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Self-Determination Realized? Consumer direction: A case study of Virginia

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Self-Determination Realized? Consumer direction: A case study of Virginia

A dissertation submitted in partial fulfillment of the requirements for the degree of Ph.D. in Public Policy and Administration at Virginia Commonwealth University.

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Abstract

SELF-DETERMINATION REALIZED? CONSUMER DIRECTION: A CASE STUDY OF VIRGINIA

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Consumer direction, a model of long-term care service delivery where service recipients and their families/advocates have enhanced control and choice over the services that they receive, is a growing phenomenon in United States. As it becomes greater utilized, it is important to understand the model and study its impacts. This dissertation details the history of the consumer direction movement, describes the current landscape of consumer direction in the United States, and presents a comparison study of users of consumer-directed (CD) services in three of Virginia Home and Community Based Services (HCBS) Medicaid Waivers. Self-determination theory is provided as a theoretical framework for understanding consumer direction. The influences of liberty, empowerment, and paternalism are discussed in the context of self-determination theory as well as multidisciplinary influences. Results from the study indicate that overall, CD services facilitate self-determined decision making by enhancing recipients choice and control over services. When comparing differences between waiver groups, the survey domain of “access” was the only domain where statistically significant differences ($p<.01$) were found. Implications for users, advocates, and administrators of CD services are discussed.

I. Purpose of the Dissertation

An innovative effort to reform long-term care services for the elderly and people with disabilities is gaining momentum in the United States. This form of service delivery, called “consumer direction,” represents a shift in philosophy from the traditional “agency-managed model,” where services are selected and coordinated by third-party professionals with nominal consumer involvement, to a model where service recipients and their families/advocates have greater control and choice over the services that they receive (Simon-Rusinowitz, Bochniak, Marks & Hecht, 2000). Consumer direction is borne out of a theoretical framework in the disability studies field called self-determination. Self-determination is defined as “a complex process, the ultimate goal of which is to achieve the level of personal control over life that an individual desires within those areas that the individual perceives as important” (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003, p. 26).

Over the last several years, states have been introducing aspects of consumer direction into their Medicaid long-term care benefits (Crowley, 2003; Greene, 2007; Spillman, Black & Ormond, 2006; Tilly & Wiener, 2001; Tritz, 2005). As the use of consumer-directed (CD) services continues to expand, it becomes increasingly important to evaluate its impacts. Studies have examined particular aspects of CD services, such as general satisfaction with services and/or satisfaction with CD services as compared to the traditional agency-directed model (Beatty, Adams, & O'Day, 1998; Carlson, Foster, Dale & Brown, 2007; Conroy, 2005; Conroy & Yuskauskas, 1996; Doty, 2000; Doty et al., 1996; Doty et al., 1999; Foster, Brown, Phillips, Schore, & Carlson, 2001, 2002, 2003; Schore, Foster & Phillips, 2007; Young & Sikma, 2003). However, an aspect of consumer direction that has not been studied in depth in academic literature is how individuals with different types of disabilities experience CD services.

This dissertation bridges this gap using the state of Virginia as a case study. Specifically, this study compares the experiences of individuals who receive CD personal assistance services[1] from three of Virginia's Home and Community-Based Services (HCBS) Waivers (the Mental Retardation (MR) Waiver, Individual and Family Developmental Disabilities Support (DD) Waiver, and Elderly or Disabled with Consumer Direction (EDCD) Waiver across several dimensions. These dimensions include: access to information about CD services, using CD services, choice and control, and satisfaction. Data used for this analysis is from a survey conducted by the Partnership for People with Disabilities (Partnership) in 2005-2006 with grant funding from the Centers for Medicare and Medicaid Services (CMS).

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[1] The Virginia Department of Medical Assistance Services defines "personal assistance services" as providing assistance with Activities of Daily Living (ADLs): eating, bathing, dressing, transferring, and toileting, it includes medication monitoring and monitoring health status and physical condition. This service does not include skilled nursing services with the exception of skilled nursing tasks that may be delegated pursuant to the Virginia Administrative Code 18VAC90-20-420 through18VAC90-20-460. When specified in the plan of care, personal assistance services may include assistance with Instrumental Activities of Daily Living (IADLs), such as bedmaking, dusting, vacuuming, shopping and preparation of meals, but does not include the cost of the meals themselves. Assistance with IADLs must be essential to the health and welfare of the individual, rather than the individual's family. These services substitute for the absence, loss, diminution, or impairment of a physical, behavioral, or cognitive function. Provision of these services is not limited to the home. An additional component to personal assistance is work- or school-related personal assistance. This allows the personal assistance provider to provide assistance and supports for individuals in the workplace and for those individuals attending post-secondary educational institutions. This service is only available to individuals who also require personal assistance services to meet their ADLs. Workplace or school supports through the Elderly or Disabled with Consumer-Direction Waiver are not provided if they are services provided by the Department of Rehabilitative Services, under IDEA, or if they are an employer's

Research Questions and Hypotheses

The central research question examined in this dissertation is, “How do the experiences of individuals with intellectual disabilities, developmental disabilities (not including intellectual disabilities), and physical disabilities who receive CD personal assistance services in Virginia differ? Specifically, do these populations differ in how they access information about CD personal assistance services, use CD personal assistance services, exercise choice and control with CD personal assistance services, and experience satisfaction with CD personal assistance services?” Of particular interest is whether participants uniformly report that CD services enable them to determine the context and the extent to which they want to make choices in their supports (ie. facilitate self-determined decision-making) as is the goal of consumer direction (Nadash & Crisp, 2004; National Council on Disability [NCD], 2004; Tritz, 2004; Kosciulek, 1997). The hypotheses tested include:

H_1 Individuals who receive CD personal assistance services from Virginia’s MR, DD, and EDCD Waivers will report that this service delivery option facilitates self-determined decision-making;

H_2 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report access to CD services;

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responsibility under the Americans with Disabilities Act or Section 504 of the Rehabilitation Act. This service is agency-directed and consumer-directed.

H_3 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report how they use CD services;

H_4 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report how much choice and control is afforded to them through CD services; and

H_5 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report satisfaction.

Rationale for Hypotheses

As is discussed in depth in the forthcoming section, "Previous Research on Consumer Direction," there have been multiple studies in the academic literature that have documented that CD services afford users greater choice and control in service decision-making (see Carlson et al., 2007; Conroy, 2005; Conroy & Yuskauskas, 1996; Doty, 2000; Doty, Benjamin, Matthias & Frank, 1999; Foster et al., 2001, 2002, 2003; Schore et al., 2007; Young & Sikma, 2003). It is anticipated that individuals who use CD services in Virginia will further reinforce the findings of these studies.

While greater decision-making power for CD service recipients is presumed, it is also hypothesized that differences exist among waiver groups in the domains of access, use, choice, and satisfaction. The primary rationale for these anticipated differences is that each group receives CD services from different waiver programs that are governed by different Medicaid regulations and that are supported by a variety of different agencies. For example, access to and overall coordination of CD services in the MR Waiver is handled though a case manager while in the EDCD Waiver, no such role exists. These differences could lead to different experiences for program participants.

An additional reason for anticipated differences among waiver groups relates to the characteristics of each disability group. The nature of one's disability (eg. an intellectual disability versus a physical disability) may impact how one accesses and experiences services. Using access as an example, a person with an intellectual disability who does not read will not be able learn about how to access CD services through written promotional materials or through internet websites, while this would not be a barrier for someone with a physical disability who reads.

The same can be said for the "use" domain. A person who reads and writes may have a different experience in filling out payroll timesheets and other required paperwork than someone who does not read or write and must seek assistance from others. Consequently, it is presumed that differences associated with one's disabilities, may impact their experience with CD services.

Also, although personal assistance services are provided in each of the three waiver programs, it is anticipated that the support needs among service recipients in each program are somewhat different. For example, a person who uses a wheelchair may need more "hands on" assistance (i.e., someone to lift him or her from a wheelchair and transfer him or her to a bed) than someone with primarily an intellectual disability who may need support with cooking, cleaning, and shopping for groceries. These different types of support needs may result in differences in how the consumer experiences CD services.

Consumer-Directed vs. Agency-Managed Services

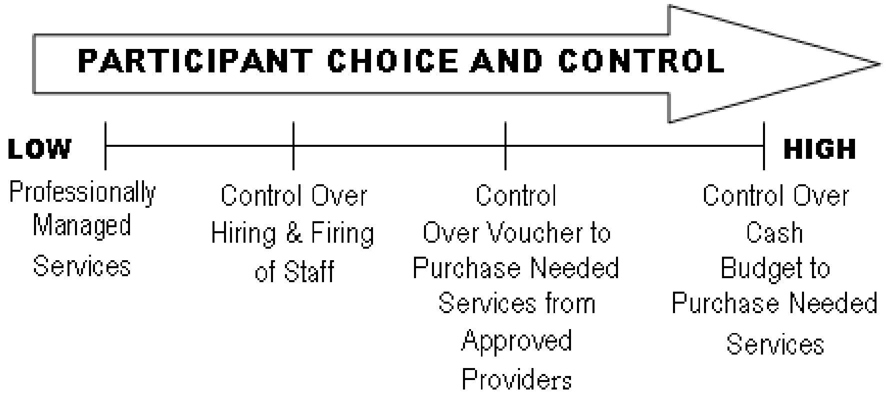
Change in the Locus of Control

In contrast to the more traditional agency-driven model, with CD services, the consumer exercises a great deal more control. Kosciulek defined consumer direction as,

> a philosophy and orientation whereby informed consumers have control over the policies and practices that directly affect their lives. It is a mechanism by which individuals with disabilities can develop the skills to take control of their lives and their environment (1999, p.4).

Consumer direction reflects a continuum of approaches based on the level of decision making, control, and autonomy allowed in a particular situation (Kosciulek, 1999; Nadash & Crisp, 2004; NCD, 2004; Tritz, 2004). At one end of the spectrum are programs that offer cash to consumers to purchase needed services and supports. Professionally managed service packages are at the other end of the continuum. Many approaches, however, lie within these two extremes. These include programs that allow individuals to hire and fire their own workers (including family members) and voucher programs that afford consumers great flexibility in how and where benefits can be used (Knickman & Stone, 2007; Kosciulek, 1999; Scala & Mayberry, 1996; Stone, 2006). Figure 1 illustrates the continuum of choice and control offered in several CD programs (see Figure 1).

Figure 1. Continuum of Choice and Control in Selected Consumer-Directed Programs



Kendrick, Petty, Bezanson, and Jones (2006) use a six point scale to illustrate the continuum of choice and control for services provided to individuals with disabilities. "Level one" identifies the traditional agency-managed model of services while "level-six" characterizes programs that offer a high degree of consumer direction.

- Level One: At this level, participants make no substantive decisions about their service.
- Level Two: At this level, participants make no substantive decisions about their service, but they are routinely informed about the decisions others will be making on their behalf.
- Level Three: At this level, participants are routinely consulted about their service preferences by the actual decision makers.
- Level Four: At this level, service users routinely make a minority of the substantive decisions about their personal services. (A minority ranges from 25% to 45% of key decisions.)
- Level Five: At this level, service users routinely make a majority of the substantive decisions about their personal services. (A majority ranges from 55% to 90% of key decisions.)
- Level Six: At this level, service users so routinely make the vast majority of key decisions that they consider themselves to be fully in control of the services and supports they receive.

Beyond the degree to which an individual has control over their services and supports, Kendrick et al. (2006) also identify the *scope of control* as an important element within consumer direction. The scope of control can include specific elements such as service goals and priorities; budget for services; hiring, supervision, and dismissal of staff; risk management; and quality management.

Nadash (1998) further delineates a set of elements through which one can determine the level of consumer direction offered through a program. These elements include:

- *The ability of consumers to control and direct the delivery of services*. How much control do consumers have over how, when, and by whom services are delivered, and to what extent do they determine the type and quality of services received?
- *The variety and type of service delivery options actually available to consumers*. Do consumers genuinely have choices, ideally a range of viable service options, available?
- *The availability of appropriate information and support*. Are information and support available that enable consumers to take advantage of a CD system of service delivery?
- *The ability of consumers to participate in systems design and service allocation*. What level of participation do consumers have at the policymaking level; for example, in the overall design of service delivery systems?

Service Delivery Models

In most CD programs, consumers take responsibility for many of the worker management tasks that have been traditionally performed by agencies or organizations. Recipients often recruit their own providers, and then train, supervise, and replace them when necessary (Benjamin, Matthias, & Franke, 2000; Doty et al., 1999). Additionally, some CD programs provide cash benefits to beneficiaries, who then shop for particular supports and services that fit their needs and budgets (Tilly, Weiner & Cuellar, 2000).

In *Understanding Medicaid Home and Community-Based Services: A Primer* (2000), Smith et al. excerpted the following state definitions of CD and agency-directed services to illustrate the differences between these two service delivery options:

Consumer-Directed Personal Assistance Service Delivery Model

> Consumer-directed (CD) models enable individuals to hire and fire, schedule, train, and supervise their own personal assistance providers (usually termed aides, attendants, or workers), with few restrictions on who can be hired. A CD model typically puts all responsibility for recruiting and selecting an aide on the individual (or family) and usually assigns the individual responsibility for ensuring that the aide(s) know how to do the work and for training the worker(s) if necessary. Public programs occasionally assist in identifying potential candidates, by providing a worker registry or helping the consumer perform a criminal background check. A CD model may also make publicly funded consumer and worker training available. Although the number of hours of personal assistance authorized for the individual in any particular month might be limited, individuals have the authority to schedule when the assistance will be provided, and both consumer and worker are free to negotiate schedule changes. A full-fledged CD model also involves individuals in the process of paying their workers (e.g., by signing timesheets), even though the actual wages are paid from public funds (¶3).

Professionally Managed Service Delivery Models

> Professionally managed models require that aides be employees of authorized home health or home care agencies. Agencies hire workers according to agency criteria and assign employees to serve particular consumers. Choice among agencies is limited by the number of authorized providers in the area where the consumer lives. Frequently, there is only one such agency. Consumer choice of agency aides is generally restricted to “veto” power--although dissatisfied consumers may ask to have a worker replaced, and the agency will generally honor such a request as long as another worker is available. Agencies may shift employees from one individual to another--although they typically try to honor individuals’ requests to have the same workers on a regular basis. Agencies also schedule the aides’ work hours and may determine whether or to what extent they will accommodate consumer scheduling preferences. Agencies also conduct aide training and supervision. Some public programs mandate minimum training and supervision requirements. Others leave it up to the agencies or state licensing laws to set such requirements. Since training, certification, and professional supervision requirements can affect service costs, the added value of such requirements needs to be carefully assessed (¶3).

Additionally, Tritz (2004) compared CD services and agency-directed services within several key program features highlighted in Table 1 (see Table 1).

Table 1. Key features of Agency-Directed and Consumer-Directed Long-Term Care Programs

Feature	**Agency-based provider model**	**Consumer-directed model**
Services provided	A prescribed number of service hours are authorized	Variable. Some programs use an authorized number of service hours. Other programs provide cash to purchase goods and services.
Screening of service recipient	None	Variable. Some programs have no screening. Others may screen the consumer for his or her financial competency in managing an individualized budget or the direct cash option.
Hiring legally responsible family members as a Provider	Generally not permitted	Variable. Is permitted in some programs, but not others.
Role of case manager	Variable. Some programs have a case manager while others do not. When programs do have a case manager the duties often include assessing the need for services and locating, managing, coordinating and monitoring those services.	Variable. Generally, the consumer has more independence and responsibility and assumes many of the functions of a case manager. The case manager may take on other functions such as education, guidance, and reviewing a consumer's expenditure plan and receipts for purchased goods and services.
Supervision of direct care Worker	Agency	Consumer

Feature	Agency-based provider model	Consumer-directed model
Fiscal responsibilities	Agency	Variable. May be handled by the county, state, a contracted intermediary, or the consumer.
Degree of consumer choice	Variable	In most cases there is a high degree of choice.

Note. From Tritz, K. (2004). Long-term care: Consumer-directed services under Medicaid. Washington DC: Congressional Research Service. Retrieved August 17, 2006 from www.law.umaryland.edu/marshall/crsreports/crsdocuments/RL322191212005.pdf

Funding for CD Services

While a significant number of CD programs for the aging are financed through state general revenues or receive Title II Older Americans Act funds, the majority of publicly-financed CD long-term care programs are operated through the Medicaid program (Nadash & Crisp, 2004). Medicaid is a program jointly funded by the federal and state governments whose purpose it is to provide medical care and long-term supports and services for certain groups of low-income individuals who are seniors, blind, or have a disability; members of families with children; and pregnant women. Under Section 1902 of the Social Security Act, all states must comply with some basic requirements for their Medicaid program. States must:

- serve certain mandatory populations, such as poverty-level children and low-income pregnant women;
- provide certain mandatory services, such as hospital care and physician services;
- provide services that are “sufficient in amount, duration, and scope to reasonably achieve (their) purpose;” and
- provide services throughout the state (Smith et al., 2000).

Long-term care benefits are offered through “state plan” Medicaid programs and also through HCBS Waiver programs. State plan Medicaid is the basic Medicaid health care insurance program offered in each state. Twenty-six states and the District of Columbia offer optional state plan personal care services through Medicaid (Summer & Ihara, 2005).

Medicaid waivers allow states to waive certain federal requirements to permit greater flexibility or expand the Medicaid populations it serves. States can operate several waiver programs at once, each with a distinct package of services and supports to different groups of individuals. These choices give states considerable latitude in deciding which services and supports will be offered and in customizing benefit packages to meet the needs of particular groups (Smith et al., 2000).

Within Medicaid, *CD services* can either be offered through the state plan Medicaid program or through Medicaid waivers. Within state plan Medicaid, states can opt to offer a CD personal care benefit. This benefit allows a recipient to hire, train, and fire his or her own personal care provider, but the state Medicaid program retains responsibility for monitoring service delivery and ensuring that qualified providers are delivering the personal care services (Tritz, 2004). Historically, with state plan CD personal assistance services, states were not permitted to provide Medicaid funds directly to a consumer to pay for the personal care services (Tritz, 2004).

With the passage of the Deficit Reduction Act of 2005 (DRA), significant changes were made to the Medicaid program including the creation of another option for states to provide consumer-directed personal care services through their state plan (Cohen, Scully

Bockweg, Richardson & Goolsby, 2007). CMS, the federal agency that oversees the Medicaid program, continues to support options for greater consumer direction offered through state plan Medicaid services. As recently as January 18, 2008, the agency issued a proposed rule to offer greater flexibility to states in providing CD options within state plan Medicaid services. This rule would put into place a provision of the DRA that allows states to elect a state plan option to provide care in ways that previously required waivers of Medicaid laws.

Within Medicaid waivers, there are two ways to offer CD options to service recipients: section 1115 research and demonstration waivers and 1915(c) home and community-based services waivers. Section 1115 research and demonstration waivers (authorized under Section 1115 of the Social Security Act) offer significant flexibility in that they are considered to be a research platform for testing program innovations (Spillman et al., 2006). These waivers are limited to five years in duration, but states can apply for renewal for subsequent three-year periods. States who seek to combine different disability populations, include individuals who do not meet functional requirements for institutional care, or provide a cash allowance directly to beneficiaries must use Section 1115 waivers (Spillman et al., 2006).

Section 1915(c) waivers (authorized under Section 1915(c) of the Social Security Act) offer a broad variety of community services for individuals who would otherwise receive these services in an institutional setting. These services include: homemaker/home health aide services, personal care services, respite care, adult day health, and home-delivered meals (Trinz, 2004). For 1915(c) waivers, states must specify all services that will be subject to participant direction, define provider qualifications, and execute provider agreements with each individual provider (Spillman et al., 2006; Trinz, 2004).

In May 2002, as part of President Bush's New Freedom initiative, CMS launched the Independence Plus program. This program offers greater flexibility in Medicaid home and community based long-term care services through individual control over hired workers and discretion over long term care benefit dollars (Yuskauskas, 2005). Currently, ten states including New Hampshire, South Carolina, Louisiana, North Carolina, Maryland, Delaware, Connecticut, Florida, California, and New Jersey have operating Independence Plus programs (Yuskauskas, 2005).

History of CD Services in Long-Term Care

In the United States, the historical roots of consumer direction are outside of the Medicaid program. For the past 30 years, the Veterans Administration has operated the Housebound Aid and Attendance program which provides additional cash benefits to qualified veterans or their surviving spouses if they require ongoing personal care services, are housebound, or require nursing home services. This unrestricted cash benefit provides veterans with additional monthly income to purchase needed services and supports (Tritz, 2004).

Consumer direction in long-term care grew out of the disability rights and independent living movement in 1970s (Doty, Kasper & Litvak, 1996; Mahoney & Simon-Rusinowitz, 1997; Nadash, 1998; Yamada, 2001). In advocating for full inclusion in society, many working-age adults with disabilities began to demand a greater role in managing their services and supports in community settings (Tilly, 1999). Concurrently in the 1970s, people with intellectual and other developmental disabilities and their families began to lobby more stridently for a greater voice in planning for their lives. This culminated with the development of a self-determination movement in the 1980s which argued for participant control and choice in where, how, and from whom support services are provided (Stone, 2006).

Consumer direction in aging services and supports is a more recent development (Tilly, 1999; Mahoney & Simon-Rusinowitz, 1997). During the 1980s, advocates for older people and younger people with disabilities found common ground for legislative advocacy with the Health Care Reform Act of 1993. This act offered provisions for the development of new CD home and community-based services for people of all ages (Stone, 2006; Tilley & Weiner, 2001). Additionally, the development of assisted living options for the aging in the 1980s was based on the principle that older people should be able to have choice and control in their residential and service options (Stone, 2006).

As advocacy groups in long-term care lobbied for greater control in their services and supports, many state program officials began to explore CD options (Mahoney & Simon-Rusinowitz, 1997; Stone, 2006; Tilly, 1999; Yamada, 2001). Like aging and disability advocates, administrators began to share concerns about the dependency created through public program rules and regulations (Manohey & Simon-Rusinowitz, 1997; Yamada, 2001). Additionally, with growing costs in long-term care, many state officials had a strong interest in achieving program economies (Braddock, 2007). Therefore, reasons for the increasing interest in experimenting with cash allowance alternatives included both savings on program administration and enhanced consumer empowerment (Manohey & Simon-Rusinowitz, 1997; Yamada, 2001).

In the 1990s, several national programs further spurred the growth in and interest for consumer direction in long-term care (Nadash, 1998; Stone, 2006). The Robert Wood Johnson Foundation (RWJF) initiated Independent Choices, which funded 13 projects testing new financing and service delivery options to increase choice and control in home and community-based services for people with disabilities (Stone, 2006). In 1993, the foundation also funded a demonstration grant to address several major problems in New Hampshire's developmental services program: the high costs of care, the increasing waiting lists, and consumer dissatisfaction with the ways in which support was provided (Nadash, 1998). Out of this project, $7 million dollars were later offered to 19 states. Lastly, RWJF and the U.S. Department of Health and Human Services jointly funded the Cash and Counseling Demonstration to test the viability of providing a cash allowance instead of agency-directed services in the states of Arkansas, Florida, and New Jersey (Stone, 2006).

CD Health Plans

Consumer direction is also an emerging element of many commercial health plans. It can take many forms, such as spending accounts or health reimbursement arrangements, but has one primary goal: to increase the knowledge of consumers and impact their choices in purchasing health care services (Dougherty, 2003; Nadash & Crisp, 2004). Unlike consumer direction in long-term care which is grounded in the value of changing the locus of control from professional agencies to individuals, the rationale for consumer direction in commercial health care is based on the containment of health care costs. The premise is that health care would be more efficient if consumers had fiscal incentives to choose more cost-effective care (Armstrong, 2004).

In CD commercial health care plans, increases in participant cost sharing (usually deductibles) are paired with a tax-free health care spending accounts, such as health reimbursement accounts (HRAs) or health savings accounts (HSAs). Tiered benefits accounts are another emerging strategy, where there is higher patient cost sharing when more expensive options are selected (Butin, Damberg, Haviland, Lurie, Kapur & Marquis, 2005). In addition to these financial incentives for cost efficiency, health care consumers are provided with information to assist them in making cost and quality comparisons (Butin et al., 2005; Scandlan, 2005).

Consumer direction in health care got a boost with the passage of the 2003 Medicare prescription-drug law. This law permits insurers and employers to offer health savings accounts (HSAs) to purchasers of high deductible coverage (Bloche, 2006). HSA holders and their employers can contribute amounts up to their deductibles (subject to caps) to tax-free accounts and spend the funds on health-related services (Bloche, 2006).

So far CD HSA–high-deductible plans make up a small percentage of the health care market, with only 20% of American workers being offered such plans in 2006, and only 4% choosing them (Bloche, 2006). However, in a 2007 study of the use of such strategies within the Medicaid program, five states were planning on offering Health Opportunity Accounts (HOA) or other health savings account-like plans in 2007 while 11 other states are considering the option for 2008 or later. Additionally, 24 states were planning in 2007 to provide quality data for recipients to compare health plans and another 13 were considering it for 2008 (Greene, 2007). These studies illustrate that CD strategies in health care plans are increasingly being adopted and considered in the commercial market as well as in Medicaid programs across the country (Bloche, 2006; Greene, 2007).

Target Population for Consumer Direction

While the practice of consumer direction could be applied to a variety of populations who participate in social welfare programs, the movement has generally been concentrated to individuals who receive long-term care services such as those with mental health needs, intellectual or physical disabilities, and seniors. One explanation for why CD programs have been targeted to these populations is that consumer direction has close ties with the disability advocacy movement of the 1970s (Mahoney & Simon-Rusinowitz, 1997; Stone, 2006; Tilly, 1999; Yamada, 2001).

Early advocacy efforts among people with physical disabilities changed the orientation in long-term supports from charity to the concepts of rights and self-definition (Mizrahi, 2006). This advocacy later spread to other long-term care populations, including seniors, people with intellectual disabilities, and those with mental health issues. Thus, the consumer direction can be seen as a natural outgrowth from these advocacy efforts (Nadash & Crisp, 2004).

Although consumer advocacy for greater choice and control has been significant in long-term care, it has not been as prominent with other population groups who use social welfare supports. Examples of this are parents of children in the child welfare system or people of low income who participate in income assistance programs such as Temporary Aid to Needy Families (TANF) (Mazrahi, 2006). In the child welfare system, research and practice in actively engaging families in case planning and as key stakeholders for system improvement has grown within the past ten years, however the movement from consumer involvement in services to consumers directing service planning has yet to be made (Altman, 2005; Littell, 2001).

For those participating in income assistance programs, systematic consumer engagement in service planning is much less prevalent (Mazrahi, 2006). The 1996 Personal Responsibility and Work Opportunity Reconciliation Act includes no recognition of welfare recipients as stakeholders who should participate in the shaping TANF policies and programs. Additionally, in TANF, welfare clients have no rights beyond a “right to a fair hearing” process when benefits are denied (Mazrahi, 2006).

While CD programs could be expanded and piloted with additional population groups outside of long-term care, it appears that there needs to be a political will and coordinated advocacy effort among service recipients to make that happen. As stated by Mazrahi (2006),

> In order to promote and successfully implement…participation, there needs to be: commitment, competence and resources provided by and coming from government. From the clients and citizen end of participation, there also needs to be a commitment of time, demonstrated or acquired competence, a willingness to play by the rules, and an ability to connect with and be accountable to other clients/residents (pp. 52-53).

Opposition to Consumer Direction

Despite the fact that consumer direction has gained considerable prominence in recent years within long-term care, many concerns have been identified with this service delivery option. One of the central issues relates to consumer direction not being appropriate for many individuals, particularly those with intellectual disabilities and the frail elderly (Benjamin, 2001; Stone, 2006). Some programs have addressed this issue by putting in place screening processes to evaluate the suitability of the model for particular participants. For those programs where screening processes are in place, only those who choose consumer direction and are deemed to be able to manage the tasks involved are eligible to participate, while others are assigned to the traditional agency model (Benjamin, 2001). Other programs require surrogate decision makers for individuals for whom decision-making capacity is in question (Stone, 2006). Many advocates for individuals with intellectual disabilities have questioned this approach by arguing not for surrogacy but for supported decision-making where a service recipient participates in decisions as part of a support team of family members, advocates, and professionals (Benjamin, 2001).

Another concern regarding consumer direction is with quality assurance, particularly in regards to fraud and abuse (Benjamin, 2001; Scala & Mayberry, 1997; Stone, 2006). A fear is that the flexibility afforded with consumer direction can offer opportunities for disreputable family members and other supporters to take advantage of vulnerable individuals. Another concern is that consumers receiving cash benefits will use the funds for purposes outside of their services or support needs (Stone, 2006).

Many programs have addressed issues regarding fraud through the use of a variety of intermediary service organization (ISO) models. An ISO is an entity that acts as a go-between with a CD program and a service recipient for purposes of disbursing public funds and assisting consumers in performing tasks associated with the employment of workers (Flanagan & Green, 1997). In this role ISOs assist government policy makers in assuring program and fiscal accountability, regulatory compliance, protection from liability, and service quality (Flanagan & Green, 1997).

Regarding abuse, critics argue that because of uncertain quality assurance mechanisms to detect problems, consumer direction puts service recipients at too great a risk (Matthias & Benjamin, 2003). Findings from several studies including Matthias and Benjamin (2003) and Simon-Rusinowitz and Mahoney (2006) indicate that those using CD services are at no greater risk for abuse than those utilizing agency-directed care.

Balancing consumer choice and autonomy with concerns of participant safety and the related issue of who assumes liability are other articulated concerns with consumer direction (Benjamin, 2003; Scala & Mayberry, 1997; Stone, 2006). While many programs seek to address these issues through the use of ISOs, Stone (2006) states,

> These are particularly thorny issues that have not been, and perhaps will never be, resolved. On one hand, consumer direction empowers the client to make decisions on how best to use resources to meet one's needs. As long as no health or security problems arise, the consumer and others are generally satisfied. On the other hand, who is responsible for a bad decision? In the litigious United States, the issues of responsibility and liability are particularly volatile and have led many policy makers and public agencies/providers to shy away from consumer direction (p.109).

Previous Research on Consumer Direction in Long-Term Care

Several major policy studies have been conducted in the United States to test the effectiveness of CD long-term care services. A review of these studies, and the findings associated with their evaluations, provides an overview of the major scholarly work in the area of consumer direction.

Robert Wood Johnson Foundation Self-Determination Project

In the early 1990s, the Robert Wood Johnson Foundation (RWJF) funded several programs to test mechanisms for giving consumers more choice in selecting the services that they receive and the people who provide them. One of the first of these projects to produce a comprehensive evaluation of the outcomes associated with the CD approach for people with intellectual disabilities was the "Self-Determination Project" in New Hampshire (Conroy & Yuskauskas, 1996).

In this evaluation, which had a pre-post design, several outcome dimensions were examined including a scale on quality of life, personal-choice-making, and consumer satisfaction. Researchers found that in the quality of life areas examined, respondents reported that they enjoyed a higher quality of life, as compared to a year ago when they received agency-managed services. Eight of the nine increases in quality of life were statistically significant ($p<.05$). With personal choice-making, similar positive results were found, with 22 increases and four decreases in the 26 dimension "decision control inventory." Seven of the changes in choice-making dimensions were found to be statistically significant ($p<.05$). Lastly, in regards to changes in consumer satisfaction, of the nine areas examined, all nine dimensions were reported to be higher as compared to a year earlier. Eight of the nine dimensions were found to be statistically significant ($p<.05$) (Conroy & Yuskauskas, 1996). No population groups were compared as part of the evaluation for the New Hampshire Self-Determination Project.

From New Hampshire, researchers went on to examine the impacts of self-determination for people with intellectual disabilities across ten of the Robert Wood Johnson-funded projects. In all states, participants and their allies reported a statistically significant improved quality of life (Conroy, 2005). Also, it was reported that participants' families believed their relatives' lives had improved in 14 out of 14 quality indicators. Once again these findings were statistically significant (Conroy, 2005).

Researchers also conducted an in-depth cost analysis in four states implementing self-determination programs. It was reported that in two states (New Hampshire and Michigan) costs were lower. In California, costs were reported as "fiscally conservative." This meant that in a comparison group study, costs went up for both for those participating in the self-determination project and for those who did not, but costs went up twice as much for those not participating in the self-determination project. Lastly, in New Jersey costs were found to be the same for before and after self-determination (Conroy, 2005).

Virginia's Department of Rehabilitative Services CD PAS Program

In the early 1990's a study was conducted of non-Medicaid consumer-directed (CD) personal assistance services (PAS) offered through Virginia Department of Rehabilitative Services (VDRS). The study design was quasi-experimental, comparing individuals with disabilities receiving CD PAS and a similar group of individuals on the waiting list to receive services. The study consisted of four rounds of mailed questionnaires, administered approximately every 6 months beginning November 1994 (Beatty et al., 1998).

Findings indicated that those receiving CD PAS had consistently higher rates of general preventive healthcare utilization compared to those on the waiting list and lower rates of utilization for doctor visits due to a medical condition, emergency room visits, hospital days, skilled nursing facility days, and visits from home health providers (Beatty et al., 1998). Additionally, those receiving CD PAS had significantly greater feelings of control over their lives than those not receiving CD services, greater employment and productivity outcomes, and were more likely to report being highly satisfied than the comparison group (Beatty et al., 1998).

Commonwealth Commission Survey of Medicaid Personal Care Services

The Commonwealth Commission Survey examined the experiences of individuals who received Medicaid personal care services in the states of Maryland, Texas, and Michigan. Michigan operated a CD long-term care program, Texas offered agency-directed personal assistance services and Maryland’s program was a cross between these two programs where consumers could hire and fire their personal assistance under the supervision of a nurse (Doty et al., 1996).

Using logistic regression, Doty et al. (1996) found a positive relationship between increasing opportunities for client direction and satisfaction with services. Individuals who reported greater CD options were significantly more likely to report being "very satisfied" than those who did not have access to those options (Doty et al., 1996).

In-home Supportive Services Program in California

The "In-Home Supportive Services" (IHSS) program in California also commissioned a pilot test of consumer direction in the late 1990s. This program is one of the few state long-term care programs that provides CD as well as agency-directed services to substantial numbers of consumers, both older and younger; with mild, moderate, and severe disabilities resulting from a wide range of underlying medical conditions. An evaluation of this program, completed in 1999, sought conclusions about the comparative effectiveness of the alternative service delivery models. This was done by isolating variations in client experiences that were caused by differences between the agency management and the CD model (Doty et al., 1999).

Researchers found that consumers receiving services under the CD model had more favorable results on six dimensions of consumer outcomes, including two measures each of empowerment, satisfaction, and quality of life. There were no outcome measures on which the consumers receiving agency-managed services fared significantly better than those receiving CD services. With the CD model, individuals who had family members as providers reported more favorable outcomes on three dimensions including aspects of safety, empowerment, and satisfaction. There were no measures on which consumers with non-family workers were found to have significantly better outcomes than those who hired family members as workers (Doty, 2000). Although this study contained a variety of population groups in its sample, no systematic examination was conducted to compare the experiences and outcomes of different population groups with consumer direction.

Washington Self-directed Support Services.

In 1998, the state legislature of Washington commissioned a study of self-directed supports and services. This study examined a variety of dimensions, including: consumer satisfaction with self-directed care, service quality, and consumer safety, number of individual providers who have been found to have abused or neglected consumers; consumer outcomes in emergency situations such as abandonment, abuse, neglect, or exploitation by individual providers; and whether coercion is a factor in consumers requesting self-directed care (Young & Sikma, 2003).

Research from this study evidenced that no negative outcomes attributable to self-directed care were demonstrated and benefits included improvements in quality of life and quality of care for consumers (Young & Sikma, 2003). Additionally, there was high overall satisfaction with self-directed care and a strong endorsement that the program supported autonomy and choice. Lastly, both individuals receiving services and case managers reported that the program prevented utilization of more expensive services (e.g., nursing homes, emergency rooms for routine care) (Young & Sikma, 2003).

Cash and Counseling

An additional program that conducted an evaluation of consumer’s experiences with consumer direction was a “Cash and Counseling” program in Arkansas. This program provides people who are eligible for Medicaid personal assistance services a monthly allowance instead of receiving traditional services (Foster et al., 2001).

An evaluation of consumers’ experiences with the program was completed utilizing a nine-month follow-up interview conducted between September 1999 and March 2000.

Consumer outcomes were measured in four dimensions, including 1) program participation; 2) uses of services, goods, and cash; 3) hiring of caregivers and revision of expenditure plans; and 4) satisfaction (Foster et al., 2001).

In this evaluation, consumers reported that they were largely satisfied with their lives and the care that they were receiving. Ninety-six percent, including disenrollees, expressed satisfaction with their quality of care. Additionally, nearly all participants were pleased with the way their paid caregivers performed their duties such as providing personal care and routine health care services (Foster et al., 2001).

In a subsequent evaluation of a "Cash and Counseling" program in Florida, similar positive consumer outcomes were found. Ninety percent of all consumers, including disenrollees, reported that they would recommend the program to others who want more control over their personal care and 97 percent of consumers who used the monthly budget to hire caregivers would recommend the program (Foster et al., 2002).

Several follow-up studies were conducted of Cash and Counseling participants in the states of Arkansas, New Jersey, and Florida. In one study it was found that Cash and Counseling participants were more likely to receive paid care, had greater satisfaction with their care, and had fewer unmet needs than the control group (non-Cash and Counseling participants) in nearly every state and age group. Additionally, within each state and age group, service recipients were not more susceptible to adverse health outcomes or injuries under Cash and Counseling (Carlson et al., 2007).

In another follow-up study, most Cash and Counseling participants were found to be able to assume the role of employer without difficulty, many hiring relatives or acquaintances as workers. In each state, more than 85 percent reported they would recommend the program to others seeking more control over their care, and more than half said the program had "improved their lives a great deal” (Schore et al., 2007). As with the other studies discussed above, none of the Cash and Counseling evaluation reports systematically compared experiences and outcomes of different population groups.

Although all of the abovementioned studies differed in design, each included as a key program quality indicator measure(s) of consumer satisfaction with services and perceived enhancements to an individual’s quality of life attributed to participation in a CD program. This is fundamental to the ethic of CD programs.

One of the major shortcomings of traditional agency-directed personal care services administered under Medicaid was a lack of consumer control that can result in unmet needs, dissatisfaction with care and diminished quality of life (Foster et al., 2003). Consumer direction is designed to change the locus of control from the agency to the individual. Therefore, in examining the quality of a CD program, fundamental concepts that need to be addressed, along with other important quality indicators include: choice and control, satisfaction with services, and changes in perceived quality of life. This is the case because choice and control, satisfaction with services or supports, and elevated quality of life are seen as fundamental goals of the consumer direction movement.

Other Noteworthy Studies Examining Aspects of Consumer Direction

In addition to large-scale studies examining satisfaction and outcomes associated with consumer direction, many studies have explored alternative aspects of this service delivery option. One such issue that has been examined in the literature is the impact of race on individual preference for CD options.

While assessing preferences for cash-benefits versus traditional agency-based services, Simon-Rusinowitz et al. (1997) found that Caucasians were less likely to be interested in a cash benefit as African Americans. Simon-Rusinowitz and Mahoney (2004) later affirmed this finding when they reported that African American and Hispanic consumers showed higher levels of interest in the cash option when compared to Caucasian consumers. An additional study by Sciegaj, Capitman, and Kyriacou (2004) found significant differences between and within race/ethnic groups for preferences CD services. Authors concluded that these differences illustrate the need for cultural competency as service systems consider the development of CD service provision (Sciegaj et al., 2004).

Another area of inquiry regarding consumer direction has been its impact on family caregivers. As stated by Friss-Feinberg and Newman (2005),

> family and informal caregivers are often key partners in consumer-directed programs. In fact, many policymakers and program administrators think of the "consumer" in consumer-directed care not as the individual with the disability, but the dyad --that is, the care recipient and his or her family (p. 4).

Feinberg and Whitlatch (1998) conducted a study in California of family caregivers who received in-home respite care. Families that participated in this program were given a choice between agency-directed and family-directed care and the study compared outcomes associated with each service delivery option.

Findings from this study indicated that caregivers preferred the CD respite option over agency-based services. Compared to the agency-based group, caregivers using CD services were found to have significantly more choice and control in decisions related to the day-to-day management of their respite aides including: hiring, paying, scheduling, supervising, and firing (Feinberg & Whitlatch, 1998). Additionally, the use of CD services was associated with more hours of respite per caregiver, and was found to be significantly less costly per hour of service than the use of agency-based respite. Findings indicated that family caregivers in the study group had a clear preference for consumer direction when using respite care in the home (Feinberg & Whitlatch, 1998).

Another study by Foster, Brown, Phillips, and Carlson (2006) further supports the findings by Feinberg and Whitlatch. The authors reported that, overall, family caregivers of CD participants reported greater well-being compared to family caregivers of those receiving agency-directed services. Caregivers of CD service recipients were less likely than caregivers of traditional service users to report high levels of physical, financial, and emotional strain. They worried less about insufficient care and safety and were more likely to be very satisfied with their family member's care arrangements. Finally, caregivers of CD program participants were also more likely than caregivers of traditional service users to say that they were very satisfied with their own lives (Foster et al., 2006).

One other area that has been examined in the consumer direction literature is the impact of this service delivery option on paid direct care workers. Benjamin and Matthias (2004) found relatively modest differences between those who provide CD or agency-directed care. However, one key finding from this study was that related workers seem to face additional pressures not encountered by other paid workers. Compared with nonfamily workers, paid family workers were more likely to assist with a wide range of tasks, and more likely to provide additional nonpaid help (Benjamin & Matthias, 2004).

Dale, Brown, Phillips and Carlson (2005) also examined the issue of how hired workers fare with consumer direction and reported similar findings to Benjamin and Matthias. In this study the vast majority of CD workers (94.7%) were the consumers' friends or relatives. Findings indicated that CD and agency workers received similar wages and both were highly satisfied with their working conditions and the supervision that they received. However, compared with agency workers, CD workers who lived with or were related to the consumer were more likely to report emotional strain and a desire for more respect from the consumer's family. No such differences were observed for directly hired workers who were not relatives. A noted difference in the findings of this study was that directly hired workers and agency workers provided comparable amounts of care (Dale et al., 2005).

Factors that Influence States' Decisions to Offer CD Services

The Medicaid program allows states considerable discretion in developing home and community-based services for people with disabilities and the aging, so long-term care options within the program can vary significantly from state to state (Coughlin, Long & Shen, 2005; Government Accounting Office [GAO], 2002; Kitchener, Carrillo & Harrington, 2004). As stated by Holahan, Weiner and Lutzky (2002), "today's system of federalism in health care leaves large variations in [Medicaid] coverage across states (p. 322)."

Several factors can influence a state's decision to participate in a Medicaid innovation such as consumer direction. A primary calculus in a state's decision-making is cost (Doty, 1996; Holahan, Wiener & Lutzky, 2002; Infield, 2004; Yamada, 2001).

The Medicaid program spent $94.5 billion on long-term care services in 2005, approximately one-third (31%) of total program expenditures. Costs for long-term care services within Medicaid increased by 38% over the five-year period since 2000 (Houser, Fox-Grange, Gibson, 2006). Pressures on states to finance Medicaid long-term care services will increase as the population ages. By 2030, the over-65 population is projected to double and the over-85 population is projected to triple (Cubanski & Kline, 2003). Thus, containing costs within Medicaid is a primary concern within states (Cubanski & Kline, 2003; Doty et al., 1996; Holahan et al., 2002; Yamada, 2001). As stated by Weiner and Stevenson (1998),

> Although states are motivated by a variety of goals, the vast majority of long-term care initiatives are aimed at controlling the rate of increase in state spending, especially since Medicaid is the primary source of financing for long-term care (p.82).

Another factor influencing state adoption of CD strategies is advocacy activity. As stated earlier, advocacy efforts among those with disabilities, the aging, and caregivers have provided a significant impetus for change in long-term care (Doty et al., 1996; Mahoney & Simon-Rusinowitz, 1997; Nadash, 1998; Stone, 2006; Yamada, 2001). Additionally, lobbying efforts by state nursing home providers can be equally as powerful in blocking the growth of consumer direction. Traditional provider agencies, such as nursing homes can feel threatened by CD options and fear a loss of business (Simon-Rusinowitz, Bochniak, Mahoney, Marks & Hecht, 2000). As concluded by Sparer (2004),

> Long-term care reform is a complex activity that requires consultation and consensus building. There is a pluralistic cast of characters that all have significant political power, and any effort to enact comprehensive reform overnight … is likely to run into determined and effective opposition (p.289)

Program implementation concerns can also impact states' willingness to support CD services (Infield, 2004). Specific issues such as worker shortages, concerns around measuring service quality, whether to pay family caregivers, who is appropriate for consumer direction, and fraud and abuse can delay or certainly delay the implementation of consumer direction in a state (Infield, 2004; Mahoney, Fishman, Doty, & Squillace; 2007; Simon-Rusinowitz et al., 2002).

Additionally, the slow pace of translating health policy innovation across states can also influence the adoption of CD approaches (Holahan et al., 2002). While experimentation within Medicaid has enabled states to address specific local needs and to enhance the reach and effectiveness of their Medicaid programs, adoption of these innovative strategies to other states have been uneven (Cubanski & Kline, 2003). As Holahan et al. (2002) assert,

> One potential benefit of variation in state policies and practices is that states can operate as laboratories of democracy. The idea is that states choose varied approaches and evaluate those that do and do not work, and then other states or the federal government makes better decisions based on lessons learned. Given the vast variation across states in administrative mechanisms, reimbursement methods, outreach and enrollment systems, organization of delivery systems, and other factors, the list of successful innovations that have been replicated by other states is disappointingly short (p. 325).

Current Landscape of Consumer Direction the United States

As of this publication date, there is no comprehensive inventory comparing all CD programs across the United States (Tilly, 1999; Tritz, 2004; Yamada, 2001). Measuring the number and types of CD programs is difficult because the definition of consumer direction is not consistent, and there are many different agencies that administer CD services (Tilly, 1999; Tritz, 2004; Yamada, 2001). However, there have been several studies that generally describe size and scope of consumer direction in the United States.

In 2001, the Home and Community-Based Resource Network at Boston College developed a descriptive inventory of publicly-funded programs offering home and community-based personal assistance services through CD service delivery models. In this inventory they identified one hundred thirty-nine (139) programs offering CD home and community-based (HCB) support services. Every state, except Tennessee and the District of Columbia, at that time offered at least one CD HCB support services program (Doty & Flanagan, 2001). Also, a 2004 survey of state aging directors and Medicaid directors about consumer direction for older persons found that 40 states operated a total of 62 CD programs (Infield, 2004).

More recently, the Kaiser Family Foundation (KFF) developed an inventory of individual budget-based community long-term care programs in the United States. This inventory serves as the foundation for a comparison of CD program across the states and a characterization as a “leader,”, “follower,” or “lagger” in promoting choice and control in long-term care services.

Table 2 presents a state by state comparison of the range of choice and flexibility offered in CD programs in the United States. States identified under the column “Planned or Active Individual Budgeting Program” have a program supporting either the aging, people with intellectual or other developmental disabilities, or physical disabilities that include the following features:

- Conversion of traditionally delivered long-term care services to a dollar value that becomes the budget that a beneficiary can use to purchase services and supports tailored to individual needs (this includes either a “cash” allocation or a allowance managed by a fiscal agent);
- Beneficiary participation in planning and discretion to shift budget dollars between types of supports—especially between types of personal assistance and between personal assistance and other disability-related goods or services;
- Independent professional support to assist in developing a flexible care plan, obtaining services, and managing the budget;
- Beneficiary discretion in hiring and managing workers including, at state option, hiring a family member or friend; and
- Availability of fiscal services and support, such as issuing checks and tax withholding for workers (Spillman et al., 2006).

States identified under the column, “Planned or Active Programs that have Participant-Directed Features,” offer programs that have elements of consumer direction but do not meet the criteria for offering individual budgeting options.

The third column in the chart “Leader, Follower, or Lagger” identifies the status of states in implementing CD services. States that are categorized as leaders have active CD programs that offer individual budgeting authority to program participants (this budget authority can be either provided as cash or as an allowance that is managed by a fiscal agent). States identified as followers either have individual budgeting program planned or an active program that offers some CD features to consumers. Lagger states either have a program planned that offers some degree of consumer direction or they offer no CD options.

Table 2. State by State Comparison of Programs that Offer Consumer Direction as of April 2006

States	Leader=⬆ Follower=➡ Lagger=⬇	Planned or Active Individual Budgeting Programs[1, 2]	Planned or Active Programs that have Consumer-Directed Features[1]
Alabama	➡	Planned	
Alaska	⬇		Planned
Arizona	⬆	Active	
Arkansas	⬆	Active	
California	➡		Active
Colorado	⬆	Active	
Connecticut	➡		Active
Delaware	⬆		Active
District of Columbia	⬇		Planned
Florida	⬆	Active	
Georgia	➡		Active
Hawaii	➡		Active
Idaho	⬆	Active	
Illinois	➡	Planned	
Indiana	➡		Planned
Iowa	➡	Planned	
Kansas	➡		Active
Kentucky	➡	Planned	
Louisiana	⬆	Active	
Maine	➡		Active
Maryland	⬆	Active	
Massachusetts	⬆	Active	
Michigan	➡	Planned	
Minnesota	⬆	Active	
Mississippi	⬇		
Missouri	⬆	Active	
Montana	➡	Planned	
Nebraska	⬇		Planned
Nevada	➡	Planned	
New Hampshire	➡		Active
New Jersey	⬆	Active	
New Mexico	➡	Planned	
New York	➡		Active
North Carolina	⬆	Active	
North Dakota	⬆	Active	

Table 2. State by State Comparison of Programs that Offer Consumer Direction as of April 2006

States	Leader=⬆ Follower=➲ Lagger=⬇	Planned or Active Individual Budgeting Programs[1, 2]	Planned or Active Programs that have Consumer-Directed Features[1]
Ohio	➲		Active
Oklahoma	➲		Active
Oregon	⬆	Active	
Pennsylvania	➲	Planned	
Rhode Island	➲	Planned	
South Carolina	⬆	Active	
South Dakota	⬆	Active	
Tennessee	⬆	Active	
Texas	➲		Active
Utah	⬆	Active	
Vermont	➲	Planned	
Virginia	➲		Active
Washington	➲	Planned	
West Virginia	➲	Planned	
Wisconsin	⬆	Active	
Wyoming	⬆	Active	

[1] Note. Based on data retrieved from http://www.kff.org/medicaid/upload/7485.pdf
[2] Note. This budget includes either a “cash” allocation or an allowance managed by a fiscal agent

As illustrated in the table, the majority of states (51 %, N=26) fall into the category of “follower” states (identified with a ➲ symbol). These states include Alabama, California, Connecticut, Georgia, Hawaii, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Michigan, Montana, Nevada, New Hampshire, New Mexico, New York, Ohio, Oklahoma, Pennsylvania, Rhode Island, Texas, Vermont, Virginia, Washington, and West Virginia.

Twenty one states (41%) can be considered “leader” states (identified with a ⬆ symbol). These states are Arizona, Arkansas, Colorado, Delaware, Florida, Idaho, Louisiana, Maryland, Massachusetts, Minnesota, Missouri, New Jersey, North Carolina, North Dakota, Oregon, South Carolina, South Dakota, Tennessee, Utah, Wisconsin, and Wyoming.

Relatively few states (N=4, 8%) fall into the category of “lagger states” (identified with a ⬇ symbol). These states include Alaska, District of Columbia, Mississippi, and Nebraska.

Table 3 further clarifies state leadership in consumer direction. This table identifies three significant national initiatives in consumer direction and state participation in those initiatives. Criteria for participation for each of these projects illustrate a significant commitment by a state in the principles of consumer direction.[2]

Table 3. Top Leader State Participation in National Initiatives Promoting Consumer Direction

States	RWJ Self-Determination Project States[1]	Cash and Counseling States[2]	Independence Plus Waiver States[3][4]
Arizona	X		
Arkansas		X	
Colorado			X
Delaware			X
Florida	**X**	**X**	**X**
Idaho			
Louisiana			X
Maryland	**X**		**X**
Massachusetts	X		
Minnesota	**X**	**X**	

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[2] For the RWJ Self-Determination Project, criteria for selection were 1) the likelihood that project would be used to jump-start statewide changes; 2) the size of the population targeted in community initiatives; 3) demonstrated support of key partners, including legislative and executive agencies, individuals with developmental disabilities and their families; and 4) the extent to which states would redirect existing service dollars to allow for greater individual control over services (RWJF, 2007). For Cash and Counseling criteria for participation include: 1) person-centered planning for personal assistance services; 2) consumer-directed individualized budgets, with flexibility to hire workers or buy other goods and services; 3) client supports, including financial management and counseling services (supports brokerage); and 4) quality assurance and improvement systems (including backup assistance for consumers and viable incident management systems) (RWJF, 2004). The CMS state requirements for the Independence Plus Home and Community-Based Waiver include the use of : 1) person-centered planning; 2) individual budgeting; 3) self-directed services and supports; and 4) quality assurance and quality improvement (QA/QI) model of discovery, remediation and continuous improvement (CMS, 2005).

States	RWJ Self-Determination Project States[1]	Cash and Counseling States[2]	Independence Plus Waiver States[3][4]
Missouri			
New Jersey		X	X
North Carolina			X
North Dakota			
Oregon	X		
South Carolina			X
South Dakota			
Tennessee			
Utah	X		
Wisconsin	X		
Wyoming			

[1] Note: Retrieved February 1, 2008 from http://www.rwjf.org/reports/npreports/sdpdd.htm
[2] Note: Retrieved February 1, 2008 from http://www.cashandcounseling.org/about/participating_states
[3] Note: Retrieved February 1, 2008 from http://www.cms.hhs.gov/IndependencePlus/
[4] Note: From O’Keeffe, J., O’Keeffe, C., Wiener, J. & Siebenaler, K. (2007). Increasing options for self-directed services initiatives of the FY 2003 Independence Plus grantees. Retrieved 1/1/08 from http://www.hcbs.org/files/130/6482/IPpaper.pdf

Top Leader State Characteristics

Table 3 identifies four “leader” states that have participated in more than two national projects that demonstrate a significant commitment to consumer direction. The states of Florida, Maryland, Minnesota, and New Jersey can be considered principle innovators in consumer direction.

A range of factors within each of these states can help to inform why they have chosen to fully embrace CD approaches. Florida has the highest percentage of residents ages 65 and over (16.8%), thus state officials have a great incentive for finding new and better alternatives to long-term care service provision (Houser et al., 2006). Additionally, much of the Medicaid innovation in Florida has been closely aligned with the Bush administration views on fostering an ownership society, which emphasizes consumer-driven decision-making (Friedland, 2005). Expenditures for services for people with intellectual and other developmental disabilities in Florida have also increased in recent years, again providing a strong rationale for testing potentially cost effective strategies for providing home and community-based support. In FY 2002, Florida’s HCBS Waiver supported over 25,000 persons with MR/DD and total MR/DD spending in the state exceeded $1 billion—almost double what the state spent when Governor Jeb Bush took office in 1999 (Braddock, 2004). These substantial spending increases in Florida were largely due to the rapid expansion of the HCBS Waiver following settlement of a major lawsuit regarding access to community services (Braddock, 2004; Smith, 2006).

Minnesota has a long history of being a leader in providing comprehensive quality Medicaid supports to its citizens and for embracing innovation in health care delivery (Long & Kendall, 2002). For FY 2005, it was ranked first for per-person expenditures for Medicaid home and community-based services in the United States (Houser et al., 2006). Additionally, the state recently undertook a major restructuring of it long-term care system (Minnesota Department of Human Services, Aging Division, 2006). As reported by Long & Kendall (2002) the state is investing heavily in home and community-based care with a growing emphasis on CD care, while reducing institutional care for those who are aging or have disabilities. Additionally, like Florida, from FY 2001 to 2002, the state experienced significant growth (41%) in home and community-based waiver expenditures for people with intellectual and other developmental disabilities (Braddock, 2004). This substantial increase in expenditures could have also provided significant motivation for experimenting with consumer direction.

Although many factors in the states of New Jersey and Maryland do not appear to point to a clear rationale for innovation in long-term care, both have operating CD programs that provide for considerable choice and control for participants. New Jersey is on the higher end for total Medicaid long-term care expenditures, however it does not stand out in fiscal effort for community services. For FY 2005, New Jersey ranked 15th in the country for total Medicaid long-term expenditures and 26th in expenditures for Medicaid home and community-based services. However, one area where New Jersey has had significant movement is in decreasing its population of people with intellectual and other developmental disabilities who live in state-operated institutions (Braddock et al., 2005).

From 2002-2004, the state had the third largest reduction in the number of persons with intellectual and other developmental disabilities served in state institutions across the country, decreasing its population by 219 individuals (Braddock et al., 2005). Despite this decrease, New Jersey still has a significant institutional population, ranking 2nd in the country the number of residents of large public residential facilities (Bruininks et al., 2006).

This gradual decrease in institutional services and growth in the demand for community services resulted in a substantial waiting list for services in the state (Lakin, 2000). As reported by McGreevey, Harris, Wilson, and Smith (2002), the waiting list in the state for supporting individuals who were living at home and in need of support services exceeded 20,000 individuals. To address this need for community services, the state launched a large-scale, governor-sponsored initiative to expand community services. This initiative sought to overhaul the intellectual and developmental disability service system fostering individualized supports and greater “consumer-driven” information and services (McGreevey et al., 2002).

Maryland, like New Jersey, does not stand out for its fiscal commitment to long-term care services. For FY 2005, it ranked 24th in the country for Medicaid long-term care expenditures and 28th in Medicaid expenditures for home and community-based services (Houser et al., 2006). However, also like New Jersey, the state has set out to expand community services and supports to address the issue of individuals waiting for services in the state. In 1998, Maryland launched a governor-sponsored initiative address the states waiting-list for services to people with intellectual and other developmental disabilities. The stated “driving component” of this initiative is “self-determination” specifically as it related to developing services and supports to meet individualized need (Maryland Department of Health and Mental Hygiene, n.d.).

Virginia: A Case Study of Consumer Direction

A case study approach will help illuminate the program effects of consumer direction on different groups of individuals receiving CD long-term care services in Virginia. Case studies can be defined as a method for learning that is based on a comprehensive understanding of a phenomena gained by extensive description and analysis to develop or test explanations (George & Bennet, 2005; GAO, 1990). As stated by Yin (2003), the case study approach is best used when “*how* or *why* questions are being posed, when the investigator has little control over events, and when the focus is on contemporary phenomena within some real-life context (p.1)."

While case studies can provide much descriptive, real-life context for exploring an issue, there is a notable drawback to this approach. Case study analysis is a descriptive method, not an explanatory one. Thus, without controlled conditions, conclusions about cause-and-effect relationships cannot be drawn. Behavior can only be described, not explained (GAO, 1990).

Therefore, while examining CD services in Virginia can provide rich detail on the impact of these supports and services on people with different disability labels, it cannot be generalized to conclusions about CD services across the country. Instead, examining CD services in Virginia highlights initial findings that may warrant further large-scale study across several states.

To provide context for an examination of CD personal assistance services in Virginia, a general discussion of the state's disability services and supports follows.

Prevalence of Disability and Disability Services and Supports in Virginia

As estimated by the Virginia Board for People with Disabilities, 1,491,965 Virginians were living with a disability in 2004 (Virginia Board for People with Disabilities [VBPD], n.d.). Of working age adults (ages 21-64), 11.2 percent reported a disability in 2004 (Rehabilitation Research and Training Center on Disability Demographics and Statistics, 2005). Additionally, as found in the 2004 American Community Survey, an estimated 169,000 people, or 2.5 percent of the population five and over, have difficulty performing self-care activities, also known as activities of daily living

(ADLs), such as dressing, bathing, or getting around inside the home (United States Department of Commerce, 2004).

Services and supports for individuals with disabilities in Virginia are administered by several state and local entities. Over fifteen state agencies operate disability service programs and these agencies are responsible for hundreds of separately administered local offices, boards, councils, commissions, programs, and other entities. Additionally, hundreds of public and private non-profit groups provide direct services to individuals with disabilities across the state. This has resulted in a complex, sometimes overlapping, multi-tiered disability services and support system in Virginia (VBPD, 2006).

Virginia is ranked 48th in per person, Medicaid long-term care expenditures in the United States (Houser et al., 2006). Additionally, funding community-based services for individuals with developmental disabilities in Virginia is one of the lowest in the country. The University of Colorado's 2005 *State of the States in Developmental Disabilities* reports that Virginia is 50 out of 51 (50 states plus the District of Columbia) in funding for community-based services as compared to institutional services. The state is 41st in per person spending on home and community based waiver services, and the state's fiscal effort ranking for community supports dropped two places from 2002, and now stands at 47th nationally (Braddock et al., 2005).

This context provides a compelling argument for new and innovative strategies to better meet the community service and support needs of individuals with disabilities in Virginia. Clearly, the community service system in Virginia is not only complex, it is not as well funded as many other states in the nation. However, any "innovations" offered in the state need to be scrutinized closely to monitor if they are being implemented with fidelity and if they are meeting the needs of the intended audiences. The purpose of this dissertation is to examine if the innovation of “consumer direction” is meeting the needs of individuals receiving personal assistance services in Virginia’s waiver programs.

A further discussion of the definition of consumer direction and how Medicaid services are structured in Virginia provides additional background for this dissertation.

CD Services in Virginia

Virginia began using a CD model in 1989 as part of a 2-year demonstration grant awarded to Virginia’s Department of Rehabilitative Services (DRS) by the VBPD. This led to CD options being added to four of Virginia’s home and community-based waiver programs to date. In these waiver programs individuals have the option of consumer-directing Medicaid-funded personal assistance, respite, and companion services. In addition, people receiving services through their local departments of social services may hire individuals of their choice through locally funded services that include chore, companion, and homemaker services (Stokes & Lawson, 2007). For each of these CD programs, service recipients (or their designees) are the employer of record for their worker; meaning they hire, manage, and fire their own workers (including family members). For Medicaid-funded CD services, a fiscal intermediary is responsible for payroll functions.

As stated earlier, in Virginia, CD services are primarily offered through the Medicaid HCBS program. Virginia currently has six HCBS Waivers. Four of these waivers offer CD services which are defined in Virginia Administrative Code [12VAC30-120-140] as “services for which the individual or family/caregiver is responsible for hiring, training, supervising and firing of the staff.” The MR Waiver supports individuals with a primary diagnosis of mental retardation and individuals under the age of 6 with developmental delays who are at imminent risk of facility placement, while the DD Waiver serves individuals 6 years of age and older with a developmental delay other than mental retardation (e.g. autism, cerebral palsy, spina bifida) at imminent risk of facility placement. The EDCD Waiver supports individuals 65 or older *or* individuals who are disabled, who meet screening criteria, and who are at imminent risk of nursing facility placement. Lastly, the AIDS Waiver provides services to people with a diagnosis of AIDS or AIDS related condition who are experiencing functional symptoms that require nursing facility or hospital care (DMAS, 2003).

DMAS reported that for fiscal year 2005, 6,421 individuals received services through the MR Waiver, with 426 opting for CD personal assistance services. In the DD Waiver, 338 people received services, with 166 selecting CD personal assistance services. For the EDCD Waiver, 11,901 individuals received services under this Waiver, with 751 receiving CD personal assistance services. Additionally, in the spring of 2003, CD services were added to the AIDS Waiver, although no individuals selected this service option.

Definitions and provisions for CD services are delineated in Medicaid provider manuals and in Virginia Administrative Code [12VAC30-120-770]. Also listed are the minimum employment standards for individuals who wish to serve as personal care attendants and job specifications for the services facilitator. The service facilitator performs plan of care development and monitoring, reassessments, and support activities for individuals participating in CD services.

Program Review and Quality Assurance for Virginia's CD Options

As part of federal requirements, DMAS must provide continuing review and evaluation of the care and services paid through Medicaid, including review of utilization of the services by providers and by recipients. Therefore, the agency conducts periodic Utilization Reviews (URs) on all programs. In addition, DMAS conducts compliance reviews on providers that are found to provide services in excess of established norms, or by referrals and complaints from agencies or individuals (DMAS, 2006).

For CD services in Virginia's waiver programs, the CD service facilitator serves as one of the primary agents for program review. As stated in the Virginia Administrative Code [12VAC 30-120-980], "the CD services facilitator must conduct face-to-face meetings with the individual or family/caregiver at least every six months for respite services and quarterly for personal care to ensure appropriateness of any CD services received by the individual." Outside of the abovementioned Medicaid utilization review, there is currently no standardized practice for soliciting input from the individuals who receive CD home and community-based waiver services on the quality of their support and service from DMAS.

Contribution of the Study

The purpose of this study is to examine the experiences of individuals with intellectual disabilities, developmental disabilities, and physical disabilities who receive

CD personal assistance services in Virginia to determine if there are differences between the groups. Comparison data on CD services among different groups contributes to disability policy studies and assists with addressing several important CD service policy and implementation issues.

CD services are growing at a rapid rate across the country. As the service is expanded to larger numbers of population groups, program administrators must consider whether different or uniform information dissemination, training, user support, and program implementation strategies should be used for the different population groups. For example, will a training curriculum designed for people with intellectual disabilities equally meet the needs of those who are aging or those with physical disabilities? Or, are information dissemination strategies such as internet webpage postings or print brochures effective for different population groups?

All program participants must have a clear understanding of the options available through consumer direction and the associated responsibilities with this service delivery option for consumer direction to be effective (Greene, 2007; Mahoney & Simon-Rusinowitz, 1997; Nadash & Crisp, 2004; Simon-Rusinowitz et al., 1997). Information, training, and support materials must be accessible to all participants to assist them in understanding their options and to make them aware of support available to assist them in managing their choices. The absence of appropriate education and skills training can be a significant barrier in the success consumer direction (NCD, 2004). This dissertation examines this issue in Virginia.

Another important issue that the data collected through this study informs is the adequacy of the quality assurance mechanisms in place for CD services. As stated by Tritz (2004), “Designing a system of quality in community-based long-term care services that balances the consumer’s preferences, the individual’s safety, and accountability to the public is an ongoing challenge for both state and federal policy makers (p.31).” Data gathered through this study identifies the general quality of CD services in Virginia as defined through several dimensions. Additionally, it allows for quality to be compared among different disability groups.

Lastly, this study has particular utility to CD services stakeholders in Virginia such as individuals with disabilities, family members, disability advocates, policy makers, and state agency representatives. Comparison data helps to highlight what aspects of CD services are and are not working well for different population groups within Virginia. Questions addressed include: are people using CD personal assistance services in each of the waiver programs in Virginia consistently receiving appropriate, accurate information? Does each population group believe that they are able to express their needs and preferences in managing their services? Are individuals provided with the support needed to make their choices viable, and have they received continuing support once a decision is made? Answers to these questions can assist state policy makers and program managers in making needed program modifications and highlight training and technical assistance needs for different program participants.

Overview of Chapters

The study is divided into five chapters. Chapter I is the introduction to the study. The introduction presents the research questions and hypotheses, defines consumer direction and describes several aspects of the service delivery option, discusses the major research on consumer direction, provides a state by state comparison of consumer-directed services in the United States, and presents Virginia as a case study in consumer direction. Next, Chapter II provides the theoretical framework for the study focusing on the theories of self-determination and empowerment as vehicles for understanding consumer direction. Chapter III includes the study methodology, research procedures, instrumentation, and data analysis plan. Chapter IV follows which presents and discusses the research findings. Lastly, Chapter V presents conclusions based on findings from the study and details policy and practice implications.

II. Theoretical Considerations

Introduction

The practice of consumer direction is an outgrowth of the greater philosophical and theoretical orientation of self-determination. Self-determination is a product of many influences. Concepts such as liberty, empowerment, and paternalism have had a profound impact on how self-determination is presently understood. Additionally, the term has historical roots in a variety of academic disciplines including political theory, social work theory, and psychological theory.

In order to offer perspective for later discussion of an operationalized form of self-determination in disability policy studies, CD services, it is necessary to provide its broad historical and theoretical context. The section that follows details several theoretical influences on self-determination including liberty, empowerment, and paternalism. After that discussion, a presentation follows on how multidisciplinary influences such as political theory, psychology, and social work have influenced the evolution of self-determination in disability studies. The chapter concludes with a review of the theoretical model guiding this dissertation.

Theoretical Influences on Self-Determination

Liberty

Championing individual choice and control, hallmarks of self-determination in disability policy studies, are certainly not new values. The pursuit of control over one's life and environment has a long and varied history within social policy, with roots grounded in the concept of liberty.

Liberty is defined by the Merriam-Webster dictionary as "freedom from arbitrary or despotic control; the positive enjoyment of various social, political, or economic rights and privileges; and the power of choice." The political and social philosopher John Stuart Mill examined the concept extensively in many of his works, among them *On Liberty* (1859) and *Utilitarianism* (1861), and his posthumously published *Chapters on Socialism* (1879).

For Mill, liberty is a fundamental human right (Wilson, 2007). He believed that liberty enables individuals to seek out their best; it fosters diversity in thinking to the benefit of individuals and society; and it promotes morality and rationality which leads to enhanced creativity and intellectual progress in society (Wilson, 2007). As Mill states of liberty, "each person becomes more valuable to himself, and is therefore capable of being more valuable to others" (1859, p. 63).

Mill also applied his conceptualization of liberty to action as well as speech. He claimed that "experiments of living" maximize the development of human individuality.

Restraints on action should be discouraged, even if the actions are inherently harmful to the individuals who engage in them (Wilson, 2007).

The only limits he puts on liberty are associated with what has been titled the "harm principal" by Fienberg (1973). Mill argues that the exclusive purpose for which power can be rightfully exercised over any member of a civilized community is to prevent harm to others (Heydt, 2006). As Mill states,

> That principle is, that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise, or even right (1859, p. 13).

That is not to say, however, that Mill saw no need for government to be involved in any matters of the individual outside of the harm principle. In *On Liberty*, he acknowledges the need for limited interference of government in individual matters. Specifically, he accepts that government may be justified in preventing any person from entering into a contract that is ultimately injurious to himself, such as a contract placing one into lifelong servitude or slavery (McCann, 2004). As Mill states,

> A voluntary slavery contract, however, violates one of the most fundamental tenets of liberty. Should a person choose freely to place himself in a condition of slavery, voluntary, free choice ceases to exist; in entering into such an agreement, the individual abdicates his liberty (1859, p. 103).

Based on this pronouncement, Mill has been accused by certain critics of endorsing paternalism (McCann, 2004). As stated by Hoffman, (1998), Mill's social liberalism "has potentially coercive and paternalistic implications because it assumes that the masses need to be "instructed" in the ways of active citizenship by a coercive state (p. 35)."

Another limitation that Mill places on the exercise of liberty involves those who he deems not "mature in their faculties" or incompetent. When discussing legitimate limits on liberty, Mill states,

> It is, perhaps, hardly necessary to say that this doctrine is meant to apply only to human beings in the maturity of their faculties…Those who are still in a state to require being taken care of by others, must be protected against their own actions as well as against external injury (1859, p. 22).

Therefore, in Mill's view, those who "are still in a state to require being taken care of by others," who could arguably include people with intellectual disabilities or those with mental health issues, need to be protected rather than afforded a right to liberty.

Additionally, in a modern day context, competence is also cited as a limiting factor in the exercise of liberty among people with disabilities. As stated by Stefan (2004)

> Both society and the law have until recently operated on global, irrefutable presumptions that individuals with psychiatric disabilities or mental retardation categorically lack competence to vote, make their own medical decisions, marry and have children, and dispose of their own financial resources. Until recently, people who were committed to mental institutions were deemed incompetent and lost all their rights. Discharged patients had to petition a court to "restore" their rights to vote, their abilities to procure driver's licenses and enter into contracts, and to be generally declared competent (p. 5).

Another prominent example of limiting liberty among people with disabilities, most notably people with intellectual disabilities, for reasons of competence is with the practice of guardianship (Herr, 2003; Nerney, 2000). Guardianship is a legal term for when an individual or entity (a guardian) is appointed by a court to assume decision making functions on behalf of, and in the place of, an individual that is legally deemed "incapacitated." When guardianship is established, the incapacitated person's legal right to make certain decisions with respect to his or her personal and/or financial affairs is removed and responsibility for making such decisions is placed in the court-appointed guardian (Miles-Valdez, 2007). As stated by Teaster et al. (2005),

> Adult guardianship – as distinguished from the guardianship of minors – is marked by an inherent tension: it protects at-risk individuals and provides for their needs, while at the same time removing fundamental rights, potentially reducing individuals to the status of children (p. 2).

There is inherent tension with the "right" to liberty for some groups of people with disabilities, most notably for those with intellectual disabilities, when issues of protection or safety are being considered.

Empowerment Theory

Another theoretical influence on self-determination is empowerment theory (Wehmeyer, 1996). Empowerment has been a research topic in many disciplines including psychology, sociology, education, social work, organizational development, and business management (Perkins & Zimmerman, 1995). The concept is heavily influenced by existentialist thinking regarding the ability for humans to create meaning in their own lives and strongly parallels definitions of self-determination by emphasizing the importance of individual freedom and choice (Sadan, 1996).

Empowerment can be defined as,

> a process of transition from a state of powerlessness to a state of relative control over one's life, destiny, and environment. This transition can manifest itself in an improvement in the perceived ability to control, as well as in an improvement in the actual ability to control (Sadan, 1996, p.144).

Empowerment theory espouses the merits of supporting oppressed groups in bringing about positive change for themselves (Turner, 2005). It emphasizes personal participation in the change process, from problem definition, to strategy implementation, to ongoing evaluation, and is predicated on a relationship between professional and client characterized by the principles of equal worth of all individuals, regardless of professional status, class, culture, race, gender, or ethnicity (Fondacaro & Weinberg, 2002). Additionally, empowerment theory, research, and interventions link individual well-being with the greater social and political environment (Perkins & Zimmerman, 1995).

Zimmerman (2000) highlights three components of empowerment: the intrapersonal, the interactional, and the behavioral. Intrapersonal empowerment includes the perceived control to influence decisions and influence actions that affects an individual’s life. The interactional aspect of empowerment is an awareness of one’s environment and those who influence that environment (those with authoritative power). Lastly, the behavioral component of empowerment involves one’s participation in collective action to exert control over his or her social or political environment (Zimmerman, 2000).

Many authors also note the distinction between individual and community empowerment (Fondacaro & Weinberg, 2002; Perkins & Zimmerman, 1995; Zimmerman, 2000). As Sadan states,

> For the individual – the micro level – the empowerment process is a process of increasing control and transition from a state of powerlessness. Community empowerment – the macro level – is a collective social process of creating a community, achieving better control over the environment, and decision making in which groups, organizations or communities participate (p.137).

A theory of empowerment also includes both processes and outcomes (Zimmerman, 1995). For example, an "empowering" process at the individual level such as learning decision-making skills leads to the "empowered" outcome of an enhanced sense of control. Feminist thinkers also highlight the need for a nuanced understanding of the role of power within empowerment theory (Parpart, Rai, & Staudt, 2003; Vathsala, n.d.). Rowlands makes the distinction between several kinds of power including: power over which is controlling power over someone and something; power to which is generative or productive power that creates new possibilities and actions without domination; power with which is power generating the concept that group action is more effective that singular action; and power from within which is the recognition of one´s own self-acceptance and self-respect enables the acceptance of others as equals (1997).

Additionally, the consumer-directed theory of empowerment advanced in the disability field of vocational rehabilitation, asserts the positive relationship between greater choice and control and greater empowerment (Kosciulek, 2005). The theory is based on the following four theoretical assumptions:

1) Greater consumer direction leads to greater community integration.
2) Greater consumer direction leads to higher levels of empowerment.
3) Greater community integration leads to higher levels of empowerment.
4) Higher levels of empowerment relates to higher levels of quality of life (Kosciulek, 2005).

Although, and maybe because, empowerment thinking has been applied to so many different contexts, it is often criticized for being vague and inadequately defined (Parpart et al., 2003; Riger, 2000; Purser & Cabana, 1998). As stated by Parpart et al. (2003),

> empowerment has thus become a ‘motherhood’ term, comfortable and unquestionable, something very different institutions and practices seem to be able to agree on. Yet this very agreement raises important questions. Why is empowerment acceptable to such disparate bedfellows? What can empowerment mean if it is the watchword of such different and often conflicting…. approaches and institutions (p. 3)?

Thus, empowerment is seen as “plastic,” given to multiple and different interpretations which can dilute the term to a meaningless level (Vathsala, n.d.).

Another concern regarding empowerment theory is what Purser and Cabana (1998) term "pseudo-empowerment" (p. 132). This is the practice of giving “lip-service” to empowerment, but making no changes within the traditional power structure to affect true change. This concern is also articulated by Riger (2000). She uses the example of a college program “empowering” African American students through enhanced academic achievement. Although increasing academic achievement may be laudable, the program does not impact decision-making power over resources or policies. Thus, it creates an illusion of power without affecting the distribution of power (Riger, 2000).

This concern with power and power structures is the basis for another criticism of empowerment theory. As stated by Buchanan (2000),

> Why has empowerment assumed such prominence in the field these days? Of all the different candidates that could possibly be contemplated, why has the interest in power become so predominant? Why not caring, or compassion, or dignity, or love, morality, respect, harmony, responsibility, or some other significant human aspiration? Why has the pursuit of power captured so much attention (p. 81)?

Buchanan instead advocates for more normative approaches for understanding and motivating human behavior. He states that greater attention should be directed towards clarifying human values; “good” reasons for deciding one way over another, and the moral considerations that support conclusions about the primacy of certain ethical principles over others (Buchanan, 2000).

Paternalistic Theoretical Orientations

Theories that emphasize liberty and empowerment are by no means exclusive approaches to the delivery of social supports. Rival philosophies exist that offer alternative theoretical orientations. One of these theoretical orientations, paternalism, has been the historical policy approach to many social supports including services for people with disabilities (Longmore, 2003; Stapleton, O'Day, Livermore & Imparato, 2006).

Paternalism is understood as limiting a person’s freedom for his or her own good (Suber, 1999). The word calls to mind the image of a father ("pater" in Latin) who makes decisions for his children rather than letting them make their own decisions, on the grounds that "father knows best” (Andre and Velasquez, 1991, p. 2). Paternalism involves curtailing freedom or autonomy in order to protect the interests of individuals (such as in life, health, or safety). In this, paternalists suppose that they can make wiser decisions than the people for whom they act (Suber, 1999).

Disability policy has historically been grounded in a paternalistic, medical model (Brisenden, 1986; Jones, 2001; Pfeiffer, 2000;). As decribed by Pfeiffer (1993), in this model,

> the person with a disability is a patient for whom decisions must be made. The problem is defined in terms of an impairment, lack of a vocational skill, poor adjustment, or lack of motivation on the part of the disabled person. The solution is intervention by the professional, who decides what is the desired outcome for the disabled (Pfeiffer, 1993, p. 724).

Much of the recent scholarship that emphasizes individual choice and control in long-term care is a critical outgrowth of the paternalistic emphasis in the medical model (Brisenden, 1986; Jones, 2001; Pfeiffer, 2000). However, paternalism is not always viewed as a negative in the context of providing social supports to individuals. Lawrence Mead and others see many benefits to paternalistic policies.

Mead discusses paternalism within the framework of social programs for the poor. In *The New Paternalism: Supervisory Approaches to Poverty* (1997), Mead describes paternalism as, "social policies aimed at the poor that attempt to reduce poverty and other social problems by directive and supervisory means (p. 2)." The presumption with this approach is that the poor need assistance and should be given so, but supervisory direction should also be provided to service recipients so that they understand how to make good and appropriate life choices (Mead, 1997).

Mead contrasts "new paternalism" with traditional social welfare policies that provide benefits to the needy, but include little to no behavioral requirements along with that assistance. These traditional policies assume that when provided financial assistance, people will choose actions that conform to societal and legal norms (Mead, 1997). Mead, however, disagrees with this assumption and instead asserts that those who receive services such as welfare "need direction by others" (Mead, 1996). As he explains,

> Personalized direction apparently meets the needs of many poor adults. Research suggests that most poor people share the values of the larger society…However, their actual lifestyle often falls short of these values…Many poor adults seem to appreciate paternalism precisely because it provides the consistent, personalized direction that they have been lacking…That structure of attention makes it possible for them to achieve the orthodox values, such as work in which they already believe. The defeatism in their lives in then relieved (Mead, 2004, p. 158).

Similarly to Mead, in *Fighting Poverty with Virtue*, Joel Schwartz argues the superiority of paternalistic approaches in social welfare policy. Schwartz asserts that poverty is not so much an economic condition as a moral problem. Thus, he states, the poor would have a better chance of attaining higher economic status if they embraced middle-class virtues of diligence, sobriety, thrift, and family responsibility" (Swartz, 2000).

Schwartz is supportive of recent welfare reforms that compel recipients to work for their benefits. He sees previous welfare policies that "make no moral demand on the poor" as damaging because they deemphasize the capacity of people to improve their own standing (Swartz, 2000). He instead asserts that

> Dependency cannot be overcome by income transfers, but it can be overcome by the promotion of the habits or virtues that foster self-reliance. The "difficult engagement" of contemporary anti-poverty policy lies in its attempt to encourage the virtues of thrift and diligence (2001, p. 52).

Michael Sandel also questions "liberal" approaches to political and social policy on moral grounds. In *Democracy's Discontent: America in Search of a Public Philosophy* (1996), Sandel articulates concern regarding the state of America,

> One is the fear that, individually and collectively, we are losing control of the forces that govern our lies. The other is the sense that, from family to neighborhood to nation, the moral fabric of community is unraveling around us. These two fears—for the loss of self-government and the erosion of community —together define the anxiety of the age. It is an anxiety that the prevailing political agenda has failed to answer or even address (p.3).

Sandel states that the reigning present-day political philosophy that "freedom consists of the capacity of people to choose their own ends" is inadequate because it fails to engender a sense of community and civil engagement (2005, p. 10). He instead advocates for a more traditional republicanism where, freedom is not only “self-rule” but is also sharing in self-government. As he states of freedom,

> It involves deliberating with fellow citizens about the common good and helping to shape the destiny of the political community. But to deliberate well about the common good requires more than the capacity to choose one’s own ends and to respect other’s rights to do the same. It requires a knowledge of public affairs and also a sense of belonging a concern for the whole, a moral bond with the community whose fate is at stake. To share in self-rule therefore requires that citizens possess, or come to require, certain civic virtues (2005, p. 10).

Sandel also takes issue with the neutrality assumed in the liberal notion of freedom and “the good life” (1996). He states that liberal values are based on tolerance, fair procedures, and respect for individual rights. Therefore, role of government in the liberal tradition is to remain neutral on controversial moral and religious ideals and instead provide a framework of rights and entitlements within which people can choose for themselves (Gergen, 1996).

It is Sandel’s view that these liberal values have led to feelings of disempowerment and disillusionment among the citizenry. He instead believes that moral ethics and civic responsibility should play a central role in government and politics. As he states,

> republican politics cannot be neutral toward the ends it citizens espouse. The republican conception of freedom, unlike the liberal conceptualization, requires a formative politics, a politics that cultivates in citizens the qualities of character that self-government requires (2005, p. 10).

Counterarguments to Paternalism

One of the chief criticisms of the paternalistic approach it that it has a moralistic, blaming orientation (O’Conner, 2002; Page & Simmons, 2000; Schram, 2000) As stated by O’Conner (2002),

> At its worst the New Paternalism promotes a form of moralism that encourages making an example of single parents for the good of the community…stigmatizing “illegitimacy” victimizes the parent and children who cannot reverse the situation and who need support and not moral condemnation…Such attempts to “normalize” the behavior of targeted groups can become too sweeping and counterproductive (p. 6).

Additionally, Schram (2000) states that the paternalistic approaches miss the mark in that poverty is not a result of poor moral character or a lack of personal responsibility, but rather a changing economic reality in the United States where there is persistent poverty, inequality, and failing manual labor market. These sentiments are echoed by Page and Simmons (2000) who quote figures in the late 1990s that over 5.6 million children live in poverty despite having at least one parent who worked over 50 weeks a year.

As for Sandel’s call for a more formative politics, many critics cite the complexity of developing a “community” ethic of civil and moral responsibility in a pluralist country such as the United States. As stated by Benier (1998),

> contemporary America, with all its ethnic and racial heterogeneity, is vastly different from the social conditions that characterized Tocqueville's America….there is no way of guaranteeing that different kinds of community will not make contradictory rather than complementary claims upon their members (p.4).

Others assert that the call for community ethics that fail to acknowledge individual differences can be equally as damaging to a nation,

> Intolerance and a lack of respect for diverse values and modes of family life are every bit as great a threat to contemporary American life as the excesses of individualism that Sandel fears. Many of those who suffer from intolerance, or from an indifference which renders them invisible, will find that talk about rights facilitates the articulation of their submerged narratives. Sandel espouses tolerance and diversity, but the false dichotomy between individual rights and communal attachment upon which he bases his discussion …undermines the possibility of realizing those laudable goals (Shanley, 1998, p. 247)

Reflections on Paternalism

In contrast to the liberty and empowerment rhetoric, Mead, Schwartz, and Sandel see the merits of directive and supervisory social welfare programs of government. Both Mead and Schwartz emphasize a legitimate role of government in enforcing socially-appropriate behavior among those receiving state assistance. Sandel further stresses that the only way to forestall further community disillusionment is for government to play a formative role in developing the moral and civic ethics of citizens. The question then becomes, how does paternalism relate or contribute to a discussion on self-determination? Is it sufficient to state that self-determination is a critical response to the concept of paternalism?

The next section traces the multidisciplinary evolution of the concept of self-determination and how various disciplines have influenced how self-determination is currently understood in disability policy studies. This section also illustrates that current understandings of self-determination do not solely reflect a contrasting relationship between paternalism and self-determination, but somewhat of an interdependence between the two terms. In each of the disciplines highlighted including political theory, social work theory, psychological theory, and disability policy studies discussions of self-determination are often coupled with references moderating paternalistic influences.

Models of Self Determination

Self-Determination in Political Theory

Self-determination and popular sovereignty. In modern political theory, the term self-determination is understood to mean the free determination of political status by individuals. The term began to take shape in the early eighteenth and nineteenth centuries as communities began to refuse to consent to, or accept any longer, the exercise of power over them by a ruler or governmental authority which they considered to be 'alien' (Cassese, 1995; Mustgrave,1997; Raič, 2002).

At the beginning of the eighteenth century, political and administrative power had become highly concentrated in many European countries and political debate predominantly centered around issues of political sovereignty, liberty, constitutionalism, and the idea of a free society governed by laws (Mustgrave, 1997). In England, revolution in the 17th century resulted in the replacement of one ruling monarchy by another, thus clearly diminishing the power and influence of the monarchy in that country. While in 18th century France, political forces were also coming together to change the power and influence of the monarchy. With the outbreak of the French Revolution in 1789, the feudal social and political order of the country was completely overthrown and monarchial authority was replaced by the doctrine of popular sovereignty (Raič, 2002).

The concepts of liberty, representative government, and popular sovereignty also influenced American thinkers during the eighteenth century (Cassese, 1995). As stated in the Declaration of Independence of the United States of America of 4 July 1776,

> We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty, and the pursuit of Happiness. That to secure these rights, Governments are instituted among Men, deriving their just powers from theconsent of the governed.

Self-determination in international policy. In the early 20th century the concept of self-determination began to be expanded into international politics and policy (Cassese, 1995). Toward the end of World War I, both the Bolsheviks and President Woodrow Wilson spoke of self-determination, but each used the term in a slightly different way. The Bolsheviks conceptualized the term similarly to those discussed above. That is, they saw internal national discord resulting from 1) the domination of individuals by autocratic governments and 2) political/ethnic majority groups oppressing minority groups (Archibugi, 2003). Although Wilson spoke of self-determination regarding freedom of political status, he also saw the term as taking on a greater meaning as well. He saw self-determination as not only a right of people to choose the form of government under which they would live, he also saw it as a rationale for the redrawing of national borders into state communities that were ethically, culturally, and linguistically homogeneous in accordance with national desires (Archibugi, 2003; Cassese, 1995).

Self-determination and indigenous peoples. Self-determination also has been used to discuss the preservation of indigenous cultures. In 1945, the concept of self-determination gained strong support from several nation states who were under colonial rule. From there it was eventually incorporated into two places in the United Nations Charter (articles 2[4] and 55) and is cited as authority for the General Assembly's call for "the granting of independence to colonial countries and peoples" in Resolution 1,514 (XX) of 14 December 1960 (Beitz , 1979; Moris, nd). The principle has rapidly been accepted as a main principle of international law appearing everywhere from the International Court of Justice advisory opinions to the charters of regional organizations to a significant number of major international conventions (Beitz , 1979; Moris, nd).

Additionally, the term has been pivotal in the evolution of the United States governmental policy towards Native Americans. During the Kennedy and Johnson administrations (1961-1968) and later expanded upon during the Nixon and Ford administrations (1969-1976), a policy called “self-determination” began to emerge (Riggs, 2002). In this context, self-determination meant tribal self-rule, the survival of the Native American culture, and economic development and self-sufficiency for Native American communities (Cook, 1994). Self-determination policy was codified in the mid-1970s with the passage of the Indian Self-Determination and Educational Assistance Act and the Indian Child Welfare Act, which directed the bureau to shift its efforts from paternalism and control, to service to tribes in their quest for greater self-determination (O’Brien, 1996).

Self-determination continues to play a role in Native American policy today. In December 2005, Native Americans were one of the many indigenous peoples advocating for self-determination at the 11th session of the U.N. Working Group on the draft

Declaration on the Rights of Indigenous Peoples. As stated by said Robert "Tim" Coulter, an attorney who directs the Indian Law Resource Center in Helena, Montana and Washington, D.C,

> What we want is the right of indigenous peoples, as distinct groups, to be self-determining and self-governing in our own right, not only as part of the countries where we are located. We are fighting to win a real right to self-determination: to determine our own futures, our own laws, our own development. This right is not fully recognized in international law. We must now bring that into reality and make it part of international law and domestic law as well (Taliman, 2005).

Conflicts with self-determination in political theory. Although self-determination has been prominent in political theory, the term is not without its controversies. Self-determination has been, and continues to be, the subject of considerable criticism (Brahm, 2003). Many feel the term is vague and ill-defined (Bietz, 1979; Brahm, 2003; Moris, nd). As stated by Simpson,

> Clearly, then self-determination at present lacks both definition and applicability. If the principle is to be salvaged from its descent into incoherence there must be renewal of the link between autonomy, democracy, human rights, and the right of self-determination….in this way self-determination would be galvanized and rescued from the theoretical confusion and political misuse that has dogged it in recent decades (1996, p. 45).

There is also continuing debate in political theory regarding a nation state's role in limiting or promoting self-determination (Ericson, 1984). In question is whether government by its very structure is paternalistic and limits self-determination or if government should play an active role in securing self-determination for citizens. Societal legal structures are created to provide guidelines for the conduct of citizens and to provide punishments for those who do not follow the established rules. These rules can impede, or certainly temper, individual self-determination (McCloskey, 1965). However, the alternate view is that the state should assume a “positive posture” in minimizing inequalities in society so that all citizens can have equal access to liberty and self-determination (Ericson, 1984).

Additionally, there is an unresolved conflict between the right of self-determination and the principle of territorial integrity of the sovereign state (Beitz, 1979, Brahm, 2003). From a human rights perspective, there is often international support for the principle of people having more control of their lives. However, when there are calls for action from minority groups or indigenous peoples, national governments are often challenged with the complexities of putting the ethic of self-determination into practice (Beitz, 1979; Brahm, 2003; Parker, 2000).

Self-Determination in Social Work Theory

As in political theory, self-determination in social work theory is rooted in the concept of individual liberty but it also incorporates many aspects of empowerment theory in its meaning. Client self-determination is defined in social work as an individual’s innate right to make choices and decisions in those areas that affect his or her life (Biestek & Gehric, 1978). Hancock (1997) identified four central responsibilities for social workers, when implementing the principle of self-determination in social work practice: 1) helping the client see his/her needs clearly and with perspective; 2) informing clients of pertinent resources; 3) activating the client's own ‘dormant’ resources; and 4) facilitating the client's pursuit of his/her needs through the helping relationship (Weisman, 2003).

In order to gain a clear understanding of how the concept of self-determination in social work is understood today, it is important to look at its beginnings and how the term has evolved over the past century. The professionalization of social work was beginning in the early 1920s (Axinn & Stern, 2005). During this time, the concept of self-determination began to appear in the social work literature. For example, in casework literature five descriptive phrases were used to designate the generic concept of client freedom including, “client participation, client responsibility for plan-making, self-help, self-direction, and self-expression (Biestek & Gehric, 1978).

With the rise of totalitarian governments in the decade of the 1930s, the importance of the concept of self-determination in social work practice was further reinforced. The reaction of social work practioners among other American citizens, to these political events, was to reaffirm democratic principles and inalienable rights of individuals (Perlman, 1975; Wehmeyer, et al., 2003). Concurrent with tumultuous world events, the economic depression was raging in the United States. As Perlman (1975) states,

> What we social workers saw for the first time was that people who were or could have been friends or relatives, who were like ourselves in background, social status, education, mores-such people in large numbers were suddenly subject to circumstances that, despite our lip-service to the contrary, we had reserved for people who were not like us. ..Each of us thought, “There but for the grace of God go I,” and each of us quaked and rebelled inwardly against the evidence that loss of economic self-dependence can mean loss of self-esteem and self-identity. So we underlined and reiterated ‘the client’s right to self-determination’ as the basic safeguard to his integrity (p. 67).

From the 1930s to the 1950s the concepts of client freedom and self-determination were further clarified and incorporated into practice. During this period, the rights of clients were expanded beyond a “participation” role to where people were viewed as having a chief responsibility in their own plan development (Biestek, 1975). In later decades, socioeconomic events such as the Korean and Vietnam wars and domestic civil rights struggles, new knowledge from the fields of psychology and cultural anthropology, and new social work practice models brought different nuances to interpretation of self-determination in social work (Biestek & Gehric, 1978).

Today, the social work profession holds the right of client self-determination among its highest values (Tower, 1994). The National Association of Social Worker’s Code of Ethics (1996) states that social workers are ethically responsible to “respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals.”

Self-Determination debates in social work theory. As seen in other disciplines, the incorporation of the principle of self-determination in social work practice has not come without debate. As stated by Rothman (1989), “client self-determination” may be the most confounding concept in the intellectual underpinnings of social work (p.598).”

The practice of social work can be viewed as one of the methods by which society secures control over or conformity by individuals and groups; thus paternalistic. This seems to be in direct conflict with the concept of self-determination (McDermott, 1975; Whittington, 1975). Additionally, competing priorities of self-determination and protection from harm to self or others continues to confound the field (Robison, Reeser & Reeser, 1999). Taylor (2002) states, “All of this debate about paternalism and beneficence versus self-determination has caused some social work authors to question the utility of the concept for social work at all (¶8).” Once again, there seems to be competing priorities between liberty and paternalism in the discipline of social work.

Self-Determination in Psychological Theory

Within social work, definitions of self-determination go beyond individual liberty and include aspects of empowerment. Similarly, in psychology, self-determination also is grounded in the concept of individual liberty but it particularly emphasizes one aspect of empowerment, called “causativity” (Bakan, 1996). Causativity involves deliberate action and includes “creating, authoring, planning, intending, transforming, and originating” (Bakan, 1996).

During the 1930s, 1940s, and into the 1950s, several psychologists devoted their studies to the holistic understanding of the human personality, giving significant attention to the individual’s movement toward self-actualization and manipulation of the environment (Warmoth, 1998). One of the first psychologists to explore the concept of the self and self-governed actions in detail was Angyl. In the text, Foundations for a Science of Personality, Angyl (1941) asserted that a chief characteristic of all living organisms is autonomy, which he defines as self-governing or governed from inside. As Angyl states, “without autonomy, without self-government, the life process could not be understood (p.34).”

It was not until Edward Deci and his colleagues proposed a theory of self-determination in the mid-1970s that the concept was fully explicated in the field of psychology. Self-determination theory (SDT) is a theory of human motivation that focuses on the development of functioning of personality. It is primarily concerned with the degree to which humans control their actions by choice (Deci & Ryan, 2000; Deci & Ryan, 1985).

SDT contends that all individuals have natural, innate psychological needs for autonomy, competence, relatedness, and are driven to master on-going challenges and to incorporate their experiences into a unified sense of self (Deci & Ryan, 2000; Malhotra, 2004; Neighbors & Knee, 2003). When these needs are satisfied, one has enhanced self-motivation and mental health. Conversely when one's ability to satisfy needs is blocked, motivation and well-being will be diminished (Deci & Ryan, 2000).

Deci describes self-determination as people's ability to choose among behavioral options and to accommodate to the situations in which only one option is available. One can be said to be nonself-determining if he or she behaves automatically, not accommodating and responding flexibly when only one behavioral option exists (Deci & Ryan, 1985).

In discussing self-determination, Deci made an important distinction between self-determination and control. He sees control as a person's ability to achieve a particular outcome; it may be operationalized as success at an activity, being the boss, or making decisions for others. He conceptualizes self-determination as related, but with important differences. Self-determination is the freedom to decide for oneself and choose one's own behaviors in accordance with his/her needs, feelings, and thoughts. Being the boss or succeeding at a task will often leave people feeling self-determining, yet one need not be the boss in order to feel self-determining. Therefore, self-determination is often achieved though control, but control does not assure self-determination (Deci & Ryan, 1985).

Limits of self-determination in psychology. Deci's conceptualization of self-determination clearly added new dimensions to the construct within the field of psychology. However, there is some debate about the impact of self-determination on the individual. As stated earlier, it is Deci's assertion that with enhanced self-determination comes improved well-being and mental health. In contrast, others contend that increased opportunities for self-determination can have a detrimental effect on a person and even lead to increases in dissatisfaction and even clinical depression (Schwartz, 2000).

As Schwartz (2000) states,

> I have tried to suggest, however, that there is a dark side to all this freedom from constraint, to all this emphasis on individuals as the makers of their own worlds, their own destinies. It leaves people indecisive about what to do and why. Freedom of choice is a two-edged sword, for just on the other side of liberation sits chaos and paralysis. Thus, there is a price for freedom-danger. There is a price for enlightenment-uncertainty….Thus, in aspiring as a culture to offer individuals self-determination without constraint, we are not doing those individuals a favor (p. 87).

Self-Determination in Disability Studies

As with the other disciplines discussed, concepts such as individual liberty, empowerment, and causativity are clearly seen in how self-determination is defined within disability policy studies. Additionally, many social and political factors have influenced the evolution of the concept over the past 35 years.

In the first half of the 20th century, the way people with disabilities were treated in the United States was significantly impacted by the countries' involvement in two world wars. As soldiers with disabilities returned home, society made provisions for them to re-enter the work force. The US Congress passed the first vocational rehabilitation acts in the 1920s to provide services and supports to World War I veterans with disabilities. The most significant changes, however, came with the civil rights movements of the 1960s. As African Americans, women and other social minorities gained political influence, so, too, did people with disabilities (United States Information Agency, 1999).

Development of self-determination in disability studies. The concept of self-determination for people with disabilities has its historical roots in the normalization, independent living, disability rights movements of the 1960s and 1970s and the self-advocacy movement of the 1980s (Wehmeyer & Schwartz, 1998). Self-determination first appeared in the disability literature in 1972, in a chapter of a book on the principle of normalization by Wolfensberger. Nirje's chapter, "The right to self-determination," was a response to what he believed to be the limitations that institutional life placed on individuals with disabilities. He asserted one's identity is shaped through individual circumstances and experiences, thus people with disabilities should be given the opportunity for training in self-assertion, community experience and independence so that they can have the opportunity to develop into fully realized individuals (Nirje, 1972).

The independent living movement was also foundational in the development of theories of self-determination. Shreve (1982) hypothesized the social movements of the 1960s and 1970s significantly contributed to independent living for people with disabilities. Lastly, the self-advocacy movement of the 1980s also significantly influenced the evolution of self-determination theories. Self-advocacy can be defined as a social movement organized and controlled by people with disabilities who actively promote the efforts of people with disabilities to achieve equality, independence, and recognition as full-participating members of society; and to work to ensure and protect legislated civil rights and basic rights of consumer participation (Rhodes, 1986). As with the normalization and independent living movements, the self-advocacy movement was, and continues to be,

> focused on the struggle for a life of quality in places and communities chose by individuals with disabilities, for more and better services controlled by people with disabilities, and for greater social and political awareness in the disability community as a whole (Cone, 1997, p.145).

With the independent living and the self-advocacy movement, the concepts of self advocacy and self-determination moved beyond individual or personal aspects of self-determination into an empowerment and "rights" orientation typically associated with the sense of the term as a national or political construct (Wehmeyer et al., 2003).

*Self-Determination theory in special education and rehabilitation***.** The growth and development of self-determination theories was additionally strengthened by a federal initiative of the late 1980s. The U.S. Department of Education, Office of Special Education and Rehabilitation Services (OSERS) funded 26 self-determination demonstration projects to focus on system-wide activities that would help children with disabilities be *self-directed decision makers*. Follow-up studies demonstrated the positive impact that self-determination can have on students with disabilities—especially in middle and high-school levels (Case, 2004; Ward, 1996).

In the special education and vocational rehabilitation fields, several constructs of self-determination have emerged. Wehmeyer (1996) asserts that,

> for purposes of education and rehabilitation, self-determination is: 1) best defined in relationship to characteristics of a person's behavior, 2) viewed as an educational

> outcome, and 3) achieved through lifelong learning, opportunities, and experiences (p. 22).

As with Ryan and Deci in the discipline of psychology, Wehmeyer, et al. (2003) stress that their conceptualization of self-determination may involve, but is not synonymous with, independence and autonomy. What they consider key to the construct is that an individual determines the context and the extent to which each of their chosen "self-determined" behaviors will be manifested. Also, the authors see self-determination as a product of both the individual and the environment in which that person lives (2003).

Wehmeyer (1996, 1997, 1998) and Wehmeyer et al. (1996) propose four essential characteristics of self-determined behavior:

> (1) the person acts autonomously,
> (2) the behavior(s) are self-regulated,
> (3) the person initiates and responds to event(s) in a psychologically empowered manner, and
> (4) the person acts in a self-realizing manner.

Therefore, individuals can be described as self-determined based on the functional characteristics of the behavior (Wehmeyer, 1998).

Similarly to Wehmeyer et al., Abery and Stancliffe (1996) emphasize the complexity of self-determination and see it as developing from a "dynamic interaction between the individual and the environment." Focusing on the external influences to self-determination they assert that environmental accommodations and support can be used to foster self-determination in individuals. As they state,

> if environmental accommodations and support can be used to enhance self-determination, even for those with severe disabilities or who are very young, a

> myriad of interventions possibilities open up that have yet to be considered. No longer will interventions need to solely be conceptualized as efforts to change the person. Rather, they can focus on providing individuals with the environmental accommodations they need to take greater control over their lives (p.137).

Doll, Sands, Wehmeyer, and Palmer also assert that self-determination emerges as children, youth, and adults develop and acquire skills that allow them to be more independent and deliberate (1996). Thus, harkening back to the work of Nirje, they contend that limited opportunities to practice skills necessary for self-determination at early ages can substantially constrain adolescents in the expression of self-determined behaviors (Doll et al., 1996).

In their discussion of self-determination, Erwin and Brown (2000) stress that self-determination skills are on a continuum and that nature, disposition, and the personality of an individual all influence self-determination. Thus, self-determination does not mean having complete control over every aspect of life, because no one has total control. It instead represents variations in personality and skill and the degree to which support is available for an individual (Erwin & Brown, 2000).

Turnbull and Turnbull (2001) emphasize how culture influences self-determination and that many definitions of self-determination are rooted primarily in an Anglo-European ethnic orientation. They assert the process of choosing how to live one's life should respect and honor the individuals and their family’s cultural values including values pertaining to parental authority over child choice and collectivism over individualism (Turnbull & Turnbull, 2001).

Self-Determination in services and supports for adults with disabilities. As the development of self-determination in the education and rehabilitation communities was spurred on by a federal OSERS initiative, the Robert Wood Johnson Self-Determination projects expanded the conceptualization of self-determination in the world of adult services and supports for people with disabilities. In the early 1990's, the Robert Wood Johnson Foundation awarded a three year grant to Monadnock Developmental Services of Keene, New Hampshire, to address three major problems in New Hampshire's developmental services program: the high costs of care, increasing waiting lists, and consumer dissatisfaction with the ways in which support was provided (Conroy & Yuskauskas, 1996; Nadash, 1998).

Building on the success of this project, the Foundation further allocated over $5 million to 19 states to support a range of demonstration activities around the country aimed at exploring the ways in which people with developmental disabilities could influence the character and configuration of the supports they receive through self-determination. With an emphasis on individual choices and preferences at the center of each of the 19 demonstrations, this initiative represented a significant departure from conventional practice (Bradley et al, 2001).

From the work of these projects, a theory of self-determination began to emerge in the context of adult supports and services for people disabilities. Nerney and Shumway (1996) identify several key value-based principles in this theory. These include,

> 1. FREEDOM: The ability for individuals with freely chosen family and or friends to plan a life with necessary support rather than purchase a program;
> 2. AUTHORITY: The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;
> 3. SUPPORT: The arranging of resources and personnel--both formal and informal--that will assist an individual with a disability to live a life in the community rich in community association and contribution; and
> 4. RESPONSIBILITY: The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities.
> 5. CONFIRMATION: Recognizing that individuals with disabilities must play a major role in the development and implementation of self-determination policies.

In this conceptualization, self-determination is not just another “program,” for individuals, but instead a reform of supports that changes the structure of how human services organizations operate (Nerney, 2005).

However, Bradley (2000) asserts that a value-based approach emphasizing the preferences of people with disabilities is not enough to change the direction of a service system. She contends that a *functional shift* in power over resources is needed. Thus, she includes individually controlled budgets that can be dispersed based on an agreed on person-driven plan as an essential aspect of self-determination. Additionally, so that people receive the information necessary to make decisions in their best interests, a form of service brokerage carried out by individuals without a direct interest in the choices made by participants is also identified by Bradley as a vital characteristic of self-determination (Bradley, 2000).

Therefore, self-determination in the context of supports and services for people with disabilities is discussed from two perspectives, a value-based perspective and a functional perspective (Turnbull & Turnbull, 2006). The *value-based* definition of self-determination centers on the guiding principles of individual freedom, decision-making authority, adequate and appropriate supports for community living, and exercising social and civic responsibility. The *functional definition* of self-determination is more specific, relating to the realization of greater levels of choice and control over paid supports (Turnbull & Turnbull, 2006). It is with this functional definition where the concept of self-determination intersects with consumer-directed services.

With the advancement of the functional definition of self-determination, the term became closely aligned with self direction or consumer direction and it was understood in the context of Medicaid services and support. As highlighted earlier, consumer direction is a philosophy and orientation to the delivery of home and community based services in which individuals receiving services make informed choices about the services they receive including: assessing their own needs; determining how and by whom these needs should be met; and monitoring the quality of services received (National Institute on Consumer-Directed Long-Term Services, 1996).

Common features of self-directed or CD services include the authority and accountability of the service user; individualized, person-directed support planning; user selection, training, and supervision of support providers; limited oversight by professionals; flexible benefits needed to maintain the person's health and quality of life in the community; individualized funding of support plans and user authorization of payment; and user monitoring of care quality (DeJong, Batavia, & McKnew, 1992; Fenton et al., 1997; Kane, 1996; Powers et al., 2002; Scala & Mayberry, 1997).

Conflicts with self-determination in disability policy. As with the other disciplines previously discussed, self-determination is also subject to criticism in the disability field. As described by Waldschmidt (1999) self-determination,

> easy to be agreed upon at first glance, proves to be ambivalent at a closer look. It is open for very differing, contradicting contents, interpretations and practices. Instead of being a consistent, precisely defined constitutional right, it rather seems to be a formal construct, whose specific meaning opens up only in relation to the specific practice stemming from it, which itself is dependent on societal and institutional contexts (p. 9).

Additionally, there continues to be debate on how to operationalize self-determination for people with disabilities. A central component of self-determination is autonomy and autonomous decision-making. As stated earlier, many people with significant disabilities are legally deemed “incompetent” to make decisions and appointed a legal decision-maker or guardian. This practice can be viewed as somewhat contradictory to the ethic of self-determination. As stated by Nerney (2000), “this formal stripping away of rights guaranteed by the constitution and the Bill of Rights presents a formidable obstacle to the exercise of self-determination.” Thus, the conflicting priorities of protection from harm and ensuring individual liberties is also apparent in the disability studies field.

Also, as pointed out by Maskos and Siebert (2006), increased self-determination can be a “double-edged sword.” People may have unrealistic expectations for self-determination and assume living in a self-determined way means that people with disabilities need no additional accommodations or supports from the general society in order to live as part of communities. In this sense, self-determination is viewed as living independent of assistance, which is not only difficult for people with disabilities, but for all members of society. As stated by Maskos and Siebert (2006),

> A lot of disabled people feel as though they are being held in a two-class society, in which the larger responsibility offered as a widened range of action through self-determination, feels rather as a burden on them than a new kind of freedom. As long as societal conditions aren't truly meeting the needs of disabled people, the conception of self-determination won't be able to get rid of its shadow of heteronomy (¶50).

Review of Theoretical and Multidisciplinary Influences

Definitions of self-determination in political theory, psychology, and social work have clearly influenced how the concept has evolved in disability studies. Table 4 details definitions of self-determination in each of these disciplines.

Table 4. Definitions of Self-Determination and Key Concerns

Discipline	Definition of Self-Determination	Key Concern
Political theory	Free determination of political status by individuals	What should government's role be in promoting/limiting self-determination?
Social Work Theory	Individual's innate right to make choices and decisions in those areas that affect his or her life	Should the primary function of social work be client protection or the promotion of self-determination?
Psychological Theory	Degree to which humans control their actions by choice	What are the limits to self-determination? Is excess self-determination psychologically healthy?
Disability Policy Theory	Individuals act in a psychologically conscience and empowered manner and are able to determine the context and the extent to which they want to make choices for their life and for their services and supports	Should government programs that support people with disabilities be primarily concerned self-determination or protection? What are the limits on self-determination for people with disabilities? Are people, especially those with intellectual disabilities, capable of making informed choices?

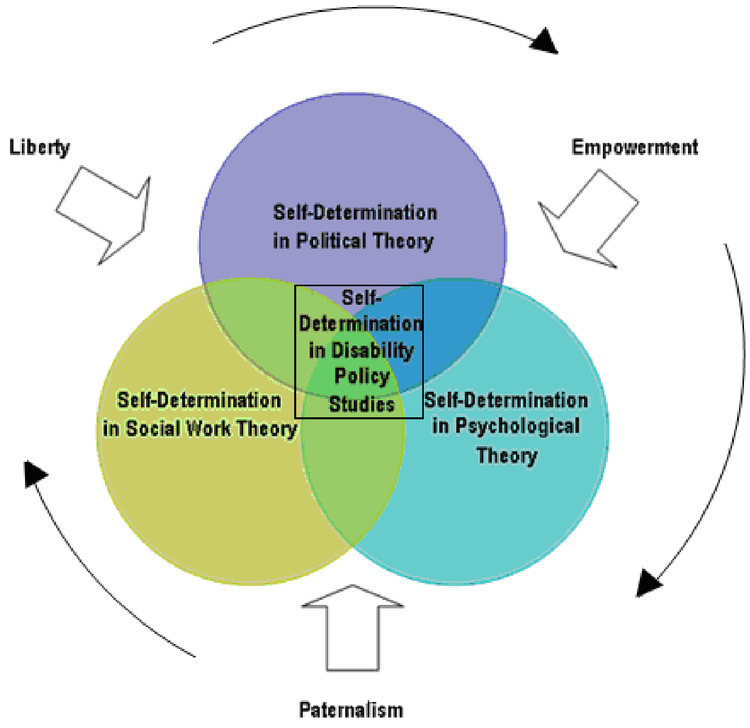
Each discipline’s definition of self-determination encompasses aspects of liberty, empowerment, freedom, and an ethic of individual control. However, there is also a key difference. While self-determination in political theory specifically focuses on the free determination of political status, social work and psychological theories of self-determination mirror the more broadly applied definition of self-determination in disability policy which addresses individual choice and control in all facets of one’s life.

Additionally, as demonstrated in the “key concern” column, scholarship about each of these theoretical models highlights lingering questions regarding the limits of self-determination. In political theory, concerns remain regarding government’s role in promoting or limiting self- determination. Specifically, should government restrict individual freedom and self-determination (ie. exercise paternalism) to preserve liberty for the nation as a whole? Additionally, some believe that government should go a step further and have a “formative,” role with its citizenry, enforcing particular behaviors and developing the moral and civic ethics of citizens. This type of active, and some might argue paternalistic, role for government in shaping behaviors clearly conflicts with the value of promoting individual self-determination.

Within the “human studies” fields of psychology, social work, and disability policy studies there is an evidenced commitment to the ethic of self-determination. However, structures have also been established in each of these disciplines to again “protect” the good of the individual by limiting the exercise of self-determination. Thus, while self-determination appears to be a fundamental value in many areas, it often exists in tandem with a corresponding value in paternalism.

Figure 2 further depicts the interrelationships among each of the discussed disciplines and their interaction the influences of paternalism, empowerment, and liberty (see Figure 2).

Figure 2. Influences on Self-Determination Theory in Disability Policy Studies



As demonstrated throughout this chapter, self-determination theory in disability policy studies shares many of the central ideas of self-determination as defined in social work, psychological, and political theories. Figure 2 illustrates the interrelationship between the various definitions of the term. Additionally, while the concepts of liberty and empowerment heavily influence understandings self-determination, in its application the concept is also tempered by paternalistic concerns in each of the disciples discussed.

Theoretical Model Guiding this Dissertation

The guiding theoretical model for this dissertation is self-determination theory as it relates to supports and services for people with disabilities. Specifically, a *functional* aspect of self-determination, consumer-directed control over the management of Medicaid-funded personal assistance services is the subject of this research. In question is whether a state controlled Medicaid support such as CD personal assistance services can truly promote individual choice and control. Or, does the competing priority of federal Medicaid policy to protect the health and safety of participants curtail choice and impact service recipients' satisfaction with CD services? These questions will be examined in a study of CD personal assistance services in Virginia's HCBS Waiver programs.

III. Research Design and Methodology

The purpose of this study is to describe how individuals from different Medicaid HCBS Waiver groups access, use, exercise choice and control, and report satisfaction with CD personal assistance services in Virginia and to examine if there are differences among groups. Of particular interest is whether participants report that CD services enable them to determine the context and the extent to which they want to make choices in their supports (ie. facilitate self-determined decision-making) as is the goal of consumer direction (Kosciulek, 1997; Nadash & Crisp, 2004; NCD, 2004; Tritz, 2004).

Data for this analysis were gathered through surveys conducted in a structured interview format with service recipients of Virginia's MR, DD, and EDCD Waivers aged 18 and above. Hypotheses will be tested using Fisher's exact test, Mann-Whitney U test, and one-way and factorial analysis of variance (ANOVA) for quantitative data. Content analysis will be used for qualitative data. The survey instrument is in Appendix A.

The central research questions examined in this analysis are:

1. Overall, do CD personal assistance services facilitate self-determined decision-making.

2. Are there differences in how CD services facilitate self-determined decision making among waiver groups receiving CD personal assistance services in Virginia?
3. Are there differences among waiver groups in how they *access* CD services?
4. Are there differences among waiver groups in how they *use* CD services?
5. Are there differences among waiver groups in how they *exercise choice and control* over CD services?
6. Are there differences among waiver groups in how they report *satisfaction* with CD services?

Hypotheses

Hypothesis 1

As detailed in “Previous Research on Consumer Direction,” multiple studies on consumer direction have evidenced that this service delivery option promotes individual choice-making and consumer control over services among a range of disability groups including people with intellectual disabilities and other developmental disabilities, physical disabilities, and the aging (Beatty et al.,1998; Conroy & Yuskauskas, 1996; Doty, 2000; Foster et al., 2002; Young & Sikma, 2003; Carlson et al., 2007). Based on this research the following hypothesis is proposed:

H_1- Individuals who receive CD personal assistance services from Virginia’s MR, DD, and EDCD Waivers will report that this service delivery option facilitates self-determined decision-making

Independent Variable: *Choice and Control*. For the “Choice and Control” scale, the questionnaire contains a series of items about the extent to which CD services enables service recipients to have more choice and control with their personal assistance services. Items in this scale include (the item number on the survey instrument is noted in parentheses):

- (Q38) I can work with my CD personal assistant to change his/her schedule.
- (Q39) My personal assistants do what I ask them to do.
- (Q40) I feel that I'm in charge of my personal assistants.
- (Q41) I am happy with the times of day that my personal assistants come to help me.
- (Q42) I am happy with the way my personal assistants help me with my personal care.

Independent Variable: *Satisfaction*: For the “Satisfaction” scale, the questionnaire contains a series of items regarding the consumer’s satisfaction with CD personal assistance services and quality measures. Items in this scale include (the item number on the survey instrument is noted in parentheses):

- (Q45) I am able to be more independent [do the things that I want to do] because of my CD personal assistance services.
- (Q46) I can do more things in the community because of my personal assistance services.
- (Q47) My CD personal assistance services have made it easier for me to go to work or to school.

- (Q48) I would tell a friend that they should try to get CD personal assistance services.
- (Q49) I am happy with my CD personal assistance services.
- (Q50) I am more in charge of my life because of my CD personal assistance service.

Dependent Variable: *Facilitating Self-Determined Decision-Making* as identified through level of agreement measured in a 4-point Likert-like scale from 4 (Agree Very Much) to 1 (Disagree Very Much).

Hypotheses 2-5

In Virginia, each waiver group receives CD services from different waiver programs governed by different Medicaid regulations and supported by different service structures. Additionally, participants in each waiver program have different primary disabilities with varying levels of support needs. These differences are anticipated to result in dissimilarities among waiver groups in how they access, use, exercise choice and control, and experience satisfaction with CD services. Based on this rationale the following hypotheses are proposed:

H_2-There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers access CD services.

Independent Variable: *Waiver Program*. Waiver program is identified through question #8 on the survey instrument, “Through what Medicaid waiver do you get CD personal assistance services?" Choice options are the MR Waiver, the DD Waiver, and the EDCD Waiver.

Dependent Variables: *Access*. For the "access to services" scale, the questionnaire contains a series of items concerning how consumers gained knowledge about CD services. Items in this scale are (the item number on the survey instrument is noted in parentheses):

- (Q13) It was easy to find out [get information about] CD assistance services.
- (Q14) Before starting to use CD services, I got enough information about how CD services worked.
- (Q15) The information I was given (for example brochures or other material) helped me to understand my job responsibilities as a CD employer (like hiring my personal attendant, and paperwork).
- (Q16) My CD facilitator helped me to understand my job responsibilities as a CD employer.
- (Q17) It was easy to find a CD service facilitator to work with me.
- (Q18) The CD services facilitator did a good job of explaining to me how CD services work.

The Access response set is measured by a 4-point Likert-like scale from 4 (Agree Very Much) to 1 (Disagree Very Much).

H_3-There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers use CD services.

Independent Variable: *Waiver Program*. Waiver program is identified through question #8 on the survey instrument, “Through what Medicaid waiver do you get CD personal assistance services?” Choice options are the MR Waiver, the DD Waiver, and the EDCD Waiver.

Dependent Variables: *Use*. For the “Use” scale, the questionnaire contains a series of items about implementing CD services. Items include (the question number on the survey instrument is noted in parentheses):

- (Q25) It was easy to fill out the paperwork to hire my personal assistant.
- (Q26) I have enough personal assistance services to meet my support needs
- (Q27) If I need to increase my CD personal assistance hours, I can increase my hours easily.
- (Q28) The hourly pay for my CD assistant is enough for the job he/she does.

The Use response set is measured by a 4-point Likert-like scale from 4 (Agree Very Much) to 1 (Disagree Very Much).

H_4-There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers will report how much choice and control is afforded to them through CD services.

Independent Variable: *Waiver Program*. Waiver program is identified through question #8 on the survey instrument, “Through what Medicaid waiver do you get CD personal assistance services?” Choice options are the MR Waiver, the DD Waiver, and the EDCD Waiver.

Dependent Variables: *Choice and Control*. For the "Choice and Control" scale, the questionnaire contains a series of items about the extent to which CD services enables service recipients to have more choice and control with their personal assistance services. Items in this scale include (the item number on the survey instrument is noted in parentheses):

- (Q38) I can work with my CD personal assistant to change his/her schedule.
- (Q39) My personal assistants do what I ask them to do.
- (Q40) I feel that I'm in charge of my personal assistants.
- (Q41) I am happy with the times of day that my personal assistants come to help me.
- (Q42) I am happy with the way my personal assistants help me with my personal care.

The Choice and Control response set is measured by a 4-point Likert-like scale from 4 (Agree Very Much) to 1 (Disagree Very Much).

H_5 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report satisfaction.

Independent Variable: *Waiver Program*. Waiver program is identified through question #8 on the survey instrument, "Through what Medicaid waiver do you get CD personal assistance services?" Choice options are the MR Waiver, the DD Waiver, and the EDCD Waiver.

Dependent Variables: *Satisfaction*: For the "Satisfaction" scale, the questionnaire contains a series of items regarding the consumer's satisfaction with CD personal assistance services and quality measures. Items in this scale include (the item number on the survey instrument is noted in parentheses):

- (Q45) I am able to be more independent [do the things that I want to do] because of my CD personal assistance services.
- (Q46) I can do more things in the community because of my personal assistance services.
- (Q47) My CD personal assistance services have made it easier for me to go to work or to school.
- (Q48) I would tell a friend that they should try to get CD personal assistance services.
- (Q49) I am happy with my CD personal assistance services.
- (Q50) I am more in charge of my life because of my CD personal assistance service.

The Satisfaction response set is measured by a 4-point Likert-like scale from 4 (Agree Very Much) to 1 (Disagree Very Much).

Control Variables

Several variables will be analyzed as "control variables" to determine their effects the dependent variables. These variables included the consumer's (the survey question is in parentheses):

- *Age* (Q1. How old are you?)
- *Gender* (Q2. Are you: Male/Female)

- *Race* (Q3. Are you: Black, not of Hispanic origin/Hispanic/White, not of Hispanic origin/American Indian or Alaskan Native/Asian or Pacific Islander/Other
- *Length of time receiving CD services* (Q7. When did you start to get CD personal assistance services?)
- *Severity of disability* (Q12. What things *[tasks*] does your personal assistant help you with? Bathing/Meal preparation/Dressing/Shopping/Eating or feeding/Housekeeping /Toileting/Laundry/Getting around inside my home/Access to the community/ Monitoring of my health status and physical condition /Monitoring of my self-administered medications or other medical needs/Transferring between my bed and wheelchair/Other)

Open-Ended Questions

At the conclusion of the survey, several open-ended questions were posed to participants to gather specific, detailed information regarding their experiences with CD personal assistance services in Virginia. The specific questions posed to waiver participants included:

- What do you like most about CD personal assistant services? (Q51)
- If you could change one thing about your CD personal assistance services to make services work better for you, what would you change? (Q52)

Survey Development

The survey instrument was developed with an advisory group made up of individuals with disabilities who use waiver services and family members of service recipients. Several survey instruments including the Participant Experience Surveys[3] and the National Core Indicator Consumer Survey[4] served as models for the group. One drafted, the instrument was piloted with a sample of 10 CD services waiver recipients and the instrument was refined based on lessons learned from the piloting process.

Population

The participants in this study were individuals over the age of 18 who have received CD personal assistance services from the MR, DD, and EDCD Medicaid Waiver programs for a minimum of 6 months as of March 2005. Fifty individuals were randomly selected from each waiver program to be interviewed. The preferred respondent was the individual receiving CD services, however, some individuals were unable to respond to questions due to a significant intellectual impairment. A proxy, primarily the person who serves as the "employer of record[5]" for the individual receiving CD services, was asked to represent the perspective of an individual who was unable to respond to the survey.

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[3] Participant Experience Surveys (PES) are interview tools developed by MEDSTAT under a contract from CMS. The surveys capture data that can be used to calculate indicators for monitoring quality within HCBS waiver programs. Two versions of the PES have been developed, one for frail elderly and adults with physical disabilities and another for adults with mental retardation and developmental disabilities.

[4] The National Core Indicator Project developed nationally recognized performance and outcome indicators that enable developmental disabilities policy makers to benchmark the performance of their state against the performance of other states. The consumer survey collects data on work, community inclusion, choice, supporting families, family involvement, relationships, and satisfaction.

[5] If a service recipient is unable to direct his own care or is under 18 years of age, a family/caregiver may serve as the employer on behalf of the individual.

Informed consent was obtained from all participants and from legal guardians or legally authorized representatives where appropriate.

The use of proxy respondents for collecting data from people with disabilities is debated in the academic literature. One view is that a proxy respondent cannot fully understand and represent the day-to-day living of people with disabilities and is therefore a poor substitute for self-response. Another view is that a proxy respondent, while possibly biased, is preferable to no respondent at all (Mitchell, Ciemnecki, CyBulski, & Markesich, 2006).

A significant issue that has been identified with the use of proxies is in the context of answering subjective questions. In one study, interview responses of sample persons with intellectual disabilities were compared with the responses of proxy respondents. Researchers found that for objective measures there was correspondence in the responses of self and proxy respondents but correspondence was not good for subjective measures (Perry & Felce, 2002).

However, as stated by Hendershot of the Research and Training Center on Community Living, in an examination of National Health Interview Survey data,

> The high rate of proxy response for sample persons with mental retardation is not necessarily undesirable from the viewpoint of data quality. By using a proxy, interviews can be completed which would otherwise not have occurred at all. Even when a person with mental retardation could have been interviewed, a proxy may provide information of equal or better quality (2004, p. 6).

Therefore, to maximize the representation of those unable to respond to questions for themselves, the decision was made to allow proxy respondents, emphasizing self-response as the preferred method.

The population described above was appropriate for the proposed research study for a variety of reasons. The study was concerned with examining differences in how CD personal assistance services are structured, implemented, and experienced by different population groups. The chosen population included diverse representation from different disability groups, thus enabling an examination of differences among populations. Additionally, because the chosen population had had at least 6 or more months experience with CD personal assistance services, they had adequate knowledge and understanding of the service to address implementation and satisfaction questions.

Virginia was chosen as the focus state for this study for a variety of reasons. In 2004, funding was awarded to the Partnership from CMS to examine CD services in Virginia's Medicaid waivers, thus recent, relevant data were available for this analysis. Additionally, Virginia, as with many states across the nation, is planning for and implementing major expansions in the availability of CD and self-directed services to a variety of population groups. Therefore, this analysis can serve as a sound mechanism for illuminating if and how CD services are experienced differently among different population groups.

Data Collection

The protocol for soliciting participation in the survey included: 1) sending a letter to recipients of CD personal assistance services in the MR, DD, and EDCD Waivers that described the survey project and informed individuals that the Partnership for People with Disabilities would be contacting them by phone to see if they would be interested in participating in the survey, 2) randomizing the lists of CD personal assistance services recipients from each waiver program, and 3) contacting CD personal assistance services recipients according to the randomly ordered list to solicit participation in the study. If a service recipient was unable to respond to the survey due to his or her intellectual disability, participation was sought from the individual's "employer of record." When an individual or their employer agreed to be interviewed for the survey, their name was then given to an interviewer who then set up an interview place and time. Data were collected for this study from June 2005 through May 2007.

Participation in the study was entirely voluntary. Individuals who chose not to participate experienced no adverse consequences. Also, no identifying information was recorded from program participants when they completed the survey. All surveys were coded with random identifiers, thus protecting the identities of project participants. Additionally, informed consent was obtained from all research participants. The survey instrument and protocol were approved by the Virginia Commonwealth University Institutional Review Board in spring 2004.

Because interviewees included those with intellectual disabilities, special attention was given to the construction of the consumer survey instrument. Efforts were made to assure that questions and response options were worded in a simple and straightforward way. The survey was piloted with a sample of individuals using CD services, and a consumer advisory group extensively reviewed and approved the instrument. Additionally, all interviewers were required to participate in a six hour training session on interview protocols and received a training manual with all training content documented. They were also provided with prompts to assist consumers with comprehension of the survey questions. Lastly, interviewers were asked to respond to a series of questions after they finished each interview, which solicited their opinion on whether the respondent generally understood the content of the survey.

Sampling

The sample for the study was stratified by waiver program and was disproportional. The stratification of the sample ensured that the users of CD services in each waiver program were adequately represented in the sample. The sample was also "disproportional," in that 50 individuals were selected from each waiver program rather than having research subjects proportional to the number of individuals who receive CD services from each waiver program. For fiscal year 2005 (the year when the sample was selected), 426 individuals received CD personal assistance services through the MR Waiver, 166 through the DD Waiver and 751 received CD services through the EDCD Waiver.

The decision to use a disproportional sample was made because, as illustrated above, CD services in certain waivers have much larger usage rates than in other waiver programs. Therefore, in order to get adequate diversity in the sample, a disproportional sampling frame was necessary.

The sampling frame used to select the sample was a list provided by DMAS. This list contained the names of all participants in the MR, DD, and EDCD Waiver programs who received CD personal assistance services for a minimum of 6 months as of March 2005.

Data Analysis Plan[6]

To begin the data analysis, descriptive statistics and frequency distributions were conducted to get an initial understanding of the dataset. Percentages for all variables were presented and discussed. To test for significant differences between the primary independent variable (waiver group) and various dependent categorical variables in the dataset, the Fisher's exact test was used. Fisher's exact test is a statistical significance test used in the analysis of categorical data when sample sizes are small (Mehta & Patel, 1997).

To test for statistically significant differences between the mean scores in the 4 scales of *access, use, choice and control,* and *satisfaction*, the Mann-Whitney U test was used. The Mann-Whitney U is a nonparametric statistical test used to determine if a difference exists between groups. The assumptions that need to be met for the Mann-Whitney U test are the samples need to be random from the population, there needs to be independence within samples and mutual independence between samples, the data needs to be at least at an ordinal scale (Conover, 1998).

A multi-factor analysis of variance (ANOVA) was conducted that includes the main dependent variable "waiver program" and the demographic characteristics or "factors" that were found to be significantly different when the initial analysis of

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[6] An initial exploratory analysis was conducted on quantitative data to reveal possible outliers in the data, to examine features of the dataset, (e.g. symmetry, skew, scatter), to test for a normal distribution, and to determine whether parametric or non-parametric statistical tests should be used. This analysis indicated that

background characteristics was completed. The assumptions for ANOVA tests include: 1) independence of cases, 2) normality - the distributions in each of the groups are normal, 3) random sampling of cases, and 4) homogeneity of variances - the variance of data in groups should be the same (Lindman, 1974).

As noted, an exploratory analysis of the data indicated that they were not normally distributed. However, several authors have noted that the ANOVA test is robust in its ability to handle violations of the normality assumption, with little effects on the validity of the findings (Ferguson & Yoshio, 2005; Ito, 1980; Leech, Caplovitz, Barrett & Morgan, 2005; Lindman, 1974; Ofte, 2002; Scheff, Saucier & Cain, 2002). All other assumptions for the ANOVA test were met (specific results of these tests appear in Chapter 4, which details all of the research findings).

Responses to open-ended questions were analyzed through content analysis. Content analysis facilitates the production of core constructs from textual data through a systematic method of reduction and analysis (Miles & Huberman, 1994). Open-ended responses will be placed into particular analytic categories. Data will then be further coded so that more detailed indexing can be undertaken. Concepts will be further explored and indexed according to content in a process known as ‘nesting’ (Priest, Roberts & Woods, 2002). The coding scheme and definitions appear in Appendix C.

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the data was not normally distributed, thus primarily nonparametric statistical tests will be used for the analyses (specific results of these tests appear in Chapter 4, which details all of the research findings).

Research Constraints

A variety of constraints impacted the proposed research project. The project was funded as part of a grant from the CMS. The CMS grant funded approximately one hundred and fifty interviews of individuals receiving Medicaid-funded CD personal assistance services across Virginia. Interviewers were paid for each interview that they completed.

Although it was very beneficial to have grant funding, it did pose some limitations on the scope of the project. Only one-hundred and fifty interviews were conducted for the project, and there are three comparison group strata. Therefore, the sample size for each stratum was relatively small. This can be problematic because if too few subjects are used in a study, a hypothesis test can result in such low power that there is little chance to detect a significant effect (High, 2000). Thus, small sample size impacts the conclusion validity of the research study.

As the population for this study included those with cognitive disabilities, special attention was given to the construction of the consumer survey instrument. Efforts were made to assure that questions and all provided response options were worded in a simple and straightforward way. The survey was piloted with a sample of individuals using CD services and a consumer advisory group extensively reviewed and approved the instrument. Additionally, all interviewers were required to participate in a six hour training session on interview protocols and received a training manual with all training content documented. They were additionally provided with prompts to assist consumers with comprehension of the survey questions. Interviewers were also asked to complete a series of questions after they complete each interview, which solicited their opinion on whether the respondent generally understood the content of the survey. These protocols, however, cannot assure that all participants fully comprehended all aspects of the survey.

Also, as mentioned earlier, the use of proxy respondents for those individuals who are not able to respond for themselves is the subject of debate in the academic literature. A specific shortcoming of the survey instrument related to proxies was that the survey instrument did not allow the interviewer to stipulate if a proxy was responding to survey items, only if the interview included participants other than the service recipient. This made it impossible to explore response errors resulting from proxies.

One other noted constraint in this research is the time that lapsed while interviews were being conducted for this survey from 2005 to 2007. Program changes could have occurred during this period which may have caused service recipients experiences to have changed from the outset of the interview period in 2005 to the close of interviews in 2007.

Relatedly, the sample was drawn during a time of change in one of the waiver programs at DMAS. During March 2005, the Elderly and Disabled (E&D) Waiver and the Consumer-Directed Personal Assistance Services (CD-PAS) Waiver were being combined into the EDCD Waiver. While CD services were well established in the CD PAS Waiver, the ED Waiver did not include CD services. Thus, the sample of participants from the ECDC Waiver is heavily weighted towards former users of the CD PAS Waiver, which had a much longer history with CD services.

IV. Results

There were a total of 145 respondents to the survey, with 50 participants from the MR Waiver, 44 participants from the DD Waiver, and 51 participants from the EDCD Waiver[7]. Of the 783 individuals with whom contact was attempted by phone, 43 (6 percent) declined participation in the survey and 482 (62 percent) were unable to be reached by telephone, were no longer receiving services, or were under the age of 18. Thus, the response rate for the survey was 19 percent. Securing participants from the DD Waiver was most challenging because it has the smallest number of participants of the three waiver programs and many of the participants are under the age of 18, which made them ineligible for participation in the survey.

Background and Demographic Characteristics of Service Recipients

In the full sample, there were slightly more male CD personal assistance services recipients who responded to the survey (53 percent) and the majority of these individuals were White (79 percent). Ages of respondents ranged from 18 to 88, with a mean of 36 years. The largest group of respondents (29 percent, n=42) was between the ages of 18 and 24 years. The Southwest part of the state had the highest percentage of respondents (37

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[7] One extra survey interview was conducted with EDCD waiver participants than planned. In the interest of utilizing all collected data, a total of fifty-one responses for this group were included in the analysis.

percent, n=53), with the next largest groups being in the Northeast (21 percent, n=30) and Tidewater areas (15 percent, n=22).

Demographic characteristics of the total population of CD personal assistance service recipients were requested from the state Medicaid agency to compare attributes of the survey sample to the program population, however, this information was not made available to the researcher as of this publication date. However, the total Medicaid population for FY 2005 was 60 percent female and 40 percent male. Forty-five percent of recipients were White, 45 percent African American, and 10 percent were categorized as "Other." The largest group of service recipients over the age of eighteen was 21 to 44 year olds (N=145,861, 19%) (DMAS, 2005).

Seventy-five percent (n=108) of the survey interviews included the person receiving services. For those interviews that did not include the service recipient, the majority of the interviews included a parent/guardian (57 percent, n=21) and/or an employer of record (54 percent, n=20) who served as a proxy(ies).[8]

The majority of respondents (51 percent) employed one personal assistant (PA), while 38 percent employed either 2 or 3 PAs. Sixty-nine percent of individuals stated that they knew their PA before hiring him or her. When responding to the question regarding their support needs for activities of daily living (ADLs), the majority of survey participants (56 percent) reported that they needed assistance with 10 to 14 tasks, the highest option of support needs available on the survey[9]. Thirty-eight percent (n=52) of the overall sample

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[8] For interviews that included multiple parties, the interviewer instructed respondents to reach consensus answers.

[9] ADL support needs (item number 12 on the survey) served as a proxy for severity of disability

had received, or was currently receiving, agency-directed services and of those 52 individuals, 88 percent reported that CD services better met their needs. Table 5 details the total sample's background and demographic characteristics (see Table 5).

Table 5
Selected Demographic Characteristics and Background Information of Waiver Participants Receiving CD Personal Assistance Services

Characteristic Sample		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full N=145
Gender					
	Male	62.0%	54.5%	43.1%	53.1%
	Female	38.0	45.5	56.9	46.9
Age**					
	18 to 24 yrs.	34.0	45.5	9.8	29.0
	25 to 32 yrs	28.0	29.5	15.7	24.1
	33 to 40 yrs.	18.0	4.5	15.7	13.1
	41 to 60 yrs.	16.0	20.5	31.4	22.8
	61 to 75 yrs.	2.0	-	11.8	4.8
	75 and over	2.0	-	15.7	6.2
Race					
	Black	26.0	18.2	10.0	18.1
	White	72.0	81.8	82.0	78.5
	Other	2.0	-	8.0	3.5
Number of PAs Employed					
	1	39.6	46.5	65.3	50.7
	2	31.3	32.6	20.4	27.9
	3	12.5	11.6	6.1	10.0
	4	10.4	2.3	8.2	7.1
	5	4.2	4.7	-	2.9
	More than 5	2.1	2.3	-	1.4
ADL Support Needs					
	1-4 Tasks	2.0	5.6	2.1	3.0
	5-9 Tasks	34.7	38.9	50.0	41.4
	10-14 Tasks	63.3	55.6	47.9	55.6
Service Regions					
	Northwest	8.0	14.3	15.7	12.6
	Northeast	20.0	26.2	17.6	21.0
	Southwest	36.0	28.6	45.1	37.1
	Central	24.0	14.3	3.9	14.0
	Tidewater	12.0	16.7	17.6	15.4

Characteristic Sample	MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full N=145
Did you know your main CD PA before you hired him/her?**				
Yes	92.0	59.1	56.0	69.4
No	8.0	40.9	44.0	30.6
Received Agency-Directed PAS				
Yes (n=52)	43.5	36.6	34.0	38.0
No	56.5	63.4	66.0	62.0
Which Service Better Met Needs (n=33)				
Agency-Directed	20.0	20.0	0.0	15.2
Consumer-Directed	80.0	80.0	100.0	84.8

* p<.05, two tailed Fisher's exact test
**p<.01, two tailed Fisher's exact test

Comparing Characteristics of Users of CD Services Among Waiver Groups

When comparing users of CD personal assistance services in the three waiver groups, although observed differences were apparent in several characteristics, very few statistically significant differences in demographic and background characteristics were found[10]. The only variables where there were statistically significant differences among groups were: age (*F*(2,142), *p*<.01), knowing the main PA before hiring him/her (*p*<.01, two-tailed Fisher's exact test[11]), and if the interview included the person who receives CD personal assistance services (*p*<.01, two-tailed Fisher's exact test).

Regarding age, DD Waiver participants were a slightly younger group (*M*=28.6, *SD*=11.7) than those receiving services through the MR Waiver (*M*=31.1, *SD*=10.4,) while EDCD participants were older (*M*=48.3, *SD*=19.8). Additionally, an overwhelming

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[10] Lack of statistically significant differences among groups indicates that there is a high probability that any observed differences among groups have arisen by chance.

[11] The Fisher's exact test was used because one or more cells had an expected frequency of five or less. Fisher's exact can be used regardless of how small the expected frequency is.

majority (92 percent) of service recipients from the MR Waiver knew their PAs before hiring them, while under the DD and EDCD Waivers, lower percentages were reported (59 and 56 percent, respectively). For the survey respondents, the majority of service recipients from the EDCD and DD Waivers participated in the interview sessions (82 percent and 86 percent, respectively), while 56 percent of individuals from the MR Wavier were involved in the survey interview.

Access to Information Domain[12]

Among the overall sample, the majority of CD personal assistance services recipients agreed with statements indicating ease with accessing information about CD services. Sixty-eight percent of respondents reported that they "agreed" that it was easy to find out about CD personal assistance services, 69 percent stated that they got enough information about how CD services worked before they began services and 87 percent of CD personal assistance services recipients agreed that the information that they received helped them understand their responsibilities as a CD employer. With regards to CD services facilitation, 71 percent of respondents agreed that it was easy to find a CD services facilitator to work with, 86 percent stated that their CD services facilitator helped them to understand their job responsibilities as a CD employer, and 71 percent of survey participants reported that the CD services facilitator did a good job of explaining how CD services work. Table 6 outlines the total sample frequency responses for each survey item in the "Access" domain (see Table 6).

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[12] In the survey, Likert-scaled questions offered four response options including "strongly agree" (1) to "strongly disagree" (4). For the purposes of analysis, the four categories were collapsed into two response options of (1) "agree" and (2) "disagree."

Table 6
Access to Information Domain

Item Sample		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full N=145
It was easy to find out about CD personal assistance services.					
	Agree	73.5%	62.8%	68.6%	68.5%
	Disagree	26.5	37.2	31.4	31.5
Before starting to use CD services, I got enough information about how CD services worked.*					
	Agree	66.0	53.5	82.0	67.8
	Disagree	34.0	46.5	18.0	32.2
The information I was given helped me to understand my job responsibilities as a CD employer.*					
	Agree	93.8	74.4	91.5	87.0
	Disagree	6.3	25.6	8.5	13.0
My CD services facilitator helped me to understand my job responsibilities as a CD employer.*					
	Agree	94.0	72.7	89.8	86.0
	Disagree	6.0	27.3	10.2	14.0
It was easy to find a CD services facilitator to work with me.*					
	Agree	70.0	58.1	83.7	71.1
	Disagree	30.0	41.9	16.3	28.9
The CD services facilitator did a good job of explaining to me how CD services work.*					
	Agree	88.0	67.4	82.4	79.9
	Disagree	12.0	32.6	17.6	20.1

* p<.05, two tailed Fisher’s exact test
**p<.01, two tailed Fisher’s exact test

When comparing items within the “Access” domain among CD personal assistance services participants in the three waiver groups, statistically significant differences were found in five of the six survey items (p<.05, two-tailed Fisher’s exact test). As indicated in Table 6, in all of the items where significant differences were found, individuals who receive CD personal assistance services from the DD Waiver reported lower levels of agreement with regards to ease of accessing CD services as compared to those receiving CD personal assistance services through the MR and EDCD Waivers. For example, while a substantial majority of individuals receiving CD personal assistance services from the MR and EDCD Waivers indicated agreement with the statement that the information that they were given helped them to understand their job responsibilities as a CD employer (94 and 92 percent, respectively), 75 percent of DD Waiver participants agreed with this statement. Likewise, 94 percent of service recipients from the MR Waiver and 90 percent of service recipients from the EDCD Waiver stated that they agreed that their CD services facilitator helped them to understand their job responsibilities as a CD employer, while 73 percent of individuals from the DD Waiver agreed.

Using CD Services Domain

As highlighted in Table 7, overall responses in the “Using CD Services” domain were mixed. The majority of recipients agreed that it was easy to fill out the required paperwork to hire a personal assistant and that they have enough personal assistance services to meet their support needs (74 and 70 percent, respectively). However, a lower percentage (55 percent) felt that they could increase their personal assistance hours easily if needed and that the hourly pay for their PAs was enough money for the job that they do (41 percent). These two items have the lowest level of agreement of any items within the survey (see Table 7).

Table 7
Using CD Services Domain

Item Sample		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full N=145
It was easy to fill out the paperwork to hire my CD personal assistance services.					
	Agree	71.4%	64.3%	85.7%	74.3%
	Disagree	28.6	35.7	14.3	25.7
I have enough personal assistance services to meet my support needs.					
	Agree	74.0	64.3	72.0	70.4
	Disagree	26.0	35.7	28.0	29.6
If I need to increase my CD PA hours, I can increase my hours easily.					
	Agree	68.2	43.2	51.2	54.9
	Disagree	31.8	56.8	48.8	41.5
The hourly pay for my CD personal assistance services is enough money for the job that they do.					
	Agree	35.4	32.6	54.2	41.0
	Disagree	64.6	67.4	45.8	59.0
Generally, do your PAs get paid on time?					
	Always	34.0	31.0	28.0	31.0
	Most of the time	43.0	47.6	54.0	49.3
	Sometimes	14.0	21.4	14.0	16.2
	Never	6.0	-	4.0	3.5
If your PAs do not get paid on time what is the reason?	Time sheet mistake	8.3	6.3	19.0	11.8
	Late handing in time sheet	13.9	15.6	16.7	15.5
	Fiscal agent	47.2	53.1	38.1	45.5
	Don't know	19.4	6.3	14.3	13.6
	Other	11.1	18.8	11.9	13.6
Was it easy or hard to hire your main CD PA?					
	Easy	35.7	25.9	38.4	77.8
	Hard	31.3	43.8	25.0	22.2
How hard was it to set up your emergency back up plan?					
	Very hard	19.6	12.5	13.6	15.4
	Somewhat hard	17.4	32.5	19.2	20.0
	Not at all hard	63.0	55.0	75.0	64.6

Using CD Services Domain

Item Sample		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full N=145
What problem do you have most often with CD personal assistance services?					
	Finding employees	61.0	68.3	42.9	58.1
	Hiring employees	9.8	2.4	2.9	5.1
	Keeping employees	12.2	9.8	28.6	16.2
	Training employees	2.4	2.4	-	1.7
	Managing employees	-	4.9	8.6	4.3
	Other	14.6	12.2	17.1	14.5
What is the hardest problem you have with personal assistance services?*					
	Finding employees	48.6%	63.2%	28.9%	46.9%
	Hiring employees	2.7	2.6	-	1.8
	Keeping employees	27.0	5.3	21.1	17.7
	Training employees	-	2.6	2.6	1.8
	Managing employees	2.7	7.9	7.9	6.2
	Finding a CD services facilitator	5.4	10.5	13.2	9.7
	Other	13.5	7.9	26.3	15.9

* p<.05, two tailed Fisher's exact test
**p<.01, two tailed Fisher's exact test

The majority (78 percent) of respondents stated that it was "very easy" or "easy" to hire their main PA and that their PAs get paid in a timely manner, with 80 percent of respondents stating that their PAs "always" or "most of the time" get paid on time (31 percent and 49 percent, respectively). Additionally, 65 percent of respondents reported that it was "not at all" hard to set up their emergency back up plan.

When asked to identify the problem that they have *most often* with CD personal assistance services, individuals indicated "finding employees" (58 percent) and "keeping employees" (16 percent) were the most frequently occurring problems. Relatedly, when asked to select the *hardest problem* with CD personal assistance services, individuals reported “finding employees” (47 percent) and “keeping employees” (18 percent) were the most difficult problems that they face.

Very few statistically significant differences emerged when comparing waiver groups on questions in the “Use” domain. The only item where differences were found was with service recipients’ “hardest problem” with CD personal assistance services. A higher percentage of participants from the DD Waiver (63 percent) indicated that “finding employees” was their hardest problem, as compared to 49 percent from the MR Waiver and 59 percent from the EDCD Waiver. Additionally, while 27 percent of respondents from the MR Waiver and 21 percent from the EDCD Waiver indicated that keeping employees was the hardest problem that they face with CD personal assistance services, only 5 percent of individuals from the DD Waiver reported keeping employees as a challenge. Table 7 compares items in the “Using CD Services” domain by waiver group.

Choice and Control Domain

In the “Choice and Control” domain, survey participants agreed that CD personal assistance services afforded them choices and control over their CD services. As highlighted in Table 5, in four of the five items in the scale, service recipients reported over 90 percent agreement with statements about the flexibility, staffing control, and quality of PA care with CD personal assistance services. For the fifth item in the scale, “I am happy with the times of day that my PAs come to help me,” 86 percent of respondents indicated agreement.

Eighty-two percent of survey participants reported “no” when asked if they ever felt that their PA did not help them with something when they needed help. Delineated areas where help was not given were specific in nature and included personal care duties, housekeeping, meal preparation, and transportation. When asked if there were duties in the *plan of care* that their PAs do not do, 89 percent of service recipients indicated "no." The duties in the plan of care that individuals specified were very similar in nature to the previous item. Other areas identified included community inclusion and exercise activities.

For the "Choice and Control" scale, there was only one item where a statistically significant difference among waiver groups was found. A higher percentage of individuals who receive supports from the DD Waiver (32 percent) indicated that they felt that their CD personal assistant did not help them when they needed help as compared to those on the MR Waiver (11 percent) and EDCD Waiver (12 percent). Table 8 details the results in the "Choice and Control" domain (see Table 8).

Table 8
Choice and Control Domain

Item		MR Waiver	DD Waiver	EDCD Waiver	Full
Sample		n=50	n= 44	n=51	N=145
I can work with my CD PA to change their schedules.					
	Agree	93.3%	95.2%	100.0%	96.3%
	Disagree	6.7	4.8	-	3.7
My PAs do what I ask them to do.					
	Agree	91.3	92.9	100.0	94.4
	Disagree	8.7	7.1	-	5.1
I feel that I am in charge of my PAs.					
	Agree	92.9	90.2	96.0	92.5
	Disagree	4.7	14.6	4.0	7.5
I am happy with the times of day that my PAs come to help me.					
	Agree	95.3	85.4	96.0	86.0
	Disagree	4.7	14.6	4.0	7.5
I am happy with the way my PAs help with my personal care.					
	Agree	97.7	92.9	100.0	97.0
	Disagree	2.3	7.1	-	3.0
Have you ever felt that your CD PA did not help you with something when you needed help?*					
	Yes	10.9	31.8	11.8	17.7
	No	89.1	68.2	88.2	82.3
Are there jobs that are in your plan of care that your CD PA DID NOT DO that you want them to do?					
	Yes	6.4	20.9	8.0	88.6
	No	93.6	79.1	92.0	11.4

* p<.05, two tailed Fisher's exact test
**p<.01, two tailed Fisher's exact test

Quality and Satisfaction Domain

Overall, respondents indicated high levels of satisfaction with CD services and reported that CD services enhance aspects of their lives. Participants overwhelmingly indicated that the services enabled them to be more independent (96 percent) and that they are more in charge of their life because of CD personal assistance services (96 percent). Additionally, 94 percent of individuals reported that they are happy with their CD personal assistance services and 97 percent would tell a friend that they should try to get CD personal assistance services. The majority of survey participants also stated that they could do more things in the community because of their CD personal assistance services (88 percent) and that their CD personal assistance services made it easier for them to go to work or school (86 percent). No significant differences among waiver groups were found in the items included in the quality and satisfaction domain. Results for the "Quality and Satisfaction" domain appear in Table 9 (see Table 9).

Table 9
Quality and Satisfaction Domain

Item		MR Waiver	DD Waiver	EDCD Waiver	Full
Sample		n=50	n= 44	n=51	N=145
I am able to be more independent because of my CD personal assistance services.					
	Agree	93.8%	97.6%	98.0%	96.4%
	Disagree	6.3	2.4	2.0	3.6
I can do more things in the community because of my CD personal assistance services.					
	Agree	93.8	82.5	87.5	88.3
	Disagree	6.3	17.5	12.5	11.7
My CD personal assistance services has made it easier for me to go to work or to school.					
	Agree	87.5	81.0	88.9	85.7
	Disagree	12.5	19.0	11.1	14.3
I would tell a friend that they should try to get CD personal assistance services.					
	Agree	95.8	93.2	100.0	96.5
	Disagree	4.2	6.8	-	3.5

Table 9
Quality and Satisfaction Domain

Item		MR Waiver	DD Waiver	EDCD Waiver	Full
Sample		n=50	n= 44	n=51	N=145
I am happy with my personal assistance services.					
	Agree	91.8	93.0	96.1	93.7
	Disagree	8.2	7.0	3.9	6.3
I am more in charge of my life because of my CD personal assistance services.					
	Agree	93.8	94.9	100.0	96.3
	Disagree	6.3	5.1	-	3.7

* p<.05, two tailed Fisher's exact test
**p<.01, two tailed Fisher's exact test

Domain Scale Scores

Factor analysis was used to confirm scales within the survey domains of "Access," "Use," "Choice and Control" and "Satisfaction and Quality." Factor analysis is a statistical approach that helps to condense information contained in a number of original variables into a smaller set of domains (factors) with a minimum loss of information (Hair, Black, Babin, Anderson & Tatham, 1992). A summary of the factor analysis results appear in Appendix B.

An internal consistency analysis by each survey domain also appears in Appendix B.

The data were initially analyzed to see if the scale scores in interviews that included the person with a disability and "proxy" interviews that did not include the person who receives services were significantly different. No statistically significant differences were found on any of the 4 scales.

The overall means and standard deviations for each survey dimension are presented in Table 10 (see Table 10).

Table 10
Overall Mean Scale Scores

Domain	N	Mean	Standard Deviation
Access to Information	145	1.24	.27
Using CD Services	144	1.39	.30
Choice and Control	139	1.05	.15
Quality and Satisfaction	144	1.06	.17

Note. In the survey, Likert-scaled questions offered four response options including “strongly agree” (1) to “strongly disagree” (4). For the purposes of analysis, the four categories were collapsed into two response options of (1) “agree” and (2) “disagree.”

As illustrated in Table 11, a one way analysis of variance (ANOVA) revealed significant differences among waiver participants in the areas of “Access” ($F(2,142) = 7.18$, $p < .01$) and “Use” ($F(2,141)=3.64$, $p<.05$) (see Table 11).

Table 11

Mean and Standard Deviation of Scale Scores by Waiver Program

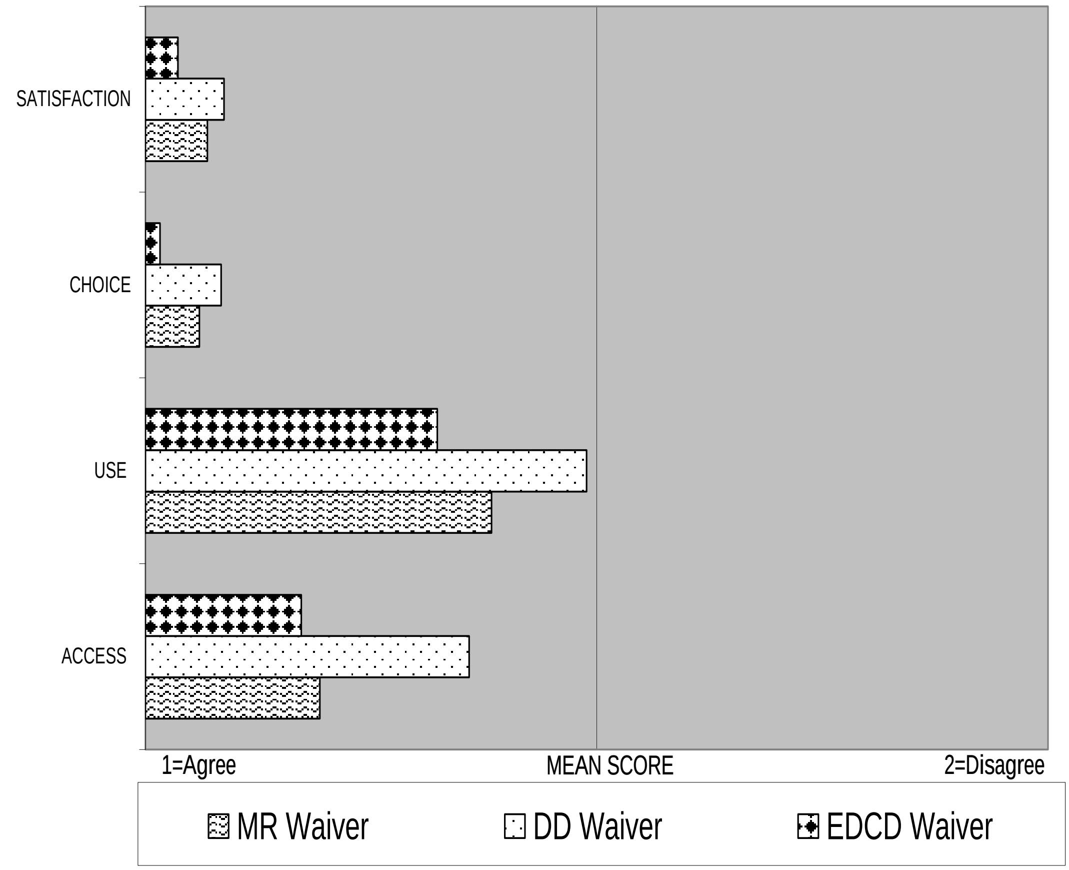
Domain	MR Waiver N=50		DD Waiver (n=44)		EDCD Waiver (n=51)	
	M	*SD*	*M*	*SD*	*M*	*SD*
Access to Information**	1.19	.24	1.36	.30	1.17	.23
Using CD Services*	1.38	.30	1.49	.31	1.32	.29
Choice and Control	1.06	.68	1.08	.19	1.02	.07
Quality and Satisfaction	1.07	.21	1.09	.20	1.04	.10

* p<.05
**p<.01

Note. In the survey, Likert-scaled questions offered four response options including “strongly agree” (1) to “strongly disagree” (4). For the purposes of analysis, the four categories were collapsed into two response options of (1) “agree” and (2) “disagree.”

Post hoc comparisons using the Fisher LSD test revealed that individuals who receive support from the DD Waiver reported lower levels of agreement with statements about the adequacy and quality of information about CD services than those on the MR or EDCD Waiver. Additionally, DD Waiver participants responded less favorably than EDCD participants to statements regarding the ease of using CD services. These differences are illustrated in Figure 3 (see Figure 3).

Figure 3
Mean Scale Scores by Waiver Program



Note. In the survey, Likert-scaled questions offered four response options including “strongly agree” (1) to “strongly disagree” (4). For the purposes of analysis, the four categories were collapsed into two response options of (1) “agree” and (2) “disagree.”

To assure that differences found in the domains of “Access” and “Use” were due to differences in the waiver groups’ experiences rather than differences in the demographic makeup of the waiver participants, a multi-factor analysis of variance was completed. This

ANOVA included the independent variable or main effect “waiver program” and “age,” the demographic characteristic that was found to be significantly different among waiver groups during the initial analysis of background characteristics.

Results indicated that for the “Access” domain, type of waiver group was statistically significant main effect *F*(2,129)=3.174, p<.05, age was not significant *F*(5,129)=1.371, p>.05, and the interaction effect between waiver group and age was not significant *F*(8,129)=1.367, p>.05. For the “Use” domain, after introducing age as a factor, the variability of the mean scores decreased, resulting in no significant main effect for waiver group *F*(2,128)=1.526, p>.05, age *F*(5,128)=.729, p>.05, and the interaction effect between age and waiver group was also not significant *F*(8,128)=.063, p>.05. Thus, the significant difference that was originally found in the “Use” domain when age was not introduced into the analysis appears to be due to dissimilarity in age of the waiver participant groups rather than differences in waiver groups’ ease with using CD services. Table 12 details the results from the multi-factor ANOVA (see Table 12).

Table 12

Factorial ANOVA for Access and Use Domains

Factorial ANOVA	*F*-Value	df,err	P
Access Domain			
Main Effects			
Waiver Program	3.174	2,129	.045*
Age	1.371	5,129	.239
Two-way interactions			
Waiver Program X Age	1.367	8,129	.217
Use Domain			
Main Effects			
Waiver Program	1.526	2,128	.221
Age	.729	5,128	.603
Two-way interactions			
Waiver Program X Age	.688	8,128	.702

* p<.05
**p<.01

Open-Ended Questions

At the conclusion of the survey, two open-ended questions were posed to respondents requesting overall comments about their experiences with CD services. Content analysis was used to analyze these data. To check the reliability of the coding, intercoder (or interrater) agreement tests were conducted to measure the extent to which different judges assigned exactly the same rating to each comment. Reliability was measured for these variables using Krippendorff's alpha [13]. The agreement coefficients for each question (.864 for “like most” and .863 for “change one thing”) met Krippendorff's (1980) standards of reliability.

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[13] Krippendorff's alpha is a measure that takes chance into account and allows the calculation of reliability coefficients for different scales of measurement. Alpha must reach a value between 0.60 and 0.80 to be conditionally reliable and between 0.80 and 1.00 to be unconditionally reliable.

One hundred and fifty-one responses were provided for the question, “What do you like most about your CD personal assistance services?” Comments were categorized into five major themes: 1) family respite, 2) quality care, 3) independence, 4) ability to pay family to provide care, and 5) choice in selecting, hiring, firing, and managing personal assistants**.**

The theme mentioned most frequently by respondents was “quality care.” Thirty-eight percent (n=60) of responses focused on how CD services meet personal and support needs of service recipients in ways that are most beneficial to them and their family. Examples of comments that fell under this theme included “assistants are nice and give good care” and “that she is taken care of competently and flexibly.”

The themes of “independence” and “choice” were also frequently highlighted by service recipients. Twenty-six percent of responses (n=42) concerned the “independence” that CD services affords, while 20 percent of responses (n=32) highlighted how “choice” was enhanced with CD services. The categories of “family respite” and “ability for family to be paid to provide care” appeared less frequently, at a rate of 10 percent (n=16) and 6 percent (n=10), respectively.

Chi-square analysis was used to determine if any statistically significant differences were present between waiver participants regarding what they “like most” about CD services. No significant differences were detected between waiver groups.

One hundred and thirty-one responses were given to the question, “If you could change one thing about your CD personal assistance services to make services work better for you, what would you change?” Responses were coded into six themes: 1) increasing pay of personal assistants, 2) adding benefits, 3) increasing personal assistance hours, 4) finding qualified PAs and services facilitators, 5) concerns with the way a personal assistant is performing his or her job, and 6) CD services program administration issues. The coding scheme and definitions appear in Appendix C.

The most frequently occurring issue identified by service recipients was the compensation for personal assistants. Thirty percent of responses (n=39) were coded into this category. Examples of responses included “make sure pay is sufficient” and “increase the rate of pay.” Lack of benefits was also identified as an issue for survey participants, but at a lower rate, with 17 responses (13 percent) highlighting this concern.

CD services program administration issues was the second most frequently occurring response. Twenty-four percent of responses (n=31), fell under this theme, which encompassed paperwork, payment and/or program design concerns, such as an expansion of allowable reimburseable tasks functions, and/or adjustments to the parameters of the program.

Other “change” areas highlighted by survey respondents included finding qualified PAs and/or services facilitators, personal assistance hours, and PA job performance issues. Twenty-four responses (18 percent) were coded into the qualified personnel theme, 11 percent (n=14) fell into the needed increases in personal assistance hours, and 5 percent (n=6) of the comments pertained to how specific PAs were performing their job.

Chi-square analysis was used to determine if any statistically significant differences were present between waiver participants regarding what they would like to change about CD services. The only area in which a statistically significant difference was detected was under the theme “program administration issues.” Individuals who receive support from the DD Waiver identified this issue more frequently (55 percent) than those on the MR (13 percent) and EDCD (32 percent) Waivers.

V. Discussion

Review of Purpose of Dissertation

Consumer-direction is a growing phenomenon in long-term care in the United States. The vast majority of states are currently operating CD programs and several offer individual budgeting options where service users routinely make key decisions that enable them to be fully in control of the services and supports that they receive. As the use of CD services continues to expand, it becomes increasingly important to evaluate its impacts.

Many studies have examined particular aspects CD services, but the issue of how individuals with different types of disabilities experience CD services has not been explored in the literature. This study contributed this perspective to the consumer direction literature. Additionally, this study examined consumer direction in depth in Virginia, which has not been studied to date.

Utility of Self-Determination Theory for this Study

In many ways self-determination theory was an instructive framework for examining consumer direction. The disability studies literature rarely cites the broad history of self-determination in various disciplines; it is instead described as a movement largely concerning long-term care. Understanding that the concept of self-determination has meaning outside of disability studies helps to frame this study in a larger context. The struggle to realize greater individual choice and control has been played out countless times in our history, and the pursuit of self-determination for people with disabilities is one more example.

Additionally, it was helpful to see that a primary conflict concerning self-determination, balancing liberty and paternalism, is also not unique to the disability field. Self-determination is an important and cherished value in our society, however taking the ideal and putting into practice can be fraught with complications. Whether it is indigenous people seeking self-rule or individuals with mental illness who want to live more independently, allowing for greater self-determination comes with a price. Granting self-determination to one means another has less control.

A discussion that was particularly useful for this study was the distinction that was made between the value-based perspective and the functional perspective of self-determination in disability policy studies. In one regard, the distinction was helpful in that the “functional definition” plainly shows the relationship between self-determination and consumer-direction. However, at the same time it also illustrated how the concept of self-determination is noticeably narrowed when it is equated with consumer direction. Control over Medicaid supports and services clearly enables greater choice and decision-making power, but it is only one aspect of life. As stated by Yuskauskas (2005),

> A self-determined life reaches far beyond choices associated with services and supports. Life goals and fundamental freedoms related to economic access and social justice surpass in scope the ability to have choice and control over paid supports in a Medicaid program. Suffice it to say that [consumer direction] is one step on the road to a self-determined life. It is a means to an end, but a “program” cannot and should not be confused with a self-determined life (p. 8).

Hypothesis Testing

The central research question for this study was, “How do the experiences of individuals with intellectual disabilities, developmental disabilities (not including intellectual disabilities), and physical disabilities who receive CD personal assistance services in Virginia differ? Specifically, do these populations differ in how they access information about CD personal assistance services, use CD personal assistance services, exercise choice and control with CD personal assistance services, and experience satisfaction with CD personal assistance services?” The stated hypotheses were:

H_1 Individuals who receive CD personal assistance services from Virginia’s MR, DD, and EDCD Waivers will report that this service delivery option facilitates self-determined decision-making.

H_2 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report access to CD services;

H_3 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report how they use CD services;

H_4 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report how much choice is afforded to them through CD services; and

H_5 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers report satisfaction.

Hypothesis 1 was clearly supported in the findings. Respondents overwhelming reported that CD services enabled them to have greater choice and control and that these services enhanced their ability to be more in charge of their life.

Of the four hypotheses presented where the experiences of waiver groups are compared (H_2 to H_5), only H_2 could be supported by the data analyzed in this study. The survey domain of "access" was the only domain where statistically significant differences were found among groups. While the majority of DD Waiver participants indicated moderate ease with accessing CD services, individuals using this waiver reported lower mean levels of agreement on particular items within the "access" domain and on the scale as a whole as compared to those using the MR or EDCD Waiver.

For hypotheses 3 through 5, the data suggested no statistically significant differences in the overall domain scores for use, control, and satisfaction with services. Generally, service recipients reported relative ease with using CD services. However, overall mean scores were the lowest of any of the domains within the survey. Of particular concern to respondents was the hourly pay for personal assistants and the ability to easily increase personal assistance hours, if needed.

For the choice and satisfaction domains, individuals receiving services from the MR, DD, and EDCD Waivers were consistently satisfied with CD services and concurred that this service delivery option afforded them choice and control over their personal assistance services. Notably high levels of agreement in each of the groups were found on items related to the flexibility of CD services and how CD services allow for enhanced control and independence.

However, there were a few individual items within the use and choice domains where statistically significant differences among groups were found. When asked about the “hardest problem” that they face in using CD services, DD Waiver participants’ answers were significantly different than MR and EDCD service recipients. This was later found in the “choice” domain in an item that asked participants if they felt that their PAs helped them when they needed help. Again, DD Waiver participants indicated lower levels of agreement and their responses were statistically different from those of MR and EDCD Waiver groups.

The open-ended responses generally reinforced the data gathered through the scaled items. Individuals stated that CD services meet their needs in ways that are most beneficial to them and their families. With regard to difficulties noted with CD services, the inadequacy of personal assistant pay and lack of benefits were significant barriers as well as finding qualified personal assistants and services facilitators. Table 13 details the hypotheses supported and not supported through the data analysis (see table 13).

Table 13. Results of Hypothesis Testing

Hypotheses	**Supported/Not Supported**
H_1 Individuals who receive CD personal assistance services from Virginia’s MR, DD, and EDCD Waivers will report that CD services facilitate self-determined decision-making.	Supported
H_2 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers will report access to CD services.	Supported
H_3 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers will report how they use CD services.	Not Supported

Hypotheses	**Supported/Not Supported**
H_4 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers will report how much choice is afforded to them through CD services.	Not Supported
H_5 There will be statistically significant differences in how recipients of CD personal assistance services from the MR, DD, and EDCD Waivers will report satisfaction.	Not Supported

One of the primary rationales for the anticipated differences among groups was that each group receives CD services from different waiver programs that are governed by different Medicaid regulations, and that are supported by a variety of different support agencies. It was expected that these differences in structure would result in different experiences among the waiver groups.

Given the survey results, it appears that these differences may have impacted how individuals access CD services. In several items within the domain, particularly related to access to and quality of service facilitation services, individuals using services from the DD Waiver reported lower levels of agreement on items, as compared to those from the MR or EDCD Waivers. Although there could be a host of explanations for these findings, they could be related to the fact that there is no single state agency coordinating services for individuals with developmental disabilities while there are single state agencies that support those with intellectual disabilities (Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services), those with physical disabilities (Virginia Department of Rehabilitative Services) and seniors (Virginia Department of Aging). Without the consistent support of a single state coordinating agency, ease with finding and accessing CD services, particularly finding the support of a quality services facilitator, could vary greatly in local communities.

Another calculus for the stated hypotheses was that there were anticipated differences in characteristics among each disability group and it was thought that these characteristics would influence domain scores. However, when examining the attributes of users of CD services among different Waiver groups, very few statistically significant differences were found. Most notably, there were no statistically significant differences found in level of support needed among the three Waiver groups. This was an interesting and unexpected finding.

Largely, differences between groups were found in the variable of age and whether or not individuals knew their PA before hiring him or her. Users of EDCD Waiver services were older than MR and DD Waiver participants, which seems logical given that one of the program's target groups is individuals over the age of 65. Additionally, differences were found in who participated in the survey interview. More proxies were used for individuals who are recipients of MR Waiver services. This was not a surprising finding in that the need for proxies for people with intellectual disabilities was anticipated at the outset of this study.

Applying Results to Theoretical Framework

This study examined an operationalized component of self-determination, CD services. A central question posed was whether a state controlled Medicaid support such as CD personal assistance services can promote individual choice and control. Or, would the competing priority of federal Medicaid policy to protect the health and safety of participants curtail choice and impact service recipients' satisfaction with CD services.

Data from the survey suggest that service recipients are highly satisfied with the level of choice and control offered with CD services. In four of the five items in the choice scale, service recipients reported over 90 percent agreement with statements about the flexibility, staffing control, and quality of PA care with CD personal assistance services. Additionally, opened ended questions reinforced domain scale scores with individuals who stated that the quality of care with CD services met personal and support needs of service recipients in ways that are most beneficial to them and their family. Service recipients also responded that independence and choice were fostered through CD services.

From the "liberty" and "empowerment" perspective, CD services appear to be facilitating choice and control for users of services. However, from a paternalist perspective, the data from this survey may not address certain key questions. Paternalist policies often focused on the protection of individuals, particularly as it relates to health and safety. While the survey asks questions about the quality of the personal assistance services, it does not specifically include subjective or objective measures of whether the health and safety needs of consumers are adequately being addressed with CD services. Additionally, an area of concern identified in paternalist social policies is the quality of choices and decision-making by service recipients. In this survey, quality was defined by the service recipients. In all of the identified domains, users of services were asked about their perceptions regarding CD services. Thus, quality was defined by their opinions.

Paternalists may not support such a consumer-focused approach in assessing the quality of social welfare services.

Research Implications

Findings from this research have important implications for users, advocates, and administrators of CD services. For current and potential users of Medicaid waivers considering the CD services option, information from this study further substantiates findings from previous research on CD services. People like CD services. In Virginia, 97 percent of respondents indicated that they would tell a friend they should try CD personal assistance services. This is a strong endorsement and helpful information to those who are thinking about trying this service delivery option.

However, while results from this study were largely positive, several program administration concerns were apparent in the survey results. Some service recipients indicated difficulty in areas such as workers getting paid on time, hiring personal assistants, setting up emergency back-up plans, and finding quality information about how to access and use CD services.

The open-ended responses generally reinforced the data gathered through the scaled items. The inadequacy of personal assistant pay and lack of benefits were significant barriers as well as finding qualified personal assistants and services facilitators.

Individuals considering CD services and their supporters need to balance the high participant satisfaction ratings from this survey with the apparent concerns around program administration. Issues such as finding and retaining qualified personnel who are willing to work for low wages are very difficult problems. CD services open up an array of options to services users, but they also put a much greater responsibility on individuals to find their own staff.

Data from this study should also be of interest to advocates for people with disabilities. As with many states across the country, there has been some concern articulated in Virginia about the implications of affording individuals greater choice and control through CD services. There has been particular trepidation about decreasing quality of care for vulnerable individuals. These data illustrate that individuals are highly satisfied with the quality of care offered through CD services and that those who have used both agency-directed and CD services, prefer the latter. No evidence was found that quality of care had decreased with the introduction of CD services.

This study provides evidence that CD services are working well for the people who currently use them. This information can also be helpful to service recipients and advocates who are lobbying for the expansion of CD services and for program administrators who are contemplating program growth.

The central research question of this study focused on differences between disability groups who receive CD services. Specifically, do groups access, use, experience choice and satisfaction differently? When looking at individual items within the survey, significant differences were found primarily in items within the access domain but also in the use and choice domains. For the mean domain scores, once again access stood out as an area where significant differences between disability groups were found.

Although there may be many explanations for the differences found among the three waiver groups, one of the most important findings from this research is that *differences were found* among populations. CD service recipients who participated in this study perceive access to services differently.

In all of the items within the access domain where significant differences were found, individuals who receive CD personal assistance services from the DD Waiver reported lower levels of agreement with regards to ease of accessing CD services as compared to those receiving CD personal assistance services through the MR and EDCD Waivers. From a program administration perspective, this is important information.

As highlighted in the section describing the rationale for this study's hypotheses, each of the three waiver programs discussed has different agencies who administer their CD services program. Data from this study suggest that that administering agency for CD services in the DD Waiver, the Department of Medical Assistance Services, may want to thoroughly examine their processes for advertising and enrolling individuals for CD services to assess why program participants have lower levels of satisfaction.

Additionally, it may be beneficial to consider how individuals (particularly those receiving services from the DD Waiver) learn about CD services and examine how program marketing, development of promotional materials, information dissemination, and services facilitation activities are being handled. Targeted strategies geared towards the needs and concerns of particular population groups, such as those with developmental disabilities, made need to be piloted. Also, given that the overall survey population who use CD services was very satisfied, it is critical that potential users have available to them thorough and accurate information that addresses their specific needs, so that access does not become a barrier for people to benefit from the service.

It is important to note that this study is only a first step in learning more about CD services among different population groups. As mentioned previously, there is currently no standardized practice for soliciting input from the individuals who receive CD Home and Community-based Waiver Services on the quality of their support and services in Virginia. Consumer direction is clearly focused on the person receiving services, therefore measures for soliciting feedback from service recipients on the quality of services should be a routine practice in the state. Studies with larger numbers of participants and greater representative power should be conducted on a routine basis given the increasing reliance on CD services and self-direction in Virginia and across the nation. Consumer direction is a service delivery innovation that places power in the hands of service recipients to manage their own services. Quality assurance and improvement strategies need to correspond with this service delivery model. Service recipients need to be at the center of monitoring the accessibility and quality of consumer direction.

This is not to say, however, that the perceptions of service recipients should be the *exclusive* mechanism for assessing quality in CD services. Objective measures of quality that address such vital issues as the health and safety of service recipients need to be coupled with participant-focused quality assurance strategies so that individuals, family members, state government officials, and policy makers have a complete picture of the program impacts of social policy innovations such as consumer direction.

VI. References

VI. References

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APPENDIX A

CPASS SURVEY

Code # ______________ Date of Interview: ________________________

Consumer-Directed Personal Assistance Services
Structured Interview Instrument

<u>INTERVIEWER NOTES</u>: *Examples of alternate phrasing for questions are in italics. In all questions CD refers to "consumer-directed."*

SECTION I- BACKGROUND INFORMATION

<u>DIRECTIONS FOR THE RESPONDENT</u>*: The following questions ask you for some background information. This is being asked so that we can make sure that we talk to a wide variety of people in our survey group. Remember that you can skip any question that you do not want to answer.*

1) How old are you?_________

2) Are you:

○ Male
○ Female

3) Are you:

○ Black, not of Hispanic origin
○ Hispanic
○ White, not of Hispanic origin
○ American Indian or Alaskan Native
○ Asian or Pacific Islander
○ Other

4) What city or county do you live in?

____

5) What disability qualifies you for SSI or for CD personal assistance services [*what disability do you get your SSI or CD personal assistance services for* or *what is your primary disability]*?

____

6) Do you have any other disabilities? If yes, please list.

____

____

____

7) When did you start to get CD personal assistance services?_______________

8) Through what Medicaid waiver do you get CD personal assistance services?

○ Mental Retardation (MR) Waiver
○ Developmental Disabilities (DD) Waiver
○ Consumer-Directed Personal Assistance Services Waiver (CD-PAS)

9) Do you receive other CD services besides personal assistance (ex. respite, companion services)?

○ Yes ➘
○ No

If yes, what other CD services do you receive?

____

10) Did you, or do you now, have agency-directed personal assistance services?

○ No, I did not, and do not now, have agency-directed services
○ Yes, I had, or still have, agency-directed services ➘

If yes, which service, agency-directed or consumer-directed, better meets your needs?

○ Agency-directed services
○ Consumer-directed services

11) How many CD personal assistants work for you now?

○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ more than 5

12) What things *[tasks]* does your personal assistant help you with? (PLEASE CHECK ALL THAT APPLY)

❍Bathing
❍Dressing
❍Eating/feeding
❍Toileting
❍Getting around inside my home
❍Monitoring of my health status and physical condition
❍Transferring between my bed and wheelchair
❍Meal preparation
❍Shopping
❍Housekeeping
❍Laundry
❍Access to the community
❍Monitoring of my self-administered medications or other medical needs
❍Other ______________________

SECTION II-ACCESS TO INFORMATION

DIRECTIONS FOR THE RESPONDENT: *The next group of questions ask how you learned about consumer-directed personal assistances services. The first set of questions in this section are on a scale that gives you a choice to say that you "agree very much," "agree," "disagree," or "disagree very much." You may also choose to say that you "don't know."*

Information on CD Services	Agree Very Much	Agree	Disagree	Disagree Very Much	Don't Know/ Does Not Apply
13) It was easy to find out [*get information*] about CD personal assistance services.	○	○	○	○	○
14) Before starting to use CD services, I got enough information about how CD services worked.	○	○	○	○	○
15) The information I was given (for example, brochures or other written material) helped me to understand my job responsibilities as a CD employer (like hiring my personal assistant, and paperwork.)	○	○	○	○	○
16) My CD services facilitator helped me to understand my job responsibilities as a CD employer.	○	○	○	○	○
17) It was easy to find a CD services facilitator to work with me.	○	○	○	○	○
18) The CD services facilitator did a good job of explaining to me how CD services work.	○	○	○	○	○

19) How did you find out about CD personal assistance services? (PLEASE CHECK ALL THAT APPLY)

❍I read about it
❍A service provider told me
❍A case manager told me
❍A family member or friend told me
❍Other ____

20) Are there some things about CD personal assistance services that you feel you need to know more about ?

❍Yes
❍No

If so, what are they?

21) What do you think is the **best** way to tell people about how CD services work? (CHOOSE ONE)

❍Brochures/short written material
❍Internet website
❍Video
❍Group training workshop
❍Person to person, or one on one, explanation
❍Other ____

SECTION III-USING CD SERVICES

<u>DIRECTIONS FOR THE RESPONDENT</u>: *The next set of questions asks about using CD personal assistance services. The first three questions are about your MAIN personal assistant. This is the person who provides you with the MOST personal assistance service.*

22) Did you hire, or help hire, your <u>main</u> CD personal assistant?

❍Yes
❍No

23) Did you know your <u>main</u> CD personal assistant before you hired him/her?

❍Yes
❍No

24) Was it very easy, easy, hard, or very hard to hire your <u>main</u> CD personal assistant?

❍Very Easy
❍Easy
❍Hard
❍Very Hard

DIRECTIONS FOR THE RESPONDENT: *The next set of questions are about your CD services in general. The first four questions in this section are on a scale that gives you a choice to say that you "agree very much," "agree," "disagree," or "disagree very much." You may also choose to say that you "don't know."*

Using CD Services	Agree Very Much	Agree	Disagree	Disagree Very Much	Don't Know/ Does Not Apply
25) It was easy to fill out the paperwork to hire my CD personal assistants.	○	○	○	○	○
26) I have enough CD personal assistance services to meet my support needs.	○	○	○	○	○
27) If I need to increase my CD personal assistance hours, I can increase my hours easily.	○	○	○	○	○
28) The hourly pay for my CD personal assistants is enough money for the job that they do.	○	○	○	○	○

29) Generally [*most of the time*], do your CD personal assistants get paid on time?

❍Never
❍Sometimes
❍Most of the time
❍Always

30) If your personal assistants do not get paid on time, generally [*most of the time*], what is the reason?

❍Time sheet mistakes
❍Employee/employer late handing in time sheet
❍Problem with fiscal agent (agency that gives out the checks)
❍I don't know
❍Other________________________

31) Did you decide the jobs for your personal assistant that are listed in your plan of care?

❍Yes
❍No

32) What problem do you have most often with CD personal assistance services? (CHOOSE ONE)

❍Finding employees
❍Hiring employees (getting and filling out paperwork)
❍Keeping employees
❍Training employees
❍Managing employees
❍Other

33) What is the hardest problem you have with CD personal assistance services? (CHOOSE ONE)

❍Finding employees
❍Hiring employees (getting and filling out paperwork)
❍Keeping employees
❍Training employees
❍Managing employees
❍Finding a CD services facilitator
❍Other ___________________________

34) Who do you go to for help with your hardest problem with your CD personal assistance services? (CHOOSE ONE)

❍CD services facilitator
❍Case manager
❍Family member
❍Other ___________________________

DIRECTIONS FOR THE RESPONDENT*: Now I am going to ask about your emergency back up plan.*

35) How hard was it to set up your emergency back up plan?

❍Very hard
❍Somewhat hard
❍Not at all hard

36) Who helped you to set up your emergency back up plan? (PLEASE CHECK ALL THAT APPLY)

❍CD services facilitator
❍Case manager
❍Family member
❍Other ___________________________

37) Have you ever had to use your emergency back up?

❍Yes ⤵
❍No

If yes, did it work as planned?

❍Yes
❍No ⤵

If no, what went wrong? ___________________________________

SECTION IV- CHOICE AND CONTROL

DIRECTIONS FOR THE RESPONDENT: *The next questions ask about whether you feel that you have choice and control over different things in your life. The first group of questions in this section are on a scale that gives you a choice to say that you "agree very much," "agree," "disagree," or "disagree very much." You may also choose to say that you "don't know."*

Choice and Control	Agree Very Much	Agree	Disagree	Disagree Very Much	Don't Know/ Does Not Apply
38) I can work with my CD personal assistants to change their schedules.	○	○	○	○	○
39) My personal assistants do what I ask them to do.	○	○	○	○	○
40) I feel that I am in charge of my personal assistants.	○	○	○	○	○
41) I am happy with the times of day that my personal assistants come to help me.	○	○	○	○	○
42) I am happy with the way my personal assistants help with my personal care.	○	○	○	○	○

43) Have you ever felt that your CD personal assistants did not help you with something when you needed help?

○Yes ➘
○No

If yes, what did you need help with? ____

44) Are there jobs that are in your plan of care that your CD personal assistants DO NOT DO that you want them to do?

○Yes ➘
○No

If yes, what are those jobs?____

SECTION V-QUALITY OF LIFE AND SATISFACTION

DIRECTIONS FOR THE RESPONDENT: *The last group of questions are about your quality of life and your satisfaction with CD personal assistance services. The first set of questions in this section are on a scale that gives you a choice to say that you "agree very much," "agree," "disagree" or "disagree very much." You may also choose to say that you "don't know."*

Quality of Life and Satisfaction	Agree Very Much	Agree	Disagree	Disagree Very Much	Don't Know/ Does Not Apply
45) I am able to be more independent [*do the things that I want to do*] because of my CD personal assistance services.	○	○	○	○	○
46) I can do more things in the community because of my CD personal assistance services.	○	○	○	○	○
47) My CD personal assistance services have made it easier for me to go to work or to school.	○	○	○	○	○
48) I would tell a friend that they should try to get CD personal assistance services.	○	○	○	○	○
49) I am happy with my CD personal assistance services.	○	○	○	○	○
50) I am more in charge of my life because of my CD personal assistance services.	○	○	○	○	○

51) What do you like most about CD personal assistant services?

____

____

____

52) If you could change one thing about your CD personal assistance services to make services work better for you, what would you change?

____

____

____

53) Do you have any additional comments you would like to make? Are there any concerns or issues that have not been brought up in this survey that you would like to talk about?

____

____

____

Interviewer Notes/Comments:

____
____
____
____
____
____

Who participated in this interview? (PLEASE CHECK ALL THAT APPLY)

○ Person receiving services
○ Employer of Record
○ Parent or guardian
○ Sibling
○ Friend/advocate
○ Spouse
○ Other____

APPENDIX B

Factor Analysis Summary Tables and Internal Consistency Analysis by Survey Domain

Summary results for the factor analysis of the access, use, and choice scales (holding the satisfaction scale out as a separate outcome dimension) are detailed below.

Summary Factor Analysis Results for Access, Use and Choice Scales[a]

	Name of item	Direction of loading	Rotated factor loadings [b]	Percent of total variance explained by factor
Factor 1 (Choice)	Q38 I can work with my CD personal assistant to change his/her schedule.	+	High	22.5%
	Q39 My personal assistants do what I ask them to do.	+	High	
	Q40 I feel that I'm in charge of my personal assistants.	+	Very High	
	Q41 I am happy with the times of day that my personal assistants come to help me.	+	High	
	Q42 I am happy with the way my personal assistants help me with my personal care.	+	Very high	
Factor 2 (Access)	Q13 It was easy to find out [get information about CD assistance services	+	Moderate	17.6%
	Q14 Before starting to use CD services, I got enough information about how CD services worked	+	Moderate	
	Q15 The information I was given (for example brochures or other material) helped me to understand my job responsibilities as a CD employer (like hiring my personal attendant, and paperwork.)	+	Moderate	
	Q16 My CD facilitator helped me to understand my job responsibilities as a CD employer.	+	Very high	
	Q17 It was easy to find a CD service facilitator to work with me	+	High	
	Q18 The CD services facilitator did a good job of explaining to me how CD services work.	+	Very high	
Factor 3 (Use)	Q25 It was easy to fill out the paperwork to hire my personal assistant.	+	Moderate	10.1%
	Q26 I have enough personal assistance services to meet my support needs	+	Moderate	
	Q27 If I need to increase my CD personal assistance hours, I can increase my hours easily.	+	High	
	Q28 The hourly pay for my CD assistant is enough for the job he/she does.	+	Moderate	

[a] The extraction method used was principal axis factoring (PAF). PAF allows for communality estimates less than one. Principal components analysis stipulates that the communality, or shared variance between the item and all other items, must be one – meaning that all of the variance in each item is shared with the other items. As this assumption could not be met with confidence (violation of which can lead to inflated factor loadings), PAF was selected as the extraction method.
[b] Varimax rotation factor loadings. Very high: |.76 - .99|; high: |.51-.75|; moderate: |.25 - .50|.

Summary results for the factor analysis of the satisfaction scale are detailed below

Summary Factor Analysis Results for the Satisfaction Scale[a]

	Name of item	Direction of loading	Rotated factor loadings [b]	Percent of total variance explained by factor
Factor 1 (Satisfaction)	Q45 I am able to be more independent [do the things that I want to do] because of my CD personal assistance services.	+	Very High	66.8%
	Q46 I can do more things in the community because of my personal assistance services.	+	Very High	
	Q47 My CD personal assistance services have made it easier for me to go to work or to school.	+	High	
	Q48 I would tell a friend that they should try to get CD personal assistance services.	+	High	
	Q49 I am happy with my CD personal assistance services.	+	Very High	
	Q50 I am more in charge of my life because of my CD personal assistance service.	+	Very High	

[a] The extraction method used was principal axis factoring (PAF). PAF allows for communality estimates less than one. Principal components analysis stipulates that the communality, or shared variance between the item and all other items, must be one – meaning that all of the variance in each item is shared with the other items. As this assumption could not be met with confidence (violation of which can lead to inflated factor loadings), PAF was selected as the extraction method.
[b] Varimax rotation factor loadings. Very high: |.76 - .99|; high: |.51-.75|; moderate: |.25 - .50|.

Results for the internal consistency analysis by each survey domain are detailed below:

Internal consistency analysis by survey domain

Survey Domain	Cronbach's Alpha
Access	.855
Use	.651
Choice and Control	.890
Satisfaction	.906

APPENDIX C

Content Analysis Coding Tables

Q51. What do you like most about your CD personal assistance services?

Code	**Code Number**	**Description**	**Example**
Family respite	1	Enables family to have a break from providing full-time support to the service recipient	✓Allowing mother to get out of the home
Quality Care	2	Helps meet personal and support needs of service recipient in a way that is most beneficial to service recipient and his/her family	✓Support in personal care needs ✓You don't have to go through agencies and wait for someone to show up
Independence	3	Enables service recipient to live more independently and with greater freedom to access the community	✓Allows me to live on my own and not live in a nursing home ✓Ability to access community
Family care	4	Allows family to get paid to provide support	✓Caregiver is from family and not a stranger
Choice	5	Allows the service recipient to have more choice in selecting, hiring, and firing his/her personal care attendant and choice in developing a schedule for a PA	✓That I can hire my own PA ✓He was able to choose an employee he likes and cares about.

Q52. If you could change one thing about your CD personal assistance services to make services work better for you, what would you change?

Code	Code Number	Description	Example
Pay	1	Increase in compensation for personal assistants	✓Better pay for worker ✓Pay PA for more money
Benefits	2	Offer healthcare benefits and paid holidays to personal assistants	✓Benefits package ✓Add benefits
Hours	3	Increase the number of hours that an individual receives personal assistance services	✓Wish to get PA for morning hours ✓Make it easier to get more hours
Finding qualified personal assistants and/or service facilitators	4	Make it easier for service recipients to find service facilitators and/or personal assistants.	✓Make it easier to find qualified facilitators, dependable and knowledgeable ✓Availability of dedicated personnel or PA who will stick with you for a period of time
Program administration issues	5	Paperwork, payment and/or program design concerns (such as an expansion of allowable reimburseable tasks functions and/or adjustments to the parameters of the program).	✓Paperwork is cumbersome or confusing ✓Payroll problems and getting paid on time ✓Provide mileage to CD employees ✓PAs should be able to perform assignments like a CNA (shots, catheterization)
Issues with individual personal assistants	6	Issues with individual personal assistants and they way they perform their tasks	✓Make them (PA) take me places and do more things with me. ✓I would like a more social P.A.

VITA

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