CASH AND COUNSELING DEMONSTRATION AND EVALUATION

Consumer Directed Care
Florida Department of Children and Families, Developmental Services Program
Report on Focus Groups

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Introduction and Methodology

Florida's Cash and Counseling Demonstration and Evaluation (known as Consumer Directed Care) began enrolling consumers during Spring, 2000. Despite survey results indicating great interest in a cash option among Florida consumers, enrollment began slowly. To enhance marketing efforts and increase enrollment, the Robert Wood Johnson Foundation provided funding to conduct qualitative research (focus groups) with targeted groups who have direct contact with eligible program consumers. The goals of the focus group discussions are:

- To understand participants’ viewpoints about consumer-directed services in general, and specifically, Consumer Directed Care (CDC).

- To provide focus group participants an opportunity to provide input and ideas on ways to enhance interest and enrollment in CDC.

Staff from The Department of Children and Families recommended several groups for participation in the discussions including the Family Care Council, Independent Support Coordinators (ISC’s), and Self Advocates (i.e. consumers who serve on a state task force to address issues related to consumer direction). The group with Family Care Council members was conducted in Orlando during the Council’s quarterly meeting in early December 2000. After several failed attempts to conduct groups with agency staff and independent support coordinators, both on-site, and via conference call, we were able to hold one conference call with several Independent Support Coordinators in mid-December. In addition, in mid-January, individual telephone interviews were conducted with administrative and supervisory staff from several of the agencies serving clients who are eligible for Consumer Directed Care. The group with self-advocates was also conducted via conference call in mid-December.

Note: Please refer to the Appendix to review a copy of the letters of invitation and the Moderator's Guide. The National Program Office and Florida Consumer Directed Care staff received transcripts of the focus groups that provide a complete overview of the entire group discussion.
Twenty-four people participated in the focus groups – 11 on site and 13 via conference call.

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The moderator provided each focus group with an overview of the Cash and Counseling Demonstration and Evaluation and a description of how the project worked in Florida. The referral and selection process for Consumer Directed Care, the demographics of current enrollees, and marketing activities for the program were also presented. Throughout the discussion, information and clarification was provided to the participants about the program, including eligibility, the referral process, impact on other benefits, the evaluation process, and program oversight.

Following is a summary of key findings from each of the focus groups and the interviews. Each section provides a review of the following:

- Participants' reactions and concerns about Consumer Directed Care.  
  (Note: Given that the primary purpose of these focus groups was to identify ways to further market the Cash and Counseling Demonstration, detailed discussion about focus group participant concerns is omitted from this report. This information is available in the focus group transcripts.)

- Ideas about marketing Consumer Directed Care, both to professional colleagues and to those consumers who might be eligible for the program.

**Statement of Limitations:** Focus groups afford the opportunity to observe and record spontaneous reactions – perceptions, opinions, and attitudes – from a selected group of participants on a variety of issues and topics. The groups help develop insight and direction rather than quantitatively precise or absolute measures. Therefore this research must be considered in a qualitative frame of reference and the results viewed as exploratory and directional in nature.

Statements in the report noted in *italics* are actual quotes taken from the focus group transcripts. In some cases, the sentence structure may seem awkward – a result of the spoken word seen in writing.
1. Summary of Focus Group with Family Care Council

Each district in Florida has a Family Care Council whose members consist mainly of parents of children receiving services through the Department of Family and Children’s Services. The Councils serve as a source of information, advocacy and education for families who have a member with developmental disabilities. The chairs of each of the district Councils meet together quarterly. This focus group was conducted at the December 2000 quarterly meeting in Orlando.

General Reactions to Consumer Directed Care

Most members of the Family Care Council had positive reactions to the concepts of self-determination and consumer direction. They thought that CDC could provide more control and more choice for their children and for themselves. They did however have some reservations:

- There is confusion about several pilot programs – including CDC - related to self-determination and consumer direction that are currently operating in the state. FCC members were unsure about the purpose of the different programs and which programs provide what services. They felt that there needs to be a better way to distinguish the programs – what they provide, who is eligible, etc.

  …there are so many things going on that it is hard to keep up.

  It’s hard to keep track of which one you are talking about because they all have the same words.

- They discussed the issue of self-determination/freedom vs. safety for the child or client. This issue is particularly significant for those parents whose children have serious mental disabilities.

- They felt that for many, any program fostering consumer direction will not work unless attitudes towards persons with disabilities change in the community…. both among the public and professionals.

  I do see a big hurdle out there because the state people and the caseworkers, the support ---- do not believe that the families of the consumers are able to do this. They think that we are incapable, you know, we are going to misuse this tax payers’ money and that is one reason why you probably do not have as many applicants as you could have had.

- There is an ongoing concern about the lack of qualified providers. They recognized that CDC could help alleviate this problem in that consumers would not necessarily be dependent on agency staff.
It's horrendous as far as getting providers and it's great to be able to know you can use your family members. You can use your neighbors. You can use people from church and it gives you a sigh of relief.

Family Care Council parents see advocacy as part of consumer direction and self-determination; many feel they have “pushed the envelope” to get what they need for their children. In this way, they believe that they already have been practicing consumer direction in many ways.

I’d like to think of the advocacy role as part of the self-determination or consumer control because we’ve been consumers from the point our children were identified as needing services…each and every one of us stepped outside of the boundaries of what we have been told we were able to get and so in some ways we’ve been consumer driven all along. It’s just been limited by what opportunities we could develop.

Concerns about Implementation of CDC

FCC members feel there has been a lack of aggressive marketing and education about CDC to eligible clients and families. Many FCC members believe that the Independent Support Coordinators are a part of this problem. FCC members feel that many of the ISC’s do not believe families are capable of managing the cash plan. They also feel that ISC’s are threatened by CDC as they might lose clients to the program, and ultimately lose their jobs. As a result, according to these Family Care Council members, the ISC’s are not doing a good job of marketing the program to eligible clients and families.

It’s that there’re afraid that they are going to lose their clients and their job.

The support coordinator said, ‘oh, you don’t want to do that.’ So, I had to educate her. And, so now she’s starting to get other people involved but there’s a lot of misinformation.

What they’ve done in our district is that they have basically assigned a quota to each of the support coordinating groups, right? And, either obviously some of them are more advocates for this than others but, one in particular, they are extremely excited. And they are signing them up as fast as they can.

And some of the support coordinators like it, some of the support coordinators don’t like it. It’s…the type of individual, a lot of people who go into support coordination are the caregiver type individual and only I can do it. It’s attitudinal. ‘I know best.’ I can do it and maybe something bad will happen. Well, I respect each and every individual enough that,
yes, they can do and make bad mistakes, bad choices and that's part of being under the consumer direction.

FCC members expressed concern that ISC's have received inadequate training about CDC and therefore are not comfortable presenting the program to families. One FCC member described sitting through a new intake evaluation with a friend of hers. Never once did the ISC mention the CDC project to the family.

I think it all has to do with attitude and the way – the positive or negative way it is presented by the support coordinator.

Some FCC members said families might be reluctant to enter into the project, given the new influx of money and services that has come to the Department of Families and Children within the past several months. They may fear losing what they have fought so long to get.

I'm in a program on the community based waiver services. I'm getting the services I need for the most part. Not all of them but, for the most part and I'm relatively happy. Okay? Why should I want to jump out into something new and it's a pilot, if you will, that has no certainty of ever being adopted forever because it may crash and catch fire.

Working with The Department of Children and Families

Family Care Council members expressed frustration related to the Department of Children and Families. They discussed the need to work together as partners for the greater good of clients and families, and believe the Department operates in an "us versus them" mentality. The Family Care Council believes it can and should be a vital communication link to families, but Council members see little effort from the Department to work with families as peers. As an example, several members spoke of not receiving information about programs in a timely manner, often getting "old" information that was incorrect by the time they received it. None of the FCC members knew about brochures describing CDC, or they assumed brochures were sitting in DS district offices. FCC members feel strongly that they need to be at the front end of communication about CDC in order to have credibility with families in promoting CDC.

They don't know how to work with us as peers.

By the time the district administrator or program person or that person in charge of gets it to the family care council it’s a past event. And, we are getting their interpretation and not what was sent out and I get wrong information quite frequently through e-mails and it just drives me up the wall cause I have to go through at least seven different people to clarify whether it is true or not and I find out most times some body just didn't swoop it up there.
A number of FCC members have gone through the staff training for the Consumer Directed Care project. Those who sat through training found it disorganized, and offering little useful information. They sensed that the Independent Support Coordinators were very hostile towards training—they were not there by choice. In some districts, the Family Care Council had invited the staff person in charge of training, Michael Freeman, to attend regional meetings to discuss the Consumer Directed Care project with families. Independent Support Coordinators from the region were invited as well. In each case, none of the Support Coordinators attended.

**Role of the Family Care Council**

- Family Care Council members believed that people currently hear about CDC primarily through the FCC. Council members strongly believe that they can and should have a key role in marketing Consumer Directed Care to eligible families across the state, but have not been properly utilized by the Department in this role. Most were not aware of the eight funded outreach worker positions. One mom had tried to apply for a position and was told money was not available.

  ... our role... is to try to get more people involved. But, it is an extremely difficult role because our people... have so many other commitments. And you know, we could use as much help as possible. And when we come up against the department that has their own little ax to grind and their agenda and so on. It is very difficult to bridge that gap.

**Other Marketing Ideas**

Other marketing ideas suggested by FCC members included:

- Working with the school systems,
- FCC members making home visits to eligible families, and
- Providing signing bonuses, creating a competition among ISC’s, FCC’s, consultants, etc.

**2. Summary of Focus Group Conference Call with Self Advocates**

The Self-Advocates are persons with developmental disabilities who participate as advisory team members for the self-determination movement within the Department of Children and Families. A discussion group was conducted via conference call with six self advocates. Several parents also participated in the calls.
Note: Due to the nature of some self-advocates' communication limitations, the focus group moderator had difficulty understanding all aspects of the telephone discussion. Participants put forth much effort in making their views known, and they were patient with frequent requests to repeat statements.

- These self-advocates were clear about consumer direction and what it means to them.

  Act as your own service provider.

  It means I have control over who I hire and fire and where I get my medical equipment.

- Most participants said they would enroll in CDC if given the opportunity, although one or two were still uncertain how CDC would be different from the services now received under the Medicaid waiver. Several parents questioned whether CDC would really be as flexible as it purports to be.

  I haven’t done it [signed up for the program] because like I said I’ve been doing my own thing for so long. You know I don’t know if I could deal with somebody telling me what I could and couldn’t do.

  We’re wondering whether or not the flexibility of the thing is as flexible as it was intended or as we were led to believe.

- One participant who lived in a very rural area was uncertain about accessing services.

  We’re still in the project and we’re sort of challenging the parameters of it to see how flexible it’s going to be to meet the requirements in a more rural district.

Comments about Using the Cash Plan

- Self-advocates viewed hiring their own worker as one of the most attractive aspects of Consumer Directed Care. One participant mentioned the desire to hire an aide who could do tasks the current aide was unable to do because of licensing requirements.

  I would hire my own aide, right now I have a trach… and I have…I had a nurses aide but because I had to let one go because she was abusing me…I have to have a nurse…at night because a aide can not do trach care according to the nurse practitioner.
Under CDC she could hire whom she wanted to, they wouldn’t have to be med-waiver certified. It’s hard to get med-waiver certified providers, very hard.

- Participants also liked that they could use the cash to purchase needed equipment.

  They would pay for my wheelchair.

Marketing CDC

- Participants expressed the concern that social workers (ISC’s) are not telling clients about CDC. Several remarked that they did not think that many of the home health agencies were even aware of the project.

  Another thing that would be helpful in this project, there are a lot of agencies out there like home health, who have qualified individuals with the appropriate background checks and they have everybody from nurses down to personal care attendants to aides to sitters… these agencies are not aware of this program in which they could fill a void for many of the consumers.

- Self-advocates had many ideas for marketing CDC. They suggested utilizing TV ads, radio, PSA’s (local cable channels, FL cable TV), and mailings (only one had received a mailing), as well as communicating through the Family Care Council and clubs/organizations involved with the disability community.

  By word of mouth, put an ad in newspapers because one of the…so that providers couldn’t keep information from the consumers, or at least you could have a mailing.

- One participant pointed out the need to have marketing materials translated into Spanish. (When the focus group facilitator explained that materials are, indeed, written in Spanish, all expressed surprise, and were unaware of this).

  I got another concern. TV in Miami, the population is over 50% Hispanic and the information about the project needs to be translated into Spanish.

- According to several self-advocates, an increasing number of consumers in the disability community are using the Internet. Thus using Internet sites geared for people with disabilities would be another way to market Consumer Directed Care.

  I’m on a couple of listserves they are geared towards people with disabilities and that seems to be a good way of getting things out.
• Another focus group participant suggested marketing CDC at special events for the disability population held around the state, such as an "Inclusion Day".

  We did an Inclusion Day on March the 4th of this year and we put a non-profit and profit [agency]… on display and showed it off up in Sanford and it went really great to that point and getting the people up there was really hard…we got about 50 sponsors…

Role of Self-Advocates with the Project

• These self-advocates see themselves as “ambassadors” to the disability community in informing others about Consumer Directed Care. Several focus group participants said they have told their friends about CDC and one has even made phone calls for them to inquire about enrollment. (All said their friends have not heard of the program before the self-advocates told them about it).

  I just make the call myself and make the referral so if anybody doesn't feel comfortable making the initial call, I would do it for them.

Role of Developmental Services

• Most focus group participants felt the Department has not been good in responding to questions about CDC. Several have enrollment papers, but have not heard back from their Independent Support Coordinators. They felt that support coordinators are too busy to talk to clients about the program.

  I think some problems is with Support Coordinators to ask the clients about what choices they want to make for themselves. Some of the Support Coordinators are really, really too busy or never have time to talk to each client…to ask them what choices they want to see to be happening for themselves.

• Echoing views expressed by Family Care Council members, the self-advocates also believed that the support coordinators were not communicating to clients about the program because they were afraid of losing clients and then losing their jobs.

  [Social workers] they are afraid of losing clients.

  You got to re-educate the Service Providers, support coordinators their clients are not being taken away from them, they are giving them choices.

3. Summary of Focus Group Conference Call with Independent Support Coordinators
In mid-December, a conference call was conducted with seven Independent Support Coordinators who work in the Orlando, Fort Lauderdale, and Miami areas. In addition several phone interviews were conducted with supervisors and staff from two of the Tampa area agencies serving the developmental disabilities community, two staff members from the Developmental Services District Office in Tampa, and one Independent Support Coordinator, also in the Tampa area.

**General Reactions to Consumer Directed Care**

- ISC’s concerns about Consumer Directed Care were very similar to those heard from others involved in the project. Most can see the value of CDC for clients and their families, particularly the ability to hire one’s own worker. However, the complexity of implementing the program has created some negativity about CDC, and perhaps, limited their enthusiasm and willingness to market the program to eligible consumers.

- Independent Support Coordinators, Consultants and District Staff alike state that involvement with families in completing the application and budget plan procedures has taken far more time than anticipated. No one working with CDC clients seemed to have a clear picture of the procedures – from completing application forms, to developing a budget plan, to looking at implementation issues. They said that questions about procedures constantly arise, and it is often difficult to get answers from Department staff due to the many administrative “layers” that may have to be consulted. Waiting to get answers further delays the process.

- The delay in the project start-up seems to have negatively affected ISC’s feelings about the program.

> Unfortunately, once the training was completed nothing further was done. And I had some families that seemed ready and almost put themselves in place to do something like this even before they were aware that there might be a program out there, simply because they felt comfortable with having family members or friends involved with their child or brother or sister of something like that.

> That was the big issue, the fact that we did the training, we were told that things should be happening very shortly and then there was a significant gap at that point.

- While some of the ISC participants said they had a choice to become a consultant, others did not have that choice.

- Several participants felt that agency support of CDC is “lukewarm” at best. Several explained that while their agency directors did not discourage them
from participating in the focus group discussion, their directors were indifferent about their participation. One ISC stated her director is not encouraging ISC’s to present CDC to families.

• Some have felt pressure to get people enrolled as other districts have already enrolled significant numbers.

Family Reactions and Concerns

• According to agency staff and Independent Support Coordinators, consumers who have been receiving waiver services for a while have not been interested in CDC for the reasons cited above. ISC’s thought those consumers who were just beginning to receive waiver services might be more interested in CDC. They also thought that consumers who are not in a day program and those with more complicated needs (e.g. those with elderly parents who could use respite services) might have greater interest.

You have individuals who have been on the waiver for quite a while since inception in ’83. And for most of those people the services that are being provided at that time or up to this point, it is pretty much set and in place. We are talking about day programs; we are talking about residential services...And the families are pretty comfortable with that.

The people that I have been presenting it to, and the ones that are the most receptive are not the ones that are in the day program, but those individuals who have been home and have been home for an extended period of time.

• Some focus group participants reported that the program is confusing, overwhelming, and hard to understand for parents and staff. The seeming complexity of the program has also led to limited interest by families, according to several of the support coordinators. ISC’s stated that while families may be interested in CDC, there are so many “safeguards” in CDC that it is overwhelming to families (i.e., bookkeeping and employer responsibilities).

I find it a little confusing, you know, for the parents. The parents are a little overwhelmed with the way the paperwork goes and working with accounting and the budget...

What I’ve seen is, that people that don’t feel like they have a background don’t feel like they can do it.

• One ISC coordinator spoke of one family who was very interested in the program. The ISC coordinator emphasized that because both parents were professionals, one an accountant, they could handle the program.
This sentiment was echoed by other ISC’s: the parents who are interested are those who are professionals (some had mothers who are RN’s). Those who are already very involved in their child’s care are savvy and know the system well.

• Some of the ISC’s felt their families would not want to participate in CDC because they are now getting adequate services with the additional infusion of money in the DCF. ISC’s predicted that these families would see no benefits to participating in CDC, and they may view the cash option as requiring more work without necessarily improving services. ISC’s also expressed concern about a reduction in the budget plan in CDC. They explained that parents are concerned that it will be difficult to increase their budget on CDC if a child’s needs significantly change.

   I think the reason we are not getting people signed up… [people] are getting the services they want for the most part.

• Some focus group participants reported that families are fearful of becoming an employer…they see the tasks and responsibilities as overwhelming. Focus group participants reported that families are used to DS doing things for them. Participants thought families do not want the extra responsibility of CDC. “It’s difficult enough for them just to get through each day.”

   They have been accustomed to the state or in this case the DS doing a lot of the work for them and they are already caught up with just trying to maintain their lives and keeping things together and when we have to tell them that there is going to be additional responsibility that they will have to bear a lot of folks are not interested in that because they really don't have the time for that.

ISC’s reported that parents are nervous that they would end up on a waiting list for services if they leave CDC and will not get services needed.

• Some participants were skeptical about the use of randomization in the CCDE, expressing concern that families who were randomized to the control group would be so mad they would not participate. They worried that this problem could sabotage the research.

   You know, people want to do it they want to be in an experimental group. They don't want to be in a control group. I don't see how we are even going have good studies because the people in the control group are going to be mad.

Training
• Focus group participants had very negative reactions to training. One described it as like an “Amway presentation – very gung ho on the program, but no substance.”

• Participants felt that the long lag time between training and program start-up was also a problem.

  I think if the training was done close to the time that we were going to apply that training – it might have helped a lot because to be honest I forgot a lot before I had presented to these people.

• ISC’s reported that they did not get answers to questions about program operations. Clearly, their own uncertainty about the program affects ISCs’ decisions about whether and how they will present the cash option to families.

  We don't have enough information to assist the clients. They ask a lot of questions and I try to look through the information that I have but I can't find it and it is just very overwhelming and they're a little afraid.

  There is too much paper work given to us so that it's very difficult to wade through that when you're presenting it to them. And, when they have questions and I don't know if they could have simplified it somehow and maybe even some kind of a hands on liaison, on the job training almost and just like you are out there on an island with no body else to help you so it's kind of scary.

• ISC’s voiced many complaints about the lack of follow-up to questions on the part of DS staff. Others said they were unable to get information and forms needed to work with families. Several spoke of sending e-mails and getting no response to questions.

  I was asked and you know what happened too me. You know that I got no response. Actually I know one of my parents e-mailed as well and we go no response.

• Focus group participants suggested that DS needs an 800 hotline that ISC’s could use to get questions answered in a timely fashion.

Role of the Independent Support Coordinators in CDC

• ISC’s feel frustrated that they cannot answer clients’ questions about the budget and other procedures, and explained that they have inadequate background information about CDC to do their jobs well.
I didn’t have the information. I mean, I had initial information but there is still a lot of confusion and I haven’t been able to answer [clients’] questions on specifics. I guess I haven’t had anybody to really go to, to try to get those answers in the meantime.

• Focus group participants believe that ISC’s inability to answer parents’ questions increases the families’ mistrust of DS. They explained that families have been promised a lot before and DS has not come through.

  We don't have enough answers when we go out there. It gets to a point where they are asking us questions and I'm sitting there going well, I really don't know. I'll have to get back to you on that. And, it makes you feel very uncomfortable, like why are we going out there presenting this if we don't have the information. If we don't have the information how are they going to feel comfortable saying yes, or, that they are interested?

• ISC’s seemed unclear about their role with clients enrolled in CDC.

  There was some talk, there were different groups that were advocating, perhaps, that the work of the support coordinator be done away with and someone else assume that responsibility. So there was some concern as to how it would impact on us and what we do.

• Some ISC’s think they will have to monitor clients closely at first to make sure they stick with their budgets.

  The monitoring would be close in the beginning. You know monitoring their budget and make sure they are staying within their means and there would be less – well my thoughts was the face to face would be eliminated away from the situation but there would still be phone in times when I would have to go to the home and help them out with training. Some of the families will require a lot more training than others.

• Other ISC’s see more phone consulting and less home visits, which they think families would like.

Making Changes

• ISC’s believe parents need to hear about the program from one source. They are hearing different descriptions of CDC from different sources, some of which is misinformation. Focus group participants suggested that DS have an informational meeting about CDC for both parents and ISC’s. Thus, ISC’s and clients would hear the same information at the same time. This procedure would perhaps make it easier and less frightening for parents to consider participating in CDC.
• ISC’s also suggested that it would be valuable for parents to go to a training session to learn more detailed information about participating in CDC. They felt that it would be a big advantage for ISC’s and families attend a training session together.

  *The parents need training too. And, they should be made to have information directly. There is a lot of confusion.*

• The ISC’s see an advantage to having designated CDC workers. A staff member working only with Consumer Directed Care could play a major role during outreach and enrollment, providing information about the program and facilitating completion of enrollment forms. ISC’s could be with their clients during this introductory phase.

  *I think that's what they need. I think they need a specialist. I think that's being fair to everybody because I think it's a great program. I think it's being fair to everybody especially to the clients and the family because they have somebody who is an expert, you know. It's a dissemination of information that's causing the problem.*

• ISC’s stated that a hotline is a good idea, if staffed adequately, as people need to get feedback in a timely manner. They suggested that it should be staffed with knowledgeable people who could provide standard information to everyone about frequently asked questions. They felt that using e-mail has not worked well. E-mail has not provided answers, and in many situations, there is a need for dialogue.

• ISC’s saw some advantage to peer-to-peer consultation, but some said it should be done within each district, not necessarily statewide.

**Marketing Ideas for CDC**

• ISC’s had many ideas for marketing CDC, including: conducting direct mailings to consumers and families, distributing a CDC brochure through the schools (e.g. in students’ backpacks), and presenting information about CDC at provider meetings. They also recommended involving the Family Care Council, (several ISC’s said their FCC members knew more about the program than they did.)

**Conclusions and Observations**

• Focus group participants’ concerns about Consumer Directed Care offered through the Developmental Services Program are very similar to those heard during previous focus group discussions with Elder Affairs staff. While a majority of participants see the value of CDC for clients and their families, the complexity of implementing the program has created
some negativity about CDC, and perhaps, limited ISC’s enthusiasm and willingness to market the program to eligible consumers.

- Independent Support Coordinators, Consultants and District Staff alike state that they have spent far more time with families completing the application and budget plan than they anticipated. Staff working with CDC clients do not seem to have a clear picture of key procedures – from completing application forms, to developing a budget plan, to implementing other steps in the program. ISC’s and others frequently have questions about procedures, and often have difficulty obtaining answers due to the many administrative “layers” in the program. Waiting for answers further delays completion of procedures.

- Development of the budget plan seems to be one of the most complicated and confusing procedures in CDC. The formula to determine the budget amount is confusing. Because of recent changes in services covered by Medicaid and the Medicaid waiver, determining the actual dollar amount for the budget plan is a complicated, time-consuming process. Consultants state that it is almost impossible for a client and/or representative to complete the necessary paperwork in developing the plan, and as a result, budget plans are developed almost entirely by the consultants. Several mentioned that the budget plans they have submitted have been returned (sometimes more than once) for being incorrect. Yet, consultants have a hard time obtaining answers about the problems in the plan. District supervisors are now urging staff to meet with them after they have developed a budget plan with a client, prior to submitting it, to determine whether the plan was completed correctly.

- District staff would like to see their bi-weekly conference calls with state Developmental Services staff extended to others who are involved in the project, including Elder Affairs staff and staff from the bookkeeping service. Staff believes that if all key players participate in these conference calls, they would have questions addressed in a timelier manner.

- District Six has recently hired an outreach coordinator for CDC who is contacting eligible clients and will assist in outreach and completion of applications. District supervisors want her to concentrate on clients from agencies that have not been aggressively marketing the program. Most agency staff and district personnel believe the addition of an outreach worker will facilitate marketing CDC to clients and families. It should be noted that one agency reported that the outreach worker has created some confusion among clients by visiting some who had decided that they were not interested in CDC. According to the supervisor, these clients don’t realize that CDC is the same project that they had initially decided not to pursue.
Independent Support Coordinators and Consultants seem overwhelmed by the size and complexity of their caseloads. As one district supervisor stated, “Being an Independent Support Coordinator is difficult to begin with.” The difficulty in working with CDC adds to that sense of being overwhelmed. ISC’s view CDC as one more complicated program they need to address. Unless one has a caseload with a significant number of clients enrolled in CDC, it appears difficult to grasp program logistics and gain needed expertise. In one agency, one staff member has been given most of the clients who are interested in CDC and is becoming knowledgeable in the many aspects of the program. This “specialist” approach has been a significant help to other ISC’s as they know that someone who is knowledgeable about the program will work with clients during the application and enrollment procedures.

Based on these focus group discussions, it appears that the limitations of Developmental Services state-level staff in responding to questions in a timely manner often slows down outreach, application, and enrollment procedures. The multiple administrative levels that need to be consulted to obtain correct answers create even more difficulty.

Addendum

After these discussion groups were conducted, Developmental Services staff was provided a detailed overview of the major themes and issues discussed. As a result of these findings, Developmental Services (DS) staff implemented several changes in program operations. Program staff submitted the following summary of steps taken to address these issues. It should be noted that enrollment in CDC has increased greatly in the months after the focus group discussions.

- A Developmental Disabilities staff person, who is a mother of a son in the project, has started conducting presentations to all 15 Family Care Councils.

- DS staff has revised the training and the material is now more DD specific and we include the outreach and enrollment staff from the area we are conducting the training to answer questions related to district issues. Department of Elder Affairs staff do not participate in DD training. This has been an additional workload for us. As you know we received no money for training and when the project was designed all the training was to be conducted by DOEA. I believe this is just another example of our commitment to this project.

- We have sent to the district contact people to pass on to the trained consultants, updates of material to clarify implementation issues.
• Bi-weekly, we conduct a telephone conference call with the district staff, outreach workers and any consultant or provider who wants to participate. Purpose of this call is to clarify issues and provide TA. Also we have a toll-free line and we receive many calls daily related to implementation issues. All of this is to improve the communication between consumers, families, district, and FI and other interested people.

• DS staff sent a letter to 12,000 consumers to introduce CDC. Staff received an “overwhelming response” to the letter, which had been signed by Governor Jeb Bush.