Medicaid Consumer-Directed Personal Assistance Services in Virginia: A Survey of Service Recipients

A study conducted for the Centers for Medicare and Medicaid Services

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Executive Summary

In September 2003, the Partnership for People with Disabilities at Virginia Commonwealth University was awarded grant funds from the Centers for Medicare and Medicaid Services (CMS) to learn, through interviews, about the experiences and satisfaction of recipients of consumer-directed (CD) personal assistance services in Virginia. The participants in this study were individuals over the age of 18 who have received CD personal assistance services from the Mental Retardation (MR) Waiver, Individual and Family Developmental Disabilities Support (DD) Waiver, and Elderly or Disabled with Consumer Direction (EDCD) Waiver programs for a minimum of 6 months as of March 2005.

Fifty individuals were randomly selected from each waiver program. Proxies, primarily people who serve as the "employer of record" for the individual receiving CD services, were asked to represent the perspective of individuals who are unable to respond to questions due to a significant intellectual impairment. A questionnaire administered in a semi-structured interview format was used to evaluate "access," "implementation," "choice and control," and "consumer satisfaction and quality" with CD personal assistance services for this study.

Results indicate that respondents were overwhelmingly satisfied with CD services and that this service delivery option afforded them choice and control over their personal assistance services. Notably high levels of agreement were found on items related to the flexibility of CD services and how CD services allow for enhanced control and independence.

Service recipients also reported relative ease with gaining access to and using CD services. However, the percentage of agreement on items in these domains was lower than with items in the "choice" and "satisfaction" domains. Regarding the "access" domain, respondents indicated lower levels of agreement with items concerning the availability of information and

resources explaining CD services. In the “using CD services” domain, overall mean scores were the lowest of any of the domains within the survey.

When examining the characteristics of users of CD services among different waiver groups, very few statistically significant differences were found. Largely, differences between groups were found in the variable of age and whether or not individuals knew their PA before hiring him or her. The survey domain of “access” generated the greatest mean differences in survey responses among waiver 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.

Implications from this study such as the need for “targeted” strategies geared towards the needs and concerns of particular population groups for accessing services are highlighted. Additionally, the need for additional studies with larger numbers of participants and thus greater representative power are recommended given the increasing reliance on CD services and self-direction in Virginia and across the nation.

I. Introduction

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 consumers and their families/advocates have control and choice over the services that they receive (Simon-Rusinowitz, Bochniak, Marks, & Hecht, 2000). Consumer-directed (CD) programs have become a central component of states' long-term care systems, with at least 139 publicly-funded programs operating in 49 states across the country. Some of these programs have operated for over 30 years; one serves more than 370,000 people, although the average program is much smaller (Nadash & Crisp, 2005; Doty & Flanagan, 2002).

As the use of CD services continues to expand, it becomes increasingly important to evaluate the impact of this service delivery option. To this end, the Partnership for People with Disabilities at Virginia Commonwealth University applied for and was awarded grant funds from the Centers for Medicare and Medicaid Services (CMS) in September 2003. The focus of the project was to learn, through interviews, about the experiences and satisfaction of recipients of consumer-directed (CD) personal assistance services and then to use the findings to inform the development of educational, training, and technical assistance materials. Additionally, results from the survey were to be used for the identification of relevant policy areas to target for infrastructure changes.

This report details the findings from the survey of Virginia's CD personal assistance services[1] recipients. Specifically, descriptive information is provided on service recipients and their experiences across several domains, including 1) access to information about CD services, 2) using CD services, 3) choice and control, and 4) satisfaction. Additionally, survey responses from individuals from the Mental Retardation (MR) Waiver, Individual and Family Developmental Disabilities Support (DD) Waiver, and Elderly and/or Disabled with Consumer Direction (EDCD) Waiver programs are compared to assess if there are significant differences in the experiences of each of these groups across the access, use, choice, and satisfaction domains.

CD Services in Virginia

In Virginia, consumer-directed services are primarily offered through the Medicaid home and community-based waiver program. Medicaid is funded jointly by the federal and state governments, and its purpose is to provide medical care and long term supports and services for certain groups of low-income individuals who are aged, blind or have a disability; members of families with children; and pregnant women. In Virginia, the state Medicaid agency is the Department of Medical Assistance Services (DMAS). As reported by DMAS, in state fiscal year

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

2005, over 1.7 billion dollars were expended in Virginia for services and supports to over 137 thousand individuals who are blind and/or have a disability (2005).

Virginia currently has six home and community based waivers. The term "waiver" means that certain Medicaid statutes, regulations, and limits on services and eligibility are "waived" so that services can be provided in the community (DMAS, 2003). 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.

Participants

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[2]" for the individual receiving CD services, was asked to represent the perspective of an individual who was unable to respond to the survey. 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,

[2] 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.

> 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.

II. Method

Data Collection

Information for this analysis was gathered through a questionnaire administered in a semi-structured interview format. 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 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 was 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. An individual 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. The decision to use a disproportional sample was made because 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.

Instrumentation

A questionnaire administered in a semi-structured interview format was used to evaluate "access," "implementation," "choice and control," and "consumer satisfaction and quality" with CD personal assistance services for this study. For the "access to services" dimension, the questionnaire contained a series of open and closed-ended questions concerning how consumers gained knowledge about CD services. The "implementation of CD services" dimension included open and closed-ended questions about current supports consumers use to successfully execute CD services. The next dimension addressed in the consumer survey was "choice and control." This section posed a set of questions to service recipients regarding the extent to which CD services enabled them to have more choice and control with their personal assistance services. Lastly, the questionnaire contained a series of questions about the consumers' satisfaction with CD personal assistance services and the extent to which services enriched the quality of their lives.

Research Design and Methodology

The research design for this analysis was descriptive and cross-sectional. The characteristics of individuals who receive CD personal assistance services in Virginia are described. Additionally, service recipients' experiences with CD personal assistance services across the domains of access to information about CD services, using CD services, choice and control, and satisfaction are presented. One specific research question examined in this data analysis is, "How do the experiences of individuals with cognitive disabilities, developmental

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 survey instrument is included in Appendix I.

Limitations of Data

One of the most significant limitations to the data gathered for this study is the relatively low sample size. 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 affects the conclusion validity of the research. Additionally, 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 (CD PAS) Waiver were being combined into the EDCD waiver. While consumer-directed services were well established in the CD PAS Waiver, the ED Waiver did not include consumer-directed services. Thus, the sample of participants from the ECDC Waiver is heavily weighted towards former users of the CD PAS Waiver, who had a much longer history with CD services.

III. 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. 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. 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 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.

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).[3]

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

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

survey[4]. Thirty-eight percent (n=52) of the overall sample had received, or was currently receiving, agency-directed services and of those 52 individuals, 88 percent reported that consumer-directed services better met their needs. Table 1 details the total sample's background and demographic characteristics (Insert Table 1).

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[5]. 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[6]), 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 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.

[4] ADL support needs (item number 12 on the survey) served as a proxy for severity of disability
[5] Lack of statistically significant differences among groups indicates that there is a high probability that any observed differences among groups have arisen by chance.
[6] 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.

Access to Information Domain[7]

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 2 outlines the total sample frequency responses for each survey item in the "Access" domain (Insert Table 2).

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 2, 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

[7] 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."

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 3, overall responses in the "Using CD Services" domain were mixed (Insert Table 3). 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.

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 3 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 4, 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 (Insert Table 4). 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).

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 5 (Insert Table 5).

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 II.

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 ($p>.05$, Mann Whitney test).

The means and standard deviations for each survey dimension are presented in Table 6. 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" ($F(2,141)=3.64$, $p<.05$). 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 Chart 1 (Insert Chart 1).

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 7 details the results from the multi-factor ANOVA (Insert Table 7).

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 [8]. The agreement coefficients for each question (.864 for "like most" and .863 for "change one thing") met Krippendorff's (1980) standards of reliability.

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

[8] 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.

care, and 5) choice in selecting, hiring, firing and managing personal assistants**.** The coding scheme and definitions appear in Appendix III.

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.

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 III.

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.

IV. Discussion

Data gathered through this survey clearly illustrate that respondents are overwhelmingly satisfied with CD services and that this service delivery option affords them choice and control over their personal assistance services. Notably high levels of agreement were found on items related to the flexibility of CD services and how CD services allow for enhanced control and independence.

Service recipients also reported relative ease with gaining access to and using CD services. However, the percentage of agreement on items in these domains was lower than with items in the "satisfaction" and "choice" domains. Regarding the "access" domain, respondents indicated lower levels of agreement with items concerning the availability of information and resources explaining CD services. In the "using CD services" domain, 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.

Several program administration issues were also apparent in the survey results. A relatively high percentage of respondents reported ease with different aspects of using CD services, although several service recipients indicated difficulty in areas such as workers getting paid on time, hiring personal assistants, setting up emergency back-up plans and, as noted earlier, finding quality information about how to access and use CD services.

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.

When examining the characteristics of users of CD services among different waiver groups, very few statistically significant differences were found. 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.

The survey domain of "access" generated the greatest mean differences in survey responses among waiver 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.

Additionally, 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.

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 these populations. CD service recipients who participated in this study perceive access to services differently.

These findings have important implications for users, advocates, and administrators of CD services. Clearly, service recipients value CD services and are very satisfied with this service delivery option. Overall, 97 percent of respondents indicated that they would tell a friend they should try CD personal assistance services. This is a strong endorsement for CD services.

Regarding program enhancements, for access to CD services, it may be beneficial to consider how individuals learn about CD services and by examining activities such as program marketing, development of promotional materials, information dissemination and services facilitation with "targeted" strategies geared towards the needs and concerns of particular population groups. 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 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 in Virginia. Studies with larger numbers of participants and thus greater representative power should be continued 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.

Table 1
Selected Demographic Characteristics and Background Information of Waiver Participants Receiving CD Personal Assistance Services

Characteristic	MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full Sample 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
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<.01, two tailed Fisher's exact test

Table 2
Access to Information Domain

Item		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full Sample 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

Table 3
Using CD Services Domain

Item		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full Sample 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

Table 3 cont..
Using CD Services Domain

Item		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full Sample 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

Table 4
Choice and Control Domain

Item		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full Sample 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

Table 5
Quality and Satisfaction Domain

Item		MR Waiver n=50	DD Waiver n= 44	EDCD Waiver n=51	Full Sample 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
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

Table 6
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

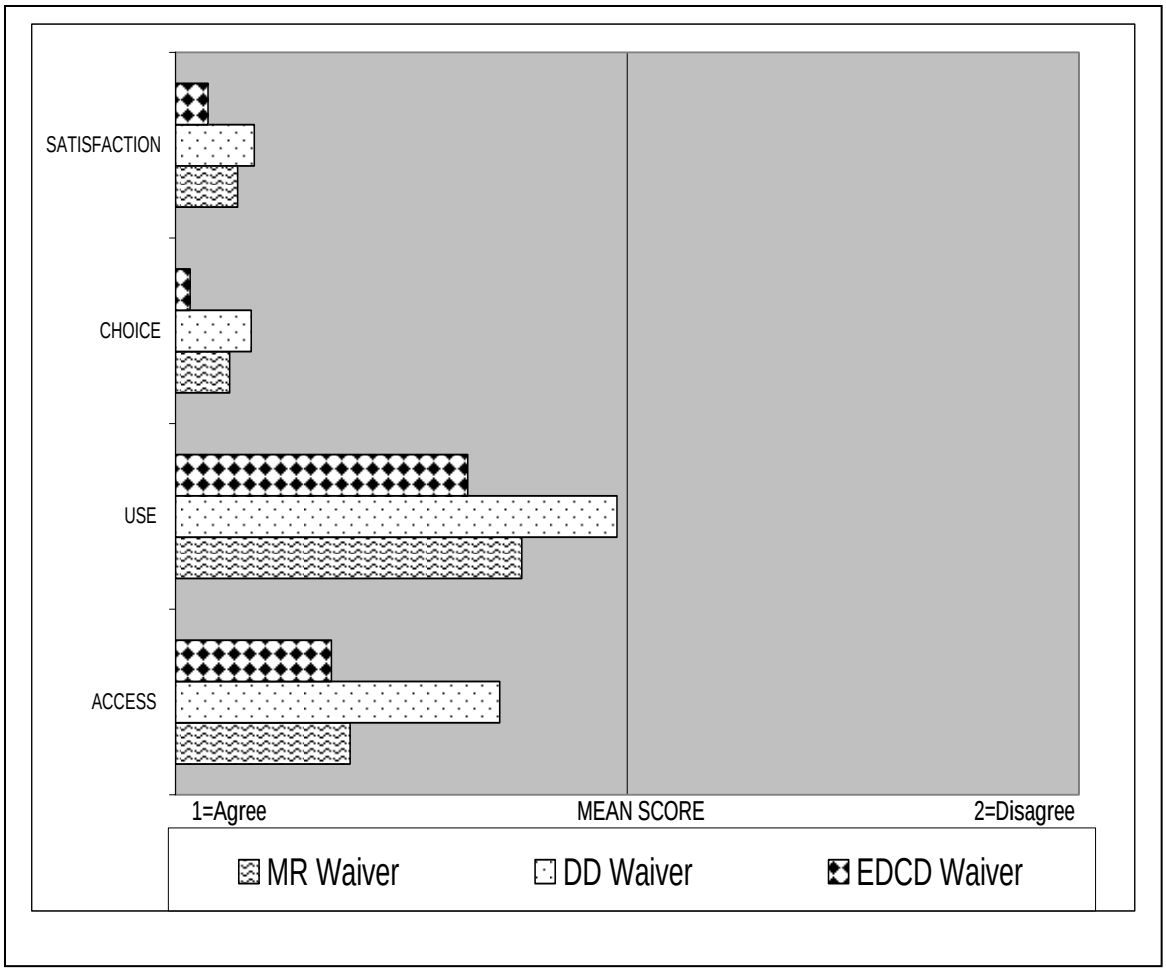
* In the survey, Likert-scaled questions offered four response options including “strongly agree” (1) to “strongly disagree” (4). For the purposes of analysis, the four categories were collapsed into two response options of (1) “agree” and (2) “disagree.”

Table 7
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

* 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.”

Chart 1
Mean Scale Scores by Waiver Program*



* 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 8
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

Doty, P and Flanagan, S (2002). Highlights: Inventory of consumer-directed support programs. U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy. Washington, DC.

Hair, J., Black, B., Babin, B, Anderson R., & Tatham, R. (2005) Multivariate data analysis (6th Edition). Lebanon, Indiana: Prentice Hall.

High, R. (2000). Important factors in designing statistical power analysis studies. Retrieved May2, 2006 at http://cc.uoregon.edu/cnews/summer2000/statpower.html

Krippendorff, K. (1980). *Content analysis: An introduction to its methodology*. Newbury Park, CA: Sage.

Mitchell, S., Ciemnecki, A., CyBulski, K., & Markesich, J. (2006). *Removing barriers to survey participation for persons with disabilities*. Rehabilitation Research and Training Center on Disability Demographics and Statistics, Cornell University, Ithaca, NY.

Nadash, P & Crisp, S. *Best practices in consumer direction*. Retrieved June 14, 2007 from http://www.cms.hhs.gov/DemoProjectsEvalRpts/downloads/Section648_Report.pdf.

Perry, J., & Felce, D. (2002). Subjective and objective quality of life assessment: Responsiveness, response bias and agreement between the responses of people being supported and those of staff responding on their behalf. *Mental Retardation*, 40, 6, 445-456.

Simon-Rusinowitz, L., Bochniak, M, Marks, L & Hecht, D. (2000). Implementation issues for CD programs: A survey for policy experts. *Generations*, Fall, 34-39.

Virginia Department of Medical Assistance Services. (2003). *Long-term care and waiver program.* Retrieved November 27, 2002 from http://www.dmas.state.va.us/ltc-home.htc.

Virginia Department of Medical Assistance Services. (2005). *Statistical record of the Virginia Medicaid program and other indigent health care programs*. Retrieved August 17, 2006 from http://www.dmas.virginia.gov/ab-2005_stats.htm.