

Florida Statewide Quality Assurance Program

Quality Improvement Study
Contract Year 9 (July - December 2009)

Consumer Directed Care Plus Program Analysis

Prepared by the Delmarva Foundation

Submitted to the Agency for Health Care Administration
And
The Agency for Persons with Disabilities

Executive Summary

The Agency for Persons with Disabilities (APD) administers several Medicaid waivers to provide services to approximately 30,000 individuals with developmental disabilities (DD). In addition to these, Consumer Directed Care Plus (CDC+) is a 1915(j) State Plan Option program that provides a budget to individuals who then direct their own services and find and hire their own providers. As APD moves into a new quality assurance program in 2010, the CDC+ program will be expanded by 2,500 individuals and the system used to monitor the program will be revised. The purpose of this study was to gather information from CDC+ participants, families, representatives and consultants to help APD improve the program and monitoring system.

Focus groups were used to collect information from people who have been participating in or associated with the CDC+ program for many years, most since 2003 or sooner as part of the pilot project. Two meetings were held in Miami, Tampa, and Tallahassee (total of six), one for individuals/family members and representatives and one for CDC+ consultants. Most representatives were also parents of the participant. In addition, the current desk review instrument used to monitor consultants was reviewed to help determine if it adequately monitors CDC+ requirements.

Findings indicate an overwhelming satisfaction with the CDC+ program. Families/representatives agree the amount of control they have over hiring and paying providers has vastly improved the quality of life for the individual. Consultants indicate a higher level of comfort with providers and overall ease within the family than they experience with families using one of the other DD waivers. However, there are numerous barriers and issues faced by program participants, including the following:

- Tier placement cut many participants budgets in half, causing financial difficulties
- Completing the purchasing plan, particularly without computer access, can be very problematic and time consuming
- Communication/confirmation appears to be an issue in larger Areas where the local APD office has only a limited number of staff devoted to the CDC+ program.
- While CDC+ can make it easier to find behavioral health providers, there are several issues surrounding this and other restrictive services that make it difficult to find providers or show medical necessity for the service.
- Small area problems with a limited number of providers

In addition to barriers, it is apparent the consultants often complete the purchasing plan, a task for which the representative is responsible. The hiring process appears to be quite varied and points to the need for better social networking and support. While the major focus of the program is to enhance the person centered nature of the person's services—to have individuals direct their own services—evidence suggests they are no more or less likely to direct their services or develop their own goals than individuals on the other DD waivers. A need for more training on the forms, computer programs, and the business aspect of the program was evident in all the group discussions. Most importantly, evidence suggests a need for more oversight of individuals and providers.

These and other problematic aspects of the program generated various recommendations to the state, including a need to develop a work group to address several issues with the purchasing plan as well as a standard confirmation system to enhance communication so representatives, individuals, and consultants know where the plan is in the approval process. Abuse and neglect should be included in the initial training, and ongoing training should be offered to help representatives with different aspects of the business side of the program. APD should work with Delmarva when developing new monitoring tools to help ensure individuals direct their own services and develop their own goals, and the APD liaison in each Area should assist participants in organizing and developing grassroots networking support to help disseminate CDC+ information, share ideas, and generally provide support to one another.

The CDC+ program appears to offer an extremely positive experience for participants and their families. As APD moves into the new Florida Statewide Quality Assurance Program in 2010, it seems apparent the CDC+ program could be used to help improve the quality of life for many individuals in the state. Outcomes for individuals as well as program processes will benefit greatly by incorporating the ideas and issues provided here by long-time participants

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.

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.ⁱ 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.ⁱⁱ

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.ⁱⁱⁱ However, early results from the Cash and Counseling Demonstrations were promising and the Department of Health and Human Services (HDDS) issued grants to additional states to begin planning Cash and Counseling programs.^{iv}

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.^v 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, to help them become 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.^{vi}

Initially, the project was available statewide in Florida for people on the Development Disabilities (DD) HCBS Waiver, using 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.^{vii}

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. Participants in the CDC control group were given the opportunity to move onto the CDC+ program. In November 2003, 800 CDC consultants were trained in the new web-based FEA and AuthenticCare systems for their new roles in the CDC+ program. Currently, there are almost 1,000 registered consultants for the CDC+ program. All but five are also waiver support coordinators, serving participants on the DD or Family and Supported Living (FSL) waivers. Participation in the program is voluntary but has been limited.

Purpose of Study

APD currently uses a desk review method to monitor a sample of CDC+ Consultants each year. With the advent of a new Quality Assurance monitoring system in January 2010, a more in-depth method of monitoring consultants, as well as participant representatives and providers, will be implemented, including an interview with a sample of CDC+ participants. In addition, Florida expects to expand participation in CDC+ by 2500 individuals. As APD moves into this new phase of the program, it has become important to gauge how well CDC+ is working for current participants and to identify any initiatives that might be beneficial to the effectiveness of the program and services provided to participants as the program expands.

The purpose of this study is to help determine the current effectiveness of the CDC+ program and also the extent to which the current desk review process has identified requirements of the program

that need to be monitored. Specific research questions were developed, including the following:

- Are participants satisfied with the program?
- Are they getting the services they need?
- What is working and what is not working—benefits and barriers?
- What changes should be implemented moving forward?
- Are the roles of consultants and consumer representatives clearly defined and followed?
- What would be helpful for individuals and families to know coming into the program?
- How successful is the person-centered nature of the process?
- Does the current monitoring tool address all necessary requirements?
- What else should be monitored?

Methods

The nature of this study is to explore the various research questions, as well as to gather any additional relevant information important to consultants, individuals, families and/or representatives using the CDC+ program. To best solicit information from experts in the field, six different focus groups were conducted in three areas of the state: Miami, Tampa, and Tallahassee. In each city two focus groups convened: a focus group for individuals and their representatives in the morning, and a focus group with consultants in the afternoon. The APD Area CDC+ liaison in each Area assisted with contacting people and inviting them to join the groups.¹

A total of 21 family members participated in a focus group. Almost all of the parents were also representatives, while a couple of parents were acting as providers rather than representatives. Unfortunately, only two individuals receiving services participated in the focus groups, one in Miami and one in Tampa. However, the individual in the Tampa group was acting as his own representative and brought a unique perspective to the discussion. A provider attended to help him with communication. Almost all of the group participants had been with CDC+ since the pilot program or since it was implemented in 2004.

The consultant groups consisted of seven consultants in Miami, five in Tampa and only one in Tallahassee. Most every consultant worked with individuals receiving services through the Developmental Disabilities Waiver as well as with individuals on CDC+. The one consultant who participated in Tallahassee represented one large Waiver Support Coordination agency that serves 30

¹ APD representatives were present in both Miami focus groups and in the family focus group in Tampa.

of the 35 CDC+ participants in the Area. CDC caseloads ranged from 1 to 25, with total caseloads (including DD and FSL Waiver participants) ranging up to 48.

Focus groups were provided two hours for discussion. Some similar topic areas were presented to each group to allow for comparison across the various areas of the state. These included the following:

- Benefits of the program
- Challenges or barriers
- Representative versus Consultant responsibilities
- Consultant versus Waiver Support Coordinator responsibilities/roles (Consultant groups)
- Health (abuse and neglect issues or problems)
- Person centered process/involvement of person in decisions
- Hiring process/social support networks
- Training needs
- What should APD monitor (outcome measures)
- What to change as program expands

Several common themes emerged in each group relative to the topic areas. Issues, problems, and suggestions common to most groups are discussed in the Findings section.

In addition to the Focus Group discussions, the desk review instrument currently used to monitor CDC+ consultants was reviewed. Elements in the desk review were compared to current CDC+ requirements to help determine if key aspects of the program have been omitted from the review process and if additional elements need to be included as a new monitoring tool is created.

Focus Group Findings

This section includes major areas of benefits and concerns noted in most every focus group and by most participants. Also included is a section for comments or suggestions offered by one or two participants that may be helpful to APD as the new quality assurance program is developed in 2010. It is important to note the opinions and suggestions expressed here were from a select group of individuals and may not represent all CDC+ participants, representatives, families or consultants.

Benefits

Some key benefits include control, flexibility, and access to a wider choice of providers. In fact,

every member of each focus group expressed a high degree of satisfaction with the program because of these and other benefits. One parent noted “It is our salvation. Our son is able to grow with this program”.² The program, from a consultant’s perspective, is “transformative”. Consultants noted the family atmosphere feels more relaxed. Families with medically complex individuals are able to hire providers with whom they feel safe, and many issues families and individuals had hiring and maintaining providers on the DD or FSL Waivers have been eliminated.

Control was expressed as beneficial in several aspects of the program. The individual/family has control over which providers are hired, and “love the control of who works” for them. If the individual or representative finds a provider is not performing all aspects of a service, it is up to them to hire a different provider who will perform to their expectations. According to consultants, the ability to hire non-waiver providers is one of the most positive aspects of the program.

Hiring non-waiver providers often means hiring a family member who is familiar with the person. “We love her, trust her, take good care of her. CDC allows us to do that.” Parents and family members feel more comfortable with someone they know, who will provide the best service possible for their loved ones. This seemed especially important for “medically complex” individuals. Parents already providing many hours of service could be paid for it. However, the flexibility also means a parent can hire another family member or friend and give the parent the opportunity to work outside the home.

Individuals/families also have control over the pay rate for each provider. By setting the rate, families are able to give raises if they choose to, which provides incentive for providers to do well and stay with the individual. Under the DD/FSL Waiver system, much of the pay may go to the agency and many families indicated providers changed all the time. Therefore, providers can earn more while families actually pay less than the waiver rate.

With the ability to hire and set rates for most services, individuals are free to save money for additional services or activities that may not be available through the DD or FSL waivers. The flexibility this affords families was mentioned in each focus group as a way to tailor services to fit the real needs of the individual. Examples of services spent with savings included:

- Horse therapy
- Hydrotherapy
- Adaptive equipment (a scooter)

² Throughout this study, quotations indicate direct quotes from focus group participants.

- Lessons to get a driver's license
- Gym memberships
- Chiropractic treatment
- Health foods
- Spina Bifida camp
- Brand name diabetes medications

Another benefit noted in each group was APD taking over as the fiscal agent. While some problems have continued, most issues have been reconciled. Previously, according to many CDC+ participants they did not have a known budget for up to a year. It was almost impossible to balance monthly statements and savings accounts were erratic, "one month there and the next month gone". All representatives and consultants stated the monthly statements were coming regularly, savings issues had been resolved, and they were very pleased with APD as the fiscal agent for the program.

One topic discussed often, as both a benefit and a barrier, was behavioral health services. CDC+ provides a wider pool of providers, waiver and non-waiver, who can work with individuals who have behavioral services needs. The individual can hire a psychologist who is very helpful to the specific needs of the person, but may not be a waiver certified behavioral analyst. While this is a great benefit of the program, it can also create a barrier, as discussed in the next section.

Barriers

While each person felt the benefits far outweighed the problems, there were many issues and barriers noted within the CDC+ program, including:

- Tiers/Financial issues
- Purchasing plan/paper work/ quick updates
- Behavioral health and restrictive services
- Small area problems/limited number of providers
- Communication/confirmation

Tiers/Financial Issues: Most every participant had been negatively impacted by the Tier placement of the individual in the program. Many group participants indicated the individuals moved from Tier 3 to Tier 4, mostly because they live at home, and many indicated their budgets had been cut in half. Some felt that by fulfilling the goals of the program, keeping individuals out of group homes or institutions and in family homes, they were "being punished" with financial and service cuts.

In addition, many group participants indicated they had received very little information about the Tier placement process. There was some confusion as to how individuals were placed in a Tier, and what the criteria were. Some specific issues noted included the following:

- “Biggest problem was cut in money.” Changes in funds required CDC+ participants to “restate their goals”
- Moving onto the Tiers generated “severe limitations”
- “Health needs have been hampered”
- Frustration with lack of communication from the central office after repeated attempts to contact the director or other staff
- Cost Plan and Purchasing Plans had to be redone
- Loss of dental impacted many CDC+ participants, even though the flexibility of the CDC+ program did help several continue to buy this service

Purchasing plan/paper work/ quick updates: While most group participants agreed having the Purchasing Plan online is beneficial, and the newly implemented Quick Updates was helpful, every participant in each group noted some aspect of completing or updating the Purchasing Plan as generally problematic, including:

- Constant changes to the form
- Timeliness issues
- Communication and confirmation of Plan approval
- Paperwork when online access is not available and/or representative is not computer literate

The most common theme was to “leave the form alone”. Although group participants indicated they are told they “can always trust the form on the web page”, they indicated that is not always true and they are not informed when a new version has been implemented. Therefore, they may complete the wrong form, which is then rejected, which delays the approval process and payment to providers, who cannot be paid until the Purchasing Plan is approved. The Quick Update appears to have alleviated some of these issues, and several group participants would like to see this expanded to include additional elements. However, as one individual stated, “sometimes the quick updates are anything but quick”, and others reiterated this sentiment. The constant modifications to the Purchasing Plan have caused confusion and an excessive amount of time “redoing” work on the Plans.

Most group participants in the larger areas, Miami and Tampa, indicated problems with getting the

Purchasing Plans through the approval process in a timely manner, and receiving confirmation the Plan had been approved. The representative needs to complete the Plan and pass it to the consultant who faxes it to the local APD office, where it is sent to the Central office in Tallahassee. However, many in these Areas indicated they “waited for months” to get the approval from APD and felt there is a lag time between the local and central office. Neither the consultant nor the representative appears to consistently receive notice the central office has the Plan, or when it is approved. This did not appear to be a problem in the Tallahassee Area, where there are far fewer CDC+ participants.

In order to use the online form, the Representative needs to have computer access and knowledge of Excel software. Without these, the paperwork “is a huge barrier”. In Excel, the calculations are done automatically. However, without use of this software package, calculations must be done by hand. Some representatives can use the consultant’s office/computer to help with this process. However, others have the consultants complete the Plan, an issue discussed in next section.

Behavioral health and restrictive services: As noted above, the ability to use non-waiver certified providers, such as a psychologist, is a huge benefit on the CDC+ program. This is particularly helpful in smaller rural areas where certified behavioral analysts are difficult to find. The provider is not required to be waiver certified and the CDC+ program does not require the same type of documentation for the service.

However, authorization to receive this restricted service is tied to the same documentation as required through the DD Waiver. The person must document the use of the service, and medical necessity, through a certified waiver provider in order to qualify for the service. Therefore, a psychologist who provides excellent service for an individual, and is a benefit of using the CDC+ program, does not generate sufficient documentation of medical necessity for the person to receive authorization to continue the service, because this professional is not waiver certified. The process for service authorization must then start over. Most families have found this to be a huge barrier to providing continuity for the individual.

Small area problems/limited number of providers: A problem that appeared to be unique to the more rural areas surrounding Tallahassee was a lack of adequate providers, particularly for the restrictive services, such as behavioral analysis. One parent felt providers did not want “to take her daughter based on her behavioral needs”. They want “kids who are docile and manageable”. This appears to be compounded by a larger issue in that one agency “holds a monopoly” on providing behavioral services through the waivers. In general, in the Tallahassee family/representative group,

there was a feeling the large agency was intimidating families and individuals. Members of the agency sit on all the Local Review Committees and deny the service if the person is medically complex or the family does not intend to use their agency for the service.

In general, getting providers in small areas, such as Monroe County or across Area 2a, can be challenging. If individuals use special education or nursing students, the students leave when the semester is over or leave for spring break, and this does not enhance continuity for the individual. One parent indicated they had “given up on finding a respite provider”.

Communication/confirmation: Communication and confirmation of receipt and/or approval of documents appears to be lacking across the three Areas. As indicated above, representatives and consultants do not consistently receive confirmation from the state that a Purchasing Plan has been received or approved. Other communication issues were noted, particularly, in the Miami and Tampa groups:

- Not getting updates on the correct codes needed to make changes in the Purchasing Plan
- Difficulty in knowing where the Purchasing Plan is in the approval process. The representative sends it to the consultant, who sends it to the Area office, who sends it to central office, and back to consultant. If there is a problem and it gets “kicked back” at any point in this process, the consultant may not be informed or may not inform the representative, who is then unable to pay providers. It appears there is not a standard confirmation process.
- “Changing something, implementing it, then notifying us”. “Changes come too fast without notification.”

Other barriers noted:

- Aspects of the monthly review forms are frustrating. There is no wrap function where details should be entered, when the “enter” key is used it changes everything to CAPS, and it is difficult to type in the form.
- It can be difficult, as a single parent or elderly caregiver, to find someone to act as a representative. It is a lot of work for no pay.
- It is good the parents can be paid for the care they provide, but if they “get used to the money” they may not purchase other needed services, such as respite care.
- Phone system/customer service was not very helpful. Parents and representatives indicated they could wait for days for a response. This is particularly important for people who must fill out forms by hand, and can seriously delay the Purchasing Plan approval process.

Representative versus Consultant Responsibilities

Most every representative and each individual in the focus groups indicated they had a “great relationship” with their consultants. The consultant is “the first place to go when they don’t know where to go.” However, it was also noted that some representatives “treat their consultants like secretaries” and the consultants do too much. The CDC+ program is structured so the representative completes the Purchasing Plan, “follows the individual’s needs and requests”, hires providers, sets the pay rate, and ensures providers have proper background screening and training documentation. The consultant’s primary responsibilities include completing the Support Plan and Cost Plan, providing initial training for representatives, acting as an advocate, reviewing monthly statements and comparing them to the Purchasing Plan.

In each focus group it was clear the consultants often complete the Purchasing Plan for representatives. Consultants estimated they “cross the line” and help with or complete the Purchasing Plan for about 70 percent of their CDC+ participants. There were several reasons provided for this, including the following:

- Lack of computer access, so the representative takes a hard copy to the consultant who enters it into the online form. This is particularly important in rural areas where families may need more technical support.
- Fear of being fired, coupled with a sense the Area and State offices do not always back the consultants if they do not agree to perform the extra work. For example, consultants feel the state does not take people off the CDC+ program when they are unable or unwilling to do the required work.
- Representatives and families are often not familiar with the waiver changes and consultants do not want them to lose services for the individual.
- Representatives are not able to “run a small business” and complete everything necessary to make it work.
- Often, there is a sense that consultants may feel obligated to help as much as they can to ensure needed services are obtained.
- Some representatives perform very well with most aspects of the service, but have difficulty with the paper work. Consultants want to help them.

Consultant versus Waiver Support Coordinator (WSC) responsibilities/roles (Consultant groups)

With one exception, every consultant who participated in a focus group was also a Waiver Support Coordinator (WSC). While responsibilities are somewhat different, some felt the workload is about

the same. The following activities must be completed by both Consultants and WSCs. An asterisk (*) indicates the current CDC+ Desk Review monitors the requirement.

- Ensure they have their own Level 2 Background Screening documentation
- Have the same training and qualifications
- Complete the cost plan annually *
- Complete the support plan annually *
- Document monthly contacts, but type and frequency differs *
- Document monthly activities, but level of detail and format differs *
- Demonstrate natural and community resources have been explored prior to requesting funding for a one time expenditure or an increase in funding for services and supports *
- Assure purchased supports and services do not exceed the annual limits of the current approved cost plan *
- Monitor CDC+ participants' health, safety and welfare, although Consultants may only see the participant once a year *

The CDC+ consultant has responsibilities specific to the CDC+ program. An asterisk (*) indicates the current CDC+ Desk Review monitors the requirement.

- Attend CDC+ training and sign a Memorandum of Agreement with Local APD office
- Ensuring Participant-Consultant Agreement and CDC+ Consent form is signed/dated *
- Monitor budget by reviewing monthly statements, comparing purchases with the Purchase Plan *
- The consultant must have monthly contact with the consumer and visit the consumer in the home or community activity no less than once per six-month period.*
- Conduct monthly telephone contacts and complete Monthly Consumer Review Form (Consultants providing Limited Consultant Services are required to call only if they have questions or concerns regarding the monthly statement. Limited Consultant Services is mandated for individuals under 21 and optional for those over 21) *
- Complete Page 1 of Purchase Plan/Quick Update and submit to APD for approval, keeping individual/representative informed of status
- Initiate Corrective Action Plan if needed *

Consultants indicated they do not hire or monitor providers, but they appear to provide a lot of technical assistance to the CDC+ representatives. One consultant noted “it is the consumer who suffers if all the t’s aren’t crossed and the i’s aren’t dotted, but the consultant is held to the fire”. “I cave means I do”, so the workload for consultants may be greater than originally intended for the

program. As a result, participants in the groups indicated some WSCs will not become consultants because of workload issues. However, others like it because they are good at it, they have less direct contact with providers and families, and it is very organized.

One of the greatest problems noted with CDC+ as opposed to WSC, is a lack of oversight. As noted, consultants do not have direct contact with individuals, seeing them maybe once a year. They do not know what is going on in the family, they do not monitor providers, they do not see progress notes, and they know less about the person than as a WSC. One parent reported locking doors both on the inside and outside (double locks), to help prevent the individual from leaving unattended, a situation that could have resulted in a safety alert from a WSC. Another parent wants cameras throughout the house, which could be considered a violation of the person's right to privacy.³

Health (abuse and neglect issues or problems)

In addition to oversight issues noted above, consultants have some concerns because they rely on families to ensure the health, safety, and welfare of the individual. For example, the program "allows an 87 year old to care for two participants". There are no guidelines or age limits as to who can be hired, unless it is a restricted service (e.g, behavioral analyst). Consultants do monitor the health of individuals but only see them once a year and they expressed concerns about a lack of oversight in this area.

Generally, representatives did not feel they had received abuse and neglect training, or needed it. They reported the individuals, often a son or daughter, would let them know if anything happened to them. Consultants "step up some" and change their role when there is a crisis, but indicated "no one is looking at the person with the disability". Some have been concerned for certain individuals but feel there is little they can do. For example, if the person is supposed to receive a designated number of services to help with community integration or getting to a doctor, and this is not happening, the consultant may think the family needs to hire another provider "but there is not much (they) can do".

Person centered process/involvement of person in decisions

One of the primary goals for the CDC+ program is to help allow individuals to direct their own services, hire their own providers, develop their own goals, and be part of all decisions concerning their lives. The program is structured to enhance the person centered nature of the person's services.

³ These comments concur with findings from the CDC+ Study completed for AHCA in 2004. Individuals on CDC+ were less likely than individuals on the DD Waiver to state they have privacy or to be free from abuse, neglect or exploitation.

Representatives are needed to help with this process, develop the Purchasing Plan, ensure providers have the necessary qualifications/certifications, and take care of the payroll. In each focus group it was evident the individual is actually no more or less involved in directing services than individuals on the DD or FSL waivers. In fact, “individuals sometimes have a difficult time seeing what is a service, if the provider is their mom.”

In almost every instance, representatives, who were most often a parent, decided who to hire. However, most indicated they involved the individual by having the prospective provider spend time with their son or daughter. It was often noted the individuals “were not necessarily involved in choosing a provider, but they do let them know when it is the wrong one.” Representatives/parents felt it was evident if the provider would relate well to the individual and that was important in the decision making process. They want someone who will “become part of their family”. While the CDC+ participant did not often have direct input into hiring, family members indicated the process was a great improvement over waiting for agencies to decide “who to send over”.

In addition, many parents/representatives indicated the individuals “were severe” and needed help with the hiring process. Because we had only two program participants in the groups, it is not clear how this might be handled within other families. One individual in the group acted as his own representative, and as such was the person directing all hiring for himself.

The participants in the family/representative focus groups appear to help develop goals for the person. Consultants echoed this in that defining and accomplishing goals was driven more by family dynamics, as “the family is still doing goals.” Only one representative/parent related what her daughter’s goals actually were: to learn how to drive, to get her own place, earn money, have a job and be independent. It is possible, however, other parents do know what goals their sons or daughters have, but they misunderstood what we were trying to ask. Other goals were related as:

- Parent has one to one eight hours a day. “This is our goal” for her.
- “My mom picks my goals for me.”
- Want to motivate them, get them doing things.
- Goal is to alleviate boredom, have different activities every day.
- “I want to start a program where my daughter will be welcomed.”
- To be able to take him out without him screaming, to be able to greet people.

Hiring process/Social network supports

Most parents/representatives indicated they had two or three hired providers. These are often a

family member, with another family member acting as the representative. Most group participants agreed one of the biggest advantages was the flexibility of hiring non-waiver providers and screening providers to help ensure they found someone who really “connects with the person”, who is not there for the salary, and either is part of the family or “becomes part of the family”.

An additional advantage of the CDC+ hiring process, compared to the DD Waiver, was “not having to use the thick packet to hire someone.” This was a very cumbersome process and often took months to get providers through all the trainings and approved to render services. According to one participant, “there are hoops with CDC+, and now more than before, but now it is much easier to hire than through the big waiver”.

There did not appear to be any consistent process used to find providers, and some group participants stated it can be very hard to find someone, particularly in smaller more rural areas. No one in the groups mentioned contacting the local APD office for a list of waiver providers.

However, several methods for finding prospective providers were mentioned, including:

- Using students from the universities
- Teachers or Aids from the local school
- Word of mouth
- Add in the newspaper
- Go someplace and watch how a provider works, see if you want to set up an interview
- Through friends at church
- Work force plus

Through the discussion of hiring providers, it became apparent there was little or no social networking or support available for families using the CDC+ program to share information. Around the Miami area, there is a support group that is organized and run by the local APD office. The CDC+ participant in the group stated enjoying the support group meetings very much. However, not all participants in the focus group knew about it, there is only one meeting “centrally located”, and this is not convenient for many CDC+ participants in Area 11. One representative indicated driving two hours from Monroe County to attend the focus group meeting in Miami. The APD representative stated a lack of funding and staff prevents them from creating groups in other locations in the Area.

Generally, family members did not feel there was a support group they could use. The APD Website offered some good information, if the representative or family member has a computer with which

to access it. It was also suggested this web site could be kept more up to date. Aaron Nangle's Support Coordinator web site (<http://www.supportcoordinators.info/>) was also used by some as a source of information. One representative indicated he thought the DD Council has a site with resources, but basically just "hears things out of the blue". Most stated the consultants were a good resource but they did not always get all the information they needed from the consultant. The APD phone system for customer service was not particularly helpful, and often took several days for a response.

Training

Consultants are responsible for training new representatives on completing the Purchasing Plan, and providing technical assistance as needed. While most representatives/family members felt the initial training they received was good, there are no training updates or refresher courses. A need for more training, and in several different areas, was expressed by many representatives. One individual felt no training was available and others indicated it would be helpful to have someone they could turn to for advice. According to many group participants, refresher training for the Purchasing Plan, including training in Excel, would be very beneficial.

Consultants echoed concerns about a lack of training for CDC+ participants. "Do they need training? Yes, with a capital T." They believe the current training for CDC+ participants/representatives and consultants is "too convoluted, complex, and not addressing CDC issues." Operational information provided to participants does not equate to "this is what you must do" to get your employees paid. Training should be provided to help representatives in several areas, including the following:

- Read monthly statements
- Invoices, checks, cash out, managing and being accountable for the state's money
- Ensure providers they hire are rendering services as specified
- Understand financial and budgetary aspects of the program (e.g., 12 percent of money is taken off the top)
- Documentation (representative and consultants)
- Workers compensation if they have more than three directly hired employees
- Computer applications for online forms, including updates

What should APD monitor (outcome measures)

Currently, APD uses a Desk Review to monitor consultants, and there is no consistent method for monitoring providers or representatives. Moving into the new Florida Statewide Quality Assurance

Program (January 2010), with the addition of 2500 participants, a new more comprehensive system will be used for the CDC+ program. Consultants and representatives/family members were provided an opportunity to indicate what they thought should be monitored and what changes could be implemented that would be beneficial to the program as it expands. Collectively, the following items were considered important for APD to monitor, at least on an annual basis:

- Ensure services are being rendered as specified
- Money received for restrictive services—is it spent as intended or saved and used for non-restrictive service
- Organizational systems for doing payroll
- Representative's paperwork, including background screening for all providers
- Consultant annually updates the Support Plan and Cost Plan
- Health and Safety
- Cash reports and receipts
- Conduct an interview in the participant's home, with providers present
- Knowledge level of representatives—Do they know the difference between the Support Plan and the Cost Plan; how to complete the Purchasing Plan; how to connect to natural supports, food stamps, local services?
- Consultant is correctly reconciling statements
- Monthly contact with consultant
- Choices participant has
- If participant is moving forward, toward self defined goals
- If consultants, providers, representatives, and participants know when, where, and how to report abuse, neglect and exploitation
- How person centered is the process? How involved is the person making decisions relevant to everyday living, goals, and dreams?
- Red flag includes situations where the entire family income is from CDC+.

Various suggestions were presented by family members to help new participants transition from the DD Waiver to CDC+. It is important to fully understand the complexity of running one's own business. Individuals need to be their own advocate and take on responsibilities of hiring, paying, and monitoring providers. They need extensive training on the Purchasing Plan, including Excel, on other documentation and paperwork, and should show competency in these areas.

Moving forward, consultants suggested APD should simplify the Purchasing Plan. APD needs to lay out very clearly what needs to be documented (bulleted and easy to understand), and what the

representative's responsibilities are. Training needs to be simplified, updated, and ongoing. It was also suggested that representatives be required to have a computer, computer skills, and knowledge of Excel in order to effectively complete the Purchasing Plan.

In addition, APD must understand that CDC+ is not for everyone. This was echoed in each consultant focus group. When representatives and participants are not able to adequately conduct the business aspect of the program, consultants complete a Corrective Action Plan. There is a need for consequences when individuals or representatives do not comply with the recommendations in this plan. APD should help ensure people in the program adhere to the requirements and agreements of the program.

Miscellaneous Comments

While not always discussed in each focus group, several other comments pointed to specific issues within the program that may be helpful to consider as APD moves into the expansion phase in 2010. It is important to note these comments may have been expressed by only one person and do not necessarily represent the opinions of all participants in the focus groups or the program as a whole. Comments include the following, with recommendations when appropriate:

- When a change is made in the purchasing plan, this often generates a necessary change in another section of the plan. However, with no notification of this, the forms are kicked back and this prolongs the process by weeks. APD should consider adding a function to the online forms that links users to all related sections when a change is made.
- When timesheets are completed there is no verification button that information has been recorded accurately. While some mistakes may not be possible to identify electronically, some errors, such as out of range dates, could be identified and emended. APD should consider adding a verification button to alert users when mistakes have been entered and avoid situations where providers may not be paid due to errors in the timesheet.
- Several group participants mentioned difficulty due to the complexity of the savings section on the purchasing plan, particularly with no computer access. They also indicated it would be helpful if their savings accounts were shown separately and not incorporated into the overall budget in the monthly statements.
- It is difficult to work with a monthly budget using a 26 week pay period. Payments on the 1st and 15th worked better.
- Many CDC+ participants are in school. School hours plus the allotted 5.5 additional hours do not add up to 40 hours a week. In addition, for parents to work an eight hour day, they need 10 hours of services, not eight. Flexibility in the number of allotted hours would be

- helpful.
- Since the passwords were issued they seem to have created some problems for several people.
- The individual acting as his own representative indicated he, along with a “provider to assist with communication over the phone”, had called the Tallahassee office. The person in the office stated he needed to get a representative to speak for him.
- A need for emergency back-up providers has also been identified, to help when a provider is suddenly ill or called out of town.

Discussion and Recommendations

The focus groups used to collect data for this study included family members, individuals, representatives, and consultants affiliated with the CDC+ program. Groups were conducted in two APD Areas where a majority of CDC+ participants reside, Miami and Tampa, as well as in Tallahassee to gain a perspective from a more rural location. While information gathered from this type of research is not generally representative of the entire CDC+ population, the intent was to use experts in the field to help identify possible problems or issues the Agency for Persons with Disabilities can incorporate into the program as it expands coverage to additional residents with disabilities.

It was apparent from discussion with participants in each focus group, the level of satisfaction with CDC+ is quite high. Parents often act as representatives or providers and feel they have much more control over the providers and services needed for the individual, usually their son or daughter. Flexibility in how their money can be used, creating savings accounts that can be used for “out of the box” services, hiring non-waiver providers, the ability to set rates, give raises, and fire providers as they deem appropriate were all seen as huge benefits of the program. There is an increased sense of safety and comfort for families knowing individuals are receiving services from family members who love them, or from providers who “become one of the family”.

However, many barriers were noted that hinder the family’s ability to complete necessary forms and find providers, particularly in rural areas. Tier placement has caused financial problems for most every group participant, generally cutting their budget in half and making it difficult to purchase needed services. Health and safety assurances may be problematic, as consultants indicated they have very little oversight of individuals and providers. In addition, many parent/representatives were not

fully aware of abuse and neglect proceedings, communicating “they would know” if something was happening to the individual. Communication within the Purchasing Plan process appears to be problematic in larger Areas, and issues surrounding behavioral health and other restricted services were noted.

While having the Purchasing Plan form online was indicated as a benefit, numerous problems appear to be associated with not only completing the form but completing the process of having the form approved so providers can be paid on time. Without computer access or Excel, the form is difficult to complete, and therefore consultants often do this for the representatives, indicating they may do this for up to 70 percent of their CDC+ consumers. Changes to the form have been numerous and while Quick Updates have been beneficial, it is not always clear which version of the plan is the most recent version, causing delays in payments to providers. Also, the savings plan section is considered by many to be too complex, particularly if the person or representative does not have access or training in Excel.

Recommendation 1: Limit the number of revisions made to the Purchasing Plan form. When changes are made, ensure adequate communication is used to minimize the chance representatives complete the wrong form in error.

Recommendation 2: APD should develop a work group with several consultants and representatives to identify problem areas when completing and updating the purchasing plan. For example, when one element of a plan is updated, often additional updates are required in other sections of the plan. APD could include a function that automatically notifies users of all sections that need to be updated.

Recommendation 3: The work group should address ways to simplify the savings plan section of the form. It is important to ensure there is adequate space to describe how the individual intends to spend the money. In addition, the budget should show savings as a separate line item.

Recommendation 4: A standard confirmation process should be developed to be used by each APD Area to help ensure all relevant consultants and representatives are informed when the purchasing plan is approved or if it is rejected.

Because many representatives need help completing the purchasing plan and other aspects of

“running a small business”, consultants often take on additional responsibility, beyond their specified roles. While some consultants did not appear to mind taking on the additional work, particularly if it helped ensure services were provided to individuals, others felt the representatives should be trained and capable of performing the work required in the CDC+ program and one indicated representatives tend to treat the consultant like a secretary. However, they did not feel they have support from APD if representatives do not follow the Corrective Action Plans (CAP), and the CAP is the consultants’ only recourse. In addition, most participants in the groups indicated additional training with the business aspect of the program would be very beneficial.

Recommendation 5: APD should consider consequences for representatives and CDC+ participants when CAP recommendations are not completed and the representative is not fulfilling his/her responsibilities to run the program.

Recommendation 6: APD should develop training modules available online to help ensure individuals and representatives understand how to run a small business, complete the necessary forms, and ensure providers are paid.

Hiring providers, particularly non-waiver providers, was noted as a huge benefit of being on the CDC+ program. The process is much more efficient than having to use the cumbersome packet associated with the DD waiver. However, the process for finding providers varied and pointed to a need for social networking to help disseminate information about providers and other CDC+ updates. While Area 11 coordinates and facilitates a monthly meeting, not all people in the Area can attend a meeting in Miami and most people indicated there are few places to go for support.

Recommendation 7: The CDC+ liaison in each Area should help identify individuals, families and/or consultants who are willing to develop grass roots support networks for CDC+ participants in the Area. Group meetings, chat rooms, or simple web sites may be developed to help disseminate information about the program and providers.

A major area of concern for many consultants was the lack of oversight of individuals and providers. This was particularly noted in terms of health and safety since the consultant may only see the individual once a year. Some statements in the groups concerning double locks on doors and cameras throughout the house may point to potentially dangerous situations or violations of the person’s privacy. While participants in the groups were clearly satisfied and felt safer because someone who loves their son or daughter is able to work with him or her through CDC+, providing

better care than through the waiver, it seemed apparent the lack of oversight throughout the program could be problematic. Most group participants did not understand the full implications of how to identify and report abuse and neglect.

In addition, consultants noted concerns about the lack of restrictions as to who is eligible to render services. Elderly people providing services to one or more individual may be unhealthy for the provider who may not be capable of rendering the services as needed. Some measures of competency should be used to help ensure all providers are capable of rendering the specified services.

Recommendation 8: The new Florida Statewide Quality Assurance Program, beginning in January 2010, allows for interviews with individuals and providers on the CDC+ program. It is important to ensure outcomes are being measured and met for individuals, individuals are safe and healthy, and they understand what abuse and neglect is and how to report it. It is also essential to ensure providers are delivering services as specified in the purchasing plan and they have completed all required training and back ground screening.

Recommendation 9: APD should consider identifying some additional requirements necessary to render services, such as an upper age limit and competency in the service area.

Several different issues were noted regarding restricted services, particularly behavioral health analysts. CDC+ requires the same documentation as the DD waiver to support medical necessity for behavioral health services. However, if CDC+ participants hire a non-waiver provider that is not a certified behavioral health analyst, such as a psychologist, this provider will not generate documentation to provide the medical necessity for approval of the service for the next year. Therefore, in this instance, using the program as designed hinders the person's ability to continue to receive needed services.

Finding behavioral health services in rural areas appears to be difficult. Around Tallahassee there is primarily one provider group. Participants in the focus group indicated frustration with the "monopoly" this provider group has in the area. The perception is the primary provider group for behavioral health makes it very difficult to get the service if the family opts to use a different provider.

Finally, consultants indicated the money designated for restricted services must be used to purchase

providers for that service. Currently, this is not well monitored. Individuals could save that money and possibly spend it on something else through the savings account, or for a non restricted service.

Recommendation 10: APD should review requirements of the restricted services and perhaps allow some flexibility in approving the service when a non-waiver certified professional is hired by the family—redefine the qualifications so professionals can be used to deliver the service. This would also alleviate the need for stricter monitoring of money allocated for restricted services.

Recommendation 11: The local APD Area Administration should investigate allegations of “monopoly-like” activity regarding behavioral health services in the Tallahassee area.

While one of the key components of the CDC+ program is to have individuals direct their own services, it appears they are no more or less likely to do this than individuals on the DD or FSL waivers. With few exceptions parents and representatives appear to choose providers and goals for individuals. However, each indicated the individuals have input into the hiring process by having them spend time with the prospective providers. In addition, each parent indicated goals for the individual but while important to the health and safety of the individual, they were goals developed for the person by the family member/parent.

For eight years the FSQAP system has used Personal Outcome Measures (POM), developed by the Council on Quality and Leadership (CQL), to measure how well outcomes are being met for individuals receiving services. The most recent analysis indicates the percent of outcomes present has increased to a level higher than for any other year of the contract.⁴ Moving into the new FSQAP, the National Core Indicator (NCI) Consumer Survey, developed by Human Services Research Institute, will be used to measure provider systems across the state, from the perspective of the individual. While each survey measures outcomes from the perspective of the individual, the POMs focus on individual outcomes and the NCI focus is on provider systems, a different unit of analysis. It is important to transition to this new system in a way that provides continuity in measuring the extent to which a person centered focus is used by providers to help individuals achieve self-defined goals, particularly through the provider’s service delivery systems.

⁴ Analysis completed for the FSQAP Year 9 Extension Period Report, to be submitted to APD and AHCA December 31, 2009.

Recommendation 12: APD should work closely with Delmarva to help develop relevant training programs for CDC+ participants to help them identify their own goals and to ensure families/representatives allow individuals to direct their own services.

Recommendation 13: The new quality assurance program tools, developed by Delmarva, APD, and the Agency for Health Care Administration, will include the NCI Consumer survey and concrete measures of the person centered nature of the participant's service delivery system. These should be analyzed regularly to ensure provider systems maintain a person centered focus that helps individuals achieve self-defined outcomes.

Some requirements identified in this report are not currently included in the desk review monitoring tool. Several additional suggestions were offered by consultants and representatives as to what APD should monitor when developing a new quality assurance system. In addition, consultants indicated that when waiver support coordinators do not adequately perform there are consequences for them, i.e., they can not increase their case load. However, there are no consequences in the CDC+ program.

Recommendation 14: APD should work with Delmarva and consider the suggestions provided in this report when developing a new CDC+ monitoring tool.

Recommendation 15: When the new FSQAP system is implemented, CDC+ consultants will be more closely monitored. APD and Delmarva should work together to establish a standard performance score that should be maintained in order to continue CDC+ consultation.

Throughout the focus group discussion, participants were free to provide recommendations for various issues. Several of these are presented here:

- Abuse, neglect, and exploitation training should be included in the initial CDC+ training.
- APD should help ensure families understand the savings account aspect of the program: the restrictions, limitations, and recoupment process if money is not used in the allotted amount of time.
- Consider offering training updates on all aspects of the program. Online modules would be helpful as one initial training session is not sufficient.
- CDC+ is not for everyone. APD should develop some method to help determine each representative's competency in operating a small business.
- Single parents have unique needs. It is difficult to find a non-paid representative

when family members are not available. Consider how non-family members could be compensated to act as representatives for individuals.

One additional recommendation concerns a lack of clarity in describing how the face-to-face meeting between the consultant and participant should occur.

Recommendation 16: The language in the CDC+ requirements is not clear as to whether the annual face-to-face meeting with individuals needs to be a home visit. APD should specify this in the hand book.

While focus groups do not constitute a representative sample of CDC+ participants, each group used for this study consisted of representatives and consultants who have participated in CDC+ for many years. It was clear in each focus group that individuals, families, representatives, and consultants agree there is a high level of satisfaction with the CDC+ program. As APD moves into the expansion of this program, findings from the collective knowledge of these experts in the field should be incorporated into the new quality assurance process.

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- ⁱ James Frogue. The Future of Medicaid: Consumer-Directed Care. The Heritage Foundation. Policy Research and Analysis. January 10, 2003.
- ⁱⁱ Cindy Higgins. The Research and Training Center on Independent Living. Consumer-Directed Care. http://www.getriil.org/consumer_care.htm.
- ⁱⁱⁱ 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>.
- ^{iv} Consumer-Directed Health Care: How Well Does it Work? National Council on Disability. <http://www.ncd.gov/newsroom/pulications/2004/consumerdirected.htm#outcomes>.
- ^v James Frogue. The Future of Medicaid: Consumer-Directed Care. The Heritage Foundation. Policy Research and Analysis. January 10, 2003.
- ^{vi} 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.
- ^{vii} A Report to the Florida Legislature: Consumer Directed Care Project. Florida Medicaid. January 15, 2004.