

Delmarva Foundation
Florida Statewide Quality Assurance Program

Consumer-Directed Care Plus (CDC+) Outcomes and Supports Analysis
Comparison of DD HCBS and CDC+

Florida DD HCBS Waiver

The Home and Community Based Waivers (HCBS) enacted in 1981 are the federally approved Medicaid programs authorized by Title XIX of the Social Security Act, Section 1915(c) that provide services in the home for persons who would otherwise require institutional care in a hospital, nursing facility, or intermediate care facility. The Developmental Disability waiver provides home and community-based supports and services to eligible persons with developmental disabilities living at home or in a home-like setting, as an alternative to living in an Intermediate Care Facility for the Developmentally Disabled (DD). While the DD HCBS Waiver enabled people with disabilities to move from institutional to family settings, the standards for long-term care that have been promulgated often had little to do with quality in the areas of care considered most important to consumers. Decisions about the services they received were directed by the opinions of professionals or other experts.¹

The Consumer-Directed Care (CDC) program enacted in Florida in June 2002 gives consumers control over the use of Medicaid resources and greater autonomy over their choice and delivery of services and related purchases. The purpose of this study is to examine the outcomes and supports received by consumers who chose to use this service delivery system in lieu of receiving services through the regular DD HCBS Waiver program. Because data have been collected on only a small number of individuals who are on this program, analysis is limited. However, by compiling data over a three year period, some preliminary comparisons to the DD HCBS Waiver consumers are possible. This study is organized into six sections:

- Background
- Previous Research
- Florida Consumer-Directed Care Plus
- Data and Methodology
- Results
 - Demographic Description
 - Comparison of Outcomes and Supports
 - Differences on Individual POM Items
- Discussion and Recommendations

Background

In 1996, the Office of the Assistant Secretary of Planning and Evaluation in the Department of Health and Human Services (DHHS), the Center for Medicare and Medicaid Services (CMS), and the Robert Wood Johnson Foundation joined to cosponsor Cash and Counseling Demonstration projects. The projects grew out of a broad-based movement of Foundation-Sponsored reforms, funding consumer-directed and consumer-oriented programs. As part of this movement, self-determination projects for people with cognitive disabilities were launched in the early 1990s, with a pilot project in New

Hampshire for individuals with developmental disabilities or acquired brain injuries. Core features of this and subsequent self-determination projects (in 20 other states) included:

- Person-centered planning, enabling individuals and families to define their own needs;
- Independent professional support to help individuals and their families identify needs and choose services;
- Individualized budgeting, so funds can be used to address individual needs and/or preferences; and
- Fiscal intermediaries, responsible for purchasing services and handling legal and accounting matters on behalf of participants (RWJF Web site, 2004).²

The overall purpose of the Cash and Counseling project was to evaluate how Medicaid beneficiaries (consumers) would fare in a system that allows them to buy their own personal and community-based services, assisted by a consultant, with a defined contribution from their state's Medicaid program.³ Under this model, Medicaid dollars are given to the people with disabilities to buy and manage their services/care. Consumers are then responsible for their services and health care, including recruiting, hiring, training, and supervising their own personal care attendants. State and Federal government officials moved to this model in order to improve people's lives, and believed that lowering the cost of service delivery was a secondary motivation.⁴

Arkansas, New Jersey and Florida were the first states to be granted Section 1115 waivers to participate in the Cash and Counseling project. Individuals were given the opportunity to manage monthly cash budgets to purchase long-term supports and services, and received counseling to help plan and administer the use of the funds. They also had the opportunity to designate a representative to make decisions on their behalf. The program model and populations served varied in each of the three states.⁵ However, early results from the Cash and Counseling Demonstrations were promising and the Department of Health and Human Services (HHS) issued grants to additional states to begin planning Cash and Counseling programs.⁶

The Florida program began as Consumer Directed Care (CDC), with 2,820 enrolled participants who were eligible for the entire list of services covered under the Section 1915c waiver for home and community-based services.⁷ The eligible populations included four different consumer groups administered by four different state agencies:

- **Frail Elders (60 or over)**-served under the Aged/Disabled Adult Medicaid waiver through the Department of Elder Affairs (DOEA).
- **Adults with Physical Disabilities**- served under the Aged/Disabled Adult Medicaid waiver through the Department of Children and Families (DCF), Office of Adult Services.
- **Adults with Traumatic Brain and/or Spinal Cord Injury**-served under the Brain Injury/Spinal Cord Injury Medicaid waiver with the Department of Health (DOH).

- **Adults and Children with Developmental Disabilities**-served under the Developmental Disabilities Medicaid waiver with the Department of Children and Families, Developmental Services Program Office (now the Agency for Persons with Disabilities-APD).

Consumers managed the dollars allocated for their care to purchase relevant services and/or technological equipment to enable them to remain in the community and to be as independent as possible. They selected representatives to assist them in managing their care and were provided with a consultant service as an alternative to traditional case management. The consultants provided training and support for consumers, who then are more responsible for directing their own care. The theory behind the use of a consultant was that once the consumer has gained experience in identifying, purchasing and managing needed services, consultant services become less intrusive than case management services.⁸

Previous Research

The National Council on Disability (NCD), in a systematic review of the literature, reported findings on certain outcomes for people who elect a consumer-directed model.⁹ Researchers in each study that was reviewed reported on varying populations, using different indicators, with a different outcome focus. However, there were some similarities. The main outcomes identified in the research literature addressed the following questions:

1. Does preference for consumer-directed health care vary by the nature of the disability, age, or other demographic, geographic, or socioeconomic factors?
2. Does consumer-directed health care lead to different outcomes for consumers, including changes in satisfaction with care, either for the consumer or for paid or unpaid caregivers, in the following areas?
 - Empowerment or control
 - Community integration
 - Extent of unmet needs
 - Health status
 - Quality of care
 - Consumer safety
3. Is consumer-directed or -oriented health care cost-effective or cost neutral?

Regarding the question of whether preference for a consumer-directed program varies by age, gender or other factors, NCD examined seven studies. Their findings are summarized here:

- In two of the Cash and Counseling preference studies, younger consumers were more likely to express a preference for self-direction than were older consumers. However, the studies are inconclusive as they suggest that sometimes age matters and sometimes it does not.

- In six of the studies researchers indicated no significant association between gender and preference for consumer-directed care. Only one found a significant relationship in multivariate analysis, with men more likely than women to prefer consumer direction.
- In five of the seven studies, researcher found that race or ethnicity was associated with preference for consumer direction. However, the results were somewhat mixed. The Florida, New York, and Arkansas studies showed a stronger preference for consumer direction among African Americans and/or Latinos than among whites. A study of older adults in Boston found that Chinese elders were more likely to express preference for consumer direction and Latinos were more likely to express preference for a traditional case management model (compared with African Americans or whites). However, with the exception of Chinese elders, the vast majority of study respondents expressed a preference for the agency-directed model of care. In most of these studies, the association between race or ethnicity and preference remained significant in multivariate analyses.
- No association has been seen between different types of disabilities and the preference for consumer-directed care.
- Other possible relevant factors explored in the literature review that might effect a preference for consumer direction included health status, education level, current service use, whether or not the individual lived at home, the availability of family members to provide care, the availability of informal caregivers in general, satisfaction with current services, the consumer's prior experience with hiring and paying caregivers, the consumer's prior experience with managing and supervising caregivers, and the consumer's willingness to assume responsibility for caregiver management at various levels. Findings were inconclusive.

Regarding satisfaction with services, comparing consumer-directed and agency-directed care, seven studies were reviewed with the following findings:

- People who received consumer-directed services were significantly more satisfied with their overall service experience and with specific aspects of service delivery. However, it was also noted that 90 percent of people with consumer-directed care and 80 percent of people receiving agency-directed care were mostly satisfied with their services.
- People who hired family members (as providers) were significantly more satisfied with their care than those who hired nonfamily members, perhaps in part because they had more stable relationships and longer tenure with their caregivers. In addition, older people (age 65+) were more likely to hire family members and younger people (under 65) were more likely to hire nonrelatives. Few people in either age group hired strangers.
- In a 2001 study, no significant difference between younger and older groups in satisfaction with services was noted, with one exception. The younger population was more satisfied with the providers' ability to accomplish tasks for them inside and outside the house.
- However, a 2004 study in Arkansas found older people (age 65+) were more satisfied with their services than were younger people (under 65).

- People with physical disabilities who received consumer-directed personal assistance were significantly more satisfied with the control they had over the choice of caregivers and the authority to direct their care than those who received agency services.
- Younger consumers felt significantly more empowered than older consumers. Empowerment was defined as how people feel about what they do and the environment in which they live. Empowerment variables remained significant in multivariate analysis as individual predictors of satisfaction.
- Individuals who hired nonrelatives were more empowered, in that they were more likely to supervise their workers and direct their own care.
- Only one study examined overall health status, and the researchers found no significant difference in changes in overall health status between those who received consumer-directed services and those who received agency-directed services.
- In one of three studies that examined safety, the researchers indicated that individuals who received consumer-directed care reported significantly higher safety indicators than those who received agency-directed care.
- People receiving consumer-directed services were nearly 20 percent more likely to be very satisfied with their lives than people receiving agency-directed services.

In response to the question of the cost effective or cost neutral aspect of consumer-directed care, results vary greatly depending upon the methods used to determine costs. The findings are summarized:

- The costs of serving people in the community were significantly lower than the costs of serving people in institutions. Direct care staff-to-client ratios in the community were higher than in the institutions, suggesting the community programs were less expensive without sacrificing client care.
- In a study based on the Arkansas Cash and Counseling demonstration, no significant difference between the consumer-directed group and the agency-directed group in expenditures for in-home respite was found. The consumer-directed group received significantly more respite hours per month than the agency-directed group, but this was offset by lower costs per hour for the consumer-directed group.
- Over the two year period, by reducing institutional and acute medical care, the Arkansas Cash and Counseling demonstration managed to increase the availability of personal assistance services for both older and younger adults with disabilities without changing the overall cost of care.

Florida Consumer-Directed Care Plus

Initially, only 20 of Florida's counties provided CDC for individuals on the Aged/Disabled Adult or Traumatic Brain/Spinal Cord Injury Medicaid waivers. However, the project was available statewide for people on the DD HCBS Waiver. The

CDC program was initiated in Florida with an experimental research design. Half of the individuals interested in participating in the program were randomly placed in a control group that continued to receive traditional waiver services. The other half were placed in the experimental group and were allowed to purchase services directly from providers of their choice. The consumers' budgets were based on their history of expenditures in the 1915c waiver, or the cost of their care plans.¹⁰

At the conclusion of the pilot project, Florida planned to continue with the CDC model. In May 2003, the CDC+ program was approved, operating under the authority of an Independence Plus 1115 waiver amendment approved by the Centers for Medicare and Medicaid Services. The Agency for Health Care Administration coordinates Florida's CDC+ program operations and administration through interagency agreements with the participating departments: The Agency for Persons with Disabilities, Department of Children and Families/Adult Services, Department of Health and Department of Elder Affairs. The goals of the program are to:

- Demonstrate that some consumers of long-term care services can effectively use Medicaid resources to direct their own plan of care;
- Empower elderly people, people with disabilities, and their families to make choices that best meet their needs;
- Provide consumers/families the ability to make cost-effective purchases from formal and informal sources that best meet their needs;
- Demonstrate the use of consultant services to assist consumers in making purchases related to long-term needs;
- Provide an opportunity for consumers to improve the quality of their lives.¹¹

If consumers elect the CDC+ approach, they may replace their case management/support coordination services and agency direct services with a monthly budget. They are then provided with a consultant who assists participants with program administration, and also with a fiscal/employment agent (FEA) who assists them with their financial responsibilities, such as paying employer taxes and paying providers. For consumers on the DD HCBS Waiver, support coordinators are trained to assume the consultant's role. In November 2003, 800 CDC consultants were trained in the new web-based FEA and AuthentiCare systems for their new roles in the CDC+ program. As of January 15, 2004, there were almost 1,000 registered consultants for the CDC program.¹² In addition, the program provides flexibility to consumers in that they can set aside some money each week to pay for a larger item related to their care: for example, a lift chair or wider front door.^{13[13]} Participation in the program is voluntary and not all people on the various waivers feel it is in their best interest to move to the CDC+ model.

Participants in the CDC control group have been given the opportunity to move onto the CDC+ program. It is similar to the CDC demonstration project with a few exceptions:

- The CDC+ program will operate statewide for all participant populations;
- Consumers will be required to use a fiscal/employer agent;

- All service providers will be required to show proof of, or undergo, a background screening; and
- There will be no randomization (no experimental research design) and all individuals who enroll in the program will have the opportunity to receive a monthly budget.

Data and Methodology

While previous research has demonstrated some significant and positive impacts for people using a consumer-directed plan, no work to date has explored the impact on consumers as measured by the Personal Outcome Measures (POM) created by The Council on Quality and Leadership.¹⁴ Personal Outcomes are the standards by which we measure quality of life, based upon what matters most to the person. The purpose of this study is to examine the outcomes and supports received by consumers on the DD HCBS waiver, comparing those who chose to use the CDC/CDC+ service delivery system with individuals receiving services through the regular DD HCBS waiver program. Throughout the remainder of the study, we use CDC+ to refer to people who were on either the CDC or the CDC+ program. We include analysis of data collected between July 2001 and June 2004.

The Council on Quality and Leadership (The Council) developed the Personal Outcome Measures after conducting individual and focus group meetings with over 3,000 individuals with developmental disabilities, chronic mental illness, brain injury and physical challenges. The 25 Personal Outcomes The Council now uses were identified, by the people who were interviewed, as most important in their lives. Principle Component Analysis (Factor Analysis) was used to group the items into seven main POM domains: Identity, Autonomy, Affiliation, Attainment, Safeguards, Rights, and Health and Wellness.¹⁵ Each domain is defined with two to six different indicators or personal outcomes.¹⁶

Through a contract with the Agency for Healthcare Administration (AHCA), Delmarva Quality Assurance Reviewers (QAR) conducted the POM interviews with over 6,500 individuals across the state of Florida who received services through the DD HCBS waiver from July 2001 through June 2004. Each QAR is trained extensively on the review process and the administration of the POM measures. In addition, they are required to pass a reliability test, given by The Council, in the use of the POM tool prior to conducting any interviews. The Council also provides on going monitoring and annual reliability for all reviewers.

A random sample of individuals/consumers was selected each year from approximately 24,000 participants on the waiver. Consumers were permanently removed from the sampling process once they were chosen, sampling without replacement each year.¹⁷ Consumers could be receiving services from providers working for a large or small agency or a solo provider. Of the 6,110 people in the random sample who received a POM interview during the study time period, 148 were enrolled in the CDC+ program at

the time of their interview. In order to be eligible for the CDC+ program, individuals must be living in a family home or in an independent or supported living environment. Therefore, people in all other living arrangements (e.g., small or large group homes) are excluded from the analyses. The final analyses include 3,832 consumers on the DD HCBS waiver who are not using CDC+ (64.3 percent), and 148 CDC+ consumers.

Results

Demographic Description

Results indicate the CDC+ population differs in some ways from the DD HCBS waiver population. The following table displays the distribution of consumers by race and gender for DD HCBS waiver and CDC+ populations. In general, consumers on the CDC+ program are more likely to be white and more likely to be female than are consumers on the DD HCBS waiver.

CDC+ and DD Waiver POM Interviews by Race and Gender
Residents of Family Homes, Independent or Supported Living
July 2001 - June 2004

Race	Number		Percent	
	DD Waiver	CDC+	DD Waiver	CDC+
White	2,647	127	69.1%	85.8%
Black	1,000	13	26.1%	8.8%
Other	185	8	4.8%	5.4%
Total	3,832	148	100.0%	100.0%

Gender	Number		Percent	
	DD Waiver	CDC+	DD Waiver	CDC+
Male	1,704	60	44.5%	40.5%
Female	2,128	88	55.5%	59.5%
Total	3,832	148	100.0%	100.0%

While close to 86 percent of the CDC+ population is white only 69 percent of the DD Waiver population in family or independent/supported living is white. Consumers in these living arrangements for both populations are more likely to be female, but this relationship is stronger for consumers on the CDC+ program than for their DD HCBS counterparts, 55.5 and 59.5 percent respectively.

The distribution of consumers across age groups in the following table informs us that consumers in the CDC+ program are most likely to be children, age 17 or younger, 50.7 compared to 18.3 percent. When the CDC program was first developed, a major focus was to help provide children with needed services. The DD Waiver has a relatively

greater proportion of adults age 26 to 44 than the CDC+ program, 45.9 percent compared to 27.0 percent respectively.

CDC+ and DD Waiver POM Interviews by Age Group
Residents of Family Homes, Independent or Supported Living
July 2001 - June 2004

Age Group	Number		Percent	
	DD Waiver	CDC+	DD Waiver	CDC+
0 - 17	701	75	18.3%	50.7%
18 - 21	284	13	7.4%	8.8%
22 - 25	406	16	10.6%	10.8%
26 - 44	1,759	40	45.9%	27.0%
45 - 54	487	3	12.7%	2.0%
55 - 64	154	1	4.0%	0.7%
65+	41	0	1.1%	0.0%
Total	3,832	148	100.0%	100.0%

Consumers in both groups are most likely to have Mental Retardation as their primary disability, but this is more likely among DD Waiver consumers than CDC+ consumers, 79.7 percent compared to 60.8 percent respectively. The CDC+ program has a relatively greater proportion of individuals who have Cerebral Palsy or Autism than the DD Waiver program.

CDC+ and DD Waiver POM Interviews by Disability
Residents of Family Homes, Independent or Supported Living
July 2001 - June 2004

Disability	Number		Percent	
	DD Waiver	CDC+	DD Waiver	CDC+
Mental Retardation	3,054	90	79.7%	60.8%
Cerebral Palsy	365	24	9.5%	16.2%
Epilepsy	2	1	0.1%	0.7%
Autism	156	21	4.1%	14.2%
Spina Bifida	108	6	2.8%	4.1%
Other	19	2	0.5%	1.4%
Unknown	128	4	3.3%	2.7%
Total	3,832	148	100.0%	100.0%

Comparison of Outcomes and Supports

When comparing these two groups across several different demographic characteristics, it is important to remember there are only a small number of CDC+ consumers in the sample. Results presented here are therefore preliminary. Again, while not always stated in the text, consumers in the analysis are people who were living only in family homes, or independent or supported living environments.

On average, consumers in the CDC+ program have a slightly higher percent of outcomes met and supports present than consumers who are on the DD HCBS Waiver program. This average three year difference is greater for outcomes than for supports. For both the percent of outcomes met and supports present, the gap between the two groups has grown over the years, and is greatest in the 12 month period ending June 2004. However, the number of CDC+ consumers each year is relatively small, so these results should be interpreted with caution.

CDC+ and DD Waiver POM Interviews by Year
Family Home, Independent or Supported Living
 Percent Outcomes Met and Supports Present

Year	Number Interviews		Outcomes		Supports	
	DD Waiver	CDC+	DD Waiver	CDC+	DD Waiver	CDC+
Jul 01 - Jun 02	1,006	27	58.7%	61.9%	64.7%	65.3%
Jul 02 - Jun 03	1,421	62	56.0%	59.5%	60.3%	61.6%
Jul 03 - Jun 04	1,405	59	50.2%	57.0%	53.8%	59.9%
Total	3,832	148	54.6%	59.0%	59.1%	61.6%

Male and Female CDC+ consumers are about equally likely to have a higher percent of outcomes met than consumers on the DD Waiver, each approximately the same as the overall average. Male and female individuals on the DD Waiver are equally likely to have supports present, but female individuals on CDC+ are somewhat more likely to have supports present than are males on CDC+.

CDC+ and DD Waiver POM Interviews by Gender
Family Home, Independent or Supported Living
 Percent Outcomes Met and Supports Present
 July 2001 - June 2004

Gender	Number Interviews		Outcomes		Supports	
	DD Waiver	CDC+	DD Waiver	CDC+	DD Waiver	CDC+
Female	1704	60	54.3%	59.6%	59.3%	63.8%
Male	2,128	88	54.9%	58.5%	58.9%	60.1%
Total	3,832	148	54.6%	59.0%	59.1%	61.6%

Because there are so few CDC+ consumers in the sample, we divided the age groups into children age 17 and under and adults age 18 and over. Data comparing these two age groups are in the following table. Of interest, is that while the percent of both outcomes and supports is greater for children on the CDC+ program compared to children on the DD Waiver, the percent of both outcomes and supports present is lower for the CDC+ adult population.

CDC+ and DD Waiver POM Interviews by Age
Family Home, Independent or Supported Living
 Percent Outcomes Met and Supports Present
 July 2001 - June 2004

Age Group	Number Interviews		Outcomes		Supports	
	DD Waiver	CDC+	DD Waiver	CDC+	DD Waiver	CDC+
0 - 17	701	75	60.7%	65.3%	63.4%	67.1%
18+	3,131	73	53.2%	52.5%	58.1%	55.9%
Total	3,832	148	54.6%	59.0%	59.1%	61.6%

The comparison of outcomes and supports by the type of primary disability is particularly interesting. We examine the difference between people with Mental Retardation and those with any other disability. Information in the following table informs us that people with disabilities living in a family home or an independent or supported living environment are about equally likely to have outcomes met and supports present, regardless of which program they are using. Individuals on CDC+ have a slightly higher percent of outcomes present. People with other disabilities, on the other hand, appear to have better outcomes and supports if they are on the CDC+ program.

CDC+ and DD Waiver POM Interviews by Disability
Family Home, Independent or Supported Living
 Percent Outcomes Met and Supports Present
 July 2001 - June 2004

Disability	Number Interviews		Outcomes		Supports	
	DD Waiver	CDC+	DD Waiver	CDC+	DD Waiver	CDC+
Mental Retardation	3054	90	53.3%	55.1%	57.8%	57.9%
Other Disabilities	778	58	59.7%	64.9%	64.3%	67.4%
Total	3,832	148	54.6%	59.0%	59.1%	61.6%

Differences on Individual POM Items

The table in Attachment 2 at the end of this report displays the percent of outcomes met and supports present for each of the 25 POM items, for the CDC+ and the DD Waiver populations. The last two columns on the table show the difference between the two populations on each item. For example, on "chooses goals", individuals on the CDC+

program were 10.1 percentage points higher on the percent of outcomes met, and 5.3 points higher on the percent of supports present. A graphic display of the data is in Figure 1 on the following page.

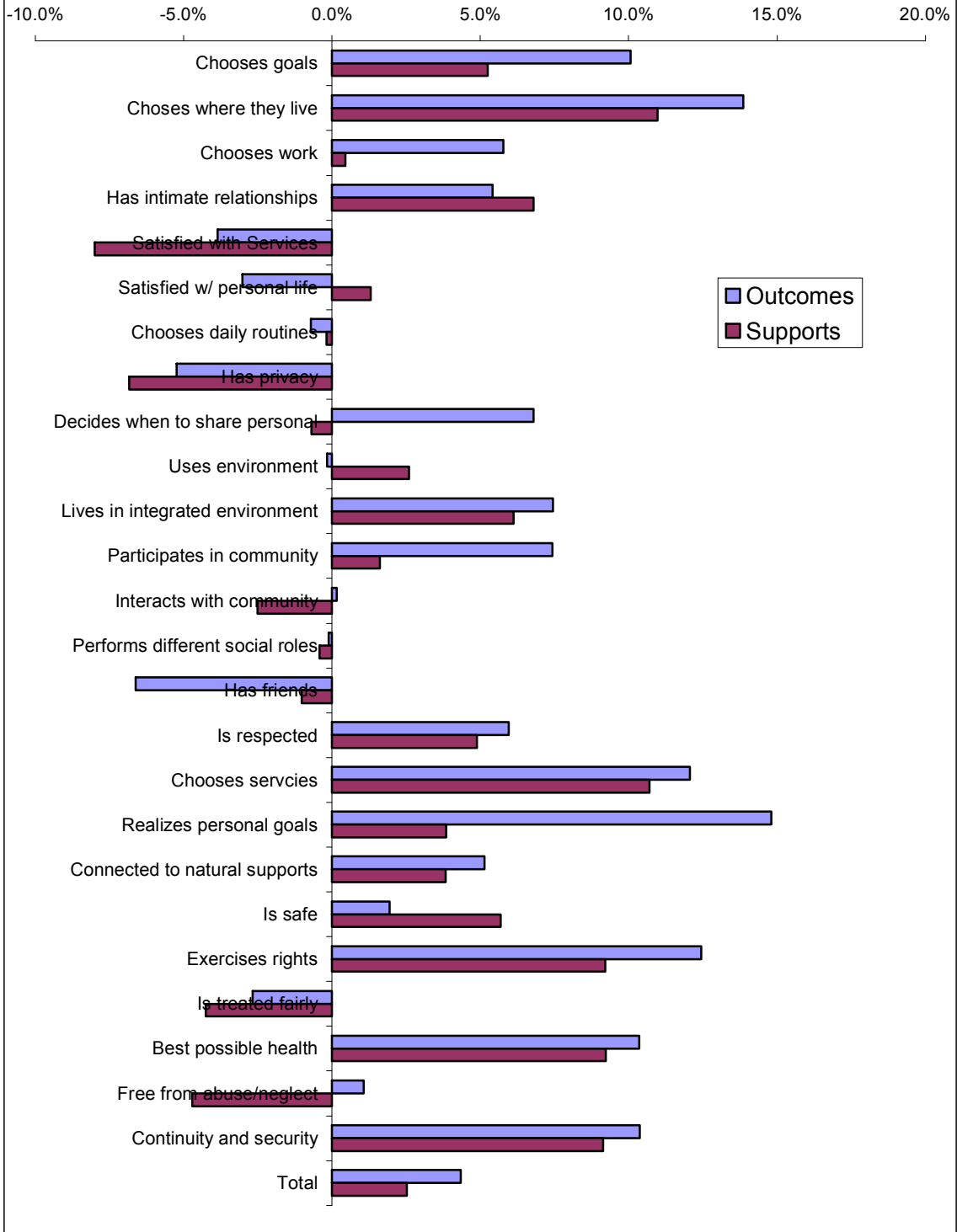
In this figure, any bars to the right of center (positive) indicate the percentage points consumers on the CDC+ program are above consumers on the DD HCBS Waiver for the outcome (blue or top line) or supports. When the bars are to the left of center (negative), this indicates the CDC+ population has a lower percent of outcomes or supports present. The farther away the bar is from center, the greater the difference. Note again that for "chooses goals", there is a positive 10 percent for outcomes and just over five percent for supports.

There is a 10 point or more positive effect on percent of outcomes met for CDC+ consumers on five of the POM items: *Chooses goals*, *Chooses where to live*, *Chooses services*, *Realizes personal goals* and *Exercises rights*. One of these is considered to be a "driver indicator". Through a regression analysis, the POMs with the highest likelihood of increasing the probability that at least 13 or more outcomes will be met and supports will be present were identified. Two "driver indicators" were selected as most important by the IQC - *Chooses services* and *Chooses where they work* as indicators to be targeted and tracked for Quality Improvement initiatives. CDC+ consumers were more likely to have outcomes met on both of these "driver indicators".

The last seven Personal Outcome Measures listed in Figure 1 include the items measuring Safeguards, Rights, and Health and Wellness. These are the Foundational Outcomes and are considered to be basic outcomes that most people with developmental disabilities would expect to have met most of the time. The greatest positive effect for CDC+ consumers within the Foundational Outcomes is on *Exercises rights*, an area CDC+ consumer were over 12 percentage points higher than consumers on the DD Waiver program. Relatively more CDC+ consumers had a higher percent of outcomes met on each of the Foundational Outcomes with the exception of *Is treated fairly*.

While the data indicate that on most of the POM areas, CDC+ individuals are more likely to have outcomes met, there are some key POM areas where they do not do as well as people who are not on the CDC+ program. It is interesting that on average CDC+ consumers have a higher percent of outcomes and supports present, but as a whole they are less likely to be satisfied with their services or to have supports in place for this outcome. They are less likely to have outcomes and supports present regarding privacy. Perhaps this is because a majority of consumers on CDC+ are children and are perceived as needing more supervision. The greatest negative difference for outcomes met is in the area of having friends, where the percent of outcomes met for individuals on CDC+ is close to seven points less. Finally, CDC+ consumers are less likely to have supports that help keep them free from abuse and neglect. However, they are slightly more likely to have outcomes met for this.

Figure 1: Difference in Percent Met: (CDC+) - (DD HCBS) for Percent Outcomes Met and Supports Present



Discussion and Recommendations

This is the first study that has compared outcomes and supports for people with developmental disabilities who are on the Florida DD HCBS Medicaid Waiver and people from this waiver who selected to use the Consumer Directed Care Plus alternative. We have provided a brief demographic description of the CDC+ population and how it compares to the consumers on the DD HCBS waiver, as well as some comparisons between the two groups on the Personal Outcome Measures as developed by The Council on Quality and Leadership. These are preliminary findings, based primarily upon a limited number of interviews with consumers in the "experimental" group from the original Cash and Counseling Consumer Directed Care program initiated in Florida. Some findings appear to be supported by previous research and some are not. However, because the number of cases reviewed is small, care should be taken not to over interpret these results.

Comparisons to previous research:

- Prior evidence from one study suggested that men were more likely than women to prefer a consumer-directed care program. However, in our sample of people who elected CDC+, the consumers were somewhat more likely to be women. In addition, women were more likely to have supports present than were men.
- Researchers have shown that people using consumer-directed services were more satisfied with their overall service experience than people using agency-directed services. Results from this study indicate the opposite. CDC+ consumers were less likely to have their outcomes met on the POM item reflecting their satisfaction with services, and less likely to have supports in this area. However, this may be due to the large number of children on the CDC+ program. Anecdotal evidence suggests that parents of children with developmental disabilities are often not satisfied with services. The children and their family's satisfaction of services are both taken into account when scoring this measure.
- Previous research has identified no significant difference in the overall health status of individuals on consumer versus agency-directed care. While not a direct "medical" comparison, CDC+ consumers in our sample were more likely to have outcomes met for *best possible health*, than were consumers on the DD HCBS waiver.
- Prior evidence suggests that individuals using consumer-directed care were 20 percent more likely to be very satisfied with their lives. In our sample, the POM item *people are satisfied with their personal life situations* showed slightly lower results for the percent of outcomes met for CDC+ participants. However, this was only a three percentage point difference.

While limited in scope, this study indicates that some people with developmental disabilities on a consumer-directed care program may have a somewhat better quality of life than people only receiving services through the DD HCBS waiver. This appears to be true most often for people with a disability other than mental retardation and for children. However, one important limitation to this research is that results have not been controlled for the type of service provided. It is possible that services most often

provided to people on the CDC+ program typically produce a higher percent of outcomes and supports for the individuals being served.

The following recommendations have been generated from the research:

1. Further research should be done when a larger sample is available. The study should explore the effect of different services on outcomes between the two groups and further examine preliminary results presented in this report.
2. In addition to a quantitative study, a survey could be completed to gather information from the two different groups regarding their satisfaction with the services, the program, and any barriers to services/care they have encountered. This survey should also gather information to help determine if consumers on CDC+ feel they actually do have more control over their services than other DD Waiver consumers, particularly among the children. Are their parents in control or do they use a person-centered approach to their children's care? Several focus groups conducted across the state could also help provide valuable information as to the successes and/or failures of the CDC+ program.
3. An analysis of the cost effectiveness of the CDC+ program should be considered. While saving money was not the initial focus of developing the Cash and Counseling demonstration projects, it is important to determine how well consumers are managing the money they are provided, and how that compares to their satisfaction with the services they receive.
4. Examine the reasons provided by consultants as to why outcomes and supports are not present for CDC+ population. Do these vary from the rest of the DD Waiver population?
5. This study provides some evidence that CDC+ consumers have better outcomes and supports than consumers on the DD Waiver. A study of interest would be a financial analysis comparing the cost of services provided to the two populations. Are some services more or less costly on CDC+ and if more costly, do the benefits outweigh the additional cost? Are Medicaid dollars appropriately and efficiently dispensed by consumers and/or their families?

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- ³ James Frogue. The Future of Medicaid: Consumer-Directed Care. The Heritage Foundation. Policy Research and Analysis. January 10, 2003.
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- ⁵ See Lessons from the Implementation of Cash and Counseling in Arkansas, New Jersey and Florida for details of similarities and difference in the three pilot programs. This is a report to the US Department of Health and Human Services: <http://aspe.hhs.gov/daltcp/reports/cclesson.htm>.
- ⁶ Consumer-Directed Health Care: How Well Does it Work? National Council on Disability. <http://www.ncd.gov/newsroom/pulications/2004/consumerdirected.htm#outcomes>.
- ⁷ James Frogue. The Future of Medicaid: Consumer-Directed Care. The Heritage Foundation. Policy Research and Analysis. January 10, 2003.
- ⁸ Martha Creel (850 488-4877 ext. 145), Jackie Kennerly (ext 126), Sara Heggen (ext 129) and Diana Lincoln (ext 147). Consumer-directed Care Research Project. March 14, 2003.
- ⁹ Consumer-Directed Health Care: How Well Does it Work? National Council on Disability. <http://www.ncd.gov/newsroom/pulications/2004/consumerdirected.htm#outcomes>. The results presented here are all extracted from this report, Section V, pp 27-44. Please see the report for more detailed information on the authors, methods and populations used in each of the studies reviewed.
- ¹⁰ A Report to the Florida Legislature: Consumer Directed Care Project. Florida Medicaid. January 15, 2004.
- ¹¹ Department of Elder Affairs; State of Florida. <http://elderaffairs.state.fl.us/doea/english/cdc.html>.
- ¹² A Report to the Florida Legislature: Consumer Directed Care Project. Florida Medicaid. January 15, 2004.
- ¹³ James Frogue. The Future of Medicaid: Consumer-Directed Care. The Heritage Foundation. Policy Research and Analysis. January 10, 2003.
- ¹⁴ See <http://www.accredcouncil.org/> for information on The Council on Quality and Leadership and the Personal Outcome Measures.
- ¹⁵ The Council on Quality and Leadership in Supports for People with Disabilities, Research Report #2, Construct Validity and Inter-rater Reliability, April 1997.
- ¹⁶ See Attachment 1 for a list of the POM domains and indicators.
- ¹⁷ See the FSQAP 1st, 2nd and 3rd Annual Reports, submitted by Delmarva Foundation to the Agency for Healthcare Administration, August 2002, 2003 and 2004, for a detailed description of the sample each year. Because some of the individuals interviewed were part of a separate Longitudinal Panel study, and some were part of reliability testing, not all of the 6,500 interviewees were part of the random sample.