models where different trainers may present material differently, and where different interaction styles from the audience may sway how much importance and time is placed on particular topical elements of the training. Finally, while standardization of content is one of the things that can make online training effective, online training platforms that are customizable are also of tremendous benefit. Customizable online training units may build upon standardized content to, for instance, relate standardized content to the individual support needs of the individual receiving supports or provide information that is published by outside organizations that the service user finds particularly pertinent.

While many states do offer access to the *College of Direct Support* or other online training tools on a statewide basis, either at no charge to employers or at a reduced cost, Minnesota is not among them for users of CDCS. Implementing this policy tool would be a positive step for the state to consider for a number of reasons. First, and most importantly, it would be a highly equitable way to close the training gap not only between traditional services and self directed services, but also between the metropolitan area and rural parts of the state, where training options are far more limited. Second, providing statewide access to an online training program is a highly cost effective way to disseminate competency-based training, which stays current with new knowledge and practices. It is difficult to gain the same array of training topics in a cost efficient manner when using traditional classroom-based training methods. Finally, because of the convenience of online training, which alleviates scheduling and travel difficulties, it is likely that DSPs in the state would complete more training if online platforms were more readily available. This is almost assuredly the case for DSPs in CDCS, who complete less training to begin with and also do not have agency-based training options readily available to them. Therefore, it seems apparent that the state could take a very strong step towards stronger training for DSPs in self directed services (and in traditional services) by purchasing statewide access to a competency based online training tool.

Mandated training is a topic that may become of greater concern in the future for users of self directed supports and their families. At present, state policy mandates that DSPs working in traditional service environments receive minimal amounts of training in specified topics during orientation and annually thereafter, while this mandate does not apply to DSPs working for an individual with IDD who uses CDCS. This flexibility in providing only the training that is directly applicable to specific job duties is generally seen as a benefit of CDCS by service users. However, as this study indicates, some DSPs may not receive any training at all. Since CDCS is a state-sponsored, Medicaid funded program, this may eventually raise questions of liability if inadequate training in medication administration or basic first aid results in negative consequences for service users. Opponents of mandated training in CDCS might argue that mandating training in specified topics reduces the amount of self determination that an individual with IDD may exert in managing his or her support staff, thereby defeating one of the central theoretical purposes of the program.

The tension has not yet come about in Minnesota, yet it is worth considering policy options for addressing this issue which may eventually arise. One possible solution may be the implementation of policy that requires some level of staff training for DSP working for individuals with IDD in self directed supports. Following a system similar to the requirements for continuing education in licensing for social workers, educators and other professionals, requiring Continuing Education Units for DSPs in self directed supports would provide the policy level requirement that all DSPs continually receive training to provide services that support the individual service user, while enabling people with IDD and their families to exercise self determination in determining what type of training may be most suitable for their DSPs.

Availability and Usage Implications. The results of the survey as well as findings from analysis of county administrator interviews indicate that there may be inequities in the availability and use of CDCS among people of different ages and in differing areas of the state. In the regression model presented in support of the first research question, both the participant’s age, and where he or she lived in the state were both significant predictors of whether an individual was using CDCS or if the user had left the program. This finding suggests that there is room to improve the equity in offering CDCS. In addition, findings from the county administrator interviews indicate a lack of guidance to counties for the roll out of the statewide CDCS program, leading to differing experiences in implementation across counties. These findings lead to specific policy recommendations concerning availability and usage of CDCS among individuals with IDD in Minnesota.

Increase Support for Implementation. At the time of county administrator interviews, many county administrators commented on the difficulty of implementing CDCS with limited procedural guidance from the state. Some counties were forced to take the lead with implementation, while other counties, particularly those in non-metropolitan areas, learned from metropolitan counties that were the first to roll out. While the number of Minnesota counties using CDCS with the DD waiver has increased over the years, policy lessons may still be learned from the Minnesota experience in early implementation. These lessons may be valuable nationally as more states move into statewide implementation of self directed supports.

Among the policy implications of the Minnesota roll out of CDCS is that states should carefully construct comprehensive systems to support implementation of self directed programs. Not only does this recommendation include the need for comprehensive training for the county personnel who will administer self directed supports at the point of usage, but also construction of information technology systems, quality assurance plans, and data tracking systems. Because self directed service options put service users at the center of service planning, instead of case managers taking the lead in service planning as in traditional services, additional training for case managers about their role in self directed services may also be necessary.

One way to address many of the difficulties of the Minnesota roll out is to implement a fully functional self directed program in a small number of pilot counties before moving to systemwide implementation. This approach has been taken by several states, including Wisconsin, which has implemented its self directed program in Dane County only, partially to enable a fairly large scale evaluation of the program before implementing statewide. In some states, such as Oklahoma, pilots have been quite small (Walker et al., 2009). Nevertheless, running a pilot program, especially one on adequate scale to provide robust analysis, could help to fine tune information technology, service planning roles, and roll out support that can help counties to implement more rapidly and confidently, while minimizing some of the tendency for some counties to be leaders and others followers in offering and promoting self directed supports.

Increasing Systemwide Equity. Although CDCS is now being used in 51 counties in Minnesota indicating a significant increase in the geographic distribution of CDCS use, there are still 36 counties that do not use CDCS for people using the Developmental Disabilities HCBS waiver. The findings of this study, consistent with the results of the original study using this data set, indicate the presence of inequities in usage of CDCS among individuals with intellectual and developmental disabilities. These inequities suggest that CDCS may only be a particularly viable service option for children, and that people with IDD living in the metropolitan core of the state appear more likely to use CDCS than are individuals in non-metropolitan counties, many of which still do not enroll any service users with IDD in CDCS.

From these findings, it appears that policy alterations are necessary if CDCS is to be a viable service option for all of the individuals who could potentially benefit from it. Although budget discounts are built into CDCS budgeting methodology, age distributions discovered in this study and reports from county administrators suggest that individualized budgets for adults are not adequate to support participation in vocational or day programs. This, combined with the fact that adult foster care is a disallowable expense based on published CDCS rules, makes

CDCS an unviable option for many adults with IDD, and especially those living outside of their family home. Revising budgeting methodology and discontinuing the policy mandating disallowable expenses would be positive steps towards increasing equitable access to CDCS across the lifespan. Since budget discounts are built into CDCS methodology, making it a more cost-effective service option than traditional supports, it is likely that the state may actually reduce overall service costs if budgets for adult users are made large enough to support attendance at day programs and supported employment programs, thus attracting adults to the program, while still including a smaller degree of budget discount into the formula, thereby saving money over traditional programs.

In addition, geographic disparities in usage of CDCS persist, despite the fact that CDCS is officially available in all counties. Findings of this research support the notion that rural counties are more resistant to CDCS implementation than metropolitan counties (all of which had implemented CDCS at the time of data collection). Some rural county administrators shared opinions that portrayed skepticism about the ability of individuals with IDD and their families to successfully manage a self directed service plan and budget. Other county interviews indicated that it was too time consuming and cumbersome for smaller counties to learn about and promote CDCS. Possibly related to the need for stronger leadership from the state to support initial implementation, improved training and preparation for county administrators may support more equitable geographic access. This is quite important since rural areas hold fewer options for traditional services and could find particular benefit in CDCS.

Practice Implications

In addition to the policy issues outlined above, the results of this study also inform social work practice in ways that may assist in improving the quality of support for individuals with IDD and their families who self direct services.

Paternalism vs. self determination. Particularly through analysis of interviews with county administrators, themes emerged to portray a continuum of attitudes about CDCS, with paternalism on one end and statements supporting self determination of individuals with IDD and their families on the other. This continuum of attitudes may represent a need for continued advocacy efforts on the part of individuals with IDD and their advocates, who have long worked towards increased opportunity for decision making and individual preference in major decision and in everyday life. If the administrators of services for individuals with intellectual and developmental disabilities continue to portray attitudes of paternalism and protectionism, a program such as CDCS, which is premised on the notion of self determination, cannot be expected to grow.

While the strongest advocacy for self determination in service options is likely to come from self-advocates with IDD and their families, social workers also have an ethical obligation to support programs that are aimed at increasing self determination. According to the NASW Code of Ethics (NASW, 1999), social work professionals are obligated to conduct their practice in the context of six core values, including social justice and dignity and worth of the person. Since many individuals who administer county-level services and provide case management for people with IDD are social workers, it is worthwhile to investigate how these two core social work values apply to self directed services, in making a case for why social workers are obliged to look for ways to reduce paternalism and increase self determination.

Social justice, as conceptualized in the NASW Code of Ethics (1999), involves taking action on behalf of vulnerable or oppressed persons to seek out “access to needed information, services, and resources, equal opportunity, and meaningful participation in decision making for all people.” In American society, and in societies worldwide, people with intellectual and developmental disabilities are certainly an oppressed population, experiencing high rates of discrimination, unemployment, poverty, and social exclusion. Therefore, people with IDD are to be the concern of social workers adhering to the NASW Code of Ethics. It is the final portion of the quoted material above, however, that is of particular importance in the discussion of paternalism and self determination, as social workers are ethically required to enable meaningful participation in decision making, as occurs through self directed supports. Thus, social workers in county service delivery systems have an ethical mandate to seek opportunities to implement programs such as CDCS, as this service option is presently the primary policy option that can promote decision making among individuals with IDD and their families.

Next, the NASW Code of Ethics (1999), in focusing on dignity and worth of the person, states, “Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients’ socially responsible self determination. Social workers seek to enhance clients’ capacity and opportunity to change and to address their own needs.” This passage conveys many of the same principles evident in self directed supports, in which the individual with IDD is empowered to act to address his or her own needs in a way that is consistent with his or her own self determination. When taking the ecological model of self determination espoused by Abery & Stancliffe (2003), this could mean that the individual sometimes chooses when to take direct decision making power, depending on the importance of the decision, and degree of decision making influence desired. At other times, the individual may cede decision making power to another person, but the choice to do so resides primarily within the individual. When paternalistic attitudes about the decision making capacity of individuals with IDD and their families prevail, social workers and other county workers are not adhering to the ethical mandate for respecting the dignity and worth of each person.

Person centered planning. Perhaps the most important way to work towards greater self determination and away from paternalism in service delivery is the creative and consistent use of person centered planning. Person centered planning is not a single approach, but a series of distinct methods that help an individual envision his or her short and long term goals for the future and make plans for the supports that he or she will need to realize those goals (O'Brien & O'Brien, 2002). The concentration of most person centered planning methods is on finding needed support through naturally occurring support networks (such as family, friends, and neighbors) rather than reliance on artificial networks of support (Bradley, 2000).

As one of the cornerstones of self directed services, person centered planning should occur for each service user before he or she begins using self directed supports, since the person centered plan will be instrumental in determining the overall goals pertaining to where and how the individual wishes to live, work, and play. The idea of service planning based on person centered planning represents a fundamental shift in how a service plan is constructed for an individual with IDD, since service plans are traditionally constructed by county case managers with nominal input from other service providers, the individual with IDD and the individual's family. Self directed services, driven by person centered planning, fundamentally take power away from case managers, and make the assumption that individuals who will use services, with the support of trusted advocates are best positioned to make choices about the shape of those services and supports. Focus is placed less on risk management and narrowly defined outcomes for independent living and more on quality of life, calculated risk taking that may lead to personal growth, and expression of personhood.

Because this is such a fundamental shift in how services are conceptualized, it is important for practitioners working with individuals with IDD, and especially those who self direct their supports, to be conversant and supportive of person centered planning processes and outcomes. Social work practitioners may wish to seek out opportunities to learn skills in person centered planning and thinking processes, and social work education programs may need to make curriculum additions or revisions to incorporate more ideals and practice tools for person centered practice. In this way, social work may position itself to be on the leading edge of professions in the service delivery system as self directed policy options expand, not only for individuals with IDD, but for people who are aging, experience mental illness, have physical disabilities, or have traumatic brain injuries as well.

Another benefit of added attention to person centered planning is that person centered planning may be considered as an advocacy tool supporting the rights of people with IDD to community inclusion and participation in social life. As O'Brien and O'Brien (1999) propose, person centered planning process is an inherently political process, since it promotes an individual's right to speak and plan life for him- or herself, which challenges entrenched injustices in the current system of traditional services and planning. In essence, then, person centered planning and thinking are political actions, which can serve to bring about change in large service systems by empowering people with IDD to make decisions about their lives on an individual basis.

County worker policy awareness. Finally, practice implications also suggest the need to develop better systems of information dissemination to move policy information from the Department of Human Services to the counties where it will be implemented at the practice level. Several county administrators who participated in interviews for this project suggested that they were not given adequate information about how to implement CDCS, leaving them to wait until early adopting counties set an example. While this innovation and diffusion model is common in implementation of new policy innovations, as highlighted by the policy process theory of Berry & Berry (1999), in the case of CDCS it has caused inequities in availability in different parts of Minnesota. If county administrators report that they do not have enough information to adequately implement CDCS, it is likely that frontline case managers do not have adequate knowledge of the program to inform potential users of the program about it.

Systems of training and information sharing must be improved if policy innovations such as self directed supports are to be disseminated systemwide in a timely manner. In Minnesota, as stated previously, 36 of Minnesota's 87 counties had still not implemented CDCS as of 2009, meaning that unequal utilization of self directed services persists. It is possible that a systematic program of training, including regional informational meetings or web-based information sharing opportunities would help to increase case manager awareness that a self directed option exists. Case managers could then advocate for county level implementation if they had greater knowledge about the program and how it works for people with IDD and their families. In addition, larger advocacy efforts, possibly led by local chapters of Arc, could put additional pressure on local service administrators to implement CDCS if they were given more access to practical information. This is a particularly strong need in non-metropolitan areas of Minnesota, where sources of information are more difficult to find, and where paternalistic attitudes among county administrators may halt the expansion of self directed services in the state.

Research Implications

As with any recent policy innovation, self directed service options such as CDCS have been systematically and independently studied in very limited ways. This creates a void in knowledge, and the need for future inquiry. In coming years, as self directed service options continue to expand and gain acceptance and credibility there will be both opportunity and need for continuing study on aspects of self directed service models.

Policy-Related Studies. Since self directed options are still fairly recent innovations, the first type of inquiry to be addressed in future studies consists of additional policy-related studies. Cost-benefit analysis, individual state-level evaluations, and comparative studies will be addressed in this section.

Cost Benefit Analysis. Cost benefit analysis is likely to be one of the most important forms of research in the short term for self directed models of support. Policy makers in many parts of the United States are facing budget deficits, meaning that services for people with intellectual and developmental disabilities will need to become increasingly efficient. While the overall costs of self directed supports are designed to be less than traditional services, evaluation of the Arkansas Cash and Counseling program for people who are aging indicated that actual program costs were higher in self directed services, since users of the self directed model utilized their entire funding allotment, while users of traditional services were more likely to leave some of their budgeted funds unspent (Dale & Brown, 2005). Cost studies have been fairly common and have typically found overall cost savings to states in self directed support models.

Despite wide attention to cost-of-service outcomes in early studies on self directed services, there have not been any attempts to date at developing a full cost benefit analysis, which systematically compares the quantified costs of offering self directed supports against the similarly quantified benefits of self direction. Such an analysis would go beyond simple observations of finance to develop a broader assessment of how programs such as CDCS truly benefit individuals with IDD and where inefficiencies occur. Conducting a systematic cost-benefit analysis could serve as a very powerful policy advocacy tool which could assist in further disseminating self directed methods of service provision to a wider population, both in Minnesota and nationally. Although putting the potential benefits of increased self determination and social inclusion into financial terms, as is necessitated by cost analysis, could be difficult and may run the risk of sterilizing human experience and oppression of people with

IDD, this difficulty is likely outweighed by the potential policy advocacy benefits of a carefully crafted cost-benefit analysis that could directly address the concerns of lawmakers about wise stewardship of public funds.

Continuing state-level evaluation. As states implement self directed programs for individuals with IDD more fully, there will be increased need for state level evaluation of the local outcomes of self direction. These evaluations should be both summative and formative in nature.

Formative evaluations of self directed services on the state level should concentrate on the processes by which self directed services are implemented and operated. Process-oriented formative evaluations may seek further information about how states disseminate information about self direction to counties and how counties, in turn, pass this information to potential program users. As the interviews with CDCS administrators in this study suggest, there are geographic differences in how CDCS has been implemented. Conducting careful qualitative process analysis could provide insights into how information regarding the program is disseminated and received by local administrators, and how alterations in information sharing could help to facilitate implementation. Similarly, formative evaluations focusing on the processes involved in usage of CDCS, including individualized budgeting, person-centered planning and service design, and spending decisions, may ultimately influence outcomes for program users. Policy changes could then be made based on robust findings from in-depth process analysis in the formative stages of self directed program implementation.

Summative evaluations at the state level may focus on more quantifiable aspects of CDCS and other self directed program options for individuals with IDD. These elements may include financial impacts, measures of quality of life for service users, stability of the direct support workforce, types of service usage, and desired changes in program rules.

Comparative studies. In his study of the implementation of consumer directed programs for the elderly in Austria, Germany, the Netherlands and the United States, Kodner (2003) proposed a continuum of self direction, which is roughly outlined in Table 4.1. Use of Kodner's continuum could provide a useful starting point for comparative analysis of differing approaches to self directed services that also occur between U.S. states.

Table 4.1. Kodner's Categorization of Self Directed Services

Type of Self Direction	Consumer Control	Monitoring
Professionally Monitored	Consumers hire and manage direct support workers as they please, within established guidelines monitored by a professional case manager.	High degree of monitoring. Case manager monitors services according to an approved care plan.
Professionally Assisted	Consumer hires and manages direct support workers as they prefer. Latitude for management of funds and monitoring is given to the service user.	Moderate degree of monitoring. Case manager determines eligibility and assists in setting individualized budget. Additional assistance from the case manager may or may not be provided.
Cash Model	Service users are given an occasional sum of funds to utilize on the services and goods that are essential to their living. Consumers exercise all decision making authority in determining services.	Low degree of monitoring. Professional monitoring is optional and left to the choice of the service user.

Adapted from Kodner (2003)

Conducting comparative studies of differing models of self directed services could provide vital context to the policy and outcome issues related to self direction. For instance, much could be learned by weighing the potential benefits in self determination from the cash model with the increased professional assistance and financial controls of the professionally managed approach. By investigating outcomes across typologies of self directed services, policy makers and advocates could learn valuable lessons about how to best design services that allow for flexibility and individual choice, while providing sound public stewardship. Further, comparative study could investigate the policy environments in which each type of self directed service emerges and thrives. The insights from systematic comparative studies could prove quite useful in gaining a sense of how self directed services may be best designed to meet the needs of service users and of the larger society.

Workforce-Related Research. This study has made some of the initial insights into the status of the direct support workforce in self direction, using the model of Minnesota's CDCS program for people with IDD. The outcomes of this research do provide some descriptive insights into the character of the direct support workforce in CDCS, although attempts to explain the large gains in DSP tenure in CDCS were inconclusive. The findings of this study provide an initial base of knowledge upon which to continue a research agenda aimed at deeper knowledge about workforce issues pertaining to service users and DSPs in self directed models of support.

Long term workforce outcomes. First, because self directed support options such as CDCS remain in their formative stages, and because there is still a great deal of variation both across self directed service options in different states and in the implementation of programs within states, a need exists to track staffing status and outcomes over time. This will enable knowledge about the stability of the DSP workforce and an understanding of how the direct support workforce in self directed service options share similarities with and differ from workforce development indicators in traditional services.

Long term tracking of workforce status is particularly important in light of the findings from this study that DSPs are paid higher wages than in traditional services but receive training and fringe benefits at much lower rates. While the binary logistic regression analysis in research question two of this study did not support the notion that wages, relationship with the CDCS user, benefit provision, or staff training have a significant role in predicting DSP tenure, these factors have been shown to related to DSP retention in traditional services. Therefore, it warrants further study to determine the interrelation of factors that may be present to predict more positive workforce outcomes in self directed models. It should also be noted that in the regression analysis in research question two, tenure was dichotomized based on whether reported DSP tenures were longer or shorter than the mean tenure discovered in the descriptive analysis. This length of tenure, 34 months, is far longer than would be expected in traditional agency-based services, where about 68% of all DSPs leave their employment within one year of hire. Therefore, in further studies, it may be worthwhile to compare the findings from self directed supports with traditional services, which may provide a more meaningful comparative understanding of the status of the workforce in self directed supports as compared with traditional services. Tracking the trends of each over a period of years will be very useful designing workforce improvement interventions that are specifically targeted to the needs of service users and DSPs in self directed services.

Testing of workforce interventions. Based on knowledge obtained from studies that track workforce status trends over time, as described in the previous section, it will be quite useful to test the utility of a variety of common workforce development interventions in future studies. Training guides such as the *How to Find, Choose, and Keep Great DSPs* curriculum developed jointly by the Research and Training Center on Community Living at the University of Minnesota and the Department of Disability and Human Development at the University of Illinois-Chicago (Hewitt, Keiling, Sauer, McCulloch & McBride, 2006) may provide an excellent starting point in more in depth interventions that may be developed and individually tested in self directed supports. This toolkit includes instructive intervention strategies that may be used by people with IDD who are looking for solutions for improving their skills in hiring and managing direct support workers in service models such as CDCS.

Table 4.2. Common Direct Support Workforce Development Interventions.

Type of Intervention	Description
Targeted Marketing	Service users may choose to focus on inside sources (people known to them or referred to them by trusted people) or outside sources (found outside of immediate support network). Inside sources are generally favored over outside sources. Outside sources should be used in a highly targeted way to draw candidates with the skills and characteristics favored by the service user. Thinking about how to word advertisements and where to post them, for example, can help to target the most desirable pool of candidates.
Realistic Job Previews	RJPs are a way to outline what it will really be like to do a job well. Both the positives and drawbacks of the job should be described in order to give a balanced perspective of what a candidate could expect in the job. The RJP should be shared with job candidates prior to hire, with the logic that a DSP who knows both good and bad things about the job prior to starting work will be more likely to be a strong fit for the work. RJPs may be done in many formats, including print, electronically, in videos, or in person with current DSPs.
Behavioral Interviewing	Behavioral interviewing adds to typical interview questions to get at assessing the qualities and behaviors that are really important to the service user. Behavioral interviewing may require the interviewee to envision their response to a specific, hypothetical situation that shows how they may respond to challenges on the job. It will also ask them questions about how their previous work has specifically prepared them for success as a DSP working with the service user. Behavioral interviews use carefully scripted wording and should be drafted in advance and used with each job candidate consistently.
Systematic Orientation	Orientation for a new DSP in self directed services may focus not only on typical training topics, but also on welcoming the new DSP to the support team and teaching him or her about why it is unique to work directly for a person with IDD. Orientation may also focus on getting used to daily routines and support roles, meeting co-workers, and learning specific likes and dislikes in the provision of support. The aim of orientation is to build trust, rapport, and basic competence.

Training for Professional Development	Training interventions may focus on identifying existing DSP skills in meeting the specific needs of the service user and developing a systematic plan for how to increase those skills and build new ones. Using multiple teaching methods, giving clear, honest, and continual feedback about performance and growth areas, and supporting DSPs in seeking wider professional development opportunities (such as membership in professional associations) may all help users of self directed supports to create strong training interventions that help to retain DSPs. Training and professional development works best when it is systematically planned in collaboration with the DSP.
Rewarding Performance	Performance may be rewarded in many ways. Most obviously, large incentives such as wage increases, bonuses, additional paid time off, and more fringe benefits may motivate high performing DSPs. However, performance rewards need not be costly. Simple acknowledgements such as thank you cards, training opportunities, small gift cards, or verbal recognition can also make for positive performance reward interventions in self directed services.

Building on the interventions introduced in the curriculum by Hewitt and colleagues (2006), testing targeted marketing, realistic job previews, behavioral interviewing, orientation strategies, training implementation, and strategies for recognition of performance for DSPs would all be positive research topics for determining the factors that may be particularly effective in assisting individuals who self direct services to achieve optimal workforce outcomes. In order to be of most use in understanding the workforce needs of individuals who use CDCS and other self directed support options, these intervention strategies should be tested individually and in combination to determine their likely usefulness under various conditions. Table 4.2 provides basic information about several specific interventions that could be tested to determine their usefulness in shaping strong workforce outcomes for individuals with IDD and their families who use CDCS or other self directed programs.

Development & testing of family support models. In addition to the well-established workforce development interventions in Table 4.2, family-to-family or person-to-person support may be a particularly useful method of workforce development training for self directed systems of supports. These will be generally referred to as peer-to-peer support programs in this section to acknowledge the fact that variation exists in the actual management of self directed services, with some CDCS users managing their own supports and others relying on family members to manage services on their behalf.

CDCS for Minnesotans with IDD, as well as other forms of self directed services, are based on the notion that individuals with IDD are best served when they are able to choose who provides them with support, with the assumption that many people will choose to use people from their informal support network as their formal support providers. This reliance on family and friends to provide the majority of supports, as found in this study, may mean that peer-to-peer support models may be more useful than large, formal training in teaching about direct support workforce management issues. If families with greater experience in successfully managing DSPs in CDCS may share their knowledge with families who are newer to the staff management experience, this may provide a particularly useful form of workforce intervention that has not been studied in the context of traditional services, since traditional services do not rely upon informal support systems as a source of DSPs, and because staff management issues are handled by professional human resource managers.

If applied consistently with well-trained and experienced family- or self-advocates, peer-to-peer models of support for workforce management may become increasingly vital models of training and support in self directed services such as Minnesota's CDCS. Careful design and implementation of peer-to-peer support interventions would be a particularly strong contribution to the current body of literature on self directed supports, and should be a focus of research in the short term.

Theory-Driven Research. Additional studies may wish to bring issues of social capital and self determination to the forefront. While both of these theories underlie self direction generally, and this study specifically, the use of an extant data set did not enable deep investigation into the effects of CDCS use on social capital or self-determination.

Social Capital. The descriptive findings of this research tend to support the importance of bonding social capital over bridging social capital, as the majority of direct support staff are related to or previously known to the CDCS user. While logistic regression findings did not support the notion that this relationship was important in understanding DSP retention, the theoretical relationship between social capital and self directed services is worthy of further investigation for a number of reasons.

First, self directed services assume the presence of social capital among individuals with IDD and their families in adequate amounts to create a web of expectations and obligations among direct support workers, especially those who are previously unknown. However, because people with IDD are an oppressed population it may be assumed that the social capital available to most people with IDD is relatively small compared to that of a typical employer. This may make it more difficult for people with IDD to manage their direct support network over time. This may be true particularly for DSPs who are strangers at the time of hire since no previous relationship exists to establish patters of social exchange.

Self direction fundamentally changes the nature of the support provider relationship with individuals with IDD. In traditional services, the primary social capital relationships governing work is between the DSP and the employer, typically a manager of a social service organization in practical terms. In this scenario the person with IDD who uses services receives supports somewhat passively, and is relatively disempowered to effect major changes in DSP behavior or approach to support provision, since employment decisions are made by the manager, not by the person with IDD directly. In self directed supports this power dynamic shifts, so the individual with IDD is given direct power over employment decisions. As such, the DSP is directly responsible to the individual with IDD, who is the employer. However, since individuals with IDD traditionally do not possess high degrees of social capital due to their marginalization by society, this transfer in power dynamics may be difficult. Therefore, one of the primary foci for research on the role of social capital in self directed supports may be on specific interventions that may bolster the social capital of individuals with disabilities, which will assist them in effectively managing direct support workers.

Future research on the relationship between self direction and social capital may also focus on the effects of paid caregiving by family members and friends on the gratis supports that are typically provided by family members and friends of individuals with IDD as part of the inherent social capital contract that governs interactions in families with a member who relies on support. Research on what happens to gratis support provision when paid supports are possible may be useful in understanding how much support continues to be provided without financial compensation even when an individual with IDD pays family members or friends for some supports. Additionally, it may be interesting for future research to study alterations in social capital arrangements that occur when paid support provision for family members is introduced. In particular, the attitudes towards free caregiving among extended family members, who may not have the same strength of obligation to provide free support as immediate family, may be altered by the availability of paid work as a DSP.

Self Determination & Community Inclusion. Building on this idea of the importance of studying community inclusion in self directed supports such as CDCS, future studies will need to systematically evaluate how self determination and community inclusion for people with IDD may be fostered through the use of self directed service options. While not addressed directly in this research, self determination is viewed as the main theoretical benefit of self direction for persons with intellectual and developmental disabilities. However, the current body of literature is lacking studies that address self determination as a dependent variable of CDCS or other self directed programs.

Future studies on CDCS or other self directed service options for individuals with IDD may need to build in specific survey scales to assess the degree of self determination exercised by the individual. The use of Abery & Stancliffe's (2003) ecological model of self determination will be of particular use in this type of exploration, since it adds a vital element of contextualization to traditional measures of self determination. Studying self determination longitudinally to assess how self determination may increase with greater experience in self directing services would be of particular interest, especially if paired with an intervention aimed at assisting an individual with IDD to gain skills for successfully managing his or her direct support workers. Research on self determination will be best if it focuses on individuals with IDD directly, rather than the proxies who may manage supports on the behalf of the individual with IDD in many cases. Similarly, longitudinal studies on the effect of self determination on community inclusion would also be of great benefit if furthering the understanding of self directed supports.

Self Direction for Culturally Relevant Services. Finally, previous studies have suggested that self directed services may have particular benefits for immigrant families as well as native born families from non-dominant cultural groups (Sciegaj, Capitman, & Kyriacou, 2004). In contrast, findings of this study indicate that only 20.6% of all respondents found benefits in better cultural match with their DSPs as a result of CDCS use (although it should be noted that this may be related to the fact that the vast majority of respondents were Caucasian, and therefore may have had better access to co-ethnic DSPs prior to CDCS use). Nevertheless, it appears that about a fifth of respondents in this survey did find benefit in improving cultural match as a result of self direction which, when considered in combination with findings from previous studies such as Sciegaj and colleagues (2004), suggest the importance of self direction related to the provision of culturally relevant services.

Future studies should investigate this issue further, as self directed services may enable service users from ethnic minority communities to develop supports that most adequately fit their needs within their specific cultural context. While this topic may be best addressed qualitatively at this time, targeting members of ethnic minority groups for greater participation in future survey-based research may also be of benefit. Employing stratified random sampling procedures based on ethnic identification strata may be useful in future studies in reaching a greater representation of participants.

Because the design of culturally relevant services is a major concern of social work researchers and practitioners, this topic is of particular interest. Designing and implementing specific interventions for person centered service planning and for family-to-family supports in the context of culture may be particularly useful ways to approach research about the utility of self directed services with cultural minority groups that will have direct links to practice for social workers in the field.

Limitations of the Study

While this study provides unique and important insights to the understanding of self directed supports generally, and Minnesota's Consumer Directed Community Supports program more specifically, it is not without notable limitations. The primary limitations to this study include the sample size, the restrictions in data that are inherent in any secondary analysis, and the problem of contextualizing findings within the rapidly changing landscape of self directed supports for people with disabilities.

While the qualitative portion of this study does have a large and fairly representative sample of county developmental disabilities services administrators, the sample size for the quantitative portion of the study is somewhat small. The small sample size poses two main limitations. First, the findings of this study may not have wide applicability beyond the sampling frame. Although the sample is fairly representative of CDCS users in Minnesota and accounts for about 8% of CDCS users at the time of data collection, external validity beyond this sampling frame is somewhat questionable. While the lack of generalizability beyond Minnesota's self direction program is a drawback, the wide degree of variability in implementation and characteristics of self directed funding mechanisms for people with intellectual and developmental disabilities across states would also challenge the overall external validity of findings, regardless of sample size. Therefore, the questionable application of findings beyond the Minnesotan frame of reference must be viewed as an inherent drawback of research on a fairly novel approach to programming for people with IDD, especially since there is so much fluctuation among self directed programs from one location to the next. However, these results do provide useful information that other states may consider as they develop and implement self directed service options for people with IDD.

The small sample size also impacted the analysis of quantitative data. This is a relatively small and heterogeneous group of respondents, meaning that use of complex statistical operations, and the introduction of control factors for statistical modeling as occurred to perform binary logistic regression analyses, may not produce statistically significant results. As a result, the findings from the regression analyses in this study should be seen as provisional, with additional testing with a larger sample necessary in order to confirm or refute results. Since self directed support programs, including CDCS, remain in formative stages, however, the extension of findings seeking explanation may not yet be appropriate. Research such as this is necessary to establish descriptive facts about the status of CDCS before future research can hope to develop more useful causal models to explain CDCS outcomes.

The use of an extant data set also poses limitations for data analysis, which are justifiable in the context of an exploratory study, but limit the ability to conduct higher level analysis. Primary among these limitations is the survey's reliance on categorical variables, which limits the range of statistical operations that may be utilized. For this reason, this study has used chi-squared test and binary logistic regression which, while useful statistical procedures, do have limitations in explanation. The use of extant data also limits the possibility of designing questions to elicit information about facets of the topic which may be of interest, but were not included on the original survey. For instance, this study was not able to investigate issues of self determination and social capital in much detail, because measures of these variables were not included directly in the original study. In addition, it would be quite interesting to know how the ability to pay family members as DSPs may affect the natural supports that people with disabilities often rely upon to fulfill their daily needs. Gaining information in these domains is not possible in the context of this study, although this initial work will open the path to research that will foster a deeper understanding of self direction of supports in the future.

Since this is a cross sectional study, it is important to situate the results within the context in which the findings were obtained. CDCS, like many programs for self direction of supports in other parts of the United States, is quite fluid, with policy changes and trends changing the nature of the program fairly rapidly over the course of time. Since the data from this survey were obtained shortly after a period of significant change in the CDCS program, findings must be viewed within the context of the changes in budgeting and spending rules, which fundamentally altered the usability of CDCS for many people with intellectual and developmental disabilities. These changes could have resulted in different results than would be obtained if a similar survey were to be distributed today, or at any other point in the history of CDCS. This element of context will limit the applicability of findings to other points in time, although the findings will remain quite valuable in promoting an overall understanding of CDCS and of self directed programs in general.

Additionally, the portion of the survey related to the respondent's use of CDCS funds asked the individual to think back as far as three years, introducing the possibility of maturation bias in self reporting. Also, the potential for social desirability bias that is inherent in any survey relying upon self reports may have affected results, though the extent of this impact should be minimized since the survey contains no identifying information, meaning that respondents were free to respond without concern for the researcher's opinion of the response.

Finally, the use of logistic regression may have yielded results with less predictive power than desirable, particularly in the second research question. The outcome variable, DSP tenure, was dichotomized in this research question in order to accommodate logistic regression. Logistic regression was chosen as the method for analysis because the error terms for this variable were not normally distributed, violating one of the assumptions underlying use of linear regression, which might have been preferable had assumptions been met. Because dichotomization of the outcome variable was necessitated, there is a potential that attenuation of variance may have resulted in insignificant findings. Therefore, the results of testing of the second research question should be considered particularly provisional, as the potential for interpretive richness was lost when the outcome variable was dichotomized. Although use of logistic regression was necessary due to the character of the DSP tenure variable, the evaluation of a binary variable does provide much less opportunity for interpretation than would have been feasible had the tenure variable remained continuous.

Summary

This research furthers the formative understanding of self directed supports for people with intellectual and developmental disabilities that has emerged since the mid 1990s. This study is among the largest to date to gather information from the perspective of the people who are most intimately involved with the service delivery and usage side of these services: county developmental disabilities administrators and individuals with intellectual and developmental disabilities who use self directed supports in Minnesota. Furthermore, the large scale studies that have been completed to date have concentrated most heavily on self directed services for people who are elderly, so this is among the first explorations of the status of the workforce and utility of self directed supports focusing specifically on people with intellectual and developmental disabilities. The expansion of knowledge in this area is a critical component to the ongoing evolution of self directed supports and fills a significant gap in the current literature and applied understanding on this topic.

This study focused on answering two main research questions, in addition to offering summary findings from the original study that preceded this thesis and a brief additional descriptive analysis. One of the main research questions in this study looked at the role of user age, geographic location, size of individualized budget, and perceptions of social inclusion on whether an individual is currently using CDCS or if they had left the program. Binary logistic regression findings indicated that the user's age and location help to explain status with CDCS, with age under 22 years old and residence in the metropolitan area of the state being significant predictors of current CDCS usage. In the second main research question, binary logistic regression modeling found that hourly wage, relationship to the CDCS user, the provision of fringe benefits, and the availability of training were not significant predictors of longer DSP tenure, in contrast to what is implied by the literature on traditional services. The findings from both of these questions are informative, but leave plenty of room for future inquiry.

This study used existing data in two different forms to provide an exploratory and descriptive account of the status of CDCS in Minnesota. Semi-structured interviews with county DD services administrators and a statewide quantitative survey of CDS users were used to inform the conclusions of this study. A content analysis approach to analyzing qualitative data complimented a descriptive account of quantitative data, which resulted in a comprehensive and well-rounded portrait of the status of CDCs at a critical juncture in the program's evolution. In addition, explanatory findings from binary logistic regression analyses begin to examine explanatory elements of the early experience with CDCS among users with intellectual and developmental disabilities and their families.

This study contributes to the emerging knowledge about self directed services in the United States, with particular implications for Minnesota. While the constraints of the data sources do not allow for generalizability beyond the Minnesota context, findings are instructive on a national level as sample impacts of self directed programs. Of particular interest, this study is among the first to feature the perspectives of individuals with intellectual and developmental disabilities who use self directed supports, and is among the most comprehensive studies to date on the direct support workforce outcomes associated with self direction. These findings may be instrumental in both promoting a descriptive understanding of how self directed supports are used and about how the policies that govern such programs may be shaped in the future.

There are a number of policy and practice implications for this research. First, and most obviously, policy makers in Minnesota have a stake in the results since this is the first independent study of Minnesota's model to be based largely on the input of CDCS users with intellectual and developmental disabilities, the first waiver group to receive CDCS in the state. This will be a powerful tool to alert policy makers and state administrators as to the impacts of CDCS on the lives of individuals with intellectual and developmental disabilities and how the direct support workforce looks in the self directed model. These findings may have implications for how self directed service options are shaped in Minnesota in the future.

Practice implications to emerge from this study revolve around how social workers and other human service professionals may promote the self determination of individuals with intellectual and developmental disabilities. Social workers are often in the position of assisting individuals with disabilities in shaping their supports, and have an ethical obligation to value the dignity and worth of the person in the process, so the promotion of greater knowledge pertaining to self directed options will be useful to many social workers in the field. In addition, the workforce status findings that emerged from this study will have implications for social workers in human service agencies that provide supports and staffing options for people with disabilities, as the direct support workforce is facing a crisis in DSP availability. Self directed support options are seen as a possible way to expand the pool of direct support workers, but little is known about the workforce in the setting. This study provides some of the most important findings to date in this regard.

Foremost, however, this study has highlighted the need for greater effort and further study in the promotion of self directed service options for individuals with intellectual and developmental disabilities that are grounded in findings from early research such as this. While this project contributes to the current state of knowledge about CDCS and other self directed support options, studies of the outcomes of self directed services remain limited, especially for people with IDD, and further work remains to be done in this area. Additionally, the way in which self-directed supports are implemented continues to evolve and differs from state to state and even within states, meaning that there is much yet to be learned about the specific practices that produce optimal results in self directed supports for individuals with intellectual and developmental disabilities and their families.

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Sampling Worksheet; CDCS Users

County Name ____

How many CDCS users did you have on September 1, 2004? _________

Please alphabetize your list of CDCS users from 9/1/04. Starting with the first name on the list, please identify every 2nd person on the list. Create a 'new' list using only those identified as every 2nd person. All of the people on this new list will receive a survey. Next, divide the 'new' list according to people who are current users of CDCS and those who no longer use CDCS.

Below, please record the number of people (from the 'new' list) that fall into each of the categories listed below:

Current users who are their own guardian _____________________

Current users who are NOT their own guardian _________________

Past users who are their own guardian __________________________

Past users who are NOT their own guardian _____________________

CODE:
Enter 3 digit code

LOCATION
Code by Survey Color
Yellow (Hennepin) = 0
Blue (Metro) = 1
Cream (Outstate) = 2

Consumer Directed Community Supports (CDCS)
Survey
Previous User

STATUS

Current = 0

Previous = 1

Welcome to the CDCS Survey

PLEASE COMPLETE EVEN THOUGH YOU ARE NOT A CURRENT USER

- You have been selected to participate in our CDCS survey as some who once used CDCS but **no longer uses CDCS**.

- This important survey will be used to collect the experiences of people with intellectual and developmental disabilities and their families with the CDCS waiver option.

- Survey information will be used to inform advocates, policy makers and legislators about CDCS and how people currently use this option as well as how this option was used prior to the allowables/disallowables.

- Your experiences with CDCS will help people to make better policy decisions about future services for individuals with intellectual and developmental disabilities.

- **If you need help, ask a family member or support staff to help you complete this survey.**

- If you prefer to complete the survey over the telephone, call Matt at 612-625-7593.

***** If you previously completed this survey in April 2007, thank you for your time and participation. Please DO NOT complete another survey. If you previously returned your survey to the University of Minnesota, please discard this survey packet.***

Directions

Please sit down with a family member or support staff to read this survey. Your family member or support staff can help you to answer these questions. For some questions, you will need to write a check mark (✓) in the box (or boxes) that best answers the question. For other questions you will need to write an answer in the blank (or blanks) provided.

1. **Please indicate the dates that you received CDCS:**

Start Date End Date
___ ___/___ ___ through ___ ___/___ ___
(month) (year) (month) (year)

STARTDATE enter as MM/YY (if blank, leave blank. If only year, enter 07/YY)
ENDDATE enter as MM/YY (if blank, leave blank. If only year, enter 07/YY)

2. **What was your approximate yearly CDCS budget when you last used CDCS?**

_____***LASTBUDGET: enter as xxxx.xx with no commas***
____

3. **a) What service option do you currently use (e.g. DT& H, personal supports, etc.)?**
For items in 3: Box checked=1, box not checked=0
If all items in 3 are unchecked, leave all blank

A.	In-home family support ***CUINHOME***	☐	D.	Day Training and Habilitation (DT&H) ***CUDTH***	☐
B.	Respite (not ICF/MR) ***CURESPITE***	☐	E.	Personal Support ***CUPSUP***	☐
C.	SLS ***CUSLS***	☐	F.	Safety Locks ***CULOCK***	☐
G. Other (please explain): ***CUOTHER: type text***					

4. **Please explain why you decided to move off of CDCS.**

_______***WHYOFF: type text***
____

5. **If you used CDCS** __**prior**__ **to the state set list of allowables/disallowables (October 1, 2004), what kinds of things did you spend your CDCS funds on? (*Check* (✓) *as many boxes as apply*).** *If you started using CDCS after October 1, 2004, please skip to question 6.*

5a. Goods and Services

For items in 5a – 5d: Box checked=1, Box not checked=0
If all items in 5a - 5d are unchecked, leave all responses blank

Please turn to the next page

A.	Adaptive Recreation Equipment **_BGSADAP_**	☐	L.	Organization membership (ARC, PACER, etc.) **_BGSMEM_**	☐
B.	Books and Literature **_BGSBOOK_**	☐	M.	Respite Care **_BGSRESP_**	☐
C.	Day program **_BGSDAY_**	☐	N.	Safety Locks **_BGSLOCK_**	☐
D.	Dietary Needs **_BGSDIET_**	☐	O.	Security Systems **_BGSSEC_**	☐
E.	Fencing **_BGSFEN_**	☐	P.	Sensory motor toys **_BGSTOY_**	☐
F.	Foster care **_BGSFC_**	☐	Q.	Sibling Care **_BGSSIB_**	☐
G.	Home remodeling **_BGSREMO_**	☐	R.	Skin care products **_BGSSKIN_**	☐
H.	House Cleaning **_BGSCL_**	☐	S.	Technology **_BGSTECH_**	☐
I.	Laundry Supplies **_BGSLAUN_**	☐	T.	Transportation **_BGSTRAN_**	☐
J.	Mileage **_BGSMILE_**	☐	U.	Utilities **_BGSUTIL_**	☐
K.	Personal care supplies **_BGSPERS_**	☐	V.	Vitamins & Supplements **_BGSVIT_**	☐
W. Other (please explain): **_BGSOTHER: type text_**					

5b. Staffing

A.	Household chores & cleaning **_BSTCHOR_**	☐	E.	Benefits **_BSTBENE_**	☐
B.	Provider agency **_BSTAGEN_**	☐	F.	Health care **_BSTHLTH_**	☐
C.	Training **_BSTTRAIN_**	☐	G.	Vacation **_BSTVACA_**	☐
D.	Recruitment **_BSTRECR_**	☐	H.	Sick leave **_BSTSICK_**	☐
I. Other (please explain): **_BSTOTHER: type text_**					

5c. Recreation and Leisure

A.	Camp **_BRLCAMP_**	☐	E.	Plays **_BRLPLAY_**	☐
B.	Concerts **_BRLCONC_**	☐	F.	Restaurants **_BRLREST_**	☐
C.	Dances **_BRLDANC_**	☐	G.	Sporting Events **_BRLSPORT_**	☐
D.	Movies **_BRLMOV_**	☐	H.	Travel **_BRLTRAV_**	☐
I. Other (please explain): **_BRLOTHER: type text_**					

Please turn to the next page

5d. Therapy

A.	Alternative Therapy (For example: horseback riding, massage therapy, etc.) ***BTHALT***	☐	E.	Fitness ***BTHFIT***	☐
B.	Behavioral Therapy ***BTHBEH***	☐	F.	Music Therapy ***BTHMUS***	☐
C.	Classes ***BTHCLAS***	☐	G.	Physical Therapy ***BTHPHYS***	☐
D.	Crisis Intervention ***BTHCRI***	☐	H.	Relaxation Techniques ***BTHRLX***	☐
I. Other (please explain): ***BTHOTHER: type text***					

6. <u>AFTER</u> the state set list of allowables/disallowables went into effect (October 1, 2004), what kinds of things did you spend your CDCS funds on? (*Check* (✓) *as many boxes as apply*). *If you did not use CDCS after October 1, 2004, please skip to question 7.*

For items in 6a – 6d: Box checked=1, Box not checked=0
If all items in 6a - 6d are unchecked, leave all responses blank

6a. Good and Services

A.	Adaptive Recreation Equipment ***AGSADAP***	☐	L.	Organization membership (ARC, PACER, etc.) ***AGSMEM***	☐
B.	Books and Literature ***AGSBOOK***	☐	M.	Respite Care ***AGSRESP***	☐
D.	Dietary Needs ***AGSDIET***	☐	N.	Safety Locks ***AGSLOCK***	☐
E.	Fencing ***AGSFEN***	☐	O.	Security Systems ***AGSSEC***	☐
F.	Foster care ***AGSFC***	☐	P.	Sensory motor toys ***AGSTOY***	☐
G.	Home remodeling ***AGSREMO***	☐	Q.	Skin care products ***AGSSKIN***	☐
H.	House Cleaning ***AGSCL***	☐	R.	Technology ***AGSTECH***	☐
I.	Laundry Supplies ***AGSLAUN***	☐	S.	Transportation ***AGSTRAN***	☐
J.	Mileage ***AGSMILE***	☐	T.	Utilities ***AGSUTIL***	☐
K.	Personal care supplies ***AGSPERS***	☐	U.	Vitamins & Supplements ***AGSVIT***	☐
V. Other (please explain): ***AGSOTHER: type text***					

6b. Staffing

A.	Household chores & cleaning ***ASTCHOR***	☐	F.	Benefits ***ASTBENE***	☐
B.	Provider agency A***STAGEN***	☐	G.	Health care ***ASTHLTH***	☐

Please turn to the next page

C.	Training ***ASTTRAIN***	☐	H.	Vacation ***ASTVACA***	☐
D.	Recruitment ***ASTRECR***	☐	I.	Sick leave ***ASTSICK***	☐
E.	Wages ***ASTWAGE***	☐			
J. Other (please explain): ***ASTOTHER: type text***					

6c. Recreation and Leisure

A.	Camp ***ARLCAMP***	☐	E.	Plays ***ARLPLAY***	☐
B.	Concerts ***ARLCONC***	☐	F.	Restaurants ***ARLREST***	☐
C.	Dances ***ARLDANC***	☐	G.	Sporting Events ***ARLSPORT***	☐
D.	Movies ***ARLMOV***	☐	H.	Travel ***ARLTRAV***	☐
I. Other (please explain): ***ARLOTHER: type text***					

6d. Therapy

A.	Alternative Therapy (For example: horseback riding, massage therapy, etc.) ***ATHALT***	☐	E.	Music Therapy ***ATHMUS***	☐
B.	Behavioral Therapy ***BTHBEH***	☐	F.	Physical Therapy ***ATHPHYS***	☐
C.	Classes (gymnastics, dance, etc.) ***ATHCLAS***	☐	G.	Relaxation Techniques ***ATHRLX***	☐
D.	Crisis Intervention ***ATHCRI***	☐			☐
H. Other (please explain): ***ATHOTHER: type text***					

7. What <u>benefits</u> did you experience with CDCS? (*Check* (✓) *as many boxes as apply*)

For items in #7, box checked=1, box not checked=0

A.	Paying family members ***BENPAY***	☐	G.	Increased social inclusion ***BENSOCINC***	☐
B.	Improved family life ***BENFAM***	☐	H.	Staff are more reliable ***BENRELY***	☐
C.	More friendships/relationships ***BENFRND***	☐	I.	Relaxation Techniques ***BENRLX***	☐
D.	Able to keep staff longer ***BENSTAY***	☐	J.	Increased functioning ***BENFUNC***	☐

Please turn to the next page

E.	Provided flexibility ***BENFLEX***	☐	K.	Promoted more independence ***BENIND***	☐
F.	Better quality of life ***BENQOL***	☐			
L. Other (please explain): ***BENOTHER: type text***					

8. What <u>challenges</u> did you experience with CDCS? (*Check* (✓) *as many boxes as apply*)

For items in #8, box checked=1, box not checked=0

A.	Changes in policy/rules of CDCS ***CHRULES***	☐	D.	Budget Issues ***CHBUDG***	☐
B.	Payroll ***CHPYRL***	☐	E.	Not as much case manager support ***CHCMSUP***	☐
C.	Paperwork ***CHPPWK***	☐	F.	Disallowables (things CDCS CANNOT pay for) ***CHDISAL***	☐
G. Other (please explain): ***CHOTHER: type text***					

9. Did CDCS make finding staff easier?

EZFIND Yes=1, No=0

A. Yes ☐ B. No ☐

10. Did CDCS make training staff easier?

EZTRAIN Yes=1, No=0

A. Yes ☐ B. No ☐

11. Did CDCS make keeping staff easier?

EZKEEP Yes=1, No=0

A. Yes ☐ B. No ☐

12. Where did you find new staff?

For items in #12, box checked=1, box not checked=0
If all items are not checked, leave all blank

A.	Friends ***STFREN***	☐	D.	Advertisements ***STADS***	☐
B.	Immediate family (siblings, parents) ***STIFAM***	☐	E.	Agencies ***STAGEN***	☐
C.	Extended family (aunts, cousins, uncles) ***STXFAM***	☐	F.	Other people with disabilities ***STPWD***	☐
G. Other (please explain): ***STOTHER: type text***					

Please turn to the next page

13. Did you offer staff training? (*Check*(✓) *as many boxes as apply*) *If no, please skip to question 16.*

TROFFER Yes=1, No=0

A. Yes ☐ B. No ☐

14. What kind of staff training did you offer? *(Check (*✓*) as many boxes as apply)*

For items in #14, box checked=1, box not checked=0
If all items are not checked, leave all blank

A.	Training on my specific needs ***TRNEED***	☐	D.	Fiscal support entity offers training ***TRFSE***	☐
B.	First Aid ***TRFAID***	☐	E.	Medication Administration ***TRMADM***	☐
C.	CPR ***TRCPR***	☐			
F. Other (please explain): ***TROTHER: type text***					

15. How did you deliver training? *(Check (*✓*) as many boxes as apply)*

For items in #15, box checked=1, box not checked=0
If all items are not checked, leave all blank

A.	Yourself ***DTSELF***	☐	D.	Family or friends train my staff. ***DTFAM***	☐
B.	Consultant or Outside Agency ***DTAGEN***	☐	E.	Medication Administration ***DTMADM***	☐
C.	Conferences or Workshops ***DTCONF***	☐			
F. Other (please explain): ***DTOTHER: type text***					

16. What staffing benefits did you experience with CDCS? *(Check (*✓*) as many boxes as apply)*

For items in #16, box checked=1, box not checked=0
If all items are not checked, leave all blank

Please turn to the next page

A.	Staff were reliable ***SBRELY***	☐	F.	Staff stayed longer ***SBSTAY***	☐
B.	I was able to hire people I knew ***SBKNOW***	☐	G.	I could set pay for my staff ***SBPAY***	☐
C.	I could hire family members as staff ***SBFAM***	☐	H.	I could give bonuses and/or raises ***SBBONUS***	☐
D.	I had a better cultural match ***SBCULT***	☐	I.	I had more skilled staff ***SBSKILL***	☐
E.	My staff were better trained ***SBTRAIN***	☐			
J. Other (please explain): ***SBOTHER: type text***					

17. What <u>staffing</u> challenges did you have under CDCS? ***Check (✓) as many boxes as apply)***

For items in #17, box checked=1, box not checked=0
If all items are not checked, leave all blank

A.	It was hard to find staff ***SCFIND***	☐	E.	It was hard to keep staff ***SCSTAY***	☐
B.	I had discipline issues with staff ***SCDIS***	☐	F.	It was hard to get background checks ***SCBKGR***	☐
C.	Training staff ***SCTRAIN***	☐	G.	Cultural differences ***SCCULT***	☐
D.	Payroll issues ***SCPYRL***	☐	H	No agency to train and monitor staff ***SCAGEN***	☐
I. Other (please explain): ***SCOTHER: type text***					

18. We are interested in learning about the staff that supported you during the last 12 months that you used CDCS. Please complete this table by <u>writing</u> in the following information.

Staff Name (first name only)	**Relationship to you (e.g. parent, sibling, friend, neighbor, person not previously known to me)**	**When did you hire this staff?** ___ ___/___ __ (month) (year)	**How many months did they work for you?**	**Staff Wage (at the time they stopped providing CDCS staff support)**
SNAME1: type text	***SRELN1***	***SHIRE1: MM/YY***	***STIME1***	***SWAGE1: XX.XX***
SNAME2: type text	***SRELN2***	***SHIRE2: MM/YY***	***STIME2***	***SWAGE2: XX.XX***
SNAME3: type text	***SRELN3***	***SHIRE3: MM/YY***	***STIME3***	***SWAGE3: XX.XX***
SNAME4: type text	***SRELN4***	***SHIRE4: MM/YY***	***STIME4***	***SWAGE4: XX.XX***
SNAME5: type text	***SRELN5***	***SHIRE5: MM/YY***	***STIME5***	***SWAGE5: XX.XX***
SNAME6: type text	***SRELN6***	***SHIRE6: MM/YY***	***STIME6***	***SWAGE6: XX.XX***

For items in grid 18: enter each box as noted
If box is empty, leave blank

For SRELN1 – SRELN6 code with number marked and circled in red pen

For STIME1 – STIME6 code with number marked and circled in red pen

19. Please share any additional comments about your experience with CDCS (More space on back if needed). ___________ ***ADDCOM :type text***

____

____

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____

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Please turn to the next page

To help us learn more about you, please take a minute to provide us with the following information. Please check the box (✓) that BEST describes you and your experience using CDCS.

20. What is your gender?

GENDER Male=0, Female=1

A. Male ☐ B. Female ☐

21. What is your age?

AGE Code as noted in parentheses

A.	0-4 years ***(0)***	☐	C.	16-21 years ***(2)***	☐	E.	65 years or older ***(4)***	☐
B.	5-15 years ***(1)***	☐	D.	22-64 years ***(3)***	☐			

22. What is your race or ethnic background?

RACE Code as noted in parentheses

A.	White or European American ***(0)***	☐	E.	Black or African American ***(4)***	☐
B.	Asian or Asian American ***(1)***	☐	F.	American Indian/Native American ***(5)***	☐
C.	Native Hawaiian/Pacific Islander ***(2)***	☐	G.	Hispanic or Latino ***(6)***	☐
D.	Mixed race ***(3)***	☐	H.	Other ***(7)*** ***OTHRACE: type text*** ***(8) Two or more boxes checked***	☐

23. What best describes your living situation?

LIVSIT Code as noted in parentheses

A.	Independently ***(0)***	☐	D.	Semi-Independently ***(3)***	☐
B.	Independently with roommate ***(1)***	☐	E.	With family member or caregiver ***(4)***	☐
C.	Group home (1-4 bed) ***(2)***	☐	F.	Other (please write in) ***(5)*** ___ ***OTHLIVSIT: type text*** _________	☐

24. Which county do you live in?

COUNTY Code as noted in parentheses

A.	Anoka ***(0)***	☐	E.	Carver ***(4)***	☐
B.	Dakota ***(1)***	☐	F.	Ramsey ***(5)***	☐
C	Scott ***(2)***	☐	G.	Hennepin ***(6)***	☐
D.	Washington ***(3)***	☐	H.	Other (please write in) ***(7)*** _____ ***OTHCO: type text*** __________	☐

Thank you for your input!

Please turn to the next page

CONSUMER CONSENT FORM

Study 2.1: Consumer Directed Community Supports (CDCS) - Trends and Workforce Outcomes

You are invited to be in a research study to evaluate the effectiveness of consumer directed community supports and how it has or has not assisted you in your life. You were selected as a possible participant because you receive consumer directed community supports as your Home and Community Based Waiver Service option through your county and the State of Minnesota. We ask that you read this form (or have family/staff read it for you) and that you ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Amy Hewitt, PhD and her colleagues at the University of Minnesota, in College of Education and Human Development.

Background Information

The purpose of this study is: To learn more about how well consumer directed community supports helps (or does not help) people with mental retardation and related conditions (and their families) get along in their daily lives and activities. We want to learn how consumer directed community supports are used by people with mental retardation and related conditions (or their families). For example, what services do people elect to get and how are these services organized. Additionally we want to learn more about how people find, train and keep staff who work for them in consumer directed community supports.

Procedures:

If you agree to be in this study, we would ask you to do the following things:

- ☐ Answer some questions that we are asking all participants in the study about consumer directed community supports. These questions would be asked of you in a written survey or over the telephone.

Risks and Benefits of Being in the Study

The potential risks and costs to the participants are minimal. Costs include the time required to participate in the survey. Risks may include emotional responses to questions about past experiences, particularly if the past experiences have been negative. In general, however, the research questions will not delve into potentially painful experiences, thus minimizing these risks. If we ask you at any point a question that you feel uncomfortable answering you can just tell us you do not want to answer the question and we will move on to another question.

The benefits to participation: There are no short term benefits for you regarding this study. However training materials that are developed during this study will be made available to you at the end of the study. The results of the study will be shared with people who make decisions about services to people with mental retardation throughout the United States.

Compensation:

You will not be paid for your participation in this study at all. Your participation is totally voluntary.

Confidentiality:
The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only researchers will have access to the records.

Voluntary Nature of the Study:
Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota, the Institute on Community Integration or the College of Education and human Development. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:
The researchers conducting this study are: Amy Hewitt and Traci LaLiberte. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact them at the Institute on Community integration, 612.625.1098/612.625.9700, hewit005@umn.edu/lali0017@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.
You will be given a copy of this information to keep for your records.

Statement of Consent:
I have read the above information (or it has been read to me by the researcher). I have asked questions and have received answers. I consent to participate in the study.

Signature:_____________________________________ Date: _________________

Signature of Investigator:_____________________________________ Date: ________________

CDCS County Administrator Interviews

County:________ Interviewer: ________

Phone Log:

Name of person contacted:____

Title and role of contact person:____

Telephone number:___________________________

Fax number:________________________________

E-mail address:_________________________________

Date:
☐ Voice message
☐ Left message with person __________________________
☐ E-mail message

Outcome/follow up of call:

Name of person contacted:____

Title and role of contact person:____

Telephone number:___________________________

Fax number:________________________________

E-mail address:_________________________________

Date:
☐ Voice message
☐ Left message with person __________________________
☐ E-mail message

Outcome/follow up of call:

DRAFT

Consumer Directed Community Supports

MN County DD Director Interview Guide

Introduction

This interview guide will be used during telephone interviews with County Directors of Developmental Disability Services in MN. The purpose of the guide is to try to find out what types of services and supports are offered in your county that enable individuals (or their family members) to control their own budgets and their own services; and to find out how much money is being spent on these types of services. For the purposes of this study individually controlled services are defined as Consumer Directed Community Supports as offered under Minnesota's Home and Community based Services.

This study is being conducted to increase the amount of empirical information about individually controlled services in Minnesota and how they are used by people with mental retardation and related conditions. It is being conducted by the Research and Training Center on Community Living and is funded by the NIDRR. While we do know how many people use CDCS in MN, we do not know much about how they use these services and the extent to which CDCS services resemble or are quite different from traditional licensed services. One area that we are particularly interested in is how staffing is handled CDCS and to what extent direct care turnover and vacancy is a problem for people who receive CDCS. This study is being conducted to begin to answer these important questions. The study has a few components. One is to conduct case studies and focus groups of CDCS recipients in Hennepin County and another is to talk to county level developmental disability administrative staff to learn about the services offered in their county.

You were selected for this interview because you were identified by the State of Minnesota's Department of Human Services as the Developmental Disabilities Services Director in your county. This interview will take approximately 30-60 minutes depending upon whether or not you provide such services and whether or not you are the person who has the information I am looking for.

[Probe to determine if this is the best person to be talking with and whether this is a good time. If it is not the right person obtain that person's contact info and thank this person for their time. If it is the right person ensure it is a good time to talk; if it is not a good time to talk then schedule a phone meeting].

Consumer Directed Community Supports

MN County DD Director Interview Guide

MN County DD Director telephone survey:

1. Does your county offer consumer directed community supports to people with mental retardations and related conditions? If yes when did you first begin providing this option? If not, can you please describe the reason you have not yet offered this service? [probe to learn more about when, why and how this service option is provided and also if it has not been offered try to get at the critical points that have prevented it from being offered]. Then move on to question #2.

2. How many people with mental retardation and related conditions in your county currently receive consumer directed community supports?

3. What policy considerations and decisions have affected CDCS availability for persons with mental retardation and related conditions in your county?

4. What are current challenges regarding access to CDCS for people with mental retardation and related conditions in your county?

5. What methods are used in your county to monitor quality and outcomes of CDCS for people with mental retardation and related conditions that receive this service in your county?

6. What challenges have been experienced by offering CDCS in your county to people with mental retardation and related conditions?

7. What successes have you observed for individuals with mental retardation and related conditions who receive CDCS in your county because they receive these services?

8. From your perspective what are the major similarities between CDCS and traditional licensed services for persons with mental retardation and related conditions in your county?

9. From your perspective what are the major differences between CDCS and traditional licensed services for persons with mental retardation and related conditions in your county?

10. How do the people providing supports in CDCS the same or different than the people who provide supports in traditional HCBS licensed service? Are these differences positive or negative?

11. From your perspective what are the biggest unmet needs for people who currently participate in CDCS funded supports?